Signature:

Mariya Kovaleva 12/14/2018
Date

Experiences of Caregivers of Dementia Patients with an Integrated Primary Care Model

By

Mariya Kovaleva

Doctor of Philosophy

Nursing

Kenneth Hepburn, PhD, FGSA

Advisor

Carolyn Clevenger, RN, DNP, AGPCNP-BC, GNP-BC, FAANP

Committee Member

Patricia Griffiths, PhD, MS, FGSA

Committee Member

Bonnie Mowinski Jennings, PhD, RN, FAAN

Committee Member

Mi-Kyung Song, PhD, RN, FAAN

Committee Member

Accepted:

Lisa A. Tedesco, Ph.D.
Dean of the James T. Laney School of Graduate Studies

Date

Experiences of Caregivers of Dementia Patients with an Integrated Primary Care Model

By

Mariya Kovaleva, RN, MS, AGPCNP-BC

Advisor: Kenneth Hepburn, PhD, FGSA

An abstract of
A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy
in Nursing
2018

Abstract

Experiences of Caregivers of Dementia Patients with an Integrated Primary Care Model

By: Mariya Kovaleva

Few U.S. dementia care programs are led by advanced practice registered nurses (APRNs), including a dementia patient-centered medical home, the Integrated Memory Care Clinic (IMCC) at Emory Healthcare. To our best knowledge, the IMCC is the only U.S. dementia care program where clinicians provide primary care and dementia care simultaneously.

The purpose of this study was to quantitatively and qualitatively explore the experiences of caregivers of persons living with dementia (PLWD) and PLWD (as reported by their caregivers) at the IMCC.

This longitudinal prospective cohort study employed quantitative and qualitative methods. The study began with a scoping review of the U.S. dementia care programs since 2011. Caregivers participated in three assessments (at baseline, then approximately three and six months post-baseline) that evaluated caregivers' health status and psychological well-being and PLWDs' dementia-related symptoms and quality of life. Forty-nine caregivers completed the baseline assessment. Mixed linear models were used to evaluate changes over time in client-centered outcomes. As caregivers were completing the baseline assessment, a sub-group of 12 caregivers was conveniently sampled for telephone qualitative interviews six months post-baseline.

Five outcomes demonstrated significant decreases (signifying improvements) when time was the only predictor in the model: caregivers' distress relative to their PLWDs' delusions ($p=0.048$) and their PLWDs' anxiety ($p=0.018$), and severity of PLWDs' delusions ($p=0.032$), depressive symptoms ($p<0.001$), and total symptom severity ($p=0.013$). When accounting for the total number of visits to the clinic the clients made, time no longer significantly predicted changes in caregivers' distress relative to their PLWDs' delusions. When accounting for the total number of visits to the clinic or PLWDs' total number of comorbidities besides dementia, time no longer significantly predicted changes in PLWDs' total symptom severity. Two features characterizing caregivers' experience of the clinic were discovered: the IMCC as the wished-for model of dementia care and ways to improve the IMCC.

This study provides quantitative and qualitative descriptive data on caregivers' experience within the IMCC. Since this study did not have a comparison group, the outcomes cannot be attributed to the IMCC. Future experimental or quasi-experimental studies may elucidate the effect of the IMCC on client-centered outcomes.

Experiences of Caregivers of Dementia Patients with an Integrated Primary Care Model

By

Mariya Kovaleva, RN, MS, AGPCNP-BC

Advisor: Kenneth Hepburn, PhD, FGSA

A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy
in Nursing
2018

Acknowledgments

I would like to sincerely thank my academic advisor and dissertation committee chair, Dr. Kenneth Hepburn, for his time, support, and working with me on this dissertation and several scholarly projects that helped me to grow as a professional and prepare for a career in research. I certainly would not be able to develop in my research and writing skills without all the help, patience, and support of Dr. Hepburn. I am very thankful for all his time and belief in me.

I likewise would like to thank you my dissertation committee faculty members: Dr. Carolyn Clevenger, Dr. Patricia Griffiths, Dr. Bonnie Mowinski Jennings, and Dr. Mi-Kyung Song for all their time, support, and support. This has been a wonderful journey and I have been very privileged to work with and learn from all of you.

I am more than indebted to my mother for all her love, patience, support, and sacrifice – my gratitude cannot be expressed in words. I am indebted to Olga, my grandfather and grandmother, and all of my extended family for always supporting me in the pursuit of this education, allowing me to enjoy this wonderful privilege and responsibility that comes with earning a doctorate degree from one of the best universities in the world.

This study could not have been completed without the caregivers who chose to participate despite their numerous responsibilities. I am also indebted to all the staff of the Integrated Memory Care Clinic: Carolyn Clevenger, Janet Cellar, Laura Medders, Debbie Gunter, Alison Schlenger, Tyler Finkle, Heidi Wells, and Joshua Schwartz. Thank you for always welcoming me to the clinic and helping me with this project – none of this would have been possible without each and every one you.

I would like to thank faculty and staff of the Emory School of Nursing for their work with me beginning my first semester in graduate school, writing numerous letters of recommendation, and always supporting me in the many tasks that this dissertation required.

This dissertation was generously sponsored by the Sigma Theta Tau International Small Grant and a grant from the Alpha Epsilon Chapter of Sigma Theta Tau International. I am very thankful to the Sigma Theta Tau International for enabling me to conduct this study and providing me with very important grant writing opportunities.

Lastly, I would like to thank God for bringing me to this point in my life. Words cannot express my thankfulness and understanding of how privileged I am to receive this degree.

Table of Contents

Experiences of Caregivers of Dementia Patients with an Integrated Primary Care Model

Introduction

The U.S. population of persons living with dementia (PLWD) is expected to increase from the current 5.7 million up to 16 million by 2050 (Alzheimer's Association, 2018). In 2017, over 16 million Americans served as unpaid caregivers for at least 5.7 million PLWD (Alzheimer's Association, 2018). Most PLWD not only receive dementia care in primary care settings, but they also prefer getting their dementia care in these settings (Callahan, Boustani, Sachs, & Hendrie, 2009).

But currently primary care is poorly equipped to provide quality dementia care (Borson & Chodosh, 2014). The reasons for such discrepancy between the increasing need for dementia care and primary care deficits in the care for PLWD are rooted in the way mainstream outpatient healthcare delivery is currently organized. Typical visit time in ambulatory settings in insufficient to render dementia care (Hinton, Franz, Reddy, Flores, Kravitz, & Barker, 2007). Some physicians have inadequate expertise in dementia management (Lathren, Sloane, Hoyle, Zimmerman, & Kaufer, 2013), since some physicians only have a few PLWD among their patients (Jennings et al., 2016). Not all services that PLWD need are always reimbursed (Verghese, Malik, & Zwerling, 2016). Physicians are often poorly connected to social services that PLWD and their caregivers need (Hinton et al., 2007; Lathren et al., 2013), leaving non-medical community services underutilized (Reuben et al., 2013).

To improve dementia care delivery, outpatient dementia care programs originated in the UK in the 1980s (Van Der Cammen, Simpson, Fraser, Preker, & Exton-Smith, 1987). Currently, numerous dementia care programs operate worldwide, including in the U.S. (Boustani et al., 2011; LaMantia et al., 2015; Noel, Kaluzynski, & Templeton, 2017). One of the key differences between these innovative dementia care programs and mainstream dementia care is interdisciplinary staff that is essential for dementia care programs (Geldmacher & Kerwin, 2013). Patient-centered medical home is a potential alternative to the mainstream healthcare delivery for PLWD (Callahan et al., 2011). Its key defining characteristics include comprehensiveness, patient-centeredness, coordinated care, enhanced access to care, and quality and safety (Agency for Healthcare Research and Quality, n. d.). Aging Brain Care Medical Home, to our best knowledge, is the only physician-led patient-centered medical home among the U.S. dementia care programs. It is situated within a safety-net urban healthcare system. Aging Brain Care Medical Home has demonstrated efficacy in the reduction of PLWDs' depression and dementia symptoms and in the reduction of caregivers' stress (LaMantia et al., 2015).

Integrated Memory Care Clinic (IMCC) at Emory Healthcare is a dementia patient-centered medical home founded and led by advanced practice registered nurses (APRNs) (Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018). At the IMCC, APRNs provide both primary care and dementia care, such that when patients enroll to the IMCC, an APRN becomes their primary care provider. While other nurse-led dementia care programs have been reported (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014; Tappen & Valentine, 2014), to our best knowledge, no physician- or nurse-led dementia care programs in the U.S. provide both primary care and dementia care.

Dementia care programs in the U.S. predominantly reported on their clinical outcomes – metrics that characterize productivity and work organization of the care programs. These outcomes include: hospitalization and emergency department use rates among PLWD (Boustani et al., 2011); economic performance (French et al., 2014; Noel et al., 2017); assessment of workflow intensity, measured via total number of clinic visits and patient contacts (Boustani et al., 2011; Chodosh et al., 2015; Powers, Homer, Morone, Edmonds, & Rossi, 2017); and medical and pharmacologic management of PLWD (Boustani et al., 2011; Callahan et al., 2006). Other outcomes that do not center on clinical performance include PLWD- and caregiver-centered results: PLWDs' and caregivers' satisfaction with dementia care programs (Barton et al., 2014; Fortinsky et al., 2014; Reuben et al., 2013); caregivers' psychological well-being (Bass et al., 2013; Chodosh et al., 2015; Fortinsky et al., 2014); and PLWDs' depression (Bass et al., 2014; LaMantia et al., 2015) and neuropsychiatric symptoms (Fortinsky et al., 2014; Mavandadi, Wright, Graydon, Oslin, & Wray, 2017). Fewer programs reported on these outcomes (Callahan et al., 2006; Chodosh et al., 2015; LaMantia et al., 2015).

Due to the relative scarcity of research on PLWD and caregiver outcomes in the U.S. dementia care programs, this dissertation aimed to contribute to the literature by further exploring performance of a dementia care program from the perspective of consumers – PLWD and caregivers who are the IMCC clients. Several characteristics of the IMCC presented this clinic as a valuable research setting that may help discover new knowledge on dementia care programs. These characteristics included rarely encountered among dementia care programs APRN leadership at the IMCC, unprecedented to date simultaneous provision of primary care and dementia care within a dementia care program, and scarcity of research on patient-centered medical homes (Jackson & Williams, 2015). The overarching question guiding this dissertation study was: what is it like to be a client of the IMCC? The following specific aims were used in this dissertation study.

Specific aim 1. Describe changes in IMCC-affiliated caregivers' psychological well-being outcomes (caregiver burden, depressive symptoms, anxiety, stress, and distress regarding

PLWDs’ neuropsychiatric symptoms); and health status between baseline, three, and six months post-baseline. Explore factors that contribute to caregivers’ psychological well-being outcomes and health status.

Specific aim 2. Describe changes in IMCC-affiliated PLWDs’ quality of life; cognitive, behavioral, and functional symptoms; and severity of neuropsychiatric symptoms, as reported by their caregivers, between baseline, three, and six months post-baseline. Explore factors that contribute to PLWDs’ symptoms and quality of life.

Exploratory aim. Explore caregivers’ experience at the IMCC.

Significance

Statistics. The U.S. population of PLWD is expected to increase from the current 5.7 million up to 16 million by 2050. These changes are explained by the aging of the baby boomer generation (Alzheimer’s Association, 2018), and population longevity associated with advancements in biomedical research. Years of added life often bring deterioration to the quality of life (Brown, 2015), as dementia incidence increases exponentially with age (Brayne, 2007). In other words, biomedical progress does not keep pace with the need to stave off dementia, and while many illnesses can be prevented and are handled better than dementia in terms of mortality decreases (e.g., stroke, heart disease, prostate cancer) (Alzheimer’s Association, 2018), the biomedical progress fails to attain the same success with preventing cognitive deterioration. Dementia is very costly, with total costs for healthcare in the U.S., including long-term care and hospice, estimated at $277 billion in 2018 (Alzheimer’s Association, 2018). Healthcare costs for dementia are expected to exceed $1 Trillion by 2050 (Alzheimer’s Association, 2016). The cost of healthcare for PLWD exceeds that of caring for patients with heart disease and cancer (Hurd, Martorell, Delavande, Mullen, & Langa, 2013; Kelley, McGarry, Gorges, & Skinner, 2015).

Dementia. Alzheimer’s disease is the most common of all dementias, constituting 60%-80% of all age-related cognitive impairments. Other dementia types include frontotemporal dementia, Lewy body dementia, vascular dementia, and mixed dementia (Alzheimer’s Association, 2017), which add to the total dementia prevalence. All dementias are currently incurable progressive neurodegenerative diseases (Alzheimer’s Association, 2018; Kumar, Singh, & Ekavali, 2015).

Caregivers. In 2017, over 16 million Americans served as unpaid informal caregivers to their PLWD (Alzheimer’s Association, 2018). Caregivers’ unpaid labor is estimated at 18.2 billion hours annually and would cost $230.1 billion if it were provided by salaried personnel. The primary reasons why individuals decided to become caregivers for PLWD include the desire to keep the PLWD at home, as opposed to institutional settings, proximity to the PLWD, and caregivers’ perceived responsibility for the PLWD as a spouse or a partner (Alzheimer’s Association, 2018).

Caregiving is associated with some positive aspects, including reciprocity, competence and mastery, satisfaction from the fulfillment of the role of a caregiver, and faith and spiritual growth (Lloyd, Patterson, & Muers, 2016). But negative aspects of caregiving are also well-documented. As a result of caregiving, caregivers’ psychological well-being (Schulz & Sherwood, 2008) and physical health may be compromised (von Känel et al., 2010). Caregivers are considered “secondary patients” (Reinhard, Given, Petlick, & Bemis, 2008, p. 1-341). Negative outcomes for caregivers’ psychological well-being include caregiver burden (Zarit, Reever, & Bach-Peterson, 1980), stress (Kobiske, Bekhet, Garnier-Villarreal, & Frenn, 2018), anxiety (Ostojić, Vidović, Baceković, Brecić, & Jukić, 2014), depression (Monteiro, Santos, Kimura, Baptista, & Dourado, 2018), social isolation, and perceived loneliness (Kovaleva, Spangler, Clevenger, & Hepburn, 2018).

Damage to physical health follows compromise of caregivers' psychological well-being for caregivers (Kovaleva et al., 2018). Caregivers' experience is frequently characterized by chronic stress (Allen et al., 2017). Chronic stress is damaging to caregivers' immunity (Damjanovic et al., 2007) and accelerates cellular aging (Tomiyama et al., 2012). Caregivers' sacrifice of own physical and psychological well-being yields better quality of life for PLWD. Specifically, PLWD who live at home compared to institutional settings enjoy better functional ability, cognition, and social connectedness, and have fewer depressive symptoms (Nikmat, Hawthorne, & Al-Mashoor, 2015). While caregivers' labor is unpaid, their contributions cost them expenditure for their own healthcare. The damaging effect of caregiving on caregivers' emotional well-being and physical health was estimated to cost $10.9 billion worth of healthcare costs for caregivers in the U.S. in 2016 (Alzheimer's Association, 2017).

Behavioral and psychological symptoms of dementia. Behavioral and psychological symptoms of dementia, or neuropsychiatric symptoms, deserve mention in the context of caregivers' work. Behavioral and psychological symptoms of dementia are frequently referred to as a "behavioral disturbance" or "problem behaviors" (Ornstein & Gaugler, 2012, p. 2). These behaviors complicate caregivers' work (Gerlach & Kales, 2018) and are more distressing to caregivers compared to PLWDs' cognitive and functional limitations (Ornstein & Gaugler, 2012).

While all types of dementia are incurable, behavioral and psychological symptoms of dementia are modifiable. Despite the fact that the etiology of these symptoms is neuropathology, frequently co-existing and reversible factors worsen these symptoms. Nearly all PLWD exhibit these symptoms at some point during illness progression (Desai, Schwartz, & Grossberg, 2012). Behavioral and psychological symptoms predict caregiver burden and PLWDs’ institutionalization (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016). Agitation, psychosis, and wandering are principal causes of PLWDs’ institutionalization (Miller, Schneider, & Rosenheck, 2011). Behavioral and psychological symptoms of dementia are categorized into four groups. First, mood disorders include apathy and depression. Second, psychotic symptoms include hallucinations and delusions. Third, agitation includes pacing, wandering, and aggression. Fourth, sleep disturbances include insomnia, hypersomnia, and sleep-wake cycle reversal. The Neuropsychiatric Inventory (Cummings, 1997; Kaufer, 2001) also assesses PLWDs’ appetite and eating disorders, in addition to symptoms that fall into the four abovementioned categories.

Reversible factors exacerbate behavioral and psychological symptoms of dementia. They include several medications (e.g., benzodiazepines, anticholinergic medications, opiates); medical conditions (e.g., urinary tract infections, delirium, constipation, pain, dehydration); environmental causes (e.g., noise); psychosocial aspects (e.g., boredom, loneliness, physical inactivity); and factors associated with caregiving (e.g., disrespectful treatment, impatience) (Desai et al., 2012). In advanced dementia stages, behavioral symptoms (e.g., screaming) are ways in which the PLWD communicates discomfort and emotions (Bourbonnais & Ducharme, 2010). Needs related to psychosocial disturbances, such as losses of self-esteem and socialization, are the most common PLWDs’ needs, as opposed to needs for assistance with activities of daily living (van der Roest, Meiland, Maroccini, Comijs, Jonker, & Dröes, 2007). Behavioral and psychological symptoms of dementia are subject to pharmacological and non-pharmacological management (Desai et al., 2012).

Comorbidities. PLWD are prone to having comorbidities (Banerjee, 2015; Bunn et al., 2014), which implies higher healthcare use, and worse outcomes for PLWD and their informal caregivers (Boustani, Peterson, Hanson, Harris, Lohr, & U.S. Preventive Services Task Force, 2003). Several studies found that PLWD have more comorbidities than their peers without dementia (Duthie, Chew, & Soiza, 2011; Poblador-Plou et al., 2014; Sanderson, Wang, Davis, Lane, Cornman, & Fadden, 2002). Hypertension and diabetes are the two most common comorbidities for PLWD (Poblador-Plou et al., 2014). Also, PLWD frequently have geriatric syndromes, including polypharmacy (Clague, Mercer, McLean, Reynish, & Guthrie, 2017), frailty (Rogers, Steptoe, & Cadar, 2017), and malnutrition (Saka, Kaya, Bahat Ozturk, Erten, & Akif Karan, 2010).

In line with the greater comorbidity burden from which PLWD suffer is their heavy use of healthcare. PLWD are hospitalized more often than their counterparts without dementia (Phelan, Borson, Grothaus, Balch, & Larson, 2012). Additionally, PLWD are more likely to be hospitalized for ambulatory care-sensitive conditions, such as congestive heart failure, urinary tract infections, duodenal ulcers, dehydration, and bacterial pneumonia (Phelan et al., 2012). Transitions between home, hospital, and long-term care settings are frequent for PLWD (Thacker, Skelton, & Harwood, 2017). Hospitalizations pose risk for PLWD. Preoperative cognitive impairment is linked to an increased risk of delirium and mortality post-operatively (Oresanya, Lyons, & Finlayson, 2014).

Additionally, emergency department healthcare use is burdensome for PLWD, since emergency department environment can be highly distressing and provoke manifestation of behavioral and psychological symptoms (Clevenger, Chu, Yang, & Hepburn, 2012). PLWD have higher rates of emergency department use compared to older adults without cognitive impairment (Benner, Steiner, & Pierce, 2016).

Primary care. Primary care for PLWD is suboptimal. Mainstream healthcare is deficient in several aspects regarding care for PLWD. These include ineffective care delivery (Boustani, Schubert, & Sennour, 2007), inappropriate pharmacotherapy, and inadequate caregiver education and support (Jennings et al., 2015). Primary care underperforms for PLWD in part because of high “dementia burden,” (Boustani, Schubert, & Sennour, 2007, p. 631). Dementia presents a burden in primary care settings because of gradual cognitive and functional deterioration for PLWD, behavioral and psychological symptoms of dementia, and high stress and burden on informal caregivers (Boustani et al., 2007). Additionally, among all PLWD in primary care settings, their symptoms are recognized only for less than a third of PLWD (Boustani et al., 2005). Finally, pharmacotherapy for PLWD is complex and prone to inappropriate prescribing. Over 20% of PLWD receive at least one anticholinergic medication and less than 10% of PLWD get cholinesterase inhibitors (Schubert et al., 2006).

Since mainstream primary care is significantly challenged by dementia management, a potential way to solve these challenges is by delivering dementia care in the settings of a patient-centered medical home. A patient-centered medical home is not a place but rather a concept of healthcare delivery introduced by the American Academy of Pediatrics in 1967 to denote accessible, family-centered, comprehensive, continuous, coordinated, culturally effective, and compassionate care (Patient-Centered Primary Care Collaborative, n. d.). Originally, a patient-centered medical home implied centralized location for a child’s health records (American Academy of Pediatrics, n. d.). Currently, patient-centered medical homes serve adults as well (Rich, Lipson, Libersky, & Parchman, 2012).

The patient-centered medical home has been suggested as a way to bolster primary care (Aysola, Rhodes, & Polsky, 2015; Ho & Antonucci, 2015; Jackson et al., 2013; Jackson & Williams, 2015). Defining characteristics of a patient-centered medical home include: comprehensive care, patient-centeredness, coordinated care, accessible services, and quality and safety.

Comprehensive care implies that a patient-centered medical home is accountable for managing the majority of the patient’s physical and mental health concerns. Comprehensive care likewise presumes an interdisciplinary healthcare team. This can either be a large team of representatives of various specialties in a single geographical location or a virtual team of staff from various locations acting in a partnership. Patient-centeredness presumes treating the whole person and partnering with patients and their families in the delivery of healthcare. Patients and families are considered essential members of the care team. Coordinated care presumes centralization of all elements of healthcare for the patient, including specialty, acute, home, and community care. Care coordination is especially critical during patient’s transitions between care settings. Accessible services implies enhanced care access outside of business hours, round-the-clock telephone or electronic access to a clinician from the care team, and decreased wait time when patients have urgent needs. Finally, quality and safety presumes the commitment towards high quality of care and iterative quality improvement activities. Use of evidence-based practices is prioritized. Support tools for clinical decision-making are used. Client satisfaction is measured regularly and work of the medical home is adjusted in response to these satisfaction evaluations. Disseminating quality and safety data and quality improvement activities is likewise expected from a medical home (Agency for Healthcare Research and Quality, n. d.). Therefore, a patient-centered medical home may be a viable primary care option for PLWD, since the very definition of a medical home targets areas that are currently problematic in mainstream primary care for PLWD.

IMCC. The IMCC is a patient-centered medical home led by APRNs who provide both dementia care and primary care. When patients enroll into the IMCC, they transfer their primary care to the IMCC, such that the APRN assigned to them becomes their primary care provider. Several design principles that characterize the work of the IMCC have been described in detail elsewhere (Clevenger et al., 2018). Here they are presented briefly.

Comprehensive primary care and dementia care is provided. IMCC is described as a "one-stop shop" (Clevenger et al., 2018, p. 2) to clients when they enroll into the clinic, where dementia, chronic illnesses, and minor acute illnesses are managed. A geriatrician is a formal medical director of the clinic but he does not see patients. APRNs may refer PLWD to specialist physicians, but PLWD do not have regularly scheduled appointments with a physician.

Aggressive symptom management is prioritized for all dementia and non-dementia symptoms, including depression. The reason for such approach is reduction of PLWDs' suffering and optimization of their quality of life. To address these symptoms, the clinic, in line with a typical approach of a medical home (Agency for Healthcare Research and Quality, n.d.), partners with specialists who are not the IMCC employees, but whose expertise is essential for the delivery of comprehensive care. These specialists include licensed counselors, pharmacists, geriatric psychiatrist or geriatric psychiatry APRN, and psychiatric home health staff.

Every PLWD receives an individualized care plan that lists the PLWD's goals, care team, medications, and treatment strategies and instructions for dementia and other chronic illnesses. The IMCC social worker recommends non-medical resources. Caregivers can participate in two classes. The first class is the Savvy Caregiver Program (Hepburn, Lewis, Tornatore, Sherman, &

Bremer, 2007), an evidence-based psychoeducational intervention taught by an expert (IMCC social worker in this case). The Savvy Caregiver has demonstrated its efficacy in the reduction of caregiver burden, depressive symptoms, and anxiety, and in the reduction of PLWDs' frequency of behavioral and psychological symptoms of dementia. The intervention likewise demonstrated efficacy in the increase of caregiver competence, confidence, and the ability to manage caregiving situation (Hepburn, Lewis, Sherman, & Tornatore, 2003; Hepburn et al., 2007). The IMCC social worker likewise offers a class on late-stage dementia.

Thoughtful utilization of diagnostic procedures and treatments is another guiding principle at the IMCC. APRNs advise PLWD and caregivers on the judicious use of diagnostic procedures and aggressive medical management, taken in consideration with the PLWD's dementia stage, comorbidities, and preferences and wishes.

In line with the judicious utilization of all aspects of medical care is the goal to minimize unnecessary and redundant use of emergency department and inpatient care. To that end, all caregivers have year-round and round-the-clock telephone access to an APRN on duty who answers the phone outside of business hours (during business hours clients have direct telephone line to the patient access coordinator who may connect clients to the ARPNs, social worker, or registered nurse). Caregivers are encouraged to always call an APRN with any questions, with change in PLWD's symptoms, and in any instances that may prompt an emergency department or urgent care visit. This way, an APRN may intervene first by consulting with the caregiver on strategies the caregiver may implement at home before care indeed must be escalated to the level of emergency. For example, an APRN may advise on environmental modifications, medication adjustments, clinic visit, or emergency department admission. Similarly, the IMCC aims to reduce unnecessary hospitalizations by way of averting avoidable emergency department visits, since hospitalizations frequently follow emergency department visits.

Non-pharmacologic management of behavioral and psychological symptoms of dementia and non-dementia symptoms is prioritized. APRNs provide numerous strategies on non-pharmacologic management of dementia and non-dementia symptoms, including environmental modifications, adherence to a routine and structure in daily life, and provision of activities that are feasible and enjoyable to the PLWD. Pharmacotherapy is managed using the latest evidence-based geriatric prescribing guidelines. De-prescribing (Frank & Weir, 2014) of medications that may be inappropriate for older adults or PLWD is conducted according to geriatric pharmacotherapy guidelines (e.g., Beers list of potentially inappropriate medications for older adults (American Geriatrics Society Beers Criteria Update Expert Panel, 2015)). Such de-prescribing aims to minimize common adverse effects that older adult patients experience (e.g., gastrointestinal problems, syncope, falls).

A high-functioning interdisciplinary team operates in the clinic. The team consists of three APRNs, one registered nurse, a licensed clinical social worker, and a patient access coordinator. All employees have daily “huddles” where the schedule for the day is discussed and PLWD’s previous day’s emergency department visits, hospital discharges, and caregivers’ calls are reviewed. The staff meet monthly to discuss clinic workflow and continuous quality improvement (Clevenger et al., 2018).

Previous studies of dementia care programs. Dementia care programs operate worldwide (Dreier-Wolfgramm et al., 2017; Jolley & Moniz-Cook, 2009). Several collaborative dementia care programs were implemented in the U.S. For example, the Healthy Aging Brain Care is a stationary clinic situated within a safety-net healthcare system in Indianapolis, Indiana

(Boustani et al., 2011). This program demonstrated superior results in clinical management of dementia compared to a comparison primary care cohort (Boustani et al., 2011) and annual net savings of $980-$2,856/patient (French et al., 2014). An offshoot of the Healthy Aging Brain Care is the Aging Brain Care Medical Home, a mobile clinic where care coordinator assistants make regular visits to PLWD-caregiver dyads in their homes (LaMantia et al., 2015). MemoryCare is a practice serving predominantly rural low-income racially homogenous population in North Carolina (Noel et al., 2017). The University of California Alzheimer's Disease Research Center is a dementia care program where advanced practice registered nurses work collaboratively with physicians in the delivery of dementia care to PLWD (Reuben et al., 2013; Tan, Jennings, & Reuben, 2014). The University of California Alzheimer's Disease Research Center has evaluated the quality of care that is produced by the APRN-physician co-management configuration (Jennings et al., 2016). These abovementioned dementia care programs are operational and open to the public. Additionally, several dementia care programs have been tested, but they are not operational and not open to the public yet to the best knowledge of the principal investigator (Barton, Morris, Rothlind, & Yaffe, 2011; Fortinsky et al., 2014).

Previous studies of nurse-led clinics. To the best knowledge of the principal investigator, at least two American dementia care programs are led by APRNs, in addition to the IMCC. These programs are the Behavior Management Clinic (Barton et al., 2014) and the Louis and Anne Green Memory and Wellness Center (Hain, Dunn, & Tappen, 2011; Tappen & Valentine, 2014). American APRN-led clinics originated in the 1990s in New York City, when Columbia University School of Nursing founded several nurse-led clinics to provide healthcare to underserved individuals, primarily low-income immigrants (Boccuzzi, 1998). In these clinics, APRNs had hospital privileges and consulted with physicians as needed. These practices were well-accepted by the community. Furthermore, Columbia School of Nursing founded the Center for Advanced Practice Nurse Associates. This Center became the first nurse-led primary care clinic to serve a U.S.-born high-income community where patients were mostly commercially insured. As of 2000, nurses at the Center for Advanced Practice Nurse Associates received direct reimbursement from four insurers at rates that were equivalent to those for physicians (Garfield, 2000).

Rationale for this study. The rationale for this study was to obtain longitudinal descriptive quantitative and qualitative data on caregivers' and PLWDs' (based on caregivers' reports) experience at the IMCC. These data would deepen understanding of what dementia care programs may accomplish for its clients. Importantly, it would be impossible to attribute any changes in caregivers' or PLWDs' experience to the IMCC, because this is a single-system study design. Only if a comparison group had been used, as, for example, Boustani and colleagues (2011) reported, any difference in participants' experience could have been attributed to the IMCC. In the absence of a comparison group, however, only descriptive exploratory information could be attained. Nonetheless, this information would be valuable because it would use a wide spectrum of outcomes to report on PLWDs' and caregivers' experience. Based on the principal investigator's preliminary, non-systematic literature review searches that were conducted in preparation for this study, most U.S. dementia care programs reported on various clinical metrics – variables that described performance and productivity of the programs. Fewer programs reported on client outcomes, such as caregivers' psychological well-being and health status.

Additionally, to the best knowledge of the principal investigator prior to the study, no U.S. dementia care programs conducted qualitative explorations of clients' experience at dementia care programs. By contrast, programs reported on clients' satisfaction with the program (Noel et al., 2017; Reuben et al., 2013). We deemed that in-depth qualitative exploration of caregivers' and PLWDs' (as reported by caregivers) experience of the IMCC may yield unique data on clients' experience within an innovative care dementia care and primary care delivery program. Similarly, examining caregivers' and PLWDs' experience quantitatively with the use of a wider spectrum of variables may expand understanding of clients' experience beyond variables that have been explored in previous reports of dementia care programs (e.g., caregivers' stress (LaMantia et al., 2015), caregivers' depressive symptoms (Bass et al., 2013)).

Theoretical Framework

This study was guided by the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) as its theoretical framework. According to this framework, a person-environment encounter may trigger a person's cognitive appraisal followed by an emotional response. In the context of dementia caregiving, person-environment encounter presumes all caregiving-related encounters that a caregiver has. They include interaction between the caregiver and the PLWD, caregiver and other family members, caregiver and community members who are either directly related to the caregiving situation (e.g., healthcare workers) or are related to spheres of life essential to the caregiver (i.e., workplace). With plenty of evidence on the negative effect of caregiving on caregiver's psychological and physical well-being, it is logical to assume that caregivers' appraisal of their situation is likely to be negative. In other words, cognitive appraisal of numerous chronic and acute stressors that caregiving entails may be that of a highly unfavorable environment for the caregiver. Such chronic exposure to an unfavorable environment in many respects (personal well-being and health, relationship with the PLWD, relationship with other family and community members, caregivers' obligations besides caregiving, etc.) is likely to lead to a negative emotional context for the caregiver. Hence, in this study, it is logical to assume that caregiver-centered variables are directly affected by the person-environment encounter (Figure 1).

The role of the IMCC may be that of intervening in the caregiver's cognitive appraisal and consequent emotional tone. By virtue of being a client of the IMCC, the caregiver's appraisal and subsequent emotional response may be affected. This may be achieved by the various ways in which the IMCC approaches care overall, including partnership with caregivers as essential members of the care team (Clevenger et al., 2018). For example, APRNs' reassurance and explanation of dementia symptoms and discussion of disease progression may at least partially alleviate caregivers' stress, burden, and anxiety. Similarly, APRNs, social worker, and registered nurse may all provide strategies for dementia management and education about dementia that may help caregivers discern unmodifiable aspects of dementia from those that are modifiable. This realization of modifiable aspects of dementia and acceptance of unmodifiable aspects may decrease caregivers' negative emotionality and create for a calmer, more structured environment for the caregiver and the PLWD. For example, an APRN may instruct the caregiver not to "argue" with the PLWD and simplify verbal communication with the PLWD. This may decrease caregivers' negative emotionality because the caregiver's expectations of their PLWD's behavior may be lowered and hence, there would be no "reason" to feel as stressed or anxious.

Additionally, the IMCC may intervene in the person-environment encounter-appraisal-emotion cascade (Figure 1) in a way that affects PLWD-centered variables. Specifically, by affecting the caregiver's cognitive appraisal of the caregiving situation, the IMCC may indirectly influence severity of PLWDs' neuropsychiatric symptoms and quality of life. For example, if a caregiver adjusts his or her own behavior in a way that promotes a calmer, more structured and neither overstimulating nor under-stimulating environment for the PLWD, the PLWDs' symptoms may decrease in severity and the PLWDs' quality of life may improve (Figure 1).

Innovation. This study is innovative in its setting – an APRN-led dementia medical home led by APRNs. It is also innovative in its aims: quantitative and qualitative longitudinal exploration of caregivers' and PLWDs' experience in an APRN-led dementia medical home. To the best knowledge of the principal investigator, no previous studies had the same constellation of innovative factors at once, although research on physician- and nurse-led dementia care programs has been reported (Boustani et al., 2011; LaMantia et al., 2015; Reuben et al., 2013).

National priorities. Health of caregivers of PLWD is a national priority in light of the expected increase in the population of PLWD in the U.S. (Alzheimer's Association, 2018). Research on interventions for caregivers of PLWD is congruent with the mission of the National Institute on Aging to "support and conduct clinical, behavioral, [and] social research on aging," (National Institute on Aging, n. d.a). The National Institute on Aging dedicates numerous on-line informational resources for caregivers of PLWD (National Institute on Aging, n.d.b), signifying the importance of research enterprise to help this cluster of the U.S. population whose unpaid labor continues to sustain life of the population of PLWD that is expected to increase annually for the next several decades (Alzheimer's Association, 2018). Additionally, research on dementia care and interventions for caregivers of PLWD is congruent with all four focal areas of the National Institute of Nursing Research: symptom science, wellness, self-management of chronic conditions, and end-of-life and palliative care (National Institute of Nursing Research, n. d.).

Setting, participants, inclusion and exclusion criteria

The setting of this study is the IMCC. The principal investigator conducted all caregiver recruitment and all data generation and management. Only caregivers participated in the study;

PLWDs were not interviewed. In the assessment of PLWD-centered variables, caregivers acted as their PLWDs' proxies.

For the purpose of a more streamlined management of the study data, it was logically divided into its quantitative section (pertaining to Specific Aims 1&2) and qualitative section (pertaining to the Exploratory Aim). Recruitment fort the quantitative and qualitative section varied slightly. Eligibility criteria were the same for the participants of the quantitative and the qualitative sections. They included: caregiver at least 18 years old, English-speaking, and providing unpaid help to the PLWD. Whether the PLWD and caregiver lived together in the same house was optional. Only caregivers whose PLWD lived in the community (not in institutional settings or assisted living community, apart from the caregiver) were eligible. But if a caregiver lived together with the PLWD in an assisted living community or a senior residential setting, then caregivers were eligible. This case applied to several spouse caregivers who resided in an assisted living community with their spouse PLWDs. For the quantitative section of the study, caregivers were considered eligible if at baseline interview they were within the first 90 days since their first visit to the IMCC. The day of the first visit to the IMCC was considered day 1. The rationale for such window of time when caregivers were considered new to the IMCC was that typically all PLWD at the clinic are seen every 90 days. For the qualitative section, participants were considered eligible if their qualitative interview occurred within the first 12 months since their first IMCC visit.

Recruitment

The PI conducted caregiver recruitment using several means. She distributed print brochures in the IMCC. She also collaborated with the IMCC APRNs and patient access coordinator, who introduced the study to new clients of the IMCC, asking whether the PI could provide a brief introduction to the study to the clients and inquire whether the caregiver may be interested in participating. Such introductions occurred on days when the principal investigator was present at the clinic. However, most caregivers were recruited in the following manner. The principal investigator regularly surveyed the IMCC health records for newly enrolled clients. If, based on the health records, caregivers appeared eligible, the principal investigator provided the names and contact information of the respective caregivers to the patient access coordinator who then inquired with these caregivers regarding their interest in the study participation. If caregivers were preliminarily interested in the study participation and gave consent to be contacted by email and/or telephone by the principal investigator, she contacted the caregivers and screened them for eligibility. If caregivers were eligible and still interested in the study participation, they gave their verbal agreement to participate. Verbal consent form was used. Emory University Institutional Review Board approved the study.

Recruitment for the quantitative section occurred first. After caregivers completed the baseline interview pertaining to the quantitative section of the study, the principal investigator inquired with these caregivers whether they may be interested in participating in a qualitative interview regarding their experience at the IMCC at approximately six months post-baseline. The principal investigator continued to proceed in the same manner with recruiting participants until a planned sample of 12 caregivers for the qualitative section was attained. The rationale for such sample size is discussed in the qualitative section of this dissertation. Detailed description of how recruitment for the quantitative and for the qualitative sections proceeded is provided in the qualitative section of this study (the fourth chapter of the dissertation).

Approach

This dissertation study was a longitudinal exploratory cohort study without a comparison group. The study proceeded using three parts: a scoping review of the literature, a quantitative section, and a qualitative section.

First, a scoping review of the literature on the U.S. dementia care programs since 2011 was conducted. The detailed description of the methods used to conduct the scoping review are in the scoping review section of this dissertation study (the second dissertation chapter). The rationale for the conduct of the scoping review was to provide context for the IMCC. The questions of the scoping review were: “What are the outpatient dementia care programs in the U.S.? What are their similarities and differences? What have they achieved? What is understudied or unknown about them?” Answering these questions would allow us to position the IMCC in context with previously reported dementia care programs and better understand how the IMCC is similar to and differs from other American dementia care programs. The scoping review also would allow to identify areas that are insufficiently researched and enable to answer how this dissertation study contributes to the field of dementia care programs. In other words, it was necessary to understand what other dementia care programs attained and what outcomes their investigators reported to clearly establish how this dissertation study is built upon the previous research and how it deepens understanding of dementia care programs in the U.S. Comparison of key elements of the IMCC with those of other U.S. dementia care programs are discussed in the conclusion section of this dissertation study (chapter 5).

The quantitative section of this dissertation study pertains to the Specific Aims 1&2. This section was intended to answer the broad questions: what PLWD- and caregiver-centered outcomes change over time in the IMCC? If any of the outcomes change, what predicts such changes? The quantitative section was intended to report on outcomes that are commonly used in dementia caregiving and geriatrics research. It was anticipated that any outcomes that would demonstrate significant change over time would signify potentially efficacious management of those outcomes at the IMCC. This claim, however, is made with a caveat that the only definitive way to ascertain the role of the IMCC in the changes in caregiver- and PLWD-centered outcomes would be to conduct a study with a comparison group.

The qualitative section of this dissertation study pertains to the Exploratory Aim. This section was intended to answer the question: what is caregivers' experience of the IMCC? This section was intended to contribute to the literature by providing the first known-to-date information obtained qualitatively on clients' experience with a dementia care program in the U.S. It was anticipated that caregivers' narratives would yield information on ways in which the IMCC, other dementia care programs, and mainstream healthcare may improve its delivery of dementia care and primary to PLWD.

Quantitative section of the study design and methods

The quantitative section of the study consisted of three interviews that used validated instruments that assessed caregivers' psychological well-being and health status and PLWDs' neuropsychiatric symptoms and quality of life. The principal investigator created a sociodemographic survey that evaluated several baseline sociodemographic characteristics of the caregiver and the PLWD, along with several measures that described the caregiving situation (e.g., the length of time the caregiver had been caring for the PLWD).

The first (baseline) interview occurred within the first 90 days of the caregiver's enrollment in the IMCC. Follow-up interviews occurred three and six months after the baseline interview. All interviews occurred via telephone to minimize participant burden. The only exception was for one caregiver who had substantial hearing loss, which prompted the principal investigator to conduct the three interviews of the quantitative section in-person. Participants were reimbursed with gift cards for each interview. In the quantitative section, participants were reimbursed with $15, $20, and $25 gift cards for the baseline, 3-month, and 6-month interview, respectively.

The principal investigator mailed or emailed all questionnaire forms to the caregivers before the interview to facilitate the interview. The principal investigator recorded participants' responses on paper forms. The responses were then transferred into the RedCap database (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009).

All quantitative data were obtained via telephone interviews with caregivers. The only exception was assessment with the use of the Neuropsychiatric Inventory (Cummings, 1997; Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, & Gornbein, 1994; Kaufer et al., 2000). The principal investigator administered this instrument only at the 3-month interview. For the baseline and 6-month interviews, the principal investigator collected respective data from the IMCC health records because the IMCC administered this instrument to its clients every six months.

The total number of visits that the clients made to the clinic between their first visit and before the 6-month interview was ascertained via the IMCC health records by the principal investigator. Similarly, to record comorbidities that the PLWD had on admission to the IMCC, the principal investigator used the IMCC health records.

Sample size: quantitative section. A power analysis was conducted before the study. This power analysis yielded the number of 54 caregivers as the goal. Power analysis was conducted using G*Power version 3.1.9.2 software (G*Power, n. d.). For the power analysis and required sample size calculation, repeated measures analysis of variance, within factors test, was used. Results of an interventional study with caregivers for PLWD that used several of the same caregiver-centered variables were used for the power analysis (Griffiths, Kovaleva, Higgins, Langston, & Hepburn, 2018). The reference study used a paired samples *t*-test to examine six-week changes in caregiver burden, depressive symptoms, number of behavioral and psychological symptoms of dementia that occur daily or more often, and average frequency of PLWDs' behavioral and psychological symptoms. Effect sizes were calculated with Cohen's f^2 because it is appropriate in repeated measures designs (Selya, Rose, Dierker, Hedeker, & Mermelstein, 2012). The relationship between Cohen's f^2 and Cohen's d is: $f^2 = d^2/2k$, where k is the number of groups. Here k=1 – the entire sample of caregivers. The final expected group of caregivers in this sample was 45 caregivers after an anticipated 20% attrition from the baseline sample of 54 caregivers. Eighty percent power was used. Alpha was considered 0.05. With these specifications, it was estimated that a repeated measures analysis of variance for one group and three repeated measurements would be able to detect an effect size of $f^2 = 0.47$. This effect size is is considered large (with $f^2 = 0.1$, 0.25, and 0.4 denoting a small, a medium, and a large effect size, respectively) (Cohen, 1988). Power analysis produced a range of effect sizes: a sample size of 25 participants would enable detection of the effect size of 0.64, and a sample size of 60 participants would enable detection of the effect size of 0.41 (G*Power, n. d.).

Variables and measures. With the exception of the sociodemographic questionnaire that the principal investigator created and used in the baseline quantitative interview, all instruments were validated and were used previously. Instruments included a variety of caregiver distress measures. Additionally, several instruments were used for caregivers' assessments of their PLWDs' symptoms and quality of life.

Quantitative data analysis. Changes in PLWD- and caregiver-centered outcomes were studied with the use of mixed linear models (Field, 2014; Seltman, 2018; Singer & Willett, 2003). This method is advantageous for analyzing change over time because missing data are permissible (Singer & Willett, 2003). For the analysis of outcomes over time, time of each interview (baseline, 3-month, and 6-month) was measured in months since the caregiver's first visit to the IMCC. The date of the first visit to the IMCC was considered time 0. Even though there were three data collection time points, it is recommended to use actual time of the interview as the predictor variable, since it most closely approximates the respondent's state at that point in time (Singer & Willett, 2003). Thus, for all main analyses time was used as a covariate. Time was used as a fixed effect and no random intercepts or slopes were specified (Singer & Willett, 2003). For outcomes that demonstrated significant change over time, analyses were re-run with only completers (caregivers who completed the last interview) and with both completers and non-completers (including caregivers who discontinued study participation either after the baseline or the 3-month interview for reasons such as death or institutionalization of their PLWD). This was done to observe whether significant changes could be attributed only to non-completers, as, presumably, their PLWDs' symptoms were more severe at baseline causing the caregiver to discontinue the study. Additionally, for outcomes that changed significantly over time, post hoc analyses were run to observe where between the three data collection time points a significant change occurred. To that end, time was treated as a factor and Sidak adjustment was used. All data were analyzed in IBM SPSS Statistics version 24 (IBM Corporation, 2016). In-depth description of quantitative data analysis is provided in the quantitative section of this dissertation (chapter 3).

Qualitative study design and methods

For the qualitative interviews, caregivers were interviewed about their experience of the IMCC. The key question guiding each interview was: “Please tell me about your experience at the IMCC to date.” Additional questions were used to probe caregivers and help them expand on their narrative. The date of qualitative interviews was determined at approximately six months after the completion of the baseline quantitative interview.

All interviews occurred via telephone to minimize participant burden. Limitations of qualitative interview via telephone (Novick, 2008) are noted in the qualitative study section of this dissertation. Participants were reimbursed with a $25 gift card for the qualitative interview.

The principal investigator audiorecorded each interview. The audiorecordings were professionally transcribed. The principal investigator proofed the transcript of each interview against the audiorecording, while eliminating any details from the transcript that may have revealed the participant’s identity (e.g., the first name of the PLWD) or compromised confidentiality of the information that caregivers shared.

Sample size: qualitative section. A number of 12 caregivers to participate in the qualitative section of this dissertation was selected arbitrarily. It was deemed adequate and appropriate (Morse, 1991) to answer the research question while accounting for time and practical considerations discussed in the qualitative section of this dissertation (chapter 4).

Qualitative data analysis. Qualitative description was the chosen methodology (Sandelowski, 2000), as this method allows to explore events that are relevant to practitioners and that presumes the use of everyday language of those who participate in the event under study (here, caregivers at the IMCC). Directed content analysis was used to analyze the data (Hsieh & Shannon, 2005). Directed content analysis was selected because it allows to only focus on a predetermined area of participants' narrative and ignore other comments. For this dissertation study the principal investigator only focused on caregivers' accounts of their IMCC experience, ignoring discussion of other aspects that may have been important to participants (e.g., gaining skills as a caregiver, concerns about own mental health, etc.). Constant comparison was used to inductively code the data (Miles & Huberman, 1994). In-depth description of the qualitative data analysis is in the qualitative section of this dissertation (fourth chapter of the dissertation).

References

Agency for Healthcare Research and Quality. (n. d.). Defining the PCMH. Retrieved from https://pcmh.ahrq.gov/page/defining-pcmh

Allen, A. P., Curran, E. A., Duggan, A., Cryan, J. F., Chorcoráin, A.N., Dinan, T. G., . . . Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience and Biobehavioral Reviews*, *73*, 123-164. doi: 10.1016/j.neubiorev.2016

Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. *Alzheimers & Dementia, 13*(4), 325-373. https://doi.org/10.1016/j.jalz.2017.02.001

Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 14*(3), 367-429. doi: https://doi.org/10.1016/j.jalz.2018.02.001

American Geriatrics Society Beers Criteria Update Expert Panel. (2015). American Geriatrics Society 2015 updated Beers criteria for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society, 63*(11), 2227-2246. doi: 10.1111/jgs.13702

American Academy of Pediatrics. (n. d.). What is medical home? Retrieved from https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx

Aysola, J., Rhodes, K. V., & Polsky, D. (2015). Patient-centered meidcal homes and access to services for new primary care patients. *Medical Care, 53*(10), 857-862. doi: 10.1097/MLR.0000000000000412

Banerjee, S. (2015). Multimorbidity – older adults need health care that can count past one. *Lancet, 385*(9968), 587-589. doi: 10.1016/S0140-6736(14)61596-8

Barton, C., Merrilees, J., Ketelle, R., Wilkins, S., & Miller, B. (2014). Implementation of advanced practice nurse clinic for management of behavioral symptoms in dementia: A dyadic intervention (innovative practice). *Dementia, 13*(5), 686-696. doi: 10.1177/1471301213519895

Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R., Looman, W. J., . . . Kunik, M. E. (2013). Caregiver outcomes of Partners in Dementia Care: Effect of a care coordination program for veterans with dementia and their family members and friends. *Journal of the American Geriatrics Society, 61*(8), 1377-1368. doi: 10.1111/jgs.12362.

Bass, D. M., Judge, K. S., Snow, A. L, Wilson, N. L., Morgan, R. O., Maslow, K., . . . Kunik, M. E. (2014). A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimer's Research & Therapy, 6*(1), 9. doi: 10.1186/alzrt242

Benner, M., Steiner, V., & Pierce, L. L. (2016). Family caregivers' reports of hospitalizations and emergency department visits in community-dwelling individuals with dementia. *Dementia (London).* Advance on-line publication. doi: 10.1177/1471301216653537

Boccuzzi, N. K. CAPNA: A new development to increase quality in primary care. Columbia Advanced Practice Nurse Associates. *Nursing Administration Quarterly, 22*(4), 11-19.

Borson, S., & Chodosh, J. (2014). Developing dementia-capable healthcare systems. *Clinics in Geriatric Medicine, 30*(3), 395-420. doi: 10.1016/j.cger.2014.05.001

Bourbonnais, A., & Ducharme, F. (2010). The meanings of screams in older people living with dementia in a nursing home. *International Psychogeriatrics, 22*(7), 1172-1184. doi: 10.1017/S1041610209991670

Boustani, M., Peterson, B., Hanson, L., Harris, R., Lohr, K. N., & U.S. Preventative Services Task Force. (2003). Screening for dementia in primary care: A summary of the evidence for the U.S. Preventative Services Task Force. *Annals of Internal Medicine, 138*(11), 927-937.

Boustani, M., Callahan, C. M., Unverzagt, F. W., Austrom, M. G., Perkins, A. J., Fultz, B. A., . . . Hendrie, H. C. (2005). Implementing a screening and diagnosis program for dementia in primary care. *Journal of General Internal Medicine, 20*(7), 572-577.

Boustani, M., Schubert, C., & Sennour, Y. (2007). The challenge of supporting care for dementia in primary care. *Clinical Interventions in Aging, 2*(4), 631-636.

Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M., . . . Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health, 15*(1), 13-22. doi: 10.1080/13607863.2010.49644

Brayne, C. (2007). The elephant in the room – healthy brains in later life, epidemiology and public health. *Nature Reviews. Neuroscience, 8*(3), 233-239.

Brown, G. C. (2015). Living too long. The current focus of medical research on increasing the quantity, rather than the quality, of life is damaging our health and harming the economy. *EMBO reports, 16*(2), 137-141. doi:10.15252/embr.201439518

Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine, 12*, 192. doi:10.1186/s12916-014-0192-4

Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., . . . Hendrie, H. C. (2006). Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: A randomized controlled trial. *JAMA, 295*(18), 2148-2157. doi:10.1001/jama.295.18.2148

Callahan, C. M., Boustani, M., Sachs, G. A., & Hendrie, H. C. (2009). Integrating care for older adults with cognitive impairment. *Current Alzheimer Research, 6*(4), 368-374.

Callahan, C. M., Boustani, M. A., Weiner, M., Beck, R. A., Livin, L. R., Kellams, J. J., . . . Hendrie, H. C. (2011). Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging & Mental Health, 15*(1), 5-12. doi: 10.1080/13607861003801052

Cepoiu-Martin, M., Tam-Tham, H., Patten, S., Maxwell, C. J., & Hogan, D. B. (2016). Predictors of long-term care placement in persons with dementia: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*. Advance online publication. doi:10.1002/gps.4449

Chodosh, J., Colaiaco, B. A., Connor, K. I., Cope, D. W., Liu, H., Ganz, D. A., . . . Vickrey, B. G. (2015). Dementia care management in an underserved community: The comparative effectiveness of two different approaches. *Journal of Aging & Health, 27*(5), 864-893. doi: 10.1177/0898264315569454

Clague, F., Mercer, S. W., McLean, G., Reynish, E., & Guthrie, B. (2017). Comorbidity and polypharmacy in people with dementia: Insights from a large, population-based cross-sectional analysis of primary care data. *Age & Ageing, 46*(1), 33-39. doi: 10.1093/ageing/afw176

Clevenger, C. K., Cellar, J., Kovaleva, M., Medders, L., & Hepburn, K. (2018). Integrated Memory Care Clinic: Design, implementation, and initial results. *Journal of the American Geriatrics Society.* Advance on-line publication. doi: 10.1111/jgs.15528

Clevenger, C. K., Chu, T. A., Yang, Z., & Hepburn, K. W. (2012). Clinical care of persons with dementia in the emergency department: A review of the literature and agenda for research. *Journal of the American Geriatrics Society, 60*(9), 1742-1748. doi: 10.1111/j.1532-5415.2012.04108.x.

Cohen, J. (1988). *Statisical Analysis for the Behavioral Sciences* (2nd ed.). New York, NY: Psychology Press.

Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44,* 2308-2314.

Cummings, J. (1997). The neuropsychiatric inventory: Assessing psychopathology in dementia patients. *Neurology*, *48*(Supple 6), S10-S16.

Damjanovic, A. K., Yang, Y., Glaser, R., Kiecolt-Glaser, J. K., Nguyen, H., Laskowski, B., . . . Weng, N. P. (2007). Accelerated telomere erosion is associated with a declining immune function of caregivers of Alzheimer's disease function. *Journal of Immunology*, *179*(6), 4249-42d54.

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Current Psychiatry Reports, 14*(4), 298-309. doi: 10.1007/s11920-012-0288-5

Dreier-Wolfgramm, A., Michalowsky, B., Austrom, M. G., van der Marck, M. A., Illiffe, S., Alder, C., . . .Hoffmann, W. (2017). Dementia care management in primary care: Current collaborative care models and the case for interprofessional education. *Zeitschrift für Gerontologie und Geriatrie, 50*(Suppl 2), 68-77. doi: 10.1007/s00391-017-1220-8

D'Souza, M. F., Davagnino, J., Hastings, S. N., Sloane, R., Kamholz, B., & Twersky, J. (2015). Preliminary data from the Caring for Older Adults and Caregivers at Home (COACH) program: A care coordination program for home-based dementia care and caregiver support in a Veterans Affairs Medical Center. *Journal of the American Geriatrics Society, 63*(6), 1203-1208. doi: 10.1111/jgs.13448

Field, A. (2014). *Discovering statistics using IBM SPSS statistics* (4th ed.): SAGE.

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J . . . Crumb, S. (2014). Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Research in Gerontological Nursing, 7*(3), 126-137. doi:10.3928/19404921-20140113-01

Frank, C., & Weir, E. (2014). Deprescribing for older patients. *CMAJ, 186*(18), 1369-1376. doi: https://doi.org/10.1503/cmaj.131873

French, D. D., LaMantia, M. A., Livin, L. R., Herceg, D., Alder, C. A., Boustani, M. A. (2014). Healthy Aging Brain Center improved care coordination and produced net savings. *Health Affairs, 33*(4), 613-618. doi: 10.1377/hlthaff.2013.1221

Friedman, E. M., Shih, R. A., Langa, K. M., & Hurd, M. D. (2015). U.S. prevalence and predictors of informal caregiving for dementia. *Health Affairs*, *34*(10), 1637-1641. doi: 10.1377/hlthaff.2015.0510

G*Power. (n.d.). G*Power (version 3.1.9.2) [computer software]. Kiehl, Germany: Universitat Kiehl.

Garfield, R. (2000). The marketability of nurse practitioners in New York City. *Nursing Economics*, *18(*1), 20-2, 31.

Geldmacher, D. S., & Kerwin, D. R. (2013). Practical diagnosis and management of dementia due to Alzheimer's disease in the primary care setting: An evidence-based approach. *The Primary Care Companion for CNS Disorders, 15*(4). doi: 10.4088/PCC.12r01474

Gerlach, L. B., & Kales, H. C. (2018). Managing behavioral and psychological symptoms of dementia. *The Psychiatric Clinics of North America, 41*(1), 127-139. doi: 10.1016/j.psc.2017.10.010

Griffiths, P. C., Whitney, M. K., Kovaleva, M., & Hepburn, K. (2016). Development and implementation of Tele-Savvy for dementia caregivers: A department of Veterans Affairs clinical demonstration project. *The Gerontologist,* 56(1), 145-154. doi: 10.1093/geront/gnv123

Griffiths, P. C., Kovaleva, M., Higgins, M., Langston, A. H., & Hepburn, K. (2018). Tele-Savvy: An online program for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 33*(5), 269-276. doi: 10.1177/1533317518755331

Guest, G. (2012). Describing mixed methods research: An alternative to typologies. *Journal of Mixed Methods Research, 7*(2), 141-151. https://doi.org/10.1177/1558689812461179

Hain, D., Dunn, D. J., & Tappen, R. M. (2011). Patient-provider partnership in a memory disorder center. *Journal of the American Academy of Nurse Practitioners, 23*(7), 351-356. doi: 10.1111/j.1745-7599.2011.00619.x

Harris, P. A., Taylor, R., Thielke, R., Payne,. J., Gonzalez. N., & Conde, J. G. (2009). Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377-381. doi: 10.1016/j.jbi.2008.08.010

Hepburn, K., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist, 43*(6), 908-915. doi:10.1093/geront/43.6.908

Hepburn, K., Lewis, M., Tornatore, J., Sherman, C. W., & Bremer, K. L. (2007). The Savvy Caregiver Program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing, 33*(3), 30-36. doi:10.1093/geront/43.6.908

Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *Journal of General Internal Medicine, 22*(11), 1487-1492. doi:10.1007/s11606-007-0317-y

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. doi: 10.1177/1049732305276687

Ho, L., & Antonucci, J. (2015). The dissenter's viewpoint: There has to be a better way to measure a medical home. *Annals of Family Medicine, 13*(3), 269-272. doi: 10.1370/afm.1783.

Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine, 368*(14), 1326-1334. doi: 10.1056/NEJMsa1204629

IBM Corp. (2016). IBM SPSS Statistics for Windows (Version 24.0) [Software]. Armonk, NY: IBM Corp.

Jackson, G. L., Powers, B. J., Chatterjee, R., Bettger, J. P., Kemper, A. R., Hasselblad, V., . . . Williams, J. W. (2013). Improving patient care. The patient centered medical home. A systematic review. *Annals of Internal Medicine, 158*(3), 169-178. doi:10.7326/0003-4819-158-3-201302050-00579

Jackson, G. L., & Williams, J. W. Jr. (2015). Does PCMH "work?" – The need to use implementation science to make sense of conflicting results. *JAMA Internal Medicine, 175*(8), 1369-1370. doi: 10.1001/jamainternmed.2015.2067

Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., . . . Wenger, N. S. (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of the American Geriatrics Society*, *63*(2), 282-289. doi: 10.1111/jgs.13251

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., . . . Reuben, D. B. (2016). Quality of care provided by a comprehensive dementia co-management program. *Journal of the American Geriatrics Society, 64*(8), 1724-1730. doi: 10.1111/jgs.14251

Jolley, D., & Moniz-Cook, E. (2009). Memory clinics in context. *Indian Journal of Psychiatry, 51 Suppl 1*, S70-76.

Kaufer, D. L., Cummings, J, L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., . . . DeKosky, T. (2000). Validation of the NPI-Q, a brief form of the Neuropsychiatric Inventory. *Journal of Neuropsychiatry and Clinical Neuroscience, 12*(2), 233-239. doi:10.1176/jnp.12.2.233

Kelley, A. S., McGarry, K., Gorges, R., & Skinner, J. S. (2015). The burden of health care costs for patients with dementia in the last 5 years of life. *Annals of Internal Medicine, 163*(10), 729-736. doi: 10.7326/M15-0381

Kobiske, K. R., Bekhet, A. K., Garnier-Villarreal, M., & Frenn, M. (2018). Predeath grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. *Western Journal of Nursing Research.* Advance on-line publication. doi: 10.1177/0193945918806689

Kovaleva, M. A., Spangler, S. A., Clevenger, C., & Hepburn, K. (2018). Chronic stress, social isolation, and perceived loneliness among dementia caregivers. *Journal of Psychosocial Nursing and Mental Health Services, 56*(10), 36-43. doi: 10.3928/02793695-20180329-04

Kumar, A., Singh, A., & Ekavali. (2015). A review on Alzheimer's disease pathophysiology and its management: An update. *Pharmacological Reports, 67*(2), 195-203. doi: 10.1016/j.pharep.2014.09.004

Lathren, C. R., Sloane, P. D., Hoyle, J. D., Zimmerman, S., & Kaufer, D. I. (2013). Improving dementia diagnosis and management in primary care: A cohort study of the impact of a training and support program on physician competency, practice patterns, and community. *BMC Geriatrics, 13,* 134. doi: 10.1186/1471-2318-13-134

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer Publishing Company.

LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G., . . . Boustani, M. A. (2015). The Aging Brain Care Medical Home: Preliminary data. *Journal of the American Geriatrics Society, 63*(6), 1209-1213. doi:10.1111/jgs.13447

Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15* (6), 1534-1561. doi: 10.1177/1471301214564792

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia. *Psychological Services, 14*(1), 102-111. doi: 10.1037/ser0000118

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook.* Thousand Oaks, CA: Sage Publications.

Miller, E. A., Schneider, L. S., & Rosenheck, R. A. (2011). Predictors of nursing home admission among Alzheimer's disease patients with psychosis and/or agitation. *International Psychogeriatrics, 23*(1), 44-53. doi: 10.1017/S1041610210000244

Monahan, P. O., Boustani, M. A., Alder, C., Galvin, J. E., Perkins, A. J., Healey, P., . . . Callahan, C. (2012). Practical clinical tool to monitor dementia symptoms: The HABC-Monitor. *Clinical Interventions in Aging, 7*, 143-157. doi: 10.2147/CIA.S30663

Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer's disease: A systematic review. *Trends in Psychiatry and Psychotherapy, 40*(3), 258-268. doi: 10.1590/2237-6089-2017-0065

Morse, J. (1991). *Qualitative nursing research: A contemporary dialogue.* Thousand Oaks, CA: Sage Publications.

National Institute of Nursing Research. (n.d.). Mission & strategic plan. Retrieved from https://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan

National Institute on Aging. (n.d.a). Mission. Retrieved from https://www.nia.nih.gov/about/mission

National Institute on Aging. (n.d.b). Caregiving. Retrived from https://www.nia.nih.gov/health/caregiving

NCQA. (n. d.). Program structure: ACO accreditation. Retrieved from https://www.ncqa.org/programs/health-care-providers-practices/accountable-care-organizations-aco/structure/

Nikmat, A. W., Al-Mashoor, S. H., & Hashim, N. A. (2015). Quality of life in people with cognitive impairment: Nursing homes versus home care. *International Psychogeriatrics, 27*(5), 815-824. doi: 10.1017/S1041610214002609

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality dementia care. *Journal of the Applied Gerontology, 36*(2), 195-212. doi: 10.1177/0733464815589986

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health, 31*(4), 391-398. doi: 10.1002/nur.20259

Oresanya, L. B., Lyons, W. L., & Finlayson, E. (2014). Preoperative assessment of the older patient: A narrative review. *JAMA, 311*(20), 2110-2120. doi: 10.1001/jama.2014.4573

Ornstein, K., & Gaugler, J. E. (2012). The problem with "problem behaviors": a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *International Psychogeriatrics, 24*(10), 1536-1552. doi: 10.1017/S1041610212000737

Ostojić, D., Vidović, D., Baceković, A., Brecić, P., & Jukić, V. (2014). Prevalence of anxiety and depression in caregivers of Alzheimer's dementia patients. *Acta Clinica Croatica, 53*(1), 17-21.

Patient-Centered Primary Care Collaborative. (n.d.). History. Retrieved from https://www.pcpcc.org/content/history-0

Phelan, E. A., Borson, S., Grothaus, L., Balch, S., & Larson,. E. B. (2012). Association between incident dementia and risk of hospitalization. *JAMA, 307*(2), 165-172. doi: [10.1001/jama.2011.1964]

Poblador-Plou, B., Calderón-Larrañaga, A., Marta-Moreno, J., Hancco-Saavedra, J., Sicras-

Mainar, A., Soljak, M., & Prados-Torres, A. (2014). *BMC Psychiatry, 14,* 84. doi: 10.1186/1471-244X-14-84

Powers, B. P., Homer, M. C., Morone, N., Edmonds, N., & Rossi, M. I. (2017). Creation of an interprofessional teledementia clinic for rural veterans: Preliminary data. *Journal of the American Geriatrics Society, 65*(5), 1092-1099. doi: 10.1111/jgs.14839

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses*. Rockville, MD: Agency for Healthcare Research and Quality (U.S.).

Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society, 61*(12), 2214-2218. doi: 10.1111/jgs.12562

Rich, E., Lipson, D., Libersky, J,. & Parchman, M. (2012). Coordinating care for adults with complex care needs in the patient-centered medical home: Challenges and solutions. AHRQ Publication No. 12-0010-EF. Rockville, MD: Agency for Healthcare Research and Quality.

Rogers, N. T., Steptoe, A., & Cadar, D. (2017). Frailty is an independent predictor of incident dementia: Evidence from the English Longitudinal Study of Ageing. *Scientific Reports, 7*(1), 15746. doi: 10.1038/s41598-017-16104-y

Saka, B., Kaya, O., Bahat Ozturk, G., Erten, N., & Akif Karan, M. (2010). Malnutrition in the elderly and its relationship with other geriatric syndromes. *Clinical Nutrition, 29*(6), 745-748. doi: https://doi.org/10.1016/j.clnu.2010.04.006

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. American Journal of Nursing, 108(9 Suppl), 23-27. doi: 10.1097/01.NAJ.0000336406.45248.4c

Seltman, H. J. (2018). *Experimental design and analysis.* Retrieved from http://www.stat.cmu.edu/~hseltman/309/Book/Book.pdf

Selya, A. S., Rose, J. S., Dierker, L. C., Hedeker, D., & Mermelstein, R. J. (2012). A practical guide to calculating Cohen's f(2), a measure of local effect size, from PROC MIXED. *Frontiers in Psychology, 3,* 111. doi: 10.3389/fpsyg.2012.00111

Tan, Z. S., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large, academic health system. *Health Affairs, 33*(4), 619-625. doi: 10.1377/hlthaff.2013.1294

Tappen, R. M., & Valentine, K. (2014). Building and sustaining a caring-based nurse-managed center. *Pennsylvania Nurse, 69*(2), 16-21.

Thacker, S., Skelton, M., & Harwood, R. (2017). Psychiatry and the geriatric syndromes – creating constructive interfaces. *BJPsych Bulletin, 41*(2), 71-75. doi: 10.1192/pb.bp.115.051649

Todd, S., Barr, S., Roberts, M., & Passmore, A. P. (2013). Survival in dementia and predictors of mortality: A review. *International Journal of Geriatric Psychiatry, 28*(11), 1109-24. doi: 10.1002/gps.3946

Tomiyama, A. J., O'Donovan, A., Lin, J., Puterman, E., Lazaro, A., Chan, J., . . . Epel, E. (2012). Does cellular aging relate to patterns of allostasis? An examination of basal and stress reactive HPA axis activity and telomere length. *Physiology & Behavior, 106*(1), 40-45. doi: 10.1016/j.physbeh.2011.11.016

Van der Cammen, T. J., Simpson, J. M., Fraser, R. M., Preker, A. S., & Exton-Smith, A. N. (1987). The Memory Clinic. A new approach to the detection of dementia. *British Journal of Psychiatry, 150,* 359-364.

Van der Roest, H. G., Meiland, F. J., Maroccini, R., Comijs, H. C., Jonker, C., & Dröes, R. M. (2007). Subjective needs of people with dementia: A review of the literature. *International Psychogeriatrics, 19*(3), 559-592. doi:10.1017/S1041610206004716

Verghese, J., Malik, R., & Zwerling, J. (2016). Montefiore-Einstein Center for the Aging Brain: Preliminary data. *Journal of the American Geriatrics Society, 64*(11), 2374-2377. doi: 10.1111/jgs.14473

von Känel, R., Mausbach, B. T., Dimsdale, J. E., Mills, P. J., Patterson, T. L., Ancoli-Israel, S., . . . Grant, I. (2010). Problem behavior of dementia patients predicts low-grade hypercoagulability in spousal caregivers. *The Journals of Gerontology A: Biological Sciences and Medical Sciences, 65A*(9), 1004-1011. doi: 10.1093/gerona/glq073

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655. doi:10.1093/geront/20.6.649

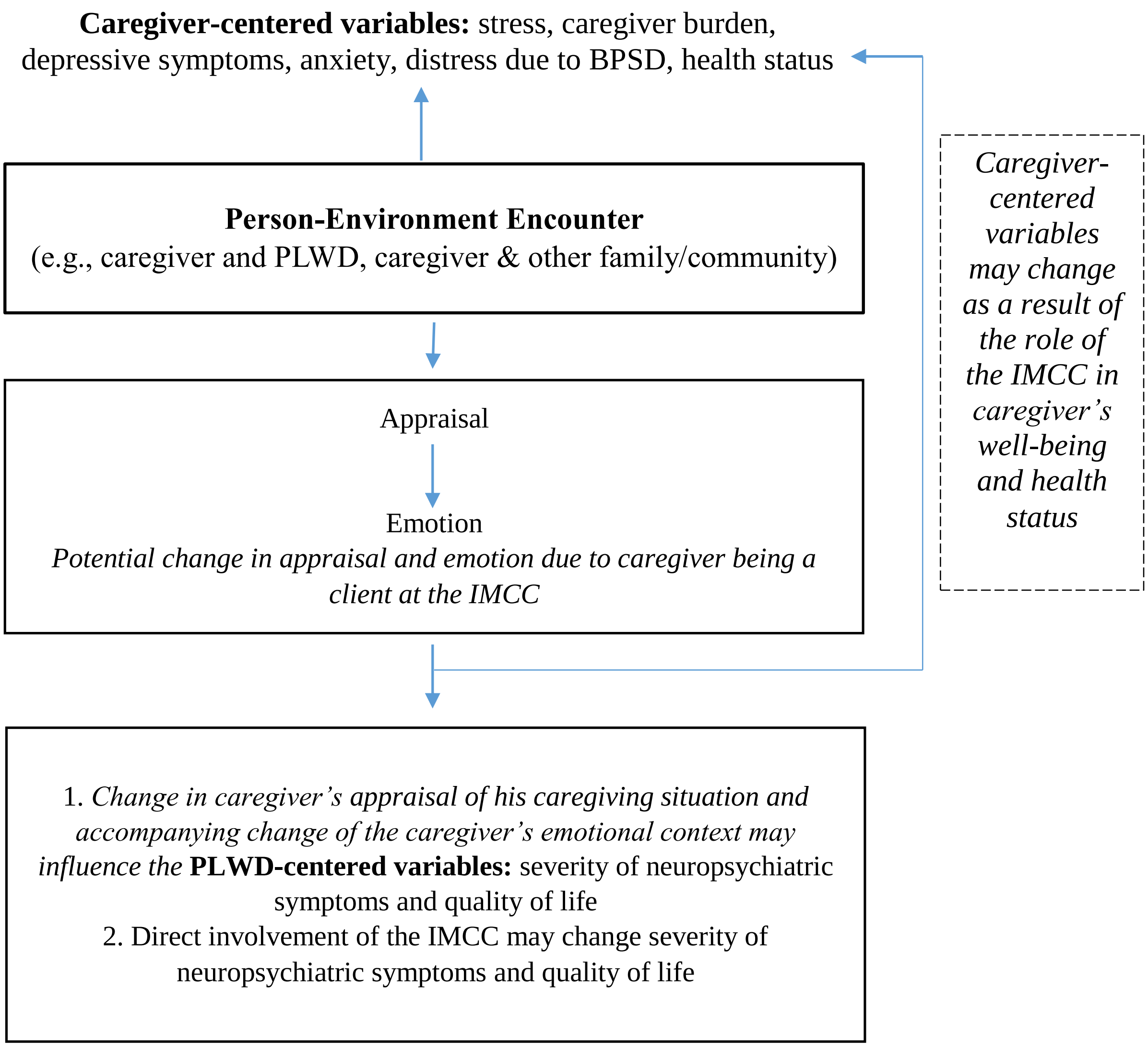

Figure 1. Theoretical framework. PLWD = person living with dementia. IMCC = Integrated Memory Care Clinic.

Outpatient Dementia Care Programs in the U.S. since 2011: Scoping Review

The U.S. population of persons living with dementia (PLWD) is expected to increase from the current 5.7 million up to 16 million by 2050 (Alzheimer's Association, 2018a). Most PLWD are cared for by their informal unpaid caregivers (Friedman, Shih, Langa, & Hurd, 2015). Approximately 15 million caregivers helped PLWD in 2016. Unpaid caregivers' labor is estimated at over $232 billion (Alzheimer's Association, 2018a).

Despite the increasing population of PLWD, the current U.S. primary care system does not meet this group's needs. Primary care for PLWD is suboptimal and heterogeneous – a "matter of luck," not a rule (Borson & Chodosh, 2014, p. 396). Most PLWD receive dementia care from primary care physicians (Callahan, Boustani, Sachs, & Hendrie, 2009) who frequently lack the expertise (King et al., 2015) and time to provide dementia care, encounter difficulties with accessing specialists, lack an interdisciplinary approach, and are dis-incentivized by low reimbursement (Hinton, Franz, Reddy, Flores, Kravitz, & Barker, 2007). Dementia is neither uniformly diagnosed in primary care, nor is it always documented in health records (Mitchell, Meader, & Pentzek, 2011). Care coordination with referring providers, communication with PLWD-caregiver dyads outside visits, and counseling are important features in dementia care, but they are not may always reimbursed (Verghese, Malik, & Zwerling, 2016). Some physicians have only a few PLWD as patients, decreasing their expertise in dementia care (Jennings et al., 2016). Referring all PLWD to specialists is impossible as demand exceeds their supply (Borson & Chodosh, 2014). Additionally, PLWD commonly have multimorbidity and geriatric syndromes, including polypharmacy (Clague, Mercer, McLean, Reynish, & Guthrie, 2017) and frailty (Rogers, Steptoe, & Cadar, 2017). Thus, multimorbidity complicates primary care for PLWD.

To improve healthcare for persons with memory problems, memory care clinics originated in the UK in the 1980s (Van Der Cammen, Simpson, Fraser, Preker, & Exton-Smith, 1987). They aimed to maximize dementia care availability in ambulatory (as opposed to inpatient) settings. Currently, numerous memory care clinics operate worldwide. They are similar in their focus on dementia. They differ in structure – staff and place and time of care provision. They vary in function: medical, psychological, functional, and social assessment; medical, psychological, and social interventions; liaison with other agencies; commitment to research and/or education; and length and depth of client interaction. Finally, they differ in measurement of outcomes (Jolley & Moniz-Cook, 2009). Outcomes range from healthcare utilization (e.g., hospitalization and emergency department (ED) use) (Boustani et al., 2011) to attainment of dementia care quality indicators (Jennings et al., 2016) to clients' psychological well-being (LaMantia et al., 2015).

Memory care clinics that are designed to deliver dementia care in an innovative way – as opposed to mainstream outpatient dementia care – are frequently referred to as dementia care models (Callahan et al., 2011) or programs (Boustani et al., 2011; Reuben et al., 2013; Vickrey et al., 2006). To the best of our knowledge, "dementia care model" lacks precise definition, but the term is commonly used (Fortinsky et al., 2014). These models are frequently aligned with the concept of person-centered care (Austrom et al., 2016), a prevalent description of quality dementia care (Edvardsson, Fetherstonhaugh, & Nay, 2010), and the contribution of caregiving dyads to understanding dementia (Brooker & Latham, 2016). No unchangeable set of attributes extends across all dementia care programs. Some features include a care manager who coordinates care, standardized protocols for care delivery and follow-up, and care management with technology (Callahan et al., 2006; Vickrey et al., 2006). These programs strive for a paradigm shift from an acute, reactive approach to illness to one that is planned, proactive, and population-based (Noel, Kaluzynski, & Templeton, 2017). Care coordination is prioritized (Chodosh et al., 2015). In some programs, multidisciplinary teams aim to close the gap between dementia care and primary care (Mavandadi, Wright, Graydon, Oslin, & Wray, 2017).

To our best knowledge, no systematic, integrative, or scoping reviews of U.S. dementia care programs focused on serving community-dwelling PLWD have been published. The variety and relative novelty of U.S. dementia care programs prompted us to conduct a scoping review of these programs, compare and contrast them, describe their outcomes, strengths, and challenges, and identify knowledge gaps on this topic. Our questions were: “What are the outpatient dementia care programs in the U.S.? What are their similarities and differences? What have they achieved? What is understudied or unknown about them?”

Design and Methods

We conducted a scoping review using the Arksey and O’Malley (2005) guidelines to summarize the state of the science on a topic previously unexplored in-depth (Arksey & O’Malley, 2005). Scoping reviews aim “to map rapidly the key concepts underpinning a research area and the main sources and types of evidence,” (Arksey & O’Malley, 2005, p. 21). “Mapping” involves summarizing evidence to illustrate its range (Levac, Colquhoun, & O’Brien, 2010, p. 1). Scoping reviews emphasize exploration of knowledge breadth rather than depth, with the latter appropriate for systematic reviews. The purpose of scoping reviews to broadly map the evidence (Arksey & O’Malley, 2005) matches U.S. dementia care programs’ heterogeneity in structure, maturity, and outcomes. This diversity became apparent when one author (blinded for review) conducted preliminary literature searches. Several recently established programs have not yet reported on many outcomes (Tan, Jennings, & Reuben, 2014; Verghese et al., 2016). Thus, the state of the field does not yet merit a systematic review in which analogously designed studies, such as randomized controlled trials, may be compared.

Scoping reviews differ from integrative reviews (Whittemore & Knafl, 2005). Scoping reviews neither evaluate evidence, nor estimate the weight of contribution of each report to a comprehensive synthesis (Arksey & O'Malley, 2005). Given the unknown state of the science on the U.S. dementia care programs, it appeared reasonable to broadly overview the field without evaluating evidence quality as required in integrative reviews (Whittemore & Knafl, 2005). Integrative reviews necessitate a highly structured review process reflective of qualitative research with constant comparison, coding, and derivation of categories (Miles & Huberman, 1994; Whittemore & Knafl, 2005). Assessment of data quality and systematic data reduction make integrative reviews more rigorous, decreasing error and bias (Whittemore & Knafl, 2005). While our data analysis resembled that described by Whittemore & Knafl (2005), searching for patterns, themes, and variations across the programs, we did not code the data (Whittemore & Knafl, 2005).

We intended to include reports of operational programs and reports on programs that have only been tested but are not available to the public yet. Accounts of operational programs highlight barriers these programs overcame in the translation of research into viable services (Callahan, Sachs, LaMantia, Unroe, Arling, & Boustani, 2014). Reports on tested but not yet operational programs demonstrate analyzed ideas and add to the all-encompassing view of these programs' achievements, obstacles, and future directions.

Data Searches and Selection

We conducted a literature search using six databases: Medline, Embase, CINAHL, PsycINFO, Scopus, and Web of Science. Terms and term combinations are listed in Table 1.

Inclusion and Exclusion Criteria

Initially, the delimiters were “humans” and “English language” (unless noted otherwise in Table 1). One author (blinded for review) aggregated all entries in EndNote (Clarivate Analytics, 2017) and then moved them into the Rayyan app for systematic reviews (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016). This tool was deemed appropriate to sort through the literature and delete articles based on inclusion and exclusion criteria. Then the first author applied exclusion criteria developed by the three investigators (blinded for review): 1) articles published before 2011; 2) manuscripts on programs outside ambulatory and home settings; 3) abstracts, conference proceedings, chapters, dissertations, opinion and editorial articles, literature reviews, position statements, and guidelines; and 4) articles on dementia epidemiology; health policy and economics; dementia diagnosis; palliative care and hospice; and biomedical aspects. We chose 2011 as a cutoff date because the currently used guidelines for Alzheimer’s disease diagnosis were issued in 2011 (McKhann et al., 2011). None of the reviewed programs mentioned using these guidelines, but this date appeared as a logical benchmark and no other dates appeared equally important in shaping current neurology and geriatrics dementia practice in the U.S. Thus, included articles were published between 2011 and 2017. In a discussion between investigators (blinded for review), one ad hoc exclusion criterion was added: studies on non-U.S. programs. Ad hoc creation of exclusion criteria after familiarization with the literature accords with scoping review methodology (Arksey & O’Malley, 2005). Two authors (blinded for review) read the studies selected for full-text review and agreed on their eligibility. Differences in opinion about eligibility were adjudicated by another author (blinded for review).

Data Extraction and Analysis

Scoping review methodology presumes charting the data according to study details and other determined criteria (Arksey & O’Malley, 2005). The following categories were used for articles’ abstraction: title; setting, organization, scope, and duration; design and purpose; team composition and roles; results/findings; challenges; and conclusions. These features resembled principal characteristics discussed in a narrative review of memory clinics worldwide: clinics’ structure, assessment, and achievements (Jolley & Moniz-Cook, 2009). Also, these features were selected because they repeated in reports based on the first authors’ preliminary non-systematic literature reviews.

Results

Study Characteristics

The initial electronic search yielded 12,228 entries, of which 3,748 were duplicates. The titles and abstracts of the remaining 8,480 entries were screened by the first author to determine if they met our inclusion criteria. This screening eliminated 8,379 articles (reasons in Figure 1), leaving 101 articles. After the ad hoc criterion was developed (eliminating all non-U.S. reports), an additional 69 articles were excluded, leaving 32 articles for full-text review. An additional 14 articles were deleted following full-text review (reasons in Figure 1), leaving 18 articles in the database. We identified an additional eight articles through the review of reference lists and other searches (first author’s graduate work), yielding 26 articles in the final review.

Fourteen programs were addressed in 26 articles. Details of the programs are displayed in Tables 2 and 3. Quantitative summary of the key characteristics of the reviewed programs is in Table 4. Patient, caregiver, and program/healthcare system outcomes are in Tables 5, 6, and 7, respectively. Such varied data display accords with evidence mapping in scoping reviews

(Peterson, Pearce, Ferguson, & Langford, 2017). Nine programs are operational and open to the public. Five other programs have been tested but no evidence on their operations beyond testing phase was found. Five programs were VA-based: some programs were in-person (Powers, Homer, Morone, Edmonds, & Rossi, 2017) and some were telehealth-based (Barton, Morris, Rothlind, & Yaffe, 2011) or telephone-delivered (Mavandadi et al., 2017). These VA programs were independent from one another. All 14 programs served PLWD. Only the Aging Brain Care Medical Home (ABC MedHome) (LaMantia et al., 2015) and the Healthy Aging Brain Care (HABC) (Boustani et al., 2011) serve PLWD, persons living with depression, and persons living with both dementia and depression.

Objectives of the Programs

All programs shared an overarching goal: improve dementia care. Dementia was at the core of all activities of the programs, determined their missions and day-to-day work. Other goals included: identify and manage biopsychosocial needs (Bass et al., 2013, 2015; Callahan et al., 2011); adhere to the standards in diagnosis, evaluation, and management (Boustani et al., 2011; Noel et al., 2017); deliver intervention to an underserved community (Chodosh et al., 2015) or a rural predominantly low-income population (Noel et al., 2017); prolong persons' life at home (D'Souza, Davagnino, Hastings, Sloane, Kamholz, & Twersky, 2015); help patient-caregiver dyads explore persons' behaviors and design an individualized approach to behavior management (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014); enhance rural Veterans' access to care via videotelemedicine (Barton et al., 2011; Powers et al., 2017); improve care transitions and access to community resources; reduce hospitalizations, neuropsychiatric symptoms, and caregiver strain (Reuben et al., 2013; Tan, Jennings, & Reuben, 2014); and monitor persons' cognition and health, and connect them to clinical trials (Verghese et al., 2016).

Socio-geographical and Organizational Context

Locations of programs mattered. Programs served populations of diverse races, socioeconomic status, and residence, and they were influenced by their position within a larger healthcare organization or lack thereof. The proportion of non-White PLWD in the programs ranged from 6% (Fortinsky et al., 2014) to 84.03% (Chodosh et al., 2015). Socioeconomic strata were mentioned in the context of clients' residence: mostly inner-city low-income population in a safety-net hospital catchment area (Boustani et al., 2011), urban underserved Latino population (Chodosh et al., 2015), highly diverse multiracial urban population (Verghese et al., 2016), rural Veterans (Barton et al., 2011), predominantly White population using community and not academic healthcare (Fortinsky et al., 2014), and rural predominantly White and low-income population (Noel et al., 2017). Telehealth and telephone-based programs for Veterans explained their mission by transportation difficulties that rural Veterans commonly experience (Powers et al., 2017) and rural Veterans being a hard-to-reach population (Bass et al., 2014). Only the HABC served PLWD with and without caregivers (Boustani et al., 2011).

Populations' needs shaped programs' activities. Such activities included subsidizing low-income clients (Noel et al., 2017; Tan et al., 2014) and hiring Latino social workers who were interacting with Latino clients, a traditionally hard-to-reach population (Chodosh et al., 2015). Staff needed to have a "deep understanding of the patient's and caregiver's needs, including what is financially possible and geographically available," (Jennings, 2016, p.7). The ABC MedHome conducted home visits, and families' financial hardship (e.g., lack of food) detracted from dementia care and required enlisting community agencies (LaMantia et al., 2015) or could cause staff resignation (Cottingham, Alder, Austrom, Johnson, Boustani, & Litzelman, 2014). Two programs, reflecting the pragmatic approach of their research, accentuated their resemblance to the mainstream competitive healthcare with fee-for-service payments (Fortinsky et al., 2014; Reuben et al., 2013).

Finally, in two programs, theoretical frameworks emphasized context. Healthy Aging Brain Care (Boustani et al., 2011) and the ABC MedHome (Callahan et al., 2011) were built on the conceptual framework of the Reflective Adaptive Process (Stroebel, McDaniel, Crabtree, Miller, Nutting, & Stange, 2005). This process assists with implementing change and it accords with the view that healthcare systems are not machines with replaceable parts and predictable behaviors. Instead, they are characterized by non-linear relationships that produce unpredictable behaviors based on the local environment (Callahan, Weiner, & Counsell, 2008). Healthcare systems are more appropriately viewed as complex adaptive systems that learn from experience and adjust to local environment (Anderson, Crabtree, Steele, & McDaniel, 2005).

Primary Care

No programs provided dementia care and primary care by the same clinicians. Programs, however, varied in their degree of approximation to primary care: from not mentioning primary care (Powers et al., 2017) to striving to close the gap between dementia care and primary care via collaboration with primary care physicians (Callahan et al., 2011). For example, ABC MedHome was created because its predecessor, HABC, was insufficiently integrated with primary care (Callahan et al., 2011). ABC MedHome did not provide primary care, but it communicated emerging concerns to primary care physicians and followed up on treatment of comorbidities (LaMantia et al., 2015). Primary care physicians provided patients' records to MemoryCare before MemoryCare enrollment (Noel et al., 2017). In five programs, dementia diagnoses or dementia-specific care plans were conveyed to primary care physicians (Barton et al., 20154; D'Souza et al., 2015; Hain, Dunn, & Tappen, 2011; Mavandadi et al., 2017; Verghese et al., 2016). Two programs made recommendations to primary care physicians, including on pharmacotherapy (Jennings et al., 2016), and referral to specialists, therapy, or hospice, and made falls prevention recommendations (D’Souza et al., 2015). Two programs required primary care physicians’ care plan approvals (D’Souza et al., 2015; Reuben et al., 2013). Two programs made primary care referrals (Chodosh et al., 2015; Verghese et al., 2016). Partners in Dementia Care advised caregivers to contact primary care physicians as needed (Judge et al., 2011). ACCESS and UCLA ADC instructed clients on establishing primary care if PLWD did not have it (Chodosh et al., 2015). Interventionists communicated with physicians regarding pharmacotherapy for PLWD (Fortinsky et al., 2014; Mavandadi et al., 2017; Reuben et al., 2013); behavioral and psychological symptoms of dementia (BPSD) management, and dyads’ needs, care, and triage (Mavandadi et al., 2017). In a telephone-delivered program, primary care physicians were updated after each care manager-caregiver encounter (Mavandadi et al., 2017). Instead of primary care physicians delivering dementia care, programs were similar in their mission of supplementation and augmentation of, adjunct to, and partnership with primary care (Boustani et al., 2011; D’Souza et al., 2015; Fortinsky et al., 2014; Mavandadi et al., 2017; LaMantia et al., 2015; Noel et al., 2017; Tan et al., 2014).

Staff Composition

Physicians. Physicians’ roles varied. In 12 programs, physicians were the main care providers (though with varying degrees of collaboration with APRNs and social workers or registered nurses (RNs)). In two programs, physicians interacted with clients the most (Noel et al., 2017; Verghese et al., 2016). Physicians assessed, diagnosed (Barton et al., 2011; Powers et al., 2017), devised care plans (D’Souza et al., 2015; Noel et al., 2017; Verghese et al., 2016), including together with APRNs (Reuben et al., 2013), and made treatment recommendations

(Barton et al., 2011; Verghese et al., 2016). Physicians advocated for the programs within overseeing healthcare organizations (Boustani et al., 2011; Judge et al., 2011).

Other employees. All programs were multidisciplinary. In two programs APRNs were principal care providers (Barton et al., 2014; Hain et al., 2011; Tappen & Valentine, 2014). In the Behavior Management Clinic, APRNs conducted one in-depth initial visit with a subsequent follow-up telephone call and updated the referring clinicians (Barton et al., 2014). Louis and Anne Green Memory and Wellness Center was founded and is led by APRNs. The Center has a physician mentor, but no protocolized collaboration with physicians was described (Tappen & Valentine, 2014). Three programs described communication between APRNs and primary care physicians. In one program, a geriatric APRN delivered the intervention and interacted with dyads the most, but consulted with PCPs regarding pharmacotherapy (Fortinsky et al., 2014). In UCLA ADC, APRNs were care managers and interacted with dyads the most but consulted with physicians on care plan development (Reuben et al., 2013). APRNs could assess patients in lieu of physicians (Powers et al., 2017).

The most common configuration was when master's- or bachelor's-prepared social workers, RNs, or counselors worked as care coordinators, directly interacting with clients (Bass et al., 2013, 2014, 2015; Boustani et al., 2011; Chodosh et al., 2015; D'Souza et al., 2015; Judge et al., 2011; Mavandadi et al., 2017). Having staff who were the interface between clients and the program assured continuity of care, established relationships and rapport between staff and families, and highlighted that dedicated staff had to help clients navigate their healthcare.

Eight programs employed social workers (Boustani et al., 2011; D'Souza et al., 2015; Hain et al., 2011; Judge et al., 2011; LaMantia et al., 2015; Noel et al., 2017; Powers et al., 2017; Verghese et al., 2016). Programs also employed other staff, e.g., medical assistants and licensed practical nurses (Powers et al., 2017). These personnel could be the interface between clients and programs (LaMantia et al., 2015; Powers et al., 2017). Employing unlicensed workers who were on the frontline with families – care coordinator assistants (LaMantia et al., 2015) – accorded with the "task shifting" mandate to hire less expensive personnel and thus increase care availability (World Health Organization, 2008). Other healthcare professionals included geriatric pharmacists (D'Souza et al., 2015); geriatric psychologists; RN managers (Powers et al., 2017); neuropsychologists (Hain et al., 2011; Verghese et al., 2017); and psychologists (Hain et al., 2011).

Eight programs involved partnerships with other healthcare or community organizations (Barton et al., 2011, 2014; Boustani et al., 2011; Chodosh et al., 2015; Fortinsky et al., 2014; Judge et al., 2011; LaMantia et al., 2015; Reuben et al., 2013). These partnerships were essential for intervention delivery (Barton et al., 2011; Fortinsky et al., 2014; Jennings et al., 2016; Judge et al., 2011), client recruitment (Barton et al., 2014; Reuben et al., 2013), or non-medical resources (LaMantia et al., 2015; Reuben et al., 2013).

Services

Medical and psychosocial assessment. All programs assessed PLWD and/or caregivers at the initial visit or contact, and 11 programs conducted re-assessments with varying frequency (all but Barton et al., 2011, 2014; and Verghese et al., 2016). In six programs, initial assessments coincided with dementia diagnostics (Boustani et al., 2011; Barton et al., 2011; Noel et al., 2017; Powers et al., 2017; Hain et al., 2011; Verghese et al., 2016). Seven programs conducted multidisciplinary initial assessment involving two or more different healthcare specialists during assessment (Boustani et al., 2011; Barton et al., 2011; 2014; Noel et al., 2017; Powers et al., 2017; Hain et al., 2011; Verghese et al., 2017). Distance programs completed psychosocial assessments without hindrance (Mavandadi et al., 2017; Chodosh et al., 2015), but medical evaluations required remote technicians' help (Barton et al., 2011; Powers et al., 2017).

Dementia management. Care plan development followed assessment in nine programs (Boustani et al., 2011; LaMantia et al., 2015; Judge et al., 2011; Chodosh et al., 2015; Barton et al., 2014; D'Souza et al., 2015; Noel et al., 2017; Reuben et al., 2013; Verghese et al., 2017). Four programs conveyed assessment results to primary care physicians (D'Souza et al., 2015) or referring physicians (Barton et al., 2014; Hain et al., 2011; Verghese et al., 2017). Four programs were limited to evaluation, with no ensuing monitoring, so only diagnostic results and recommendations were provided to families (Barton et al., 2011; Powers et al., 2017) and referring physician (Barton et al., 2011; Barton et al., 2014).

Care management and interaction with clients varied. Two programs provided minimal contact after diagnosis and evaluation, communicating information on evaluation results, prognosis, treatment, resources, and driving (Barton et al., 2011, 2014; Powers et al., 2017). Interventions emphasized pharmacological and non-pharmacological symptom management and environmental modification, focusing on BPSD and neuropsychiatric symptoms (Barton et al., 2014; Fortinsky et al., 2014; Mavandadi et al., 2017); depression (LaMantia et al., 2015, 2016); psychoses and pain (Boustani et al., 2011); and safety (Boustani et al., 2011; D'Souza et al., 2015; Noel et al., 2017; Powers et al., 2017; Jennings et al., 2016; Hain et al., 2011). HABC and ABC MedHome addressed issues besides dementia: management of comorbidities in collaboration with primary care physicians (Boustani et al., 2011; LaMantia et al., 2015) and vascular burden minimization (Boustani et al., 2011; Callahan et al., 2011). Four programs made physician referrals (Boustani et al., 2011; Chodosh et al., 2015; D'Souza et al., 2015; Jennings et al., 2016). In a telephone-based program, care managers relied on caregivers for BPSD and physical function monitoring; this information was communicated to Veterans' primary care physicians (Mavandadi et al., 2017).

Pharmacological treatment included prescription of antidepressants and anti-dementia medications (Barton et al., 2011; Boustani et al., 2011; Callahan et al., 2011; Hain et al., 2011; Reuben et al., 2013); and deprescribing medications that contribute to cognitive impairment (Powers et al., 2017), including anticholinergics and psychotropics (Boustani et al., 2011; Callahan et al., 2011). In a telephone-based program, care managers inquired with caregivers regarding Veterans' side effects and adherence; this information was conveyed to Veterans' primary care physicians (Mavandadi et al., 2017). Non-pharmacological activities included teaching behavioral management techniques, such as environment and communication modification (Barton et al., 2014; Boustani et al., 2011; Callahan et al., 2011; Fortinsky et al., 2014; Hain et al., 2011); and adjusting caregivers' expectations of behavior and cognition (Barton et al., 2011).

Care coordination with clients and within programs. Communication with clients varied. Only the UCLA ADC provided 24/7 telephone access to a geriatrician (Reuben et al., 2013). Other programs had telephone or email follow-up (Boustani et al., 2011; D'Souza et al., 2015; LaMantia et al., 2015; Reuben et al., 2013). One program (Mavandadi et al., 2017) and one intervention arm (Chodosh et al., 2015) were entirely telephone-delivered. Two programs used videotelemedicine, although on-site staff helped with the equipment (Barton et al., 2011; Powers et al., 2017). The UCLA ADC offered web-based caregiver training (Reuben et al., 2013). Distance-delivered interventions were considered cost-saving (Chodosh et al., 2015; Powers et al., 2017).

Three programs used special software for electronic medical records (Frame et al., 2013; Jennings et al., 2016; Judge et al., 2011). ABC MedHome engineered software to track individual and population trends, determine care management, and stratify clients according to mild, moderate, and severe needs (Frame et al., 2013). Specialized software allowed streamlining and centralizing care, rapidly accessing individual information and observing population trends, and creating a "mobile office" (LaMantia et al., 2015, p. 1210) where staff work is not restricted to a stationary clinic (Frame et al., 2013). The UCLA ADC planned for new software to incorporate prompts for dementia-related treatments, improving care quality (Jennings et al., 2016).

Use of technology required extra planning and presented some challenges. All elements of a neurological exam could not be performed via distance and required a remote clinician's assistance (Barton et al., 2011). Veterans' uncorrected hearing deficits complicated distance assessment (Powers et al., 2017). On-site personnel had to be present to assure connectivity and refer to local resources (Barton et al., 2011; Powers et al., 2017). Diagnosis disclosure via distance could be difficult, requiring on-site clinician's assistance, and telehealth may not suit PLWD with severe cognitive impairment (Barton et al., 2011). While telemedicine shortened Veterans' commute to rural clinics, non-uniform rural internet coverage prevented home equipment installation. Neuropsychological tests were not validated for distance use (Powers et al., 2017). Telephone interventions applied only to persons who were already diagnosed (Chodosh et al., 2015; Mavandadi et al., 2017), implying the necessity of the initial in-person or telehealth contact to start care. Training staff to use telehealth was required (Powers et al., 2017).

Care continuity. Care duration varied. It ranged from singe assessments with only as-needed follow-up (Barton et al., 2014) to several months when the program was tested (Judge et al., 2011; Mavandadi et al., 2017) to a person's lifetime and through the families' bereavement period (Reuben et al., 2013; Tan et al., 2014). Six programs continuously followed up via in-person (Fortinsky et al., 2014; LaMantia et al., 2015; Reuben et al., 2013; Verghese et al., 2017) and/or telephone contacts (Bass et al., 2015; Boustani et al., 2011; Chodosh et al., 2015). Follow-up included monitoring dementia progression and pharmacotherapy (Reuben et al., 2013; Verghese et al., 2017); intervention response assessment (LaMania et al., 2015); goals' re-assessment and tracking goals' attainment (Bass et al., 2015); overseeing care plan implementation and as needed plan adjustment (Boustani et al., 2011; Chodosh et al., 2015; D'Souza et al., 2015); monitoring PLWDs' symptoms and caregivers' burden and stress (Boustani et al., 2011; Fortinsky et al., 2014); and instructing caregivers' on stress self-management and problem-solving (Chodosh et al., 2015). At the UCLA ADC, caregivers were encouraged to contact APRNs with changes in persons' symptoms (Reuben et al., 2013).

Programs varied in their justification of the follow-up length. Advantage of lifetime or prolonged follow-up was not upheld by all programs. In one program physicians recommended follow-up reduction from 12 months to 4 months to increase the likelihood of the program being Medicare-reimbursable (Fortinsky et al., 2014). Memory Disorders Clinic emphasized that their one-visit intervention with follow-up only as-needed could be more financially sustainable than multiple home visits (Barton et al., 2014). But MemoryCare (Noel et al., 2017) and the UCLA ADC (Reuben et al., 2013) highlighted the importance of regular interactions with clients.

Care continuity was implemented via staff who were on the frontline with clients, including care managers (Mavandadi et al., 2017), social workers (Chodosh et al., 2015), RNs (Powers et al. 2017), and APRNs (Fortinsky et al., 2014; Reuben et al., 2013). Care continuity was also manifested by communication with families between scheduled in-person visits or telephone calls. In-person office visits “spilled over” visit time to include round-the-clock telephone access to a physician (Reuben et al., 2013), scheduled and as needed calls between visits (Noel et al., 2017), home visits, and visits to other care settings where persons were admitted (Jennings et al., 2016).

Care transitions coordination across healthcare settings. Seven programs assisted with care transition coordination (Boustani et al., 2011; D’Souza et al., 2015; Fortinsky et al., 2014; LaMantia et al., 2015; Mavandadi et al., 2017; Noel et al., 2017; Reuben et al., 2013). This included communication with emergency, acute, and sub-acute care physicians regarding persons’ care goals (Reuben et al., 2013); providing dementia-related information to hospital staff, reconciling medications post-hospitalization, and coordinating post-discharge care planning (LaMantia et al., 2015); and coordinating primary and specialty care (Mavandadi et al., 2017). The UCLA ADC referred persons to inpatient geriatric facilities within the UCLA system (Reuben et al., 2013). ACCESS care managers coached caregivers in conducting productive physician visits (Chodosh et al., 2015).

Caregivers. All but one (Verghese et al., 2016) program had interventions and resources for caregivers that were offered by programs or recommended in the community (Table 3). These programs expanded the definition of patient to include caregiver. Several programs equally prioritized assessing PLWDs’ and caregivers’ needs and tailoring services to dyads (Bass et al., 2013, 2014, 2015; Boustani et al., 2011; Fortinsky et al., 2014; Judge et al., 2011; LaMantia et al., 2015; Noel et al., 2017). Two programs interacted only with caregivers (Chodosh et al., 2015; Mavandadi et al., 2015).

Outcomes of Programs

Patient outcomes. Nine programs published neutral or positive patient outcomes (Table 5). The most commonly reported outcome was persons' satisfaction with, acceptability of, and feedback on the program (Barton et al., 2011; Fortinsky et al., 2014; Judge et al., 2011; Powers et al., 2017; Reuben et al., 2013). No more than two different programs each measured depressive symptoms (LaMantia et al., 2016; Bass et al., 2014), BPSD (Chodosh et al., 2015; Mavandadi et al., 2017), neuropsychiatric symptoms (Fortinsky et al., 2014; Mavandadi et al., 2017), and persons' quality of life (Barton et al., 2011; Fortinsky et al., 2014). Three programs reported improvements in persons' psychological well-being and symptoms, including decreased depressive symptoms (LaMantia et al., 2015), embarrassment about memory problems (Bass et al., 2014), and disruptive behaviors (Chodosh et al., 2015).

Caregiver outcomes. Twelve programs noted neutral or positive caregiver outcomes (Table 6). The most commonly reported outcome was caregiver' satisfaction with, acceptability of, and feedback on the program (Fortinsky et al., 2014; D'Souza et al., 2015; Barton et al., 2011; Noel et al., 2017; Powers et al., 2017; Mavandadi et al., 2017; Reuben et al., 2013; Verghese et al., 2016). Four programs measured caregiver burden (Chodosh et al., 2015; Fortinsky et al., 2014; Mavandadi et al., 2017; Powers et al., 2017). Three programs measured caregivers' depressive symptoms (Fortinsky et al., 2014; Chodosh et al., 2015; Bass et al., 2013). Other outcomes, including those commonly represented in dementia caregiving literature, such as caregivers' coping, strains (Pearlin, Mullan, Semple, & Skaff, 1990), mastery (Lawton, Moss, Hoffman, & Perkinson, 2000), and distress due to their persons' BPSD (Teri et al., 1992) or neuropsychiatric symptoms (Kaufer et al., 2000) were measured by one program each (Bass et al., 2013; Mavandadi et al., 2017).

Four programs achieved improvements in caregivers' psychological well-being, including reduction in stress and strain (Bass et al., 2013; LaMantia et al., 2015); depression (Bass et al., 2013); distress due to persons' dementia-related, neuropsychiatric, and depressive symptoms (Mavandadi et al., 2017); and burden (Powers et al., 2017). Gains were noted in support service use, number of informal helpers (Bass et al., 2013), caregiver mastery and coping (Mavandadi et al., 2017), knowledge about dementia (Noel et al., 2017), and ease of participation in a telehealth program (Powers et al., 2017). No programs explored PLWDs' or caregivers' experiences qualitatively.

Program performance and healthcare use outcomes. All programs examined healthcare use and performance of the programs (Table 8). The number of program and healthcare use outcomes across all programs (n=41) exceeded the number of caregiver (n=17) and patient outcomes (n=16). Most commonly explored outcomes were workflow parameters, measured by the total number of clinic visits and in-person and distance patient contacts (Boustani et al., 2011; LaMantia et al., 2015; Judge et al., 2011; Mavandadi et al., 2017; Noel et al., 2017; Powers et al., 2017; Tappen & Valentine, 2014); number of hospitalizations (Boustani et al., 2011; Bass et al., 2015; Chodosh et al., 2015; Noel et al., 2017; Verghese et al., 2016); and staff' satisfaction with the programs (Austrom et al., 2016; Judge et al., 2011; Fortinsky et al., 2014; Barton et al., 2011; Noel et al., 2017; Tan et al., 2014). HABC reported on 63% of the total number of program and healthcare use outcomes measured by all programs (n=41).

Four programs attained healthcare use improvements: reductions in ED use (Boustani et al., 2011); ED re-visits (Bass et al., 2015; Boustani et al., 2011); hospitalizations (Bass et al., 2015; Boustani et al., 2011; Noel et al., 2017); length of stay (Boustani et al., 2011); 30-day re-hospitalizations (Boustani et al., 2011; Noel et al., 2017); and appointment cancellations (Powers et al., 2017). ACCESS compared telephone with in-person delivery and found no healthcare utilization differences between delivery modes, justifying efficaciousness of the less costly telephone delivery (Chodosh et al., 2015). Two programs improved pharmacotherapy outcomes (Boustani et al., 2011; Powers et al., 2011). HABC achieved superior rate of diagnostic procedures and comorbidity management compared to control (Boustani et al., 2011). Three programs described meeting care quality indicators (D’Souza et al., 2015; Jennings et al., 2016; Noel et al., 2017).

Six programs reported economic data (Chodosh et al., 2015; French et al., 2014; Judge et al., 2011; Noel et al., 2017; Reuben et al., 2013; Tappen & Valentine, 2014). Comparisons between programs and mainstream healthcare indicated savings that interventions produced, from $296,952/year (French et al., 2014) to $480,160/year (Noel et al., 2017).

Implementation Challenges

Four programs noted financial challenges. The major obstacle was lack of reimbursement for the core activities, including care coordination with caregivers, other clinicians, and community agencies (Jennings et al., 2016). VA programs were funded (D’Souza et al., 2015). Three programs benefitted from philanthropy (Noel et al., 2017; Reuben et al., 2013; Tappen & Valentine, 2014). Investment from overseeing healthcare or academic institutions assisted programs: clinic space allotment (Boustani et al., 2011; Reuben et al., 2013; Tappen & Valentine, 2014), electronic medical records (Boustani et al., 2011); and on-call geriatrician (Reuben et al., 2013).

Developing and sustaining programs was complicated and costly from an organizational standpoint (Callahan et al., 2011; Fortinsky et al., 2014; Tappen & Valentine, 2014). Founding programs necessitated coordinated work of an interdisciplinary panel of stakeholders. Internal and external conflict was commonplace. Conflict was considered a required component for growth, yet conflict did not automatically equate with progress (Callahan et al., 2011). Internally, stakeholders faced a conflict of priorities when a clinic diverted resources into rebuilding itself into a patient-centered medical home, which inhibited patient recruitment for the program (Fortinsky et al., 2014). In one case, outside physicians criticized the launch of an APRN-led primary care clinic, which resulted in opening an APRN-led memory care clinic instead, without primary care provision (Tappen & Valentine, 2014). At the UCLA ADC, a discrepancy arose in APRNs’ scope of practice: not all referring primary care physicians allowed APRNs to manage conditions that influence or may be influenced by cognition (e.g., falls). Hence, negotiation of APRNs’ role was warranted (Reuben et al., 2013).

Stakeholder buy-in was essential during initiation and continued development of the programs. Excessive time for starting the program translated into excessive costs. For programs situated within a larger healthcare structure, organizational leadership support was essential (Boustani et al., 2011). After programs commenced, keeping stakeholders engaged was difficult (Callahan et al., 2011; Fortinsky et al., 2014). It was important to plan for a period of growth and associated care quality loss, which may have lessened program achievements relative to their potential (D’Souza et al., 2015).

Substantial time and resources were needed for hiring, initial training, and continuous education of staff that works directly with families (Austrom et al., 2016; Cottingham et al., 2014). Staff training covered a range of topics, from administering cognitive tests (Noel et al., 2017; LaMantia et al., 2015) to up-to-date information on local resources for families (Noel et al., 2017). A loop of “dynamic and reciprocal feedback” (Mavandadi et al., 2017, p. 104) between staff on the frontline with families and leadership was established (Austrom et al., 2016;

Fortinsky et al., 2014; D'Souza et al., 2015; Mavandadi et al., 2017). Building such communication was an evolving process, requiring reflection and reorganization (Powers et al., 2017).

Discussion

Dementia was at the core of all programs. Recognition of the effect of dementia on patients, caregivers, and families' interaction with formal healthcare united the programs despite their differences. Dementia was recognized as a condition that, despite management, not only destroys cognition and is frequently accompanied by physical illnesses, but also erodes other areas of life for care recipients and caregivers. Dementia was also seen as a "difficulty" in mainstream healthcare, demanding extra time and resources, but not bringing revenue for additional work (Jennings et al., 2016). Despite reimbursement and organizational challenges, programs were committed to raising the quality of dementia care to a higher level compared to mainstream healthcare. These programs are consistent with the disease management movement philosophy – focus on a chronic illness which is not managed well in primary care (Geyman, 2007).

Two care aspects were present in all interventions: assessment and dementia management. Assessment is the first step in a clinical process (Guo, Wang, & Johnson, 2012), so this is an expected finding. Assessment and re-assessment of persons' cognition, comorbidities, symptoms, and needs, and assessment of caregivers' needs and well-being demonstrates how attuned the programs were to their clients. Regular re-assessments aimed to close the gap between clients' changing needs and what programs provided. Thus, care was responsive and dynamic. All programs, with varying degrees of depth and duration, engaged in dementia management.

No programs provided simultaneous dementia care and primary care by the same clinicians. Instead, primary care was mentioned in the context of collaboration with primary care physicians. Programs acknowledged the importance of integration with primary care and national incentives that reimburse care for the whole patient rather a single disease (Callahan et al., 2011). Lack of programs that provide simultaneous primary care and dementia care is surprising, given the evidence on how interaction with primary care providers improves outcomes for PLWD (Chodosh et al., 2012).

The programs described themselves in broad terms that may not have precisely conveyed their scope of practice. Many programs used the phrases “comprehensive care,” “integrated care,” and “collaborative model.” These phrases, however, had different meaning. They included integration with primary care (Mavandadi et al., 2017), integration between medical model and care management model (Noel et al., 2017), and integration between medical and social services (Jennings et al., 2016). Care was described as “comprehensive” even when primary care was not provided (Reuben et al., 2013). “Comprehensive” was also used in the context of meeting dementia care quality indicators (Jennings et al.,2016) and evaluation by geriatricians, neuropsychologists, and neurologists (Verghese et al., 2016).

Potentially, aiming for comprehensiveness is reflected in the interdisciplinarity of the programs – all had staff of various specialties, implying that dementia care is an impossible task for any single provider. Secondly, the volume of medical and non-medical care that dementia demands was reflected in partnerships between and care coordination with other clinicians and community agencies. Partnerships enlarged the scope of activities for the programs.

All programs expanded the definition of care beyond the limits of a traditional office in-person encounter. Assigning staff who were on the frontline with families affirmed the importance of constant contact between families and the program. Care was available via telephone access to clinicians or staff, implying how care is always “with” the clients. Coordination with other clinicians or agencies exemplifies “behind-the-scenes” care that happens outside of regular visits.

Continuity of care is also manifested in assigning care coordinator assistants, social workers, or RNs to families. These staff are on the frontline with clients, establish rapport with them, and serve as their “navigators” to dementia management, which has been described as a “labyrinth” and permeated with uncertainty (Samsi & Manthorpe, 2014, p.1). This continuity of care demands human resources, which drives programs to hire less expensive staff. Diversifying the healthcare team beyond traditional healthcare professionals may help partially alleviate a shortage of geriatric providers (Samus et al., 2014). Lack of trained non-provider care coordinators is one reason for insufficient implementation of these programs (Callahan et a., 2011). The necessity to supply continuous care, such as via caregivers’ telephone access to clinicians, or telephone care coordination with other professionals, without reimbursement for these services, may explain the financial disadvantage of these programs.

Ninety-three percent of the programs had interventions and/or resources for caregivers. Such attention to caregivers expands the definition of patient to include the caregiver. Caregivers are provided with resources to maintain their psychological well-being and physical health. They are educated on dementia, comorbidities, and resources. They are also regarded as clinicians whose input is vital for formal care provision.

Programs are tailored to their target population and to their external environment: rural, urban, academic, VA, or community. Thus, whenever a new program is being established, its location and external resources must be considered. As business models, these programs appreciate the importance of finding a niche and solving problems specific to their population, ranging from provision of telehealth to rural Veterans (Barton et al., 2011) to hiring staff who are racially concordant with clients (Chodosh et al., 2015). Context matters because it shapes staff hiring and training, funding, purchasing ability of the target population, and how changes may or may not succeed. External settings explain why results attained in a certain program may not be applicable elsewhere. Endowment with capital investment and being embedded in a larger healthcare organization determines resources and support for the program – something solo practices outside of academic settings may not have. Program investigators often noted how their findings may not apply elsewhere.

Programs may be described as strategically “high-tech” and “high-touch.” Programs use technology to promote care access, organize care processes, and monitor individual and population trends (LaMantia et al., 2015). Thus, potentially, technology diverts human resources to work that cannot be automated – helping families navigate and manage dementia with individualized approach and established rapport.

Outcomes were positive or neutral. All programs reported on program performance and healthcare use. This is an expected finding – an intervention demonstrates its success by measuring commonly reported healthcare use outcomes, such as hospitalization and ED use rate and productivity. Staff feedback on programs is necessary as it allows continuous improvement of care delivery and determines whether the intervention is working from staff perspective. Only two programs conducted economic comparative analysis between the program and mainstream healthcare, which may explain inadequate availability of these programs (Callahan et al., 2014): evidence is insufficient that these programs are profitable. Attention to program and healthcare use outcomes may be explained by the drive to demonstrate competitiveness of these programs to increase likelihood of these services being reimbursable by Medicare and other insurance.

Fewer patient and caregiver outcomes were reported. PLWD and caregiver satisfaction with services were most frequently assessed. Variables that are commonly used in dementia caregiving research, such as caregiver burden (Zarit et al., 1980), caregiver competence (Pearlin et al., 1990), and depressive symptoms (Radloff, 1977) were measured rarely. Only two programs reported positive BPSD findings (Chodosh et al., 2015; LaMantia et al., 2015). Only Chodosh and colleagues (2015) reported decreased disruptive behaviors.

Knowledge Gaps

The maximum investigation duration was 18 months (LaMantia et al., 2015). This contrasts with the median survival time after dementia diagnosis of 3.2-6.6 years and the typical range of 7-10 years (Todd, Barr, Roberts, & Passmore, 2013). Future research should be of longer duration. Longitudinal mixed methods studies may allow us to delineate dementia progression, caregiving trajectory during dementia progression, and roles that these programs play along the disease course and caregivers' work. This knowledge would allow for programs to plan when care must be escalated to prevent adverse events.

Examination of a wider spectrum of patient and caregiver outcomes is needed. While all programs reported on some aspect of program performance, HABC accounted for the largest portion of these outcomes (Boustani et al., 2011). Hence, programs should evaluate their work on a wider range of indicators. Additional economic analyses are needed to demonstrate whether healthcare cost savings occur and if so, in what sectors (e.g., reduced hospitalization rate, caregivers' decreased healthcare expenditure, etc.). Outcomes must include those that are traditionally used in economic evaluation of healthcare models, including cost-effectiveness.

Given that BPSD are leading causes of caregiver burden and institutionalization (Cepoiu-Martin, Tam-Tham, Patten, Maxwell, & Hogan, 2016), further research should examine changes across a wider range of BPSD and over longer periods of time. Further research should focus on particularly problematic behaviors – agitation, aggression, and wandering – an outcome that is very meaningful to families (Desai, Schwartz, & Grossberg, 2012). Only two programs used the Revised Memory and Behavior Problem Checklist (Teri et al., 1992) to measure BPSD (Chodosh et al., 2015; Mavandadi et al., 2017). Only two programs used the Neuropsychiatric Inventory (Kaufer et al., 2000) to measure neuropsychiatric symptoms (Fortinsky et al., 2014; Mavandadi et al., 2017). No programs measured depressive symptoms using the Geriatric Depression Scale (Yesavage et al., 1982), validated for PLWD (Conradsson, Rosendahl, Littbrand, Gustafson, Olofsson, & Lövheim, 2013). These instruments are often used in gerontology research. Hence, future programs may evaluate their outcomes using these instruments to make their findings comparable to other interventions in gerontology. Similarly, only two studies (D’Souza et al., 2015; Noel et al., 2017) reported on persons’ institutionalization. Future research may also focus on institutionalization rate, as most PLWD want to stay at home and institutionalization is linked to increased mortality (Aneshensel et al., 2000; McClendon, Smyth, & Neundorfer, 2006). No reports had qualitative evaluation of clients’ experience, but such data may deepen understanding of clients’ experience beyond satisfaction with care. It may be advisable to include PLWD in such investigations, as excessive focus on caregivers may marginalize PLWD (Fortinsky et al., 2001), diminishing their contribution to care, which is an expectation of patient-centered care (Brooker & Latham, 2016). Likewise, the optimal intervention length remains unknown. Only 29% of the programs evaluated their work relative to dementia care quality indicators, thus, further research on the attainment of care standards by these programs is needed. Data are limited on the efficaciousness of these programs for persons with more advanced dementia. For instance, in two programs, persons who fell below a certain benchmark on cognitive evaluation were ineligible (Bass et al., 2014; Fortinsky et al., 2014).

Limitations

This review has limitations. We focused only on the U.S. programs and excluded studies published before 2011. Earlier studies may delineate evolution of these programs. We only included peer-reviewed research reports. But some reports published in editorials (Reuben, 2011; Zwerling, Cohen, & Verghese, 2016) yield essential information on chronic care interventions. Finally, articles on recently developed interventions for which no outcomes were available were excluded (Cummings, Zhong, & Bernick, 2014).

Conclusion

What ought a dementia care program be? Dementia care program components include patient- and caregiver-centeredness, fitting local environment and meeting local population's needs, interdisciplinarity, and encompassing medical and non-medical aspects of care for the whole person. Programs may implement provision of primary care and dementia care by the same clinicians. In mainstream healthcare, PLWD not only receive their care predominantly in primary care settings (Sheiban, Stolee, McAiney, & Boscart, 2018), but also prefer receiving healthcare from primary care providers (Callahan et al., 2009). Thus, provision of primary care and dementia care by the same clinicians would eliminate the need to coordinate management of comorbidities with primary care providers. It may decrease errors with the use of potentially inappropriate medications for older adults (American Geriatrics Society 2015 Beers Criteria Update Expert Panel, 2015) and facilitate early implementation of palliative care which is associated with enhanced quality of life and longer survival (Temel et al., 2010). It may also centralize management of other conditions often co-occurring with dementia: frailty (Maxwell & Mion, 2015), falls, incontinence, pressure ulcers, functional decline (Inouye, Studenski, Tinetti, & Kuchel, 2007), multimorbidity, and polypharmacy (Gnjidic, Husband, & Todd, 2018). In the UK, specialized dementia care skills are “transplanted” into primary care (Greening, Greaves, Greaves, & Jolley, 2009). Discourse of dementia and primary care is “not a question of ‘either/or’ but of togetherness,” (Jolley, Greaves, & Clark, 2012, p. 1). Adopting a research-intensive approach, such that program achievements and deficits are visible, may increase the likelihood of these interventions becoming economically sustainable and more widely available.

References

Alzheimer's Association. (2018a). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 14*(3), 367-429. doi: https://doi.org/10.1016/j.jalz.2018.02.001

Alzheimer’s Association. (2018b). MedicAlert + Safe Return. Retrieved from https://www.alz.org/help-support/caregiving/safety/medicalert-safe-return

American Medical Association. (2011). Physician Consortium for Performance Improvement (PCPI): dementia performance measurement set. Retrieved from http://neurofoundation.net/globals/axon/assets/9493.pdf

American Geriatrics Society Beers Criteria Update Expert Panel. (2015) American Geriatrics Society 2015 updated Beers criteria for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society, 63*(11), 2227-2246. doi: 10.1111/jgs.13702

Anderson, R. A., Crabtree, B. F., Steele, D. J., & McDaniel, R. R. Jr. (2005). Case study research: The view from complexity science. *Qualitative Health Research, 15*(5), 669-685.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press.

Aneshensel, C. S., Perlin, L. I., Levy-Storms, L., & Schuler, R. H. (2000). The transition from home to nursing home mortality among people with dementia. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 55*(3), S152-162.

Arksey, H., & O’Malley, L. (2005). Scoping methods: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32. doi: 10.1080/1364557032000119616

Auer, S., & Reisberg, B. (1997). The GDS/FAST staging system. *International Psychogeriatrics, 9 Suppl 1,* 167-171.

Austrom, M. G., Carvell, C. A., Alder, C. A., Gao, S., Boustani, M., LaMantia, M. (2016). Workforce development to provide person-centered care. *Aging & Mental Health, 20*(8), 781-792. doi: 10.1080/13607863.2015.1119802

Barton, C., Morris, R., Rothlind, J., & Yaffe, K. (2011). Videotelemedicine in a Memory Disorders Clinic: Evaluation and management of rural elders with cognitive impairment. *Telemedicine and E-Health, 17*(10), 789-793. doi: 10.1089/tmj.2011.0083

Barton, C., Merrilees, J., Ketelle, R., Wilkins, S., & Miller, B. (2014). Implementation of advanced practice nurse clinic for management of behavioral symptoms in dementia: A dyadic intervention (innovative practice). *Dementia, 13*(5), 686-696. doi: 10.1177/1471301213519895

Bass, D. M., Tausig, M. B., & Noelker, L. S. (1988-1989). Elder impairment, social support and caregiver strain: A framework for understanding support's effects. *Journal of Applied Social Sciences, 13*(1), 80-117.

Bass, D. M., McClendon, M. J., Deimling, G. T., & Mukherjee, S. (1994). The influence of a diagnosed mental impairment on family caregiver strain. *Journal of Gerontology, 49*(3), S146-155.

Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R., Looman, W. J., . . . Kunik, M. E. (2013). Caregiver outcomes of Partners in Dementia Care: Effect of a care coordination program for veterans with dementia and their family members and friends. *Journal of the American Geriatrics Society, 61*(8), 1377-1368. doi: 10.1111/jgs.12362.

Bass, D. M., Judge, K. S., Snow, A. L, Wilson, N. L., Morgan, R. O., Maslow, K., . . . Kunik, M. E. (2014). A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimer's Research & Therapy, 6*(1), 9. doi: 10.1186/alzrt242

Bass, D. M., Judge, K. S., Maslow, K., Wilson, N. L., Morgan, R. O., McCarthy, C. A., . . . Kunik, M. E. (2015). Impact of the care coordination program “Partners in Dementia Care” on Veterans’ hospital admissions and emergency department visits. *Alzheimer’s & Dementia, 1*(1), 13-22. doi: 10.1016/j.trci.2015.03.003

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5), 652-657. doi: 10.1093/geront/41.5.652

Blessed, G., Tomlinson, B. E., & Roth, M. (1988). Blessed-Roth dementia scale (DC). *Psychopharmacology Bulletin, 24*(4), 705-708.

Borson, S., & Chodosh, J. (2014). Developing dementia-capable healthcare systems. *Clinics in Geriatric Medicine, 30*(3), 395-420. doi: 10.1016/j.cger.2014.05.001

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002a). Improving primary care for patients with chronic illness. *JAMA, 288*(14), 1775-1779.

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002b). Improving primary care for patients with chronic illness: The chronic care model. *JAMA, 288*(15), 1909-1914.

Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M., . . . Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health, 15*(1), 13-22. doi: 10.1080/13607863.2010.49644

Brooker, D., & Latham, I. (2016). *Person-centered dementia care: Making services better with the VIPS framework* (2nd ed.). London, UK: Jessica Kingsley.

Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., . . . Hendrie, H. C. (2006). Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: A randomized controlled trial. *JAMA, 295*(18), 2148-2157. doi: 10.1001/jama.295.18.2148

Callahan, C. M., Weiner, M., & Counsell, S. R. (2008). Defining the domain of geriatric medicine in an urban public health system affiliated with an academic medical center. *Journal of the American Geriatrics Society, 56*(10), 1802-1806. doi: 10.1111/j.1532-5415.2008.01941.x

Callahan, C. M., Boustani, M., Sachs, G. A., & Hendrie, H. C. (2009). Integrating care for older adults with cognitive impairment. *Current Alzheimer Research*, *6*(4), 368-374.

Callahan, C. M., Boustani, M. A., Weiner, M., Beck, R. A., Livin, L. R., Kellams, J. J., . . . Hendrie, H. C. (2011). Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging & Mental Health, 15*(1), 5-12. doi: 10.1080/13607861003801052

Callahan, C. M., Sachs, G. A., LaMantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs, 33*(4), 626-632. doi:10.1377/hlthaff.2013.1260

Cepoiu-Martin, M., Tam-Tham, H., Patten, S., Maxwell, C. J., & Hogan, D. B. (2016). Predictors of long-term care placement in persons with dementia: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 31*(11), 1151-1171. doi: 10.1002/gps.4449.

Chodosh, J., Pearson, M. L., Connor, K. I., Vassar, S. D., Kaisey, M., Lee, M. L., & Vickrey, B. G. (2012). A dementia care management intervention: which components improve quality? *The American Journal of Managed Care, 18*(2), 85-94.

Chodosh, J., Colaiaco, B. A., Connor, K. I., Cope, D. W., Liu, H., Ganz, D. A., . . . Vickrey, B. G. (2015). Dementia care management in an underserved community: The comparative effectiveness of two different approaches. *Journal of Aging & Health, 27*(5), 864-893. doi: 10.1177/0898264315569454

Clague, F., Mercer, S. W., McLean, G., Reynish, E., & Guthrie, B. (2017). Comorbidity and polypharmacy in people with dementia: Insights from a large, population-based cross-sectional analysis of primary care data. *Age & Ageing, 46*(1), 33-39. doi: 10.1093/ageing/afw176

Clarivate Analytics. (2017). EndNote X7 [computer software].

Clark, P. A., Bass, D. M., Looman, W. J., McCarthy, C. A., & Eckert, S. (2004). Outcomes for patients with dementia from the Cleveland Alzheimer's Managed Care Demonstration. *Aging & Mental Health, 8*(1), 40-51.

Conradsson, M., Rosendahl, E., Littbrand, H., Gustafson, Y., Olofsson, B., & Lövheim, H. (2013). Usefulness of the Geriatric Depression Scale 15-item version among very old people with and without cognitive impairment. *Aging & Mental Health, 17*(5), 638-645. doi: 10.1080/13607863.2012.758231

Cottingham, A. H., Alder, C. A., Austrom, M. G., Johnson, C. S., Boustani, M. A., & Litzelman, D. K. (2014). New workforce development in dementia care: Screening for “caring”: Preliminary data. *Journal of the American Geriatrics Society, 62*(7), 1364-1368. doi: 10.1111/jgs.12886

Crabtree, B. F., Miller, W. L., & Stange, K. C. (2001). Understanding practice from the group up. *Journal of Family Practice, 50*(10), 881-887.

Cummings, J. L, Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A, & Gornbein J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44*(12), 2308-2314. doi:10.1212/wnl.48.5_suppl_6.10s

Cummings, J., Zhong, K., & Bernick, C. (2014). The Cleveland Clinic Lou Ruvo Center for Brain Health: Keeping memory alive. *Journal of Alzheimer's Disease, 38*(1), 103-109. doi: 10.3233/JAD-130791

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Current Psychiatry Reports, 14*(4), 298-309. doi: 10.1007/s11920-012-0288-5

D'Souza, M. F., Davagnino, J., Hastings, S. N., Sloane, R., Kamholz, B., & Twersky, J. (2015). Preliminary data from the Caring for Older Adults and Caregivers at Home (COACH) program: A care coordination program for home-based dementia care and caregiver support in a Veterans Affairs Medical Center. *Journal of the American Geriatrics Society, 63*(6), 1203-1208. doi: 10.1111/jgs.13448

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: Person-centered care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing, 19*(17-18), 2611-2618. doi: 10.1111/j.1365-2702.2009.03143.x

Folstein, M. F, Folstein, S. E., McHugh, P. R. (1975). "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189-198.

Fortinsky, R. H. (2001). Health care triads and dementia care: Integrative framework and future directions. *Aging & Mental Health, 5 Suppl 1,* S35-S48.

Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health, 6*(2), 153-160.

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J . . . Crumb, S. (2014). Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Research in Gerontological Nursing, 7*(3), 126-137. doi:10.3928/19404921-20140113-01

Frame, A., LaMantia, M., Reddy Bynagari, B., Dexter, P., & Boustani, M. (2013). Development and implementation of an electronic decision support to manage the health of a high-risk population: The enhanced electronic medical record Aging Brain Care software (eMR-ABC). *EGEMS, 1*(1), 1009. doi: 10.13063/2327-9214.1009

Friedman, E. M., Shih, R. A., Langa, K. M., & Hurd, M. D. (2015). U.S. prevalence and predictors of informal caregiving for dementia. *Health Affairs, 34*(10), 1637-1641. doi: 10.1377/hlthaff.2015.0510

French, D. D., LaMantia, M. A., Livin, L. R., Herceg, D., Alder, C. A., Boustani, M. A. (2014). Healthy Aging Brain Center improved care coordination and produced net savings. *Health Affairs, 33*(4), 613-618. doi: 10.1377/hlthaff.2013.1221

Geyman, J. P. (2007). Disease management: Panacea, another false hope, or something in between? *Annals of Family Medicine, 5*(3), 257-260. doi: 10.1370/afm.649

Gnjidic, D., Husband, A., & Todd, A. (2018). Challenges and innovations of delivering medicines to older adults. *Advanced Drug Delivery Reviews.* Advance on-line publication. doi: 10.1016/j.addr.2018.08.003

Greening, L., Greaves, I., Greaves, N., & Jolley, D. (2009). Positive thinking on dementia in primary care: Gnosall Memory Clinic. *Community Practitioner, 82*(5), 20-23.

Guo, Y.-J., Wang, S.-C., & Johnson, V. (2012). Clinical assessment in the counseling process: A teaching model. Retrieved from https://www.counseling.org/docs/default-source/vistas/vistas_2012_article_10.pdf?sfvrsn=1fe57056_14

Hagedorn, H., Hogan, M., Smith, J. L., Bowman, C., Curran, G. M., Espadas, D., . . . Sales, A. E. (2006). Lessons learned about implementing research evidence into clinical practice. Experiences from VA QUERI. *Journal of General Internal Medicine, 21 Suppl 2,* S21-24.

Hain, D., Dunn, D. J., & Tappen, R. M. (2011). Patient-provider partnership in a memory disorder center. *Journal of the American Academy of Nurse Practitioners, 23*(7), 351-356. doi: 10.1111/j.1745-7599.2011.00619.x

Hall, G. R., & Buckwalter, K. C. (1987). Progressively lowered stress threshold: a conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing, 1*(6), 399-406.

Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *Journal of General Internal Medicine, 22*(11), 1487-1492. doi: 10.1007/s11606-007-0317-y

Horsman, J., Furlong, W., Feeny, D., & Torrance, G. (2003). The Health Utilities Index (HUI): Concepts, measurement properties and applications. *Health and Quality of Life Outcomes, 1*, 54.

Inouye, S. K., Studenski, S., Tinetti, M. E., & Kuchel, G. A. (2007). Geriatric syndromes: Clinical, research, and policy implications of a core geriatric concept. *Journal of the American Geriatrics Society, 55*(5), 780-791.

Institute of Medicine (U.S.) Committee on the Future Health Care Workforce for Older Americans. (2008). *Retooling for an aging America: Building the health care workforce.* Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK215395/

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., . . . Reuben, D. B. (2016). Quality of care provided by a comprehensive dementia comanagement program. *Journal of the American Geriatrics Society, 64*(8), 1724-1730. doi: 10.1111/jgs.14251

Jolley, D., Greaves, I., & Clark, M. (2012). Memory clinics and primary care: Not a question of either/or. *BMJ,* 344, e4286. doi: 10.1136/bmj.e4286

Jolley, D., & Moniz-Cook, E. (2009). Memory clinics in context. *Indian Journal of Psychiatry, 51 Suppl 1,* S70-76.

Judge, K. S., Bass, D. M., Snow, L. A., Wilson, N. L., Morgan, R., Looman, W. J., . . . Kunik, M. E. (2011). Partners in Dementia Care: A care coordination intervention for individuals with dementia and their family caregivers. *The Gerontologist, 51*(2), 261-272. doi: 10.1093/geron/gnq097

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia, *The Gerontologist, 50*(3), 294-302. doi: 10.1093/geront/gnp162

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *JAMA, 185,* 914-919.

Katzman, Brown, Fuld, Peck, Schechter, & Schimmel. (1983). Validation of a short Orientation-Memory-Concentration Test of cognitive impairment. *The American Journal of Psychiatry, 140*(6), 734-739.

Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., . . . DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences, 12*(2), 233-239.

King, P. R., Vair, C. L., Wade, M., Gass, J., Wray, L. O., Kusche, A., . . . Chang, J. (2015). Outpatient healthcare utilization in a sample of cognitively impaired veterans receiving care in VHA geriatric evaluation and management clinics. *Psychological Services, 12*(1), 66-72. doi: 10.1037/ser0000015

Kohout, F. J., Berkman, L. F., Evans, D. A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D (Center for Epidemiological Studies Depression) depression symptoms index. *Journal of Aging & Health, 5*(2), 179-183.

Kroenke K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613. doi:10.1046/j.1525-1497.2001.016009606.x

LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G., . . . Boustani, M. A. (2015). The Aging Brain Care Medical Home: Preliminary data. *Journal of the American Geriatrics Society, 63*(6), 1209-1213. doi:10.1111/jgs.13447

LaMantia, M. A., Perkins, A. J., Gao, S., Austrom, M. G., Alder, C. A., French, D. D., . . . Boustani, M. A. (2016). Response to depression treatment in the Aging Brain Care Medical Home model. *Clinical Interventions in Aging, 11*, 1551-1558.

Lawton, M. P., Moss, M., Hoffman, C., & Perkinson, M. (2000). Two transitions in daughters' caregiving careers. *The Gerontologist, 40*(4), 437-448.

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer Publishing Company.

Levac, D., Colquhoun, H., & O'Brien, K. (2010). Scoping studies: Advancing methodology. *Implementation Science*, *5*, 69. doi: 10.1186/1748-5908-5-69.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, *64*(3), 510-519.

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia. *Psychological Services*, *14*(1), 102-111. doi: 10.1037/ser0000118

Maxwell, C. A., & Mion, L. C. (2015). Geriatric trauma: An opportunity for proactive palliative care. *Geriatric Nursing, 36*(6), 475-476. doi: 10.1016/j.gerinurse.2015.10.004

McClendon, M. J., Smyth, K. A., & Neundorfer, M. M. (2006). Long-term-care placement and survival of persons with Alzheimer's disease. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 61*(4), P220-P227.

McDaniel, R. R., Jr., Jordan, M. E., & Fleeman, B. F. (2003). Surprise, Surprise, Surprise! A complexity science view of the unexpected. *Health Care Management Review, 28*(3), 266-278.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R. Jr., Kawas, C. H., . . . Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia, 7*(3), 263-269. doi: 10.1016/j.jalz.2011.03.005

Mitchell, A. J., Meader, N., & Pentzek, M. (2011). Clinical recognition of dementia and cognitive impairment in primary care: A meta-analysis of physician accuracy. *Acta Psychiatrica Scandinavica, 124*(3), 165-183. doi: 10.1111/j.1600-0447.2011.01730.x

Monahan, P. O., Boustani, M. A., Alder, C., Galvin, J. E., Perkins, A. J., Healey, P., . . . Callahan, C. (2012). Practical clinical tool to monitor dementia symptoms: The HABC-Monitor. *Clinical Interventions in Aging, 7*, 143-157. doi: 10.2147/CIA.S30663

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., . . . Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society, 53*(4), 695-699.

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality dementia care. *Journal of the Applied Gerontology, 36*(2), 195-212. doi: 10.1177/0733464815589986

Odenheimer, G., Borson, S., Sanders, A. E., Swain-Eng, R. J., Kyomen, H. H., Tierney, S., . . . Johnson, J. (2014). Quality improvement in neurology: Dementia management quality measures. *Journal of the American Geriatrics Society, 62*(3), 558-561. doi: 10.1111/jgs.12630

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan – a web and mobile app for systematic reviews. *Systematic Reviews, 5*(1), 210.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594. doi: 10.1093/geront/30.5.583

Phelan, E. A., Borson, S., Grothaus, L., Balch, S., & Larson, E. B. (2012). Association of incident dementia with hospitalizations. *JAMA, 307*(2), 165-172. doi: 10.1001/jama.2011.1964.

Powers, B. P., Homer, M. C., Morone, N., Edmonds, N., & Rossi, M. I. (2017). Creation of an interprofessional teledementia clinic for rural veterans: Preliminary data. *Journal of the American Geriatrics Society, 65*(5), 1092-1099. doi: 10.1111/jgs.14839

Peterson, J., Pearce, P. F., Ferguson, L. A., & Langford, C. A. (2017). Understanding scoping reviews: Definition, purpose, and process. *Journal of the American Association of Nurse Practitioners, 29*(1), 12-16. doi: 10.1002/2327-6924.12380

Radloff, S. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401. doi:10.1177/014662167700100306

Reuben, D. B. (2011). Physicians in supporting roles in chronic disease care: The CareMore model. *Journal of the American Geriatrics Society, 59*1(1), 158-160. doi:10.1111/j.1532-5415.2010.03237.x

Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society, 61*(12), 2214-2218. doi: 10.1111/jgs.12562

Rogers, N. T., Steptoe, A., & Cadar, D. (2017). Frailty is an independent predictor of incident dementia: Evidence from the English Longitudinal Study of Ageing. *Scientific Reports, 7*(1), 15746. doi: 10.1038/s41598-017-16104-y

Roth, D. L., Burgio, L. D., Gitlin, L. N., Gallagher-Thompson, D., Coon, D. W., Belle, S. H., . . . Burns, R. (2003). Psychometric analysis of the Revised Memory and Behavior Checklist: Factor structure of occurrence and reaction ratings. *Psychology and Aging, 18,* 906-915.

Samsi, K., & Manthorpe, J. (2014). Care pathways for dementia: Current perspectives. *Clinical Interventions in Aging, 9*, 2055-2063. doi: 10.2147/CIA.S70628

Samus, Q. M., Johnston, D., Black, B. S., Hess, E., Lyman, C., Vavilikolanu, A., . . . Lyketsos, G. (2014). A multidimensional home-based care coordination intervention for elders with memory disorders: The maximizing independence at home (MIND) pilot randomized trial. *The American Journal of Geriatric Psychiatry, 22*(4), 398-414. doi: 10.1016/j.jagp.2013.12.175

Sheiban, L., Stolee, P., McAiney, C., & Boscart, V. (2018). Health care provider experiences in primary care memory clinics: A phenomenological study. *BMC Family Practice, 19*(1), 68. doi: 10.1186/s12875-018-0756-z

Stroebel, C. K., McDaniel, R. R. Jr., Crabtree, B. F., Miller, W. L., Nutting, P. A., & Stange, K. C. (2005). How complexity science can inform a reflective process for improvement in primary care practices. *Joint Commission Journal on Quality and Patient Safety, 31*(8), 438-446.

Tan, Z. S., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large, academic health system. *Health Affairs, 33*(4), 619-625. doi: 10.1377/hlthaff.2013.1294

Tappen, R. M., & Valentine, K. (2014). Building and sustaining a caring-based nurse-managed center. *Pennsylvania Nurse, 69*(2), 16-21.

Tariq, S. H., Tumosa, N., Chibnall, J. T., Perry, M. H. 3rd, & Morley J. E. (2006). Comparison of the Saint Louis University mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder – a pilot study. *The American Journal of Geriatric Psychiatry, 14*(11), 900-910. doi:10.1097/01.jgp.0000221510.33817.86

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine, 363*(8), 733-742. doi: 10.1056/NEJMoa1000678

Teri, L., Truax P., Logsdon R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist (RMBPC). *Psychology and Aging, 7*, 622-31. doi: 10.1037/0882-7974.7.4.622

Todd, S., Barr, S., Roberts, M., & Passmore, A. P. (2013). Survival in dementia and predictors of mortality: A review. *International Journal of Geriatric Psychiatry, 28*(11), 1109-24. doi: 10.1002/gps.3946

Torrance, G. W., Feeny, D. H., Furlong, W. J., Barr, R. D., Zhang, Y., & Wang, Q. (1996). Multiattribute utility function for a comprehensive health status classification system. Health Utilities Index Mark 2. *Medical Care, 34*(7), 702-722.

Valentine, K. L., Stiles, M. K., & Mangan, D. B. (1995). *Values, vision, and action: Creating a care-focused nursing practice environment.* New York, NY: National League for Nursing.

Van der Cammen, T. J., Simpson, J. M., Fraser, R. M., Preker, A. S., & Exton-Smith, A. N. (1987). The Memory Clinic. A new approach to the detection of dementia. *British Journal of Psychiatry, 150,* 359-364.

Verghese, J., Malik, R., & Zwerling, J. (2016). Montefiore-Einstein Center for the Aging Brain: Preliminary data. *Journal of the American Geriatrics Society, 64*(11), 2374-2377. doi: 10.1111/jgs.14473

Vickrey,B. G., Hays, R. D., Maines, M. L., Vassar, S. D., Fitten, J., & Strickland, T. (2009). Development and preliminary evaluation of a quality of life measure targeted at dementia caregivers. *Health and Quality of Life Outcomes*, *7,* 56. doi: 10.1186/1477-7525-7-56

Vickrey, B. G., Mittman, B. S., Connor, K. I., Pearson, M. L., Della Penna, R. D., Ganiats, T. G., . . . Lee, M. (2006). The effect of a disease management intervention on quality and outcomes of dementia care: A randomized, controlled trial. *Annals of Internal Medicine, 145*(10), 713-726.

Wenger, N. S., Roth, C. P., & Shekelle, P. (2007). Introduction to the assessing care of vulnerable elders-3 quality indicator measurement set. *Journal of the American Geriatrics Society, 55 Suppl 2,* S247-252.

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52*(5), 546-553.

World Health Organization. (2008). Task shifting: Rational redistribution of tasks among health workforce teams: Global recommendations and guidelines. Retrieved from http://www.who.int/healthsystems/TTR-TaskShifting.pdf

Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, *17*(1), 37-49.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-655. doi: 10.1093/geront/20.6.649

Zwerling, J. L., Cohen, J. A., & Verghese, J. (2016). Dementia and caregiver stress. *Neurodegenerative Disease Management, 6*(2), 69-72. doi: 10.2217/nmt-2015-0007

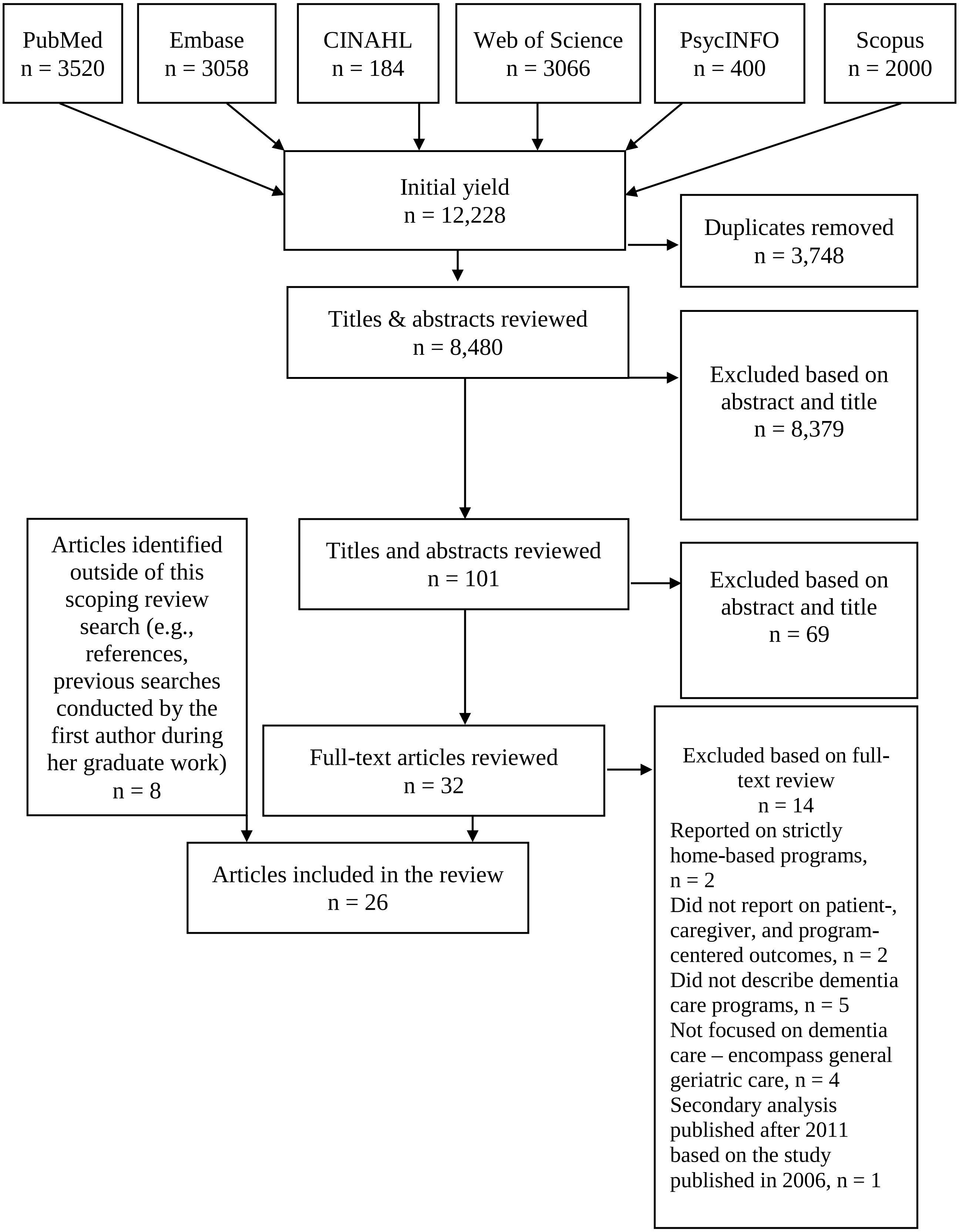

Figure 1. Literature selection

Table 1

Keywords and Search Strategy

Keywords: “primary health care;” “primary care nursing;” “physicians;” “primary care;” “ambulatory care facilities;” “outpatient clinics, hospital;” “dement*” (truncated to include “demented,” “dementia,” “dementing”); “memory care;” “outpatient department;” “outpatient service;” “ambulatory care;” “primary;” “ambulatory;” and “care.”

Initial delimiters applied towards all databases: humans, English.

PubMed: ("Primary Health Care"[Mesh] OR "Primary Care Nursing"[Mesh] OR "Physicians, Primary Care"[Mesh] OR "Ambulatory Care Facilities"[Mesh] OR "Outpatient Clinics, Hospital"[Mesh] OR memory care) AND ("Dementia"[Mesh] OR dement*)

EMBASE: 'dementia'/exp AND ('primary health care'/exp OR 'outpatient department'/exp)

CINAHL: (MH "Dementia") AND ((MH "Primary Health Care") OR (MH "Outpatient Service") OR (MH "Ambulatory Care Facilities"))

Web of Science: (dementia AND (primary care OR ambulatory care))

Additional delimiters applied in Web of Science: review, proceedings paper, meeting abstract, editorial material, book chapter

PsycINFO: (DE "Dementia") AND (DE "Primary Health Care" OR DE "Outpatient Treatment")

Additional delimiters applied in PsycINFO: academic journals

Scopus: dementia AND primary AND care OR ambulatory AND care

Additional delimiters applied in Scopus: articles

Note. Additional limiters (e.g., exclusion of all articles beyond peer-reviewed original research) were applied in some databases. It is noted underneath each respective database when such delimiters were applied.

Table 2. Summary of the Reviewed Programs

Program Title & Study Details	**Theoretical Framework, Goals, Healthcare Team, Primary Care**	**Services, Technology, Partnerships**	**Conclusions & Challenges**
<u>Healthy Aging Brain Care Monitor</u> **Location:** Indianapolis, IN **Settings:** Urban. Academic public safety net healthcare system **Study design:** Quasi-experimental non-equivalent control group prospective cohort study. Quasi-experimental non-equivalent control group	**Theoretical framework:** Complex Adaptive System. Reflective Adaptive Process **Goals:** Provide a sustainable collaborative dementia care program. Attain the standard of care in diagnosis, assessment, and treatment of PLWD. Enhance dementia care outcomes. Augment management of dementia and depression **Team: <u>dementia care coordinators (SW, RN);</u>*** geriatricians; behavioral neurologist; medical assistant;	• Assessment, diagnosis • Collaborative action plan creation with PCPs • Pharmacologic and non-pharmacologic BPSD, depression, delirium, and psychosis management • Comorbidities management in collaboration with PCPs • Reduction of anticholinergic burden, dementia-specific pharmacotherapy • Vascular burden management • Specialty referrals	• Implementation science principles enable healthcare delivery program translation from laboratory to practical settings • Positive effect on dementia care • Expand definition of patient to encompass caregivers and enlarge the scope of care beyond in-person visits

retrospective cohort study **Sample:** 208 patients, 176 caregivers; 303 HABC patients, 1453 non-HABC patients **Duration:** Since 2008. Reports: 2008; 2008-2009. **Baseline dementia severity:** 21.9 (MMSE)	research technician; administrative support **Primary care:** not provided. Collaborates with PCPs in managing dementia and comorbidities.	• Home environment modification • Care coordination with community agencies • Caregiver support, counseling, and education • Quantitative surveillance of caregivers’ emotional and physical health • Pharmacological and non-pharmacological management of caregivers’ conditions, collaboration with caregivers’ PCPs • Care protocols **Technology:** Telephone follow-up. Telephone access to the coordinator **Partnerships:** Alzheimer’s Association	• A model of bundled payment for care resulted in cost savings compared to usual primary care for PLWD • Cost savings demonstrate acceptability of this program which, if accepted nationwide, could save the U.S. healthcare system millions of dollars

Aging Brain Care Medical Home **Location:** Indianapolis, IN **Settings:** Urban. Academic public safety net healthcare system **Design:** qualitative study; descriptive retrospective study; developmental descriptive study; prospective descriptive cohort study retrospective chart review **Sample:** 16 and 62 care coordinator assistants;	**Theoretical framework:** Complex Adaptive System and Reflective Adaptive Process **Goals:** identify, assess, and address the biopsychosocial needs of PLWD and persons living with depression. Improve care and health outcomes and lower healthcare costs of Medicare beneficiaries with dementia and depression in central Indiana **Team: care coordinator assistants (high school diploma as a minim educational attainment)**;* care coordinator (RN); physician director; social worker; administrator	• Assessment: home visits • Monitoring biopsychosocial needs • Individualized care plan • Referrals for advanced assessments • Psychosocial and pharmacological interventions to decrease caregiver burden • Skills enhancement: symptom management • Caregiver handbook • Prescription of antidepressants and cholinesterase inhibitors and de-prescribing of anticholinergics • Medication adherence	• Key importance of strong communication between the program staff, PCPs, and hospital leadership • Patient recruitment difficult, despite PCPs' acceptance of the program • Importance of developing trusting, close relationships between care coordinator assistants and dyads • Importance of the health management software capacity to observe population and individual trends • Scalable program • Feasible protocol

378 PLWD, 117 persons with dementia and depression; 773 patients **Duration:** Since 2009. Reports: 2013-2014; 2012-2014 **Baseline dementia severity:** 21.2; 21.7 (MMSE)	**Primary care:** not provided. Management of dementia comorbidities coordinated with PCPs	• Minimization of cerebrovascular risk factors • Prevention and management of delirium, pain, psychosis • Care coordination with adult day care, respite care, and support groups • Home environment to adjustment • Acute and post-acute care coordination • Discuss end of life plans • Care protocols **Technology:** eMR-ABC. Follow-up: telephone, email, fax **Partnerships:** local Area Agency on Aging, Central IN Council on Aging, adult day	• Addressed dyads' essential medical and non-medical needs • Reflective Adaptive Process assisted with program implementation in a complex environment

		care facilities, senior care centers, churches	
Partners in Dementia Care **Location:** Boston, MA; Houston, TX Oklahoma City, OK; Providence, RI; Beaumont, TX **Settings:** VA, urban **Design:** RCT **Sample:** 394 veterans, 324 caregivers; 333 veterans; 328 veterans and caregivers; 93 veterans, 90 caregivers **Duration:** 12 months	**Theoretical framework:** Chronic Care Model. Stress Process Model **Goals:** Address unmet needs of dementia caregiving dyads across all stages of dementia progression. Improve access to medical and non-medical services for caregivers and veterans, strengthen the informal care network, provide health and caregiving information **Team: VA dementia care coordinators and Alzheimer's Association's care coordinators: bachelor's or master's prepared**	• Care needs assessment • Setting goals in collaboration between dyads and staff • Continuous monitoring of action steps' completion • Dementia education • Emotional support and coaching • Connection to medical and non-medical resources • Organizing informal care network	• Fits in the partnership between the VA and the Alzheimer's Association • Veterans' wives play an essential role in their care • The needs spread widely across medical and non-medical areas • Broad interventions may be more effective than those that focus on a single area

Baseline dementia severity: 6.77 (14 – most cognitive impairment); 14.6; 11.24; 12.8 (Short Blessed Orientation, Memory, and Concentration test)	**<u>RNs, SW, or counselors.</u>***Care coordinator assistants. Administrative support. MDs and administrative staff as project champions at the VA and the Alzheimer's Association **Primary care:** not provided, action steps created that may involve dyads to work with primary care	• Care coordination with the VA and the Alzheimer's Association • Dyads choose their goals • Hallmark: inclusion of PLWD in care planning as much as possible • <u>Care protocol</u> **Technology:** Care coordination mostly via telephone (80% - 84%). <u>Electronic Care Consultation Information System</u> guides service delivery and fidelity monitoring, shared between the Alzheimer's Association and the VA staff. **Partnerships:** VA and the Alzheimer's Association	• Telephone-based intervention enabled at a reasonable cost • Efficiency of the consumer-driven approach • Especially effective for high-risk veterans with more BPSD and worse cognitive impairment

The Alzheimer's Disease Coordinated Care for San Diego Seniors **Location:** San Fernando Valley of Los Angeles county, Los Angeles, CA **Settings:** Urban, predominantly underserved Latino community **Design:** RCT **Sample:** 151 patient-caregiver dyads **Duration:** 12 months	**Theoretical framework:** N/A **Goals:** Deliver a dementia care management program according to professional society guidelines. **Team: Care managers – social workers of Latino background and with experience working with Spanish-speaking populations.** In the in-person arm – two care managers, one from the healthcare organization, one from the Alzheimer's Association. In the telephone arm – one care manager from the healthcare organization. **Primary care:** Referrals can be made. Care managers send a summary of their initial assessment to the PCP.	• Structured assessment and needs identification during in-home visits • Inclusion of dyads into care plan development • Individualized care plans • Care plan customization with providers'/agencies' input • Coordination and implementation of action steps by care managers • Connecting dyads to medical and non-medical resources • Communication between medical and non-medical agencies	• No difference in care quality regardless delivery format highlights acceptability of the less costly telephone delivery

Baseline dementia severity: 10.7 (Blessed-Roth dementia cognitive test)	Help establish connection primary care. **Theoretical framework:** Progressively Lowered Threshold	• Caregiver counseling, education, instruction on self-management • Ongoing follow-up • In-person, telephone, e-mail, or mail encounters • In-home reassessments: every 6months through 18 months • Common care management protocol • Technology: one intervention arm entirely telephone-delivered. • Partnerships: Alzheimer’s Association, Meals on Wheels, Caregiver Resource Center

Proactive Primary Dementia Care **Location:** northeastern U.S. **Settings:** Community **Design:** Non-equivalent control group longitudinal experimental study **Sample:** 21 dyads (intervention); 10 dyads (control) **Duration:** 12 months **Baseline dementia severity:** 24.4	**Goals:** Augment PCP care by employing an NP with geropsychiatric expertise who provides care for PLWD and their caregivers. **Team: NP with geropsychiatric expertise,*** PCPs **Primary care:** not provided, but the NP consulted with PCPs in 3 partnering primary care practices regarding pharmacotherapy. The NP sent electronic updates to the PCP after each encounter with the dyad.	• Monthly home NP visits • Assessment of the dyad's adjustment to dementia diagnosis • NP-guided intervention: information on dementia, stress management, exercise, communication techniques, legal and financial planning, depression and anxiety prevention and management, repetitive behaviors and agitation, mobility issues, personal care, and psychotic symptoms • Medications review and adjustment based on PCPs' recommendations	• NPs with geropsychiatric expertise: ideal interventionists for a rapidly increasing population of PLWD and their caregivers • May be beneficial to combine home and office visits (not only offer home visits) • PCPs suggested shortening the intervention to 4 months: it would not lose its effectiveness and may be Medicare-reimbursable • Other priorities at the clinical site (conversion to a patient-centered medical

• Equal focus on PLWD and caregiver • Pharmacological and non-pharmacological management according to protocols • Use of RMBPC to activate non-pharmacological management protocols • Linkage to community resources • <u>Protocol from the Alzheimer's Collaborative Care Study</u> **Technology:** Electronic correspondence between the NP and PCPs **Partnerships:** NP collaborated with 3 community-based practice sites within a large PCP network	home) diverted resources from the intervention • Very small cognitive decline among PLWD over 12 months could explain lack of difference in the results between the intervention arms

Behavior Management Clinic **Location:** University of California San Francisco **Settings:** academic, urban **Design:** descriptive retrospective cohort study **Sample:** 66 dyads **Duration:** since 2010 **Baseline dementia severity:** N/A	**Theoretical framework:** N/A **Goals:** Implement a specialty clinic managed by APRNs to assess and manage behavioral symptoms associated with dementia **Team: APRN, clinical nurse specialist*** **Primary care:** not provided	• PLWD assessment by the APRN: cognitive and functional abilities, history, neurological examination, persons' challenges • Caregiver's interview by the clinical nurse specialist: history; severity, frequency, and presence of triggers for behaviors; current management and its effectiveness; caregiver's coping • Education: videos, books • Individualized strategies, recommendations for managing behavioral symptoms • Strategies: environmental, behavioral, pharmacological, physical, and internal to the caregiver	• Beneficial to discuss recommendations and interventions with caregiver alone • Consultations between nurses and caregivers alone required someone to stay with PLWD; volunteers later fulfilled that role • Follow-up clinic appointment – in additional to a follow-up call – may be useful for gauging effectiveness and adherence to recommendations

		• Care plan. Interventions: environmental changes, communication strategies, addressing caregivers’ stress and coping, exercise, community resources • Follow-up: APRNs called 1month post-meeting, encouraged dyads to call **Technology:** Dyads’ education in video format; some phone consultations **Partnerships:** Dyads referred to the clinic from the Memory and Aging Center – Alzheimer’s Disease Research Center at the University of California, San Francisco	• Long-term goals: maintain a consultation clinic and follow-up PLWD over time PRN • In the future, may provide home visits (in the community and facilities)

Caring for Older Adults and Caregivers at Home (COACH) Program **Location:** Durham, NC **Settings:** VA. Serving veterans living within 50 miles from Durham VA Medical Center **Design:** Retrospective quasi-experimental non-equivalent control group cohort study **Sample:** 133 dyads (intervention), 29 dyads (control) **Duration:** report: 2010-2012. Dyads followed	**Theoretical framework:** N/A **Goals:** Provide high quality dementia care and support caregivers of PLWD to prolong their life at home **Team: SW, RN,*** geriatrician, geriatric psychiatrist, geriatric pharmacist **Primary care:** not provided, interdisciplinary team communicates care plan and recommendation to PCPs who continue to provide usual primary care and co-sign the care plan. Recommendations made to PCPs	• Initial home visit by a SW or RN • Assessment: neuropsychiatric and depressive symptoms, delirium, sleep hygiene, general medical assessment. In-home safety assessment: firearms, fall risk • Care plan development by an interdisciplinary team • Dyads involved in plan modification • Caregiver education • Ordering durable medical equipment, implementing toileting schedule	• Feasible home-based care coordination program for PLWD and their caregivers • Attains high care quality • Stakeholders deemed the program valuable • In the early stages the program was constantly evolving, which may have lowered care quality compared to the level ultimately reached • COACH has been adopted permanently at Durham VA Medical Center and in 2 Durham VA Medical Center outpatient clinics • COACH Veterans were recognized as a high-need

as long as the veteran lives at home **Baseline dementia severity:** 16	• Care transitions support: home visits post-hospitalization and post-rehabilitation center stay • Monitoring of care plan implementation • Support group for caregivers • Dyads have telephone access to SW and RN **Technology:** Telephone follow-up. Care plans communicated to PCPs in electronic medical records, with PCPs as additional signers on the notes **Partnerships:** none	population based on ADL impairments and dementia severity. This led to the greater VA resource allocation to Durham VA Medical Center

Videotelemedicine in a Memory Disorders Clinic **Location:** Eureka, northern CA **Settings:** VA. Rural **Design:** case study **Sample:** 15 veterans **Duration:** not stated **Baseline dementia severity:** 21.8	**Theoretical framework:** none **Goals:** Using videotelemedicine, provide access for rural veterans to a specialty memory disorders clinic to conduct a comprehensive multi-disciplinary assessment and receive a diagnosis. **Team:** **Remote clinician*** (specialty not stated) assisting the patient with the assessment in Eureka and coordinating videotelemedicine connection to the memory disorders clinic in San Francisco. MDs at the memory disorders clinic. **Primary care:** Not provided. Diagnostic evaluation results communicated in electronic medical records to the person's PCP. PCP	• Multidisciplinary state-of-the-art diagnosis of cognitive impairment by videotelemedicine integrated into a clinical setting • Neurological and neuropsychological evaluation via video, assisted by a remote clinician • Treatment recommendations post-diagnosis: control of vascular risk factors, medications for depression and anti-dementia medications • Support and education to caregivers: information on diagnosis, prognosis, treatment	• Videotelemedicine is effective for the provision of consultation to rural residents who lack access to specialty services • Some aspects of the neurological exam necessitated local clinician's assistance • Careful pre-screening (obtaining history of present illness, including onset of symptoms and behavioral and functional changes) of potential patients conducted by a remote clinician is essential for successful use of videotelemedicine • Diagnosis disclosure may be difficult when done via

	could attend post-evaluation conference and discuss result and recommendations.	options, local resources, and driving **Technology:** Assessment completed via videotelemedicine, assisted by a local clinician **Partnerships:** Collaboration between a community-based outpatient clinic in Eureka and a Memory Disorders Clinic at San Francisco VA Medical Center	distance; presence of a remote clinician may help • Capabilities of videotelemedicine are limited (persons’ sensory deficit, severe cognitive impairment)

Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[40] **Location:** Philadelphia, PA **Settings:** VA. Not specified (urban, suburban, rural) **Design:** Longitudinal randomized pragmatic pilot study **Sample:** 75 veterans with dementia and their caregivers	**Theoretical framework:** Transactional Model of Stress and Coping **Goals:** Provide individualized dementia care management **Team: Care manager (RN with experience in geriatrics and treatment of behavioral symptoms),*** PCPs. Supervision/resource team: geriatric psychiatrist, geriatric RN, local VA caregiver/ dementia support coordinator **Primary care:** not provided. Care managers communicate with PCPs about veterans' medication side effects and adherence, BPSD, and dyads' needs. Collaborate with PCPs.	• Individually tailored intervention, accounting for PLWD's and caregiver's needs, preferences, and comorbidities • Caregiver psychoeducation, training in emotion- and problem-focused coping skills and problem-solving, counseling, support, active listening • Address caregivers' needs, psychological symptoms, burden, well-being, respite care • Emphasis on non-pharmacological management • Linkage to VA and community resources • Coordinating visits with primary and specialty care	• Caregivers of veterans living with dementia may benefit from a telephone-based collaborative care management program • Such distance-delivered programs may be an adjunct to dementia care in primary care settings • The multi-component intervention and the emphasis on problem-solving and coping skills may explain positive caregiver outcomes • Scalable program, may be applied outside the VA • The intervention's delivery method, brevity, and provision

Duration: 3 months **Baseline dementia severity:** N/A	PCPs get progress reports from the care manager after each encounter with the dyad	• In collaboration with caregivers: monitoring veterans' safety and environmental issues, medications' side effects and adherence, behavioral and neuropsychiatric symptoms, and physical functioning • Caregiver manual • Caregivers could select which intervention topics they wanted to focus on • Protocol **Technology:** entirely telephone-delivered **Partnerships:** N/A	of a manual intended to minimize caregiver strain • Lacking effect on caregiver burden may be due to the fact that certain factors probed on the Zarit Burden Interview were not amenable to change

MemoryCare **Location:** Asheville, NC **Settings:** urban, suburban, predominantly rural. Low-income patient population: 52% **Design:** Quasi-experimental non-equivalent control group cohort study **Sample:** 967 PLWD and 3251 caregivers **Duration:** Operating since 2000. Report: 2013	**Theoretical framework:** N/A **Goals:** Deliver care via a community-based dementia management care program that equally emphasizes patient care and caregiver support and education **Team:** **MDs (internal medicine, family medicine, psychiatry); care manager (RN and SW);*** administrative support **Primary care:** not provided, care is coordinated with PCPs for the duration of the person's program enrollment. PCPs refer patients to MemoryCare. Designed to supplement primary care. Records from a PCP are obtained before the first MemoryCare visit. If a PLWD does not have a PCP,	• Assessment. Identification and addressing needs • Individualized care plans • Home visits within the central office's county • Medication reconciliation • Non-pharmacological management of neuropsychiatric symptoms when possible • Dementia management planning • Caregiver support; • counseling; education on driving, medication errors, financial concerns	• Broader integration of caregivers into the program is beneficial to PLWD • Most efficacy for dyads stems from direct interaction with MemoryCare providers and care managers during and between visits • Key barrier: financial limitations for the reimbursement for addressing caregivers' needs and helping them with managing their persons' health concerns

Baseline dementia severity: 19.4	MemoryCare helps to establish primary care with PCPs who accept new patients.	• Instruction on medical assistance in managing BPSD and safety • Instruction on risks and benefits of medical interventions, reducing not needed acute care use • Assistance with the completion of advance directives • Care coordination with other providers and agencies: in-home an overnight respite, day programs, nutrition support, transportation, and caregiver support • Central office and 2 rural clinics	• Given the prevalence of the low-income patient population (52%) and those with significant impairment in ADLs (48%) at MemoryCare, this program may facilitate Medicaid and family financial resources' savings • Caregivers' willingness to cost-share implies perceived value of these services to families

Technology: Phone and e-mail communication between visits regarding behavioral and dementia-related medical problems

Partnerships: N/A

Inter-professional teledementia clinic for rural veterans **Location:** Beaver County, PA; Belmont County, OH, Fayette County, PA; Washington County, PA; Westmoreland County, PA; a rural VA medical center in Altoona, PA. Main tele-dementia clinic in Pittsburgh, PA **Settings:** VA. Rural **Design:** Prospective descriptive cohort study **Sample:** 95 veterans	**Theoretical framework:** N/A **Goals:** Replicate the in-person dementia clinic experience for rural veterans with the use of clinical video telehealth. Increase availability of specialized geriatric and dementia care to rural veterans, decrease patient and caregiver burden, and support community-based outpatient clinic providers **Team:** Geriatricians (may be substituted by general internists, certified registered nurse practitioners, or geriatric medicine fellows); neurologists; geropsychologists; geriatric psychiatrists (may be substituted by a dually certified psychiatrist-neurologist or geriatric	• Veterans commute to the community-based outpatient clinic in their area, where the equipment is set up for them to be assessed by clinicians at the Pittsburgh teledementia clinic • Assessment by a geriatrician, geriatric psychologist, geriatric psychiatrist, and SW • Geriatrician: history and exam, medication review, lab and imaging tests review. Advise on lab values, comorbidities, and medications, including those affecting cognition • Geriatric psychologist: neuropsychological testing • Advises on cognitive testing	• Feasible for interdisciplinary dementia evaluations and follow-up to rural residents • Reduction in travel time: alleviation of caregiver burden • Telehealth compensates for shortage of dementia specialists in rural areas • Inadequate internet connectivity in rural areas: could not install home video equipment • Neuropsychological tests not validated for distance use

Duration: 1 year **Baseline dementia severity:** mean 18.2 (Montreal Cognitive Assessment); 15.9 (Saint Louis University Mental Status)	psychiatry fellow); SW; RN manager; **telehealth technicians (MA, LPN, or RN)*** **Primary care:** not provided	results, treatment, and caregiver support services. • Geriatric psychiatrist: interview. Advises on management of psychiatric medications, help with challenging behavior, and frequent follow-up • SW: social history, assessment of caregiver stress, identification of family supports. Advises on education and on VA and community resources • In-person/telephone follow-ups: debrief caregivers	• Identification of resources in rural areas required collaboration between SW in Pittsburgh and rural SW • Some neurological examination elements could not be performed via distance • Communication hindered for patients with severe hearing loss

Technology: Clinical video telehealth equipment for distance visits.

Telephone follow-up

Partnerships: N/A

University of California at Los Angeles Alzheimer's Disease and Dementia Care Program **Location:** Los Angeles, CA **Settings:** Academic, urban, fee-for-service environment similar to most U.S. primary care settings **Design:** retrospective cohort case study (chart review); prospective cohort case study **Sample:** 797 PLWD; 150 PLWD; 510 PLWD	**Theoretical framework:** N/A **Goals:** Improve dementia care quality and decrease costs by reducing caregivers' burnout and strain, improving care transitions between care sites, and promoting access to community resources. Maximize patient function, independence, and dignity. Reduce preventable ED visits and hospitalizations. Reduce neuropsychiatric symptoms, caregiver depressive symptoms. Improve attainment of quality indicators. **Team: Geriatric APRNs (dementia care managers);*** MDs **Primary care:** not provided. Care plans sent to persons' PCPs for modification and approval. APRNs	• Assessment (medical, behavioral, psychosocial, advance care planning needs); neurological exam • Caregiver screening for strain and depression • Dementia care plan • Monitoring care plans' implementation, revisions • Pharmacotherapy • Caregiver training, support, respite care • Continuous follow-up: in-person, telephone, home • Referrals to neurology, geriatrics, psychiatry, physical therapy, clinical trials, hospice	• Operates in a competitive fee-for-service environment, similar to that in most U.S. primary care settings • Would not have been sustainable if it operated only on Medicare fee-for-service schedule and without the Centers for Medicare and Medicaid grant and philanthropy • Co-management with an APRN results in a very high quality of dementia care, especially in assessment, screening, and counseling domains • Challenge with delineating the APRN's role: some referring

Duration: Since 2011. Reports: 2012-2014; 2012-2013 **Baseline dementia severity:** 17.2; 15.8; 16.1	collaborate with PCPs on medication management for dementia and depression	• PRN hospitalization at the UCLA Geriatrics Special Care Unit or Geriatric Psychiatry Unit • Care transitions' management: ED, inpatient, long-term, post-acute rehabilitation • Advance care planning • Bereavement support **Technology:** Telephone follow-up. 24/7/365 access to a geriatrician on-call. Caregiver training: includes a web-based option. **Partnerships:** Alzheimer's Association chapter, community organizations with which the program established formal partnerships. Partner with PCPs who refer PLWD to the program.	MDs allowed the APRN to manage conditions affected by cognition (e.g., falls), others restricted practice solely to dementia management • No commercially available software product that would meet all of the program's needs

Louis and Anne Green Memory and Wellness Center **Location:** Boca Raton, FL **Settings:** Academic, urban **Design:** case study; retrospective descriptive study **Sample:** N/A **Duration:** since 2000 **Baseline dementia severity:** N/A	**Theoretical framework:** science of human caring. **Goals:** Provide memory-focused care by APRNs to persons with mild to moderate cognitive impairment. **Team: APRNs, including a doctorally-prepared geriatric APRN;*** geriatric neuropsychologist, psychologist, SW, MD advisor to the Center, volunteers. **Primary care:** not provided. Evaluation results communicated to the patient's MD.	• Memory consultation clinic • Diagnostic process in 3 visits: memory-focused history and physical exam, neuropsychological testing, comprehensive counseling and care coordination • Consultation with SW • Brain imaging and lab studies PRN, results sent to the person's MD • Goals of care and care plan established in collaboration between APRN, PLWD, and caregivers • Recommendations to patients and families in a multidisciplinary case conference • Pharmacological and non-pharmacological interventions	• Establishment of the Center made possible with a philanthropic donation, state support, Administration on Aging, and leadership of the Christine E. Lynn College of Nursing • Patient-provider partnership increases effectiveness of care and clients' satisfaction with care • One of 15 state-recognized memory disorders clinics since 2005 • Relies on philanthropy and volunteers

- Prescribing acetylcholinesterase inhibitors and antidepressants PRN
- Follow-up 1 year after the first evaluation, PRN afterwards
- Driving evaluation
- Counseling
- Cognitive retraining
- Adult day program
- Caregiver support groups, self-preservation activities days, and educational programs
- Referral to community resources
- Home nursing visits

Technology: N/A

Partnerships: N/A

Montefiore-Einstein Center for the Aging Brain **Location:** Yonkers, NY **Settings:** Urban **Design:** prospective cohort study **Sample:** 366 patients **Duration:** since 2014. Report: 2014 – 2015 **Baseline dementia severity:** Most persons diagnosed with mild dementia (Functional Assessment Staging scale)	**Theoretical framework:** N/A **Goals:** Maximize outcomes in dementia care: regular monitoring of patients' cognition and health; education and support to patients and caregivers; implementation of pharmacological and non-pharmacological treatments; connection of patients to clinical trials. **Team: 4 geriatricians, 2 neuropsychologists, 3 neurologists, SW, geriatric psychiatrist, psychiatrist*** **Primary care:** not provided. Evaluation and management plan devised by geriatric, neuropsychology, and neurology specialists shared with PCPs. PRN referrals.	• Consultative model • Pre-visit screening: assessment of ADLs, illnesses, function, goals of care, and caregiver stress • If caregivers score positively on stress inventory, appointment with SW is arranged • Assessment of persons' capacity to complete advance care planning • Assessment available in English and Spanish • Comprehensive 3-step evaluation • Cognitive, neurological, and general assessment that screens for dementia-related syndromes: frailty, fall risk, polypharmacy • Diagnosis and ongoing management by a neurologist	• Feasible program • Well-accepted among patients, caregivers, referring MDs • The Center's strengths: multidisciplinary approach, whereby all patients receive geriatric and cognitive evaluation. Such comprehensive coverage may be lacking in strictly primary care or neurology settings • Patients' age coverage exceeds that of geriatric clinics: individuals with early-onset dementias are evaluated

	• Creation of a management plan • Chronic disease management • Individualized pharmacotherapy • Referral to Alzheimer's Association **Technology:** N/A **Partnerships:** N/A	• Patients with cognitive manifestations of non-dementia syndromes are evaluated • Difficult to follow recommendations for patients without caregivers • Financial sustainability – an ongoing concern

*Note.****bold underlined healthcare professionals** indicates staff that interacts directly with PLWD and caregivers the most, someone who is on the frontline with patient-caregiver dyads or acts as an interface or a mediator between dyads and the care. Electronic medical record software titles are underlined. Care protocols are underlined. **Technology** denotes what technology models used.

*Data are based on the patient panel at the ABC Med Home (N = 773), not all of whom had dementia, since the ABC MedHome treats PLWD, persons living with depression, and persons living both with dementia and depression. ED = emergency department. PCP = primary care physician. BPSD = behavioral and psychological symptoms of dementia. RN = registered nurse. MD = medical doctor. APRN = advanced practice registered nurse. NP = nurse practitioner. SW = social worker/social work. PHQ-9 = Patient Health Questionnaire-9 (Kroenke et al., 2001). HABC-M = Healthy Aging Brain Care Monitor, an instrument measuring the person's cognitive, functional, behavioral, and psychological symptoms (Monahan et al., 2012). RCT = randomized controlled trial. RMBPC = Revised Memory and Behavior Checklist (Teri et al., 1992). MMSE = Mini-Mental State Exam (Folstein et al., 1975). ADL = activity of daily living. PLWD = person(s) living with dementia. PRN = pro re nata (as needed)

Table 3. Patient, Caregiver, and Program Outcomes Summarized

Program Title	Patient Outcomes	Caregiver Outcomes	Program Outcomes
Healthy Aging Brain Care Monitor	N/A	N/A	• 1+ ED visits in the first year since the first HABC visit: 28% of HABC patients vs. 49% in control • One-week ED re-visit: 14% (vs. 15%) • Hospitalizations: 14% (vs. 26%) • Mean length of stay: 5 days (vs. 7 days) • 30-day re-hospitalizations: 11% (vs. 20%)

- Prescriptions of neuroleptics: 5% (vs. 5%)
- Anti-dementia drugs and anticholinergics:19% (vs. 40%)
- Brain imaging: 82% (vs. 22%)
- In collaboration with PCPs, 45 % (vs. 23%) of HABC patients with high vascular burden met goal for hyperlipidemia control; 78% (vs. 62%) for diabetes control
- PCPs recognized HABC as a coordinator and facilitator of care and communication

- Annual cost: $618/patient
- Annual net savings: $980 – $2,856/patient
- Annual cost savings: $296,952/HABC cohort
- Cost savings due to decreased inpatient (53%) and ED and outpatient costs (47%)

<u>Aging Brain Care Medical Home</u>	• Significantly reduced dementia and depression symptoms • Reduction in depressive symptoms in persons with dementia and depression: 1.3 points/year • Reduction in dementia symptoms: 5.8 points/year • Slope of reduction in dementia symptoms: from – 1.9 to – 2.5 • Slope of reduction in depressive symptoms: from – 0.3 to – 0.4. • Reduction in dementia symptoms: 50%+ among 51% of PLWD with high symptom burden • The highest response to depression treatment was among those with the most severe depressive symptoms (PHQ-9 scores >10)*	• Reduction in stress: at least 50% among 51% of caregivers (measured by the HABC-M)	• Care protocols triggered: mean 1.6 for PLWD and persons with dementia and depression • Screening procedure for hiring care coordinator assistants developed • Training program for care coordinator assistants developed • Care coordinator assistants' retention rate: 84% • Care coordinator assistants reported outcomes attained through development of long-term relationships with dyads: rapport with clients, ability to engage

them, promotion of their well-being and autonomy, caregiver support, flexibility and continuity of care, and effective teamwork with ABC MedHome staff

- Services expanded from 250 to 2000 persons in 2013 due to the Centers for Medicare and Medicaid Services Health Care Innovation Challenge Award
- Mean number of visits by care coordinator assistants: 15.7

- Electronic medical records software developed: eMR-ABC. Provides for individual patient management, patient population trends' monitoring, and stratification of the patient population according to mild, moderate, and severe needs

Partners in Dementia Care	• Significantly reduced dementia and depression symptoms • Reduction in depressive symptoms in persons with dementia and depression: 1.3 points/year • Reduction in dementia symptoms: 5.8 points/year • Slope of reduction in dementia symptoms: from – 1.9 to – 2.5 • Slope of reduction in depressive symptoms: from – 0.3 to – 0.4. • Reduction in dementia symptoms: 50%+ among 51% of PLWD with high symptom burden • The highest response to depression treatment was among those with the most severe depressive symptoms (PHQ-9 scores >10)*	• Most commonly identified goal: accessing formal services • Most improvements 6 months, fewer 6-12 months post-intervention • 6 months post-intervention: all had fewer unmet needs and depressive symptoms and used more support services than the control. Positive intervention conditional effects in role captivity, relationship strain, and number of informal helpers • 12 months post-intervention: positive conditional effects in unmet needs and relationship strain	• Care coordinators assessed that the intervention presented a minor difficulty for dyads' participation, no difficulty for physicians, and a minor difficulty for the organizational partnership • Average of 2 contacts/month between coordinators and families • Average length of telephone contacts: 14 minutes • VA and Alzheimer's Association coordinators had approximately equal workload in helping dyads

• Most commonly identified goals: sensory issues, preventing falls • 6 months post- intervention: all veterans had less embarrassment about memory problems; veterans with more personal care dependencies had fewer unmet needs and less relationship strain; veterans with more severe cognitive impairment had fewer unmet needs and fewer depressive symptoms • 12 months post- intervention: veterans with less cognitive impairment had more embarrassment about memory problems and veterans • 12 months post-intervention: veterans with more personal care	• No intervention effect on the likelihood of an initial hospitalization or ED visit • Veterans with more personal care dependencies were more likely to be hospitalized • Veterans in the intervention arm and with more cognitive symptoms at baseline had 26.7% more hospitalizations than the usual care arm • Veterans in the intervention arm and with more cognitive symptoms at 6 months had 26.9%

dependencies had fewer unmet needs • Telephone-only group: PLWD had fewer disruptive behaviors 6 months post intervention than in the in-person group • No difference in PLWD quality of life at follow-up between the telephone-only and in-person groups • No intervention-related differences in neuropsychiatric symptoms or quality of life • PLWD found the NP to be able to make them feel better about their future • No significant cognitive decline over 12 months	fewer hospitalizations than the usual care arm • Veterans in the intervention arm and with more BPSD at baseline had 32 % fewer hospitalizations than the usual care arm • Veterans in the intervention arm and with more BPSD at 6 months had 28.6% fewer ED visits than the usual care arm

<u>The Alzheimer’s Disease Coordinated Care for San Diego Seniors</u>	• Telephone-only group: PLWD had fewer disruptive behaviors 6 months post intervention than in the in-person group • No difference in PLWD quality of life at follow-up between the telephone-only and in-person groups	• High baseline caregiver burden: mean Zarit Burden Interview score: 30.5 • Mild depression: mean PHQ-9 score = 5.1 • No statistically significant differences between treatment arms at 6 and 12 months post-intervention with one exception: less distress to their persons’ memory problems in the telephone-only arm 12 months post-intervention than in the control	• Dementia care quality improved regardless the delivery method: in-person vs. telephone • Quality of care no different between arms at 6 and 12 months post-intervention with one exception: in-person arm had significantly higher 12-month adherence for receipt of referral to respite care, caregiver support group, or financial planning • The proportion of meeting requirements of the following quality indicators more than doubled in both

arms at follow-up compared to baseline: 1) Advance directive discussion or completion and documentation; 2) receipt of information/services from the Alzheimer's Association; 3) receipt of services or information from social work or care manager; 4) discussion or recommendation of the Safe Return program;
5) enrollment into the Safe Return program; 6) Receipt of information on identification items; 7)

participation in a caregiver support group; 8) receipt of respite services; 9) receipt of financial or legal information.

- In-person delivery costed more than telephone delivery
- Health service utilization costs did not differ at follow-up between the study arms

Proactive Primary Dementia Care	• No intervention-related differences in neuropsychiatric symptoms or quality of life • PLWD found the NP to be able to make them feel better about their future • No significant cognitive decline over 12 months	• No intervention-related differences in self-efficacy, depression, or burden • Dyads found the NP sensitive to their concerns, able to answer their questions, enthusiastic about working with dyads, and able to connect dyads to community resources • Dyads were highly satisfied with the quality of material discussion, amount of information learned for planning for the future, and amount of information learned about community resources	• The NP intervention evaluated as highly satisfactory by all stakeholders • All caregivers found the intervention material relevant to their situation • PCPs most satisfied with the intervention's effect on PLWDs' mood and outlook when they made office visits • PCPs slightly less satisfied with the NP's reporting of PLWDs' progress • PCPs indicated preference to work with NPs who are

				already employed by their practices • Mean home visit length: 1.25 hours
Behavior Management Clinic	N/A		Caregivers found the service helpful in managing PLWDs' behaviors and caregivers' stress	Referring providers found the service helpful in managing PLWDs' behaviors and caregivers' stress
Caring for Older Adults and Caregivers at Home (COACH) Program	N/A		96% of caregivers evaluated the program highly	• COACH aligns with 90% of clinical process quality measures • Mean time to institutionalization: similar between intervention and control groups: 29.6 weeks

Videotelemedicine in a Memory Disorders Clinic	Satisfied with videotele-medicine and appreciated the ability to conduct the evaluation locally	N/A		• Videotelemedicine format allowed formulation of a working diagnosis • MDs satisfied with videotelemedicine and appreciated the ability to conduct the evaluation locally • Providers appreciated the opportunity to confer with the Memory Disorders Clinic clinicians after the evaluation and discuss cases

Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia	• No significant differences in frequency and severity of BPSD and neuropsychiatric symptoms between the intervention and the control groups • Intervention deemed acceptable by patients	• Significantly larger reduction in distress due to their persons' BPSD and neuro-psychiatric symptoms and significantly greater caregiving mastery and coping (reduction of expectations) in the intervention than in the control group over time • Significantly reduced distress in relation to their persons' depressive symptoms in the intervention than in the control group • No significant differences in caregiver burden between groups • Intervention deemed acceptable by caregivers	• Intervention deemed acceptable by providers • Caregivers in the intervention group received a mean of 3.5 contacts by the care manager and completed a mean of 2.5 educational modules • The most frequent activities performed by the care manager: medication monitoring, stress management and pleasurable event scheduling, and connection to resources

MemoryCare	N/A		• High satisfaction with services (98%), increased knowledge about dementia (95%), improved skills in the management of dementia behaviors (90%) • 2013: 139 caregivers attended Caregiver College offered by MemoryCare • 2013: 38 caregivers attended at least 2 meetings of a MemoryCare peer support group • Forty percent of caregivers used the resource center/lending library in 2013	• Each dyad: an average of 15 non-visit contacts with a care manager/MD to address interim issues • Mean annual cost-per-patient: $1,279 (excluding laboratory and radiology/neuroimaging) • Costs covered with Medicare and co-insurance (25%); annual caregiver fees (23%); and charitable funds (52%) • Caregiver fees ($495/year) are waived for families experiencing financial hardship: 31% of fees were waived in 2013

- All physicians adhered to the Centers for Medicare and Medicaid Services Physician Quality Reporting System Dementia Measures Group components
- Annual hospitalization rate: 20.4%; re-hospitalization rate: 5%
- Hospitalization rates significantly lower than in a comparable cohort
- Presumed cost savings due to lower hospitalization rates contrasted with a comparable cohort

- Annual cost savings: $480,160 from avoided hospitalizations
- PLWD with documentation of advanced care planning within 1 year of enrollment: 93%
- Prolonged time in the community - not in institutional settings

Inter-professional teledementia clinic for rural veterans	• Average driving distance patients saved: 67.1 miles • Driving time patients saved: 74.5 minutes/visit • Ease of coming to the local clinic as opposed to the main Pittsburgh clinic • Patients ranked highly their satisfaction with the service and communication via distance means • Patients did not express difficulty with distance testing	• Caregivers commented on the ease of coming to the local clinic as opposed to the main Pittsburgh clinic • Zarit Burden Interview (4-item, screening version):[42] 7.5 out of 16 after the clinic visits. Pre-clinic scores not taken, but 50% of caregivers stated that their score would have been higher prior to the visit	• Clinic visits in the first year: 156 • Interprofessional provider encounters in the first year: 251 • Veterans served: 64% rural • Lower cancellation rate among teledementia visits compared in-person geriatric clinics' visits: 24.3% vs. 31.1% • Medication changes – the most frequent recommendations

University of California at Los Angeles Alzheimer’s Disease and Dementia Care Program	• Most frequent recommendation: medication adjustment (41%) • Program well-received by patients	• High caregiver satisfaction • Most frequent recommendations: support group referrals (73%), Alzheimer’s Association Safe Return (73%), caregiver training (45%)	• Referring MDs evaluated the program highly in terms of the provision of behavioral and social recommendations • The program’s income generated from patients’ in-person visits, Centers for Medicare and Medicaid Innovations Challenge grant, and philanthropy • For 17 dementia quality indicators, 92% passed • Strengths of the APRN co-management:

assessment and screening (84%+ of quality indicators met) and counseling (93%+ of quality indicators met)

- Wider variation in adherence towards some quality indicators: from 27% of quality indicators met for discontinuation or justification of medications associated with mental status changes to 85% of quality indicators met for discussion about acetylcholinesterase inhibitors

- Preferences regarding resuscitation status, level of medical intervention, or feeding tubes documented: 75% patients
- Best source of patient recruitment: spontaneous MD referral and self-referral

Louis and Anne Green Memory and Wellness Center	N/A	N/A	• Diagnostic services funded through Medicare and secondary health insurance (76%); private pay and funds raised for non-reimbursable services for social work interventions and support groups (17%); and grants (7%) • On average, the interprofessional team cares for 47 persons/day and conducts over 1600 diagnostic clinic visits/year • Sources of income: self-pay fees – basic operations; Medicare and private insurance – diagnostic

			costs; Medicare – home nursing visits and counseling sessions; self-pay – driving evaluation
<u>Montefiore-Einstein Center for the Aging Brain</u>	• Positive informal feedback	• Many caregivers raised questions about home care eligibility and availability • Positive informal feedback	• In the year after the first visit, ED visits: 31% of patients, hospitalizations –27%, deaths – 1.6% • Complicated cases with difficult diagnostic or management issues are discussed at bimonthly case conferences, where all specialists are present and additional experts may be invited • Informal feedback from providers:

comprehensive multidisciplinary evaluation is more effective than traditional single-specialty evaluation

Note. ED = emergency department. PCP = primary care physician. BPSD = behavioral and psychological symptoms of dementia. RN = registered nurse. MD = medical doctor. APRN = advanced practice registered nurse. NP = nurse practitioner. SW = social worker/social work. PHQ-9 = Patient Health Questionnaire-9 (Kroenke et al., 2001). HABC-M = Healthy Aging Brain Care Monitor, an instrument measuring the person’s cognitive, functional, behavioral, and psychological symptoms (Monahan et al., 2012). RCT = randomized controlled trial. RMBPC = Revised Memory and Behavior Checklist (Teri et al., 1992). MMSE = Mini-Mental State Exam (Folstein et al., 1975). ADL = activity of daily living. PLWD = person(s) living with dementia. PRN = pro re nata (as needed)

Table 4

Quantitative Summary of the Key Characteristics of the Reviewed Programs

Feature	How Many Programs Accomplish It/Report on these Outcomes or Issues N (%)	Which programs accomplish it or collect these data
Assessment	14 (100)	All. Two had home visits: ABC MedHome[2-7] and MemoryCare[8]
Diagnosis	6 (43)	HABC,[9-10] Memory Disorders Clinic,[11] MemoryCare,[8] interpofessional teledementia clinic for rural veterans,[12] Louis and Anne Green Memory and Wellness Center,[13,14] Montefiore-Einstein Center for the Aging Brain[15]
Care plan	9 (64)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[16-19] ACCESS,[20] Behavior Management

		Clinic,[21] COACH,[22] MemoryCare,[8] UCLA ADC,[23-25] Montefiore-Einstein Center for the Aging Brain[15]
Care coordination (e.g., with other clinicians, healthcare settings, community agencies)	13 (93)	All but the interprofessional teledementia clinic for rural veterans[12]
Care protocols	7 (50)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[16-19] ACCESS,[20] Proactive Primary Dementia Care,[26] telephone-based collaborative care management program for caregivers of individuals with dementia,[27] Louis and Anne Green Memory and Wellness Center[13,14]
Medical management of dementia	14 (100)	All

Programs or interventions for caregivers	13 (93)	All but the Montefiore-Einstein Center for the Aging Brain[15]
Technological enhancement	12 (86)	All but the Louis and Anne Green Memory and Wellness Center,[13,14] and the Montefiore-Einstein Center for the Aging Brain[15]
Partnerships	8 (57)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[16-19] ACCESS,[20] Proactive Primary Dementia Care,[26] Behavior Management Clinic,[21] Memory Disorders Clinic,[11] UCLA ADC[23-25]
Patient Outcomes	9 (64)	ABC MedHome,[6-7] Partners in Dementia Care,[16-19] ACCESS,[20] Proactive Primary Dementia Care,[26] Memory Disorders Clinic,[11] telephone-based Collaborative Care

		Management Program for Caregivers of Individuals with Dementia,[27] inter-professional teledementia clinic for rural veterans,[12] UCLA ADC,[23-25] Montefiore-Einstein Center for the Aging Brain[15]
Caregiver Outcomes	11 (79)	ABC MedHome,[2-7] Partners in Dementia Care,[17] ACCESS,[20] Proactive Primary Dementia Care,[26] Behavior Management Clinic,[21] COACH,[22] telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia,[27] MemoryCare,[8] inter-professional tele-dementia clinic for rural veterans,[12] UCLA ADC,[23-25] Montefiore-

		Einstein Center for the Aging Brain[15]
Program/healthcare system outcomes	14 (100)	All
Economic data	6 (43)	HABC,[9-10] ACCESS,[20] Partners in Dementia Care,[17] MemoryCare,[8] UCLA ADC,[23-25] Louis and Anne Green Memory and Wellness Center[13,14]
Economic challenges	7 (50)	HABC,[91-0] Partners in Dementia Care,[17] ACCESS,[20] MemoryCare,[8] UCLA ADC,[23-25] Louis and Anne Green Memory and Wellness Center,[13,14] Montefiore-Einstein Center for the Aging Brain[15]
Implementation challenges	9 (64)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[17] ACCESS,[20] Proactive Primary Dementia Care,[26] COACH,[22] inter-professional

		tele-dementia clinic for rural veterans,[12] UCLA ADC,[23-25] Louis and Anne Green Memory and Wellness Center[13,14]
Training needed for staff[1]	8 (57)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[17] ACCESS,[20] Proactive Primary Dementia Care,[26] Memory Disorders Clinic,[11] MemoryCare,[8] UCLA ADC[23-25]
Caregivers have telephone access to the coordinator	8 (57)	HABC,[9-10] ABC MedHome,[2-7] Partners in Dementia Care,[17] ACCESS,[20] Behavior Management Clinic,[21] COACH,[22] MemoryCare,[8] Louis and Anne Green Memory and Wellness Center[13,14]

The program is currently operational	9 (64)	HABC,[9-10] ABC MedHome,[2-7] Behavior Management Clinic,[21] COACH,[22] MemoryCare,[8] interprofessional teledementia clinic for rural veterans,[12] UCLA ADC,[23-25] Louis and Anne Green Memory and Wellness Center,[13,14] Montefiore-Einstein Center for the Aging Brain[15]
VA programs	5 (36)	Memory Disorders Clinic,[11] COACH,[22] Partners in Dementia Care,[17] interprofessional teledementia clinic,[12] telephone-based collaborative care management program for caregivers of individuals with dementia[27]

Note. All these findings are based on the reports (e.g., a program may have certain features or outcomes, but if they were not clearly stated in the manuscripts, they were counted as absent here). Findings are organized according to a general question, such as, “Did the study report on the need to train staff? Have telephone access to the coordinator, etc.?" [1]When reporting on training needed for staff, we only counted instances when special training for the program was needed and was implemented as a part of the program's activities (e.g., formal training or experience working with similar populations that was a prerequisite to be employed in these programs was not counted).ABC MedHome = Aging Brain Care Medical Home. HABC = Healthy Aging Brain Care. COACH = Caring for Older Adults and Caregivers at Home. UCLA ADC = University of California Los Angeles Alzheimer's and Dementia Center [2]Austrom et al., (2016) [3]Callahan et al., (2011) [4]Cottingham et al., (2011) [5]Frame et al., (2013) [6]LaMantia et al., (2015) [7]LaMantia et al., (2016) [8]Noel et al., (2017) [9]Boustani et al., (2011) [10]French et al., (2014) [11]Barton et al., (2011) [12]Powers et al., (2017) [13]Hain et al., (2011) [14]Tappen & Valentine (2014) [15]Verghese et al., (2016) [16]Judge et al., (2011) [17]Bass et al., (2013) [18]Bass et al., (2014) [19]Bass et al., (2015) [20]Chodosh et al., (2015) [21]Barton et al., (2014) [22]D'Souza et al., (2015) [23]Jennings et al., (2016) [24]Reuben et al., (2013) [25]Tan et al., (2014) [26]Fortinsky et al., (2014) [27]Mavandadi et al., (2017)

Table 5

Patient Outcomes in the Reviewed Models

Outcome	**Instrument**	**How many programs reported this outcome** **N (%)**	**Which programs reported this outcome**
Depressive symptoms	Patient Health Questionnaire-9[1] Center for Epidemiologic Studies Depression[2]	2 (14)	ABC MedHome[3] Partners in Dementia Care[4]
Cognitive, functional, and behavioral symptoms of dementia	Healthy Aging Brain Care Monitor[5]	1 (7)	ABC MedHome[3]
Basic activities of daily living	Katz Basic Activities of Daily Living scale[6]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of

			Individuals with Dementia[7]
Instrumental activities of daily living	Lawton-Brody Instrumental Activities of Daily Living scale[8]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[7]
Care goals*	N/A	1 (7)	Partners in Dementia Care[9]
Unmet needs:* 1) understanding dementia; 2) daily living tasks; 3) accessing VA and other services; 4) legal and financial issues; 5) organizing family care; 6) alternative living arrangements; 7)	N/A	1 (7)	Partners in Dementia Care[4]

emotional support; 8) medications			
Embarrassment over memory problems*	Sum of three dichotomous items asking about embarrassment over memory problems, discomfort telling other about memory problems, and discomfort accepting help for memory problems[10]	1 (7)	Partners in Dementia Care[9]
Isolation*	Sum of four dichotomous items asking about feelings of isolation due to health problems and need for help, decreased ability to participate in group activities, decreased ability to participate in religious activities, and reduced ability to visit with family and friends[10]	1 (7)	Partners in Dementia Care[9]
Relationship strain*	Sum of four dichotomous items centered on veterans' perceptions of the quality of relationship with the caregiver[11]	1 (7)	Partners in Dementia Care[9]
			ACCESS[13]

Behavioral and psychological symptoms of dementia	Revised Memory and Behavior Problem Checklist[12]	2 (14)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[7] Proactive Primary Dementia Care[15]
Neuropsychiatric symptoms	Neuropsychiatric Inventory[14]	2 (14)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[7] ACCESS[13]
Quality of life	Health Utilities Index[16,17]	2 (14)	

	Quality of Life – Alzheimer's Disease[18]		Proactive Primary Dementia Care[15]
Satisfaction with the dementia care model/acceptability of the intervention/informal feedback	Surveys developed in the study and/or informal feedback[15,19]	5 (36)	Proactive Primary Dementia Care[15] Memory Disorders Clinic[19] Inter-professional teledementia clinic for rural veterans[20] UCLA ADC[21] Montefiore-Einstein Center for the Aging Brain[22]

			Partners in Dementia Care[9]
Estimated driving distance saved	Calculated based on the veteran’s ZIP code	1 (7)	Inter-professional teledementia clinic for rural veterans[20]
Estimated driving time saved	Calculated based on the veteran’s ZIP code	1 (7)	Inter-professional teledementia clinic for rural veterans[20]
Most frequent recommendations made to PLWD	Reported in the study (e.g., recommendations for dementia management, access of community services, etc.)[21]	1 (7)	UCLA ADC[21]

*Note.**Marks outcomes that are assessed by persons living with dementia themselves as opposed to by proxies (e.g., caregivers). PLWD = person(s) living with dementia. UCLA ADC – University of California Los Angles Alzheimer’s and Dementia Care program. ABC MedHome = Aging Brain Care Medical Home. ACCESS = The Alzheimer’s Disease Coordinated Care for San Diego Seniors. [1]Kroenke et al., (2001) [2]Kohout, Berkman, Evans, & Cornoni-Huntley (1993) [3]LaMantia et al., (2015) [4]Bass et al., (2014) [5]Monahan et al., (2012) [6]Katz, Ford, Moskowitz, Jackson, & Jaffe (1963) [7]Mavandadi et al., (2017) [8]Lawton & Brody (1969) [9]Judge et al., (2011) [10]Clark, Bass, Looman, McCarthy, & Eckert (2004) [11]Bass, McClendon, Deimling, & Mukherjee (1994) [12]Teri et al., (1992) [13]Chodosh et al., (2015) [14]Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, & Gornebin (1994) [15]Fortinsky et al., (2014) [16]Horsman, Furlong, Feeny, & Torrance (2003) [17]Torrance, Feeny, Furlong, Barr, Zhang, & Wang (1996) [18]Logsdon, Gibbons, McCurry, & Teri (2002) [19]Barton et al., (2014) [20]Powers et al., (2107) [21]Reuben et al., (2013) [22]Verghese et al., (2016)

Table 6

Caregiver Outcomes in the Reviewed Programs

Outcome	**Instrument**	**How many programs reported this outcome N (%)**	**Which programs reported this outcome**
Stress	Healthy Aging Brain Care Monitor[1]	1 (7)	ABC MedHome[2]
Care goals	N/A	1 (7)	Partners in Dementia Care[3]
Depressive symptoms	Center for Epidemiologic Studies – Depression (11-item)[4]	3 (21)	Partners in Dementia Care[7]
	Patient Health Questionnaire-9[5]		ACCESS[8]
	Center for Epidemiologic Studies – Depression (20-item)[6]		Proactive Primary Dementia Care[9]

Unmet needs: 1) understanding dementia; 2) care tasks; 3) accessing VA and other services; 4) financial and legal issues; 5) organizing family care; 6) alternative living set-up; 7) emotional help; 8) medications and medical management	N/A	1 (7)	Partners in Dementia Care[7]
Caregiver strains: role captivity, physical health strain, and relationship strain	Pearlin Caregiving and Stress Process Scale: Role Captivity subscale[10] Physical health strain and relationship strain[11]	1 (7)	Partners in Dementia Care[7]
Support resources: informal helpers and use of caregiver support services	Reported by caregivers	1 (7)	Partners in Dementia Care[7]

Caregiver burden	Zarit Burden Interview[12] (22-item) Zarit Burden Interview (12-item)[13] Zarit Burden Interview (4-item)[13]	4 (29)	ACCESS[8] Proactive Primary Dementia Care[9] Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[14] Interprofessional teledementia clinic for rural veterans*[15]
Quality of Life	Caregiver Quality of Life. Two scales used:	1 (7)	ACCESS[8]

	Spirituality and faith and Benefits of Caregiving.[16]		
Satisfaction with the dementia care model/acceptability of the intervention/informal feedback	Surveys created in the study/informal feedback	8 (57)	Proactive Primary Dementia Care[9] Behavior Management Clinic[17] COACH[18] MemoryCare[19] Interprofessional teledementia clinic for rural veterans[15] Telephone-based Collaborative Care

			Management Program for Caregivers of Individuals with Dementia[14] UCLA ADC[20] Montefiore-Einstein Center for the Aging Brain[21]
Caregiver self-efficacy	Self-efficacy scale developed in another study.[22] Two measures of self-efficacy used: symptom management self-efficacy and community support service use self-efficacy[22]	1 (7)	Proactive Primary Dementia Care[9]
Distress due to their person's behavioral and psychological symptoms of dementia	Revised Memory and Behavior Checklist[23]	1 (7)	Telephone-based Collaborative

			Care Management Program for Caregivers of Individuals with Dementia[14]
Distress due to their person's neuropsychiatric symptoms	Neuropsychiatric Inventory[24]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[14]
Coping	Pearlin Caregiving and Stress Process Scale, Management of Meaning – Reduction of Expectations subscale[10]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of

			Individuals with Dementia[14]
Mastery of caregiving role	Lawton Caregiving Appraisal Scales: Caregiving Mastery subscale[25]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[14]
Knowledge about memory disorders since enrollment into this care model	Survey developed in the study	1 (7)	MemoryCare[19]
Ability to manage their person's behavior since enrollment into this model	Survey developed in this study	1 (7)	MemoryCare[19]
Acceptability of the care model's fee for the services provided	Survey developed in this study	1 (7)	MemoryCare[19]

Note. *Only assessed caregiver burden using the Zarit Burden Interview after the intervention, burden was not assessed before the intervention. PLWD = person(s) living with dementia. UCLA ADC – University of California Los Angles

Alzheimer's and Dementia Care program. ABC MedHome = Aging Brain Care Medical Home. ACCESS = The Alzheimer's Disease Coordinated Care for San Diego Seniors. [1]Monahan et al., (2012) [2]LaMantia et al., (2015) [3]Judge et al., (2011) [4]Kohout et al.,k (1993) [5]Kroenke et al., (2001) [6]Radloff (1977) [7]Bass et al., (2013) [8]Chodosh et al., (2015) [9]Fortinsky et al., (2014) [10]Pearlin, Mullan, Semple, & Skaff (1990) [11]Bass, Tausig, & Noelker (1989) [12]Zarit, Reever, & Bach-Peterson (1980) [13]Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001) [14]Mavandadi et al., (2017) [15]Powers et al., (2017) [16]Vickrey, Hays, Maines, Vassar, Fitten, & Strickland (2009) [17]Barton et al., (2014) [18]D'Souza et al., (2015) [19]Noel et al., (2017) [20]Reuben et al., (2013) [21]Verghese et al., (2016) [22]Fortinsky, Kercher, & Burant (2002) [23]Roth et al., (2003) [24]Kaufer et al., (2000) [25]Lawton, Moss, Hoffman, & Perkinson (2000)

Table 7. Program and Healthcare System Outcomes in the Reviewed Programs

Outcome	**Instrument/method to collect these data**	**How many programs reported this outcome N (%)**	**Which programs reported this outcome**
Total number of clinic visits/home visits/telephone contacts/mail or e-mail contacts/inter-professional encounters/persons seen daily	Tracked by the program[1-8]	8 (57)	HABC[1] ABC MedHome[2] Partners in Dementia Care[3] ACCESS[4] Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[5]

			MemoryCare[6] Inter-professional teledementia clinic for rural veterans[7] Louis and Anne Green Memory and Wellness Center[8]
Length of telephone contacts or home visits	Tracked by the program[3,4,9]	3 (21)	Partners in Dementia Care[3] Proactive Primary Dementia Care[9] ACCESS[4]
Visit cancellation rate	Tracked by the program[7]	1 (7)	Inter-professional teledementia clinic for rural veterans[7]
Number of brain imaging orders	Health records[1]	1 (7)	HABC[1]

Number of comprehensive metabolic profile orders	Health records[1]	1 (7)	HABC[1]
Number of thyroid stimulating hormone orders	Health records[1]	1 (7)	HABC[1]
Number of vitamin B12 orders	Health records[1]	1 (7)	HABC[1]
Number of Complete Blood Count orders	Health records[1]	1 (7)	HABC[1]
	Health records[1]		HABC[1]
Number of patients with at least one ED visit	VA National Patient Care Database[10] Caregiver self-report[10]	2 (14)	Partners in Dementia Care[10]
	Health records[1]		HABC[1]
Total number of ED visits	VA National Patient Care Database[10]	4 (29)	Partners in Dementia Care[10]

			ACCESS[4]
	Caregiver self-report[10]		
	Not specified[4,11]		Montefiore-Einstein Center for the Aging Brain[11]
	Health records[1]		HABC[1]
Number of patients with at least one hospitalization		3 (21)	
	VA National Patient Care Database[10]		Partners in Dementia Care[10]
	Caregiver self-report[10]		
	Health records[1]		HABC[1]
	VA National Patient Care Database[10]		Partners in Dementia Care[10]
Total number of hospitalizations		4 (29)	ACCESS[4]
	Caregiver self-report[10]		
			MemoryCare[6]
	Tracked by the program[6,11]		

			Montefiore-Einstein Center for the Aging Brain[11]
Mean and median length of hospital stay	Health records[1]	1 (7)	HABC[1]
Percentage of one-week returns to an ED	Health records[1]	1 (7)	HABC[1]
Percentage of 30-day re-hospitalizations	Health records[1] Tracked by the program[6]	2 (14)	HABC[1] MemoryCare[6]
Percentage of patients with an order for anticholinergics	Health records[1]	1 (7)	HABC[1]
Percentage of patients with an order for neuroleptics	Health records[1]	1 (7)	HABC[1]
Percentage of patients with an	Health records[1]	1 (7)	HABC[1]

order for anti-dementia drugs			
Percentage of patients with an order for antidepressants	Health records[1]	1 (7)	HABC[1]
Percentage of patients who have at least one anti-dementia drug order and at least one anticholinergic order	Health records[1]	1 (7)	HABC[1]
Percentage of patients with hyperlipidemia with at least one order for LDL	Health records[1]	1 (7)	HABC[1]
Percentage of patients with hyperlipidemia with LDL < 140	Health records[1]	1 (7)	HABC[1]
Percentage of patients with	Health records[1]	1 (7)	HABC[1]

diabetes with at least one glycosylated hemoglobin order			
Percentage of patients with diabetes with glycosylated hemoglobin < 8	Health records[1]	1 (7)	HABC[1]
Percentage of patients with hypertension with last systolic blood pressure reading < 160	Health records[1]	1 (7)	HABC[1]
Net savings in healthcare utilization as a result of being enrolled in this care program as opposed to mainstream	Tracked by the program[12]	3 (21)	HABC[12] ACCESS[4] MemoryCare[6]

healthcare/control group			
Per-patient costs	Tracked by the program[4,6,12]	3 (21)	HABC[12] ACCESS[4] MemoryCare[6]
Sources of program’s income	Tracked by the program[6,8,13]	3 (21)	MemoryCare[6] UCLA ADC[13] Louis and Anne Green Memory and Wellness Center[8]
Number of care protocols triggered	Tracked by the program[2]	1 (7)	ABC MedHome[2]

Outcomes related to staff screening, hiring, training, and retention	Tracked by the program[14]	1 (7)	ABC MedHome[14]
Completion of the action steps identified in the action plan	Tracked by the program[3]	1 (7)	Partners in Dementia Care[3]
Physicians' (including referring physicians') or other staff' acceptance of/satisfaction with the care program	Formal feedback using surveys developed in the programs[3,9,15,16,18] Informal feedback[17]	6 (43)	ABC MedHome[15] Partners in Dementia Care[3] Proactive Primary Dementia Care[9] Behavior Management Clinic[16] Memory Disorders Clinic[17] UCLA ADC[18]

Organizational partnership barriers	Survey developed in the program[3]	1 (7)	Partners in Dementia Care[3]
	Set of dementia care quality indicators developed in another study[19] (for ACCESS[4])		ACCESS[4]
			COACH[21]
	Dementia Management Quality Measures[20] (for COACH[21])		
Adherence to dementia care quality outcomes			MemoryCare[6]
	Physicians' compliance with the Physician Quality Reporting Systems Dementia Group Measures (for MemoryCare[6])	4 (29)	UCLA ADC[24]
	Quality indicators from the Assessing Care of Vulnerable Elders[22] and Physician Consortium for Performance Improvement quality indicator sets[23] (for the UCLA ADC)[24]		
Participant retention*	Tracked by the program	1 (7)	ACCESS[4]
	Not specified[4]		ACCESS[4]

Nursing home placement	Chart review[21] Caregivers' self-report[6]	3 (21)	COACH[21] MemoryCare[6]
Number of educational modules completed by caregivers	Tracked by the program[5]	1 (7)	Telephone-based Collaborative Care Management Program for Caregivers of Individuals with Dementia[5]
Program growth: increase in the amount of persons served, increase in the number of offices	Tracked by the program[1,2,6,21]	4 (29)	HABC[1] ABC MedHome[2] COACH[21] MemoryCare[6]
Documentation of advanced care planning	Tracked by the program[6,21]	2 (14)	COACH[21] MemoryCare[6]
Number and characteristics of	Tracked by the program[7,13]	2 (14)	Inter-professional teledementia

recommendations made to PLWD after assessment			clinic for rural veterans[7] UCLA ADC[13]
Percentage of rural PLWD served	Tracked by the program[7]	1 (7)	Inter-professional teledementia clinic for rural veterans[7]

Note. We only report outcomes with stated results in the manuscripts. For example, if a program stated that data on certain outcomes were collected but these data were not reported in the results, these outcomes are not stated here. Unless the program stated that their outcomes were related to nursing home placement (e.g, D'Souza et al., 2015), we do not report changes to the person's living configurations (e.g., institutionalization, etc.) as these data are commonly used to describe samples and could be found in the results of the reviewed studies. *While many programs reported on attrition, we only report on participant retention when it was evaluated in comparison to usual care to gauge acceptability of being enrolled in the program. ED = emergency department. PLWD = person(s) living with dementia. UCLA ADC = University of California Los Angles Alzheimer's and Dementia Care program. ABC MedHome = Aging Brain Care Medical Home. ACCESS = The Alzheimer's Disease Coordinated Care for San Diego Seniors. [1]Boustani et al., (2011) [2]LaMantia et al., (2015) [3]Judge et al., (2011) [4]Chodosh et al., (2015) [5]Mavandadi et al., (2017) [6]Noel et al., (2017) [7]Powers et al., (2017) [8]Tappen & Valentine (2014) [9]Fortinsky et al., (2014) [10]Bass et al., (2015) [11]Verghese et al., (2016) [12]French et al., (2014) [13]Reuben et

al., (2013) [14]Cottingham et al., (2014) [15]Austrom et al., (2016) [16]Barton et al., (2014)
[17]Barton et al., (2011) [18]Tan et al., (2014) [19]Vickrey (2006) [20]Odenheimer et al., (2014)
[21]D'Souza et al., (2015) [22] Wenger, Roth, Shekelle, & ACOVE Investigators (2007)
[23]American Medical Association (2011) [24]Jennings et al., (2016)

Integrated Memory Care Clinic: Patient and Caregiver Outcomes

The population of persons living with Alzheimer’s disease is expected to increase from the current 5.7 million up to 16 million in 2050 (Alzheimer's Association, 2017). Healthcare for persons living with dementia (PLWD) is complex, reflecting PLWDs’ chronic and cumulative needs (Fox et al., 2013). PLWD prefer receiving all healthcare in primary care settings (Callahan, Boustani, Sachs, & Hendrie, 2009). But often the quality of dementia care in these settings is suboptimal (Borson & Chodosh, 2014) fraught with physicians having insufficient expertise in dementia, limited time, and financial disincentives (Bradford, Kunik, Schulz, Williams, & Singh, 2009).

Formal healthcare represents only one care dimension for PLWD, most of which is provided by informal caregivers. Eighty-three percent of older adults in the U.S. rely on informal unpaid family or friend caregivers. Of all American caregivers, 46% care for PLWD (Wolff, Spillman, Freedman, & Kasper, 2016). Caregivers confer higher quality of life and better cognitive and functional outcomes to PLWD who live at home compared to their institutionalized counterparts (Nikmat, Hawthorne, & Al-Mashoor, 2015). Caregivers save the U.S. healthcare over $230.1 billion annually with at least 18.2 billion hours of unpaid labor (Alzheimer's Association, 2017). Besides positive experiences (Lloyd, Patterson, & Muers, 2016) caregivers experience stress, burden (Zarit, Reever, & Bach-Peterson, 1980), depressive symptoms (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014), anxiety (Hopkinson, Reavell, Lane, & Mallikarjun, 2018), and worsened physical health for caregivers (Fonareva & Oken, 2014). Behavioral and psychological symptoms of dementia, or neuropsychiatric symptoms, rather than cognitive impairment, are associated with caregiver burden (Desai, Schwartz, & Grossberg, 2012).

To enhance dementia care in the community rather than in mental health institutions, dementia care programs originated in the UK in the 1980s and are currently operating worldwide, varying in staff composition and organization (Jolley & Moniz-Cook, 2009) Several U.S. in-person (Fortinsky et al., 2014; Vickrey et al., 2006) and distance (Barton, Morris, Rothlind, & Yaffe, 2011; Bass et al., 2014; Mavandadi, Wright, Graydon, Oslin, & Wray, 2017) programs have been tested. Despite evidence-based effectiveness, these programs remain unavailable for most PLWD due to the laboriousness of translating research into practice (Callahan et al., 2009). The Healthy Aging Brain Center (HABC), a stationary clinic for PLWD (Boustani et al., 2011); its successor, the Aging Brain Care Medical Home (ABC MedHome), a mobile clinic (LaMantia et al., 2015); and the University of California Los Angeles Alzheimer's Disease Center (UCLA ADC) (Jennings et al., 2016), are several of the currently operating American programs. These programs investigated PLWD and caregiver outcomes in their settings (Boustani et al., 2011; LaMantia et al., 2015; Reuben et al., 2013). The results included reduction in caregivers' stress, and decrease in depressive symptoms and improvement in cognitive, functional, behavioral, and psychological symptoms of dementia for PLWD (LaMantia et al., 2015). Other outcomes, not measured by standardized instruments, included clients' satisfaction with care (Noel, Kaluzynski, & Templeton, 2017; Reuben et al., 2013; Verghese, Malik, & Zwerling, 2016), caregivers' improved knowledge about dementia and dementia management skills (Noel et al., 2017) and reports on the ease of care access and savings in driving time and expenses in telemedicine programs (Powers, Homer, Morone, Edmonds, & Rossi, 2017).

The Integrated Memory Care Clinic (IMCC) is a dementia patient-centered medical home founded and led by advanced practice registered nurses (APRNs) (Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018), who provide dementia and primary care simultaneously. When patients transfer to the IMCC, the clinic becomes their exclusive primary care provider. While APRN-led memory care clinics operate in the U.S., (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014; Tappen & Valentine, 2014) to our best knowledge, IMCC is the only American program where primary and dementia care are rendered by the same clinicians.

We aimed to deepen understanding of clients' experience in dementia care programs. The purpose of this quantitative longitudinal study was to describe changes in caregivers' psychological well-being and health status and in PLWDs' quality of life and severity of neuropsychiatric symptoms, as reported by their caregivers, within the clients' first year at the IMCC. Additionally, we intended to explore contributors towards any significant changes.

Methods

Intervention

The IMCC, a dementia patient-centered medical home at Emory Healthcare, a level 3 patient-centered medical home, has been described in detail elsewhere (Clevenger et al., 2018). IMCC APRNs are experts in geriatrics, neurology, and palliative care. The clinic prioritizes management of neuropsychiatric symptoms. Activities are guided by individualized care plans. Clients have round-the-clock telephone access to an APRN. Caregivers are encouraged to call with questions during changes in PLWDs' symptoms or occurrences that may precipitate an emergency room visit or hospitalization. Thus, telephone access to an APRN serves as a triage and "safety net" to avoid unnecessary emergency and inpatient healthcare use that compromises PLWDs' cognition and well-being (Clevenger, Chu, Yang, & Hepburn, 2012). APRNs co-produce care with caregivers (Realpe, Wallace, Adams, & Kidd, 2015), treating caregivers as clinicians. Caregivers and PLWD, as much as possible despite dementia, participate in care planning. A Patient Family Advisory Council, consisting of current and former caregivers, advised the clinic on care protocols, including the unhindered telephone access line to APRNs and direct (no voicemail) telephone line to the patient access coordinator during business hours.

Recruitment

In this study, PLWD-caregiver dyads are considered new to the IMCC within 90 days since their first visit. Thus, caregivers whose first IMCC visit was within 90 days from the baseline interview were eligible. This window parallels the typical IMCC schedule of follow-up visits every 90 days. This interval is shortened with acute visits and lengthened up to 180 days with stable disease progression and well-controlled comorbidities. Additional inclusion criteria were: English-speaking, unpaid caregivers at least 18 years old, whose PLWD lived in the community (not in assisted living or institutions). Caregivers were recruited via print advertisement at the clinic and the clinic staff's introductions of the study and the principal investigator (PI) to clients. Most caregivers were recruited when the PI identified newly enrolled PLWD in the IMCC health records and asked the patient access coordinator to inquire whether the PI may contact caregivers. If caregivers granted permission, the PI called them, screened for eligibility, and consented via verbal consent form approved by the Emory University Review Board.

Data Collection

Caregivers were interviewed via telephone at baseline, three, and six months post-baseline between September 2016 and January 2018. They were reimbursed with $15, $20, and $25 gift cards for the three interviews, respectively. Caregivers were mailed or emailed copies of questionnaires before the interviews. During the interviews participants read questions and saw response options as the PI recorded their answers verbatim on paper forms and then transferred recordings into the REDCap data storage (Harris et al., 2009).

Theoretical Basis

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) guided the analysis (Figure). This Model (Lazarus & Folkman, 1984) focuses on the person-environment encounter followed by the person's cognitive appraisal and the emotions that this appraisal evokes. Here, the person-environment encounter represents the interaction between caregivers and their environment that includes the PLWD, caregiving responsibilities, and ways caregiving alters other areas of caregivers' lives. Such a prolonged "encounter" (i.e., caregiving situation) may be marked by caregivers' stress, burden (Kang, Choe, & Yu, 2018), anxiety (Hopkinson et al., 2018), depressive symptoms (Givens et al., 2014), distress due to PLWD's neuropsychiatric symptoms (Kaufer et al., 2000), and compromised health-related quality of life (Fonareva & Oken, 2014). The clinic's approach to care – via enhanced telephone access to APRNs, caregivers' education, and involvement of caregivers as care partners – may modify caregiver's appraisal of their situation, reducing the detrimental effect of caregiving on their psychological well-being and health. Additionally, with aggressive symptom management at the IMCC (Clevenger et al., 2018), PLWDs' symptom severity may decrease and quality of life may improve, diminishing caregivers' distress relative to their PLWDs' symptoms, which may be manifested in caregivers' enhanced psychological well-being and health. With management at the IMCC, PLWDs' symptom severity may decrease and their quality of life may improve. Finally, if caregivers' psychological well-being and health status improve following changes in their appraisal of their caregiving situation and ensuing boost in emotional context, this may indirectly influence PLWD outcomes.

Measures

At baseline, caregivers completed a sociodemographic questionnaire created for the study (information assessed in the sociodemographic questionnaire is summarized in Table 1). Measures obtained via baseline sociodemographic questionnaire and the total number of visits to the IMCC between the first visit and the last interview (ascertained via the IMCC health records) were the covariates that we used as potential predictors of changes in outcomes with time.

Other instruments were the same across the interviews. To decrease participant burden, the PI administered the Neuropsychiatric Inventory (NPI) (Cummings, 1997; Kaufer et al., 2000) at three months and obtained baseline and six-month data from the IMCC health records, since the clinic administers this instrument at the initial visit and every six months. Instruments corresponding to caregiver-centered outcomes included Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983); Zarit Burden Interview – 12-item (Bédard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980); Center for Epidemiologic Studies – Depression –10-item (Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977); Patient-Reported Outcomes Measurement Information System Anxiety – short form (PROMIS, 2011); the Neuropsychiatric Inventory (Cummings, 1997; Kaufer et al., 2000); 36-item Short-Form Survey (RAND Health, n. d.); and Healthy Aging Brain Care Monitor (Monahan et al., 2012). Instruments corresponding to PLWD-centered outcomes included the Neuropsychiatric Inventory (Cummings, 1997; Kaufer et al., 2000); Healthy Aging Brain Care Monitor (Monahan et al., 2012); and Quality of Life – Alzheimer’s Disease (Logsdon, Gibbons, McCurry, & Teri, 1999, 2002). Since the IMCC uses the Neuropsychiatric Inventory version for clinical settings (NPI-Q), (Kaufer et al., 2000), which does not assess symptom frequency, but only symptom severity and caregivers’ distress relative to the symptoms (Kaufer et al., 2000), we only reported on severity and distress for each of the

12 assessed symptoms and on total symptom severity and distress (Cummings, 1997; Kaufer et al., 2000).

Data Analysis

To characterize the sample at baseline, descriptive univariate analyses were performed, with means and standard deviations for continuous variables and percentages for categorical variables. Multilevel linear models were used to analyze the changes in caregiver and PLWD outcomes with time as the sole independent continuous variable (Field, 2014). Time 0 was the date of the dyad's first IMCC visit (ascertained via IMCC health records). The date of each interview was estimated in months starting at time 0. We compared all baseline characteristics and baseline performance in outcomes that demonstrated significant changes over time for caregivers who completed the last interview with those who discontinued participation. For these comparisons we used independent samples *t*-tests, Mann-Whitney tests, and chi-square tests for normally distributed continuous outcomes, not normally distributed continuous outcomes, and categorical outcomes, respectively. We compared these characteristics between completers and non-completers to elucidate whether any significant changes may have been attributed to several individuals discontinuing participation. Also, we computed zero-order correlations among all baseline sociodemographic characteristics with all outcomes measured at baseline.

To estimate changes over time since the clinic enrollment in caregivers' psychological well-being and health status and in PLWDs' neuropsychiatric symptoms and quality of life, time was used as a fixed effect. We did not account for random slopes or intercepts (Singer & Willett, 2003) in any analyses. All outcome values that were not normally distributed according to Kolmogorov-Smirnov or Shapiro-Wilk tests were normalized with a square root transformation. For outcomes that demonstrated significant changes over time, we explored what variables predicted these changes. The variables included baseline sociodemographic measures (data collected in the baseline sociodemographic questionnaire) and the total number of visits that caregivers made to the IMCC between their first visit and until the last interview (extracted from the IMCC health records). To test whether any variable significantly predicted change in the outcome with time, we constructed a model that contained time and covariate of interest as independent variables and time*covariate of interest as the interaction term. If the interaction term was significant, it indicated that the corresponding covariate predicted change over time in the outcome. Additionally, for outcomes that demonstrated significant changes over time, we tested whether these changes were maintained after controlling for all baseline covariates and total number of visits to the IMCC. Finally, for outcomes that demonstrated significant changes over time, we conducted post hoc tests to assess between which time points significant changes occurred using Sidak adjustment. For main analyses, exploring whether any significant changes occurred with time, time was treated as a covariate and as a continuous variable to reflect the actual time when the interview was conducted relative to the caregiver's first IMCC visit. This approach is recommended because it provides more accurate information about the participant at the time of testing, compared to the wave method, when all interviews are clustered into the three waves, without regard to the actual interview timing (Singer & Willett, 2003). But for post hoc analyses, time was treated as a factor, with the time points 1, 2, and 3, corresponding to the three waves of data collection. Analyses were conducted in IBM SPSS v. 24.(IBM Corp., 2017) For all analyses, $\alpha<0.05$ indicated significance. The only exception was when we used $0.05<\alpha<0.1$ as a benchmark of potential association for analyses of covariates that predicted changes in the outcomes with time, where we used interaction terms such as "covariate of interest*time" along with time and covariate of interest as predictors.

Results

Sample

Forty-nine caregivers completed baseline assessment; 46 caregivers completed baseline and three-month assessment; and 42 caregivers completed all assessments (attrition 16%). Table 1 summarizes sociodemographic characteristics of the sample. Caregivers (mean age 63.8, 71% women, 28% African Americans) were highly educated (78% had at least college education), with 40% having paid in-home assistance, and caring for PLWD for an average 3.9 years. PLWD (mean age 77.2, 53% spouses) had on average six chronic conditions besides dementia. Between the clinic enrollment and the last interview (up through 9.2 months since the first IMCC visit), participants had on average 3.2 clinic visits.

Table 2 summarizes comparisons in sociodemographic characteristics and baseline values in outcomes that demonstrated significant changes over time. Several differences were noted between caregivers who completed the study (N=42) and those who discontinued after the first or the second interview (N=7). Non-completers were younger (mean 52.7 years) than completers (mean 65.7 years). This difference, 13 years, 95% confidence interval [CI] [4.019; 21.933] was significant, (47) = 2.914, p=0.005. There was a significant association between the relative for whom the caregiver cared and whether or not the caregiver completed the study, $X^2(1)=4.93$, p=0.026. The odds of caregivers who cared for their spouse to complete the study were 8.8 times higher compared to caregivers who cared for their parent. There was a significant association between the type of dementia the PLWD had (Alzheimer’s disease vs. another dementia) and whether or not the caregiver completed the study, $X^2(1)=4.864$, p=0.027. The odds for caregivers whose person had Alzheimer’s disease to complete the study were 5.8 times higher than for caregivers whose person had a different dementia type. Quality of life of PLWD whose caregivers discontinued the study (median = 27, mean = 25.5) was significantly lower compared to the quality of life of PLWD whose caregivers completed the study (median = 29.3, mean = 30.6), U=237, z=2.574, p=0.008. No other significant differences between completers and non-completers were observed.

Caregiver Outcomes

Caregiver and PLWD outcomes are summarized in Table 3. Post hoc analyses are summarized in Table 4. Two caregiver-centered outcomes changed significantly over time (when time was the only predictor in the model). Specifically, there was a significant decrease in the distress that caregivers experience regarding their PLWDs' delusions (delusions-distress) and decrease in the distress that caregivers experience regarding their PLWDs' anxiety (anxiety-distress) (Cummings, 1997; Kaufer et al., 2000).

Delusions-distress. Delusions-distress correlated significantly with caregivers' employment outside of home status (r=0.675, p=0.008) and the amount of time the PLWD needed care for dementia (r=-0.613, p=0.02). Delusions-distress decreased by an average 0.14 points/month, F(1,38)=4.163, p=0.048. Post hoc analysis failed to demonstrate significant reduction in delusions-distress between the three assessment points. With seven non-completers removed, the decrease was no longer significant.

Caregiver employment outside of home significantly predicted changes in Delusions-distress with time (p=0.015). Caregivers who were not employed outside of home had significantly lower Delusions-distress at baseline compared to those who were employed outside of home (mean 4.62 points vs. mean 2.88 points, p=0.006). Caregivers who were not employed outside of home had significantly slower decline in Delusions-distress compared to caregivers who were employed outside of home (average 0.03 points/month vs. 0.47 points/month).

The amount of time PLWD needed care for dementia may act as a proxy measure for dementia stage, since it is logical to assume that the longer the PLWD needed care for dementia, the more advanced dementia stage is. Although the amount of time PLWD needed care for dementia correlated significantly with baseline Delusions-distress, this covariate did not significantly predict changes over time in Delusions-distress. But the longer the PLWD needed care for dementia, the lower baseline Delusions-distress caregivers tended to report. With each additional year that the PLWD needed care for dementia, baseline Delusions-distress decreased by an average 0.23 points (p=0.023).

While total number of comorbidities that the PLWD had as of baseline and total number of visits the PLWD-caregiver dyad made to the clinic did not correlate significantly with baseline Delusions-distress, we explored whether adjustment for these covariates would alter the significant effect of time in the decrease of Delusions-distress. These covariates appeared important from the clinical standpoint: number of comorbidities may increase the difficulty of treatment and require more resources from the clinic. Total number of visits to the IMCC may highlight the intensity with which the clients used the clinic. When we accounted for the number of visits clients made to the IMCC during the study period, time no longer significantly predicted a decrease in Delusions-distress. But when we adjusted the model for the total number of chronic comorbidities the PLWD had besides dementia as of baseline, time still significantly predicted decrease in Delusions-distress and constituted an average 0.14 points/month, F(1,37)=4.757, p=0.036.

Anxiety-distress. Anxiety-distress correlated significantly with caregivers’ employment outside of home (r=0.392, p=0.048) and whether the caregiver and PLWD were living together (r=-0.544, p=0.004). Anxiety-distress decreased with time by an average 0.13 points/month, F(1,71)=5.85, p=0.018. Post hoc analysis failed to demonstrate a significant decrease between either of the three time points. When seven non-completers were removed, Anxiety-distress still decreased significantly over time by an average 0.41 points/month, F(1,67)=4.7, p=0.034.

Caregivers' employment outside of home did not significantly predict changes in Anxiety-distress over time or baseline Anxiety-distress. Co-residence status – whether the caregiver and PLWD resided together – significantly predicted baseline Anxiety-distress. Specifically, caregivers who did not live with their PLWD reported significantly higher baseline Anxiety-distress compared to caregivers who lived with their PLWD: mean 4.78 points vs. mean 2.46 points (p=0.016). But co-residence status did not significantly predict changes in Anxiety-distress over time.

When the model was adjusted for the total number of PLWD's chronic comorbidities besides dementia as of baseline, Anxiety-distress still decreased significantly over time at an average 0.13 points/month, F(1,70)=5.709, p=0.02. Similarly, when the model was adjusted for the total number of visits the PLWD-caregiver dyad made to the IMCC over the study period, Anxiety-distress still decreased significantly over time at an average 0.13 points/month, F(1,70)=5.801, p=0.019.

PLWD Outcomes

As noted in Table 4, three PLWD-centered outcomes changed significantly with time: severity of delusions, severity of depression/dysphoria (depression hereafter), and total symptom severity (Cummings, 1997; Kaufer et al., 2000).

Delusions- severity. Severity of delusions at baseline (delusions-severity) correlated significantly with caregiver employment outside of home (r=0.68, p=0.007). Severity of delusions decreased significantly with time at an average rate of 0.099 points/month, F(1, 38)=4.963, p=0.032. Post hoc analysis failed to demonstrate significant decreases between either of the three time points. With seven non-completers removed, decrease in Delusions-severity was no longer significant over time.

Caregiver employment outside of home significantly predicted changes in PLWDs' delusions-severity over time. Caregivers not employed outside of home reported significantly lower baseline delusions-severity, compared to caregivers employed outside of home, average 1.67 points vs. 2.8 points (p=0.006). Caregiver employment outside of home did not significantly predict changes in Delusions-severity over time.

When we adjusted the model for the total number of PWLDs' chronic comorbidities besides dementia at baseline, time still significantly predicted decrease in Delusions-severity at the rate of 0.1 points/month, F(1,37)=5.064, p=0.03. When we adjusted the model for the total number of visits the PLWD-caregiver dyad made to the clinic, time also still significantly predicted decrease in Delusions-severity at the rate of 0.1 points/month, F(1,37)=4.739, p=0.036.

Depression severity. Depression severity at baseline among PLWD correlated significantly with caregivers' employment outside of home (r=0.525, p=0.004) and with PLWDs' number of chronic comorbidities besides dementia (r=0.384, p=0.043). Depression severity decreased significantly with time by an average 0.12 points/month: F(1, 71)=17.108, p<0.001. Post hoc analyses revealed that significant drops in depression severity occurred between the baseline and the 3-month assessment (mean difference 0.717 points, p<0.001) and between the baseline and the 6-month assessment (mean difference 0.65 points, p=0.006). With seven non-completers excluded, depression severity still decreased with time by an average 0.12 points/month: F(1,64)=16.886, p<0.001.

Caregiver employment outside of home significantly predicted PLWDs' baseline depression severity. PLWD whose caregivers were not employed outside of home had significantly lower baseline depression severity compared to PLWD whose caregivers were employed outside of home, mean 1.98 points vs. 2.57 points (p=0.026). Caregiver employment did not predict changes in PLWDs' depression severity over time.

When we adjusted the model for the total number of PLWD's comorbidities besides dementia at baseline, Depression-severity still decreased significantly over time at the average rate of 0.12 points/month, F(1,70)=16.488, p<0.001. Similarly, when controlling for the total number of visits the PLWD-caregiver dyads made to the IMCC over the study period, Depression-severity still decreased significantly over time at the average rate of 0.12 points/month, F(1,70)=17.839, p<0.001.

Total symptom severity. Raw scores for total symptom severity for PLWD were transformed via square root transformation to attain normality. Thus, all reported results, except for baseline bivariate correlations, use square root of total symptom severity values as the outcomes. Total symptom severity at baseline correlated significantly with caregiver age (r=-0.487, p=0.001), caregiver gender (r=0.346, p=0.025), and caregiver ethnicity (r=-0.388, p=0.011). Total symptom severity decreased: F(1,106)=6.357, p=0.013. Despite the overall significant effect of time, post hoc analyses failed to demonstrate significant drops in total symptom severity between either of the three time points. With seven non-completers removed, total symptom severity decreased: F(1,97)=4.711, p=0.032.

Several covariates predicted baseline total symptom severity and changes in total symptom severity over time. Older caregivers reported significantly lower total symptom severity at baseline: F(1,104)=10.417, p=0.002. Caregivers' age also significantly predicted changes in total symptom severity with time, F(1,104)=3.963, p=0.049. Each additional year of increase in caregiver's age was associated with a significantly higher total symptom severity for PLWD at any given time.

Caregivers' gender significantly predicted baseline total symptom severity. Specifically, for PLWDs whose caregivers were men, total baseline symptom severity was significantly lower compared to PLWDs whose caregivers were women (p=0.01). Caregivers' gender, however, did not significantly predict changes in PLWDs' total symptom severity over time.

When we adjusted the model for the total number of clinic visits that the PLWD-caregiver dyad made during the study, time no longer significantly predicted a change in total symptom severity. Likewise, when we adjusted the model for the total number of chronic comorbidities besides dementia that the PLWD had, time no longer significantly predicted a change in total symptom severity.

Discussion

The caregiver sample in this study was highly educated (78% college graduates and with post-graduate/professional degrees). Potentially as a reflection of higher socioeconomic status, 39% of the sample had paid in-home caregiving assistance.

The results of this study indicate five significant findings that were attained when time was used as the sole predictor in the model (without any adjustments for covariates). But out of five significantly changed outcomes, two findings – caregivers' distress relative to their PLWDs' delusions and PLWD's total severity – did not change significantly with time when models were adjusted either for the total number of comorbidities that PLWDs had at baseline or the total number of visits that PLWD-caregiver dyads made to the clinic during the study period.

Therefore, it cannot be concluded that time significantly predicted changes in these two outcomes: other covariates may have accounted for the variability in these outcomes.

On the contrary, adjusting models for the total number of visits to the IMCC or the total number of chronic comorbidities besides dementia did not cancel the significant effect of time on caregivers’ Anxiety-distress and PLWDs’ severity of delusions and severity of depression. This is an important finding because it demonstrates that these significant results were attained regardless of the number of visits to the IMCC that the PLWD-caregiver dyads made and regardless of the total number of comorbidities that PLWD had. This is an important conclusion because improvements in Delusions-severity and Depression-severity occurred for PLWD despite arguably higher comorbidity burden. Therefore, individuals who may require greater resources and time for the management of their conditions due to their multiple comorbidities still benefitted from the improvements in two PLWD-centered outcomes. Similarly, it did not require PLWD-caregiver dyads to make more visits to the IMCC to attain improvements in caregivers’ Anxiety-distress and PLWDs’ Delusions-severity and Depression-severity. These results may not be attributed to the IMCC due to a lacking comparison group in this study design. Nonetheless, it is possible that if the IMCC is responsible for such improvements, the IMCC conducts management in such manner that there is no need for more visits to implement effective changes in PLWDs’ Delusions-severity and Depression-severity and caregivers’ Anxiety-distress. If the IMCC may be responsible for such changes, this demonstrates potentially efficient use of time and resources both for the clients and for the clinic: improvements begin earlier rather than later without the need for greater expenditure of resources and time for clients and staff.

Two findings are caregiver-centered outcomes and the other three findings are PLWD-centered outcomes. Since this study did not have a comparison group, none of the positive changes in outcomes may be attributed to the clinic. Nonetheless, caregivers' distress relative to their persons' delusions may possibly be explained by the direct management of this psychotic symptom at the IMCC or education that caregivers receive about their PLWDs' symptoms. If the IMCC educates caregivers about PLWDs' delusions, this may allow caregivers adjust their expectations about the symptom and hence, it may lower their distress in response to this symptom. Potentially, expecting certain delusions (e.g., delusion of stealing) from the PLWD and receiving an explanation from the clinician that such behaviors are typical is what reduces caregivers' distress.

Similarly, potentially caregivers may receive explanations from the IMCC staff about the expected anxiety that PLWD may manifest. While severity of anxiety for PLWD did not decrease significantly, it is possible that caregivers may expect it as a common symptom among PLWD. More realistic expectations may prevent caregivers from fruitlessly expecting no display of anxiety by their PLWD. Adjustment expectations to the reality of dementia symptoms may lower caregivers' distress.

It is likely that the clinic does manage delusions efficaciously because severity of PLWDs' delusions also decreased significantly – when the model only included time as the single covariate. PLWD depression severity had the most robust improvement ($p<0.001$). With the prevalence of depression among PLWD, especially in early stages of dementia,(Desai et al., 2012) this is an important improvement for the quality of life for PLWDs and caregivers. Management of depression is essential because depression may cause physical aggression (Lyketsos et al., 1999). Given that depression is the second most prevalent dementia symptom after apathy (Desai et al., 2012), observations of significant improvement in depression severity in a relatively short period of time is an encouraging finding. Lastly, total symptom severity decreased significantly when the model included time as the only predictor. Since behavioral disturbances are often the most challenging aspects of dementia (Desai et al., 2012), this is the most important finding in this study. Overall, while the changes may not be attributed to the clinic, these improvements in PLWDs' delusions and depression severity and in total symptom severity are congruent with the IMCC design: aggressive non-pharmacologic and pharmacologic symptom management (Clevenger et al., 2018).

While the relatively short duration of the study is a limitation (discussed below), it is also its strength because it shows what changes occurred in the immediate period since the clinic enrollment. It is impossible to attribute these changes to the clinic, since the study is descriptive and does not have a control group. Nonetheless, these relatively rapid changes point to potential advantages in this clinic, which may be ascertained in a future study with a comparison group. Some examinations of other dementia care programs also did not have a comparison group, including the ABC MedHome (LaMantia et al., 2015) and the UCLA ADC (Reuben et al., 2013) whereas other programs had either an actual comparison group in primary care settings (Boustani et al., 2011) or they compared their findings (Noel et al., 2017) to another study with a cohort of PLWD in an integrated health system (Phelan, Borson, Grothaus, Balch, & Larson, 2012). This study is similar to other initial examinations of new dementia care programs (Barton et al., 2014) or programs that have only been tested and are not publicly available yet (Fortinsky et al., 2014) in that we did not have a comparison group. Nonetheless, compared to other studies, we explored a wider range of PLWD and caregiver outcomes.

The results of this study are paired with and extend results of another study that described initial clinical outcomes at the IMCC in the first 12 months of operation: decreased rate of ambulatory care-sensitive hospitalizations, a relatively small rate of emergency department visits (less than one ED visit/year on average), and non-significant decreases in PLWDs symptoms' severity and caregivers' distress regarding these symptoms (Clevenger et al., 2018). Overall, the results of the current and the previous study (Clevenger et al., 2018) demonstrate preliminary positive outcomes that clients attain at the IMCC, but future studies of longer duration, with larger sample sizes, and with comparison group are needed to elucidate whether these changes can be attributed to the IMCC.

The timing of the significant drops in the severity of depression (between the baseline and the 3-month assessment and between the baseline and the 6-month assessment) indicates that significant improvements occurred rapidly after the clinic enrollment. Without a comparison group it is impossible to attribute these drops to the management that the clinic renders, but these are encouraging findings. Decreases in the severity of several symptoms for PLWD and Delusions-distress stress for caregivers may be considered in the context of findings of one UK study (Clare et al., 2002). That study demonstrated that in the absence of any intervention at a memory clinic, PLWDs' anxiety and depression and caregivers' anxiety and depression remain stable. Potentially, this may allude to the ability of the clinic to efficaciously manage several of the symptoms that PLWD experience and caregivers' Delusions-distress and Anxiety-distress, but the definitive role of the clinic may be elucidated in a future study with a comparison group.

Testing changes with time while controlling for baseline covariates and total number of visits to the IMCC leads to several conclusions. PLWD depression severity decreased with time regardless of the total number of comorbidities that PLWDs had at baseline. This is an important finding because it suggests that, potentially, the clinic is able to manage depression regardless of PLWDs' comorbidity burden. Overall, depression is very common among PLWD,(Bennett & Thomas, 2014) and depression is more prevalent among persons with physical illnesses, and especially among persons with multiple physical illnesses (Kang et al., 2015). Hence, this study suggests that the IMCC, potentially, can manage depression rapidly, counteracting the effect of multimorbidity. Depression severity decreased regardless of the number of visits that the PLWD-caregiver dyad made to the clinic during the study. Hence, if the decrease in depression may be attributed to the clinic, we may conclude that the clinic is managing depression efficaciously and rapidly: no further benefit is conferred with more visits, hence, symptom management is initiated immediately upon enrollment.

With regard to total symptom severity, potentially, older caregivers tended to care for their persons longer (although no correlation was noted between caregivers' age and the amount of time caregivers had been providing care) which made them more used to their PLWDs' symptoms, prompting them to report lower symptom severity. Possibly, younger caregivers are less experienced, and symptoms appear more severe to them. Additionally, men reported significantly lower baseline total symptom severity. Potentially, men tend to perceive their PLWDs' symptoms as less severe or they indeed are less severe. This is an important finding because women tend to score higher on neuroticism (Weisberg, Deyoung, & Hirsh, 2011), which would make it an expected finding that women may find symptoms more severe compared to men. The implications for clinicians include educating women about the nature of these symptoms, such that they have more realistic expectations. While no significant changes in caregivers' distress regarding neuropsychiatric symptoms were observed, it is reasonable to assume that greater symptom severity may provoke more distress regarding these symptoms.

Therefore, adjusting women’s expectations may relieve unnecessary stress, burden, and anxiety that likely accompany perceptions of symptoms as severe. On the contrary, simply because men report symptoms as less severe does not mean that men do not experience distress relative to these symptoms. It may be that they do not express as much distress. Men may have reported symptoms as less severe with an implicit expectation that they should not “complain.” Reliance on numeric reports may not fully picture caregivers’ journey. In Western culture men are socialized to emphasize instrumental abilities, self-efficacy and efficiency (Oksuzyan, Juel, Vaupel, & Christensen, 2008), which may make it unacceptable to report their persons’ symptoms as too severe. Nonetheless, clinicians should not omit discussion of these symptoms and should offer education and support to men caregivers.

The majority of findings did not demonstrate neither significant improvement nor worsening for PLWDs and caregivers. This can be explained by the fact that the clinic still treats PLWD as the key player, and while caregivers are essential, they are not direct recipients of any intervention. Additionally, lacking significant worsening in any of the examined outcomes may also be interpreted as an encouraging finding in light of the terminal nature of dementia and logical assumption that none of the PLWD- or caregiver-centered outcomes in dementia are ever expected to improve.

Limitations

Among the limitations of this study is that the sample was highly educated; thus, results may not generalize to other settings. IMCC is situated within an academic health center in a metropolitan area. Potentially, this selects a certain patient population that is not representative of other locales, including rural, non-academic community, and safety-net settings. To prevent attrition and maximize data completeness the PI interviewed each caregiver as opposed allowing them to complete the surveys anonymously and return them. This may have introduced a social desirability bias and some caregivers may have concealed their or their persons' unfavorable experience. The study spanned at a maximum, 9.2 months since the dyads' enrollment. Given that most PLWD are seen once every three months, this is likely a very short time span within which to observe meaningful changes (or preservation of certain outcomes). For instance, the ABC MedHome reported on the dyads' outcomes after 18 months (LaMantia et al., 2015). Future studies may benefit from duration of comparable and greater length. The single-system design without a comparison group prevented comparing this cohort's outcomes to that in a mainstream dementia healthcare. This may be the next step of this line of inquiry. The PI obtained data for the Neuropsychiatric Inventory at baseline and six months from the IMCC medical record, in an effort to reduce participant burden. But not all participants had these data at six months, resulting in missing data.

Conclusion

In this study, the investigators described PLWD- and caregiver-centered outcomes in the initial year since IMCC enrollment. Findings demonstrated significant improvements in two outcome for caregivers and three outcomes for PLWD. The short duration of the study is, in a way, a strength of this study design, demonstrating what changes occurred rapidly, and hence, alluding to the potential strengths of the clinic to address important and bothersome concerns of PLWD and their caregivers quickly. Given the incurable terminal nature of dementia, the findings of improvements in the outcomes that largely encompass quality of life and symbolize what still can be done in dementia management, demonstrate potential strengths of the IMCC.

References

Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 13*(4), 325-373. doi: http://dx.doi.org/10.1016/j.jalz.2017.02.001

Andresen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med, 10*(2), 77-84.

Barton, C., Merrilees, J., Ketelle, R., Wilkins, S., & Miller, B. (2014). Implementation of advanced practice nurse clinic for management of behavioral symptoms in dementia: a dyadic intervention (innovative practice). *Dementia (London), 13*(5), 686-696. doi:10.1177/1471301213519895

Barton, C., Morris, R., Rothlind, J., & Yaffe, K. (2011). Video-telemedicine in a memory disorders clinic: evaluation and management of rural elders with cognitive impairment. *Telemed J E Health, 17*(10), 789-793. doi:10.1089/tmj.2011.0083

Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R. O., Maslow, K., . . . Kunik, M. E. (2014). A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimers Res Ther, 6*(1), 9. doi:10.1186/alzrt242

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *Gerontologist, 41*(5), 652-657.

Bennett, S., & Thomas, A. J. (2014). Depression and dementia: cause, consequence or coincidence? *Maturitas, 79*(2), 184-190. doi:10.1016/j.maturitas.2014.05.009

Borson, S., & Chodosh, J. (2014). Developing dementia-capable health care systems: a 12-step program. *Clin Geriatr Med, 30*(3), 395-420. doi:10.1016/j.cger.2014.05.001

Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M., . . . Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging Ment Health, 15*(1), 13-22. doi:10.1080/13607863.2010.496445

Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord, 23*(4), 306-314. doi:10.1097/WAD.0b013e3181a6bebc

Callahan, C. M., Boustani, M., Sachs, G. A., & Hendrie, H. C. (2009). Integrating care for older adults with cognitive impairment. *Curr Alzheimer Res, 6*(4), 368-374.

Clare, L., Wilson, B. A., Carter, G., Breen, K., Berrios, G. E., & Hodges, J. R. (2002). Depression and anxiety in memory clinic attenders and their carers: implications for evaluating the effectiveness of cognitive rehabilitation interventions. *Int J Geriatr Psychiatry, 17*(10), 962-967. doi:10.1002/gps.735

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *J Health Soc Behav, 24*(4), 385-396.

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Curr Psychiatry Rep, 14*(4), 298-309. doi:10.1007/s11920-012-0288-5

Field, A. (2014). *Discovering statistics using IBM SPSS statistics* (4th ed.): SAGE.

Fonareva, I., & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *Int Psychogeriatr, 26*(5), 725-747. doi:10.1017/S1041610214000039

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J., . . . Crumb, S. (2014). Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Res Gerontol Nurs, 7*(3), 126-137. doi:10.3928/19404921-20140113-01

Fox, C., Maidment, I., Moniz-Cook, E., White, J., Thyrian, J. R., Young, J., . . . Chew-Graham, C. A. (2013). Optimising primary care for people with dementia. *Ment Health Fam Med, 10*(3), 143-151.

Givens, J. L., Mezzacappa, C., Heeren, T., Yaffe, K., & Fredman, L. (2014). Depressive symptoms among dementia caregivers: role of mediating factors. *Am J Geriatr Psychiatry, 22*(5), 481-488. doi:10.1016/j.jagp.2012.08.010

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform, 42*(2), 377-381. doi:10.1016/j.jbi.2008.08.010

Hopkinson, M. D., Reavell, J., Lane, D. A., & Mallikarjun, P. (2018). Cognitive Behavioral Therapy for Depression, Anxiety, and Stress in Caregivers of Dementia Patients: A Systematic Review and Meta-Analysis. *Gerontologist*. doi:10.1093/geront/gnx217

IBM Corp. (2017). IBM SPSS Statistics for Windows (Version 25.0). Armonk, NY: IBM Corp.

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., . . . Reuben, D. B. (2016). Quality of Care Provided by a Comprehensive Dementia Care Comanagement Program. *J Am Geriatr Soc, 64*(8), 1724-1730. doi:10.1111/jgs.14251

Jolley, D., & Moniz-Cook, E. (2009). Memory clinics in context. *Indian J Psychiatry, 51 Suppl 1*, S70-76.

Kang, H. J., Kim, S. Y., Bae, K. Y., Kim, S. W., Shin, I. S., Yoon, J. S., & Kim, J. M. (2015). Comorbidity of depression with physical disorders: research and clinical implications. *Chonnam Med J, 51*(1), 8-18. doi:10.4068/cmj.2015.51.1.8

LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G., . . . Boustani, M. A. (2015). The Aging Brain Care Medical Home: Preliminary Data. *J Am Geriatr Soc, 63*(6), 1209-1213. doi:10.1111/jgs.13447

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York, NY: Springer Pub. Co. .

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London), 15*(6), 1534-1561. doi:10.1177/1471301214564792

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21-32.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosom Med, 64*(3), 510-519.

Lyketsos, C. G., Steele, C., Galik, E., Rosenblatt, A., Steinberg, M., Warren, A., & Sheppard, J. M. (1999). Physical aggression in dementia patients and its relationship to depression. *Am J Psychiatry, 156*(1), 66-71. doi:10.1176/ajp.156.1.66

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia. *Psychol Serv, 14*(1), 102-111. doi:10.1037/ser0000118

Monahan, P. O., Boustani, M. A., Alder, C., Galvin, J. E., Perkins, A. J., Healey, P., . . . Callahan, C. (2012). Practical clinical tool to monitor dementia symptoms: the HABC-Monitor. *Clin Interv Aging, 7*, 143-157. doi:10.2147/CIA.S30663

Nikmat, A. W., Hawthorne, G., & Al-Mashoor, S. H. (2015). The comparison of quality of life among people with mild dementia in nursing home and home care - a preliminary report. *Dementia, 14*(1), 144-125. doi:doi: 10.1177/1471301213494509.

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality Dementia Care. *J Appl Gerontol, 36*(2), 195-212. doi:10.1177/0733464815589986

Oksuzyan, A., Juel, K., Vaupel, J. W., & Christensen, K. (2008). Men: good health and high mortality. Sex differences in health and aging. *Aging Clin Exp Res, 20*(2), 91-102.

Phelan, E. A., Borson, S., Grothaus, L., Balch, S., & Larson, E. B. (2012). Association of incident dementia with hospitalizations. *JAMA, 307*(2), 165-172. doi:10.1001/jama.2011.1964

Powers, B. B., Homer, M. C., Morone, N., Edmonds, N., & Rossi, M. I. (2017). Creation of an Interprofessional Teledementia Clinic for Rural Veterans: Preliminary Data. *J Am Geriatr Soc, 65*(5), 1092-1099. doi:10.1111/jgs.14839

PROMIS. (2011). *Promis scoring guide*. Retrieved from

Radloff, S. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401. doi:doi:10.1177/014662167700100306

RAND Health. (n. d.). 36-item short survey from the RAND Medical Outcomes Study. Retrieved from http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html

Realpe, A. X., Wallace, L. M., Adams, A. E., & Kidd, J. M. (2015). The development of a prototype measure of the co-production of health in routine consultations for people with long-term conditions. [Published online ahead of print July 8 2015]. *Patient Educ Couns*. doi:10.1016/j.pec.2015.07.005

Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc, 61*(12), 2214-2218. doi:10.1111/jgs.12562

Singer, J. D., & Willett, J. B. (2003). *Applied longitudinal data analysis: modeling change and event occurrence*. New York, NY: Oxford University Press.

Tappen, R. M., & Valentine, K. (2014). Building and sustaining a caring-based nurse-managed center. *Pa Nurse, 69*(2), 16-21.

Verghese, J., Malik, R., & Zwerling, J. (2016). Montefiore-Einstein Center for the Aging Brain: Preliminary Data. *J Am Geriatr Soc, 64*(11), 2374-2377. doi:10.1111/jgs.14473

Vickrey, B. G., Mittman, B. S., Connor, K. I., Pearson, M. L., Della Penna, R. D., Ganiats, T. G., . . . Lee, M. (2006). The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med, 145*(10), 713-726.

Weisberg, Y. J., Deyoung, C. G., & Hirsh, J. B. (2011). Gender Differences in Personality across the Ten Aspects of the Big Five. *Frontiers of Psychology, 2*, 178. doi:10.3389/fpsyg.2011.00178

Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med*, *176*(3), 372-379. doi:10.1001/jamainternmed.2015.7664

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-655. doi:10.1093/geront/20.6.649

Table 1. Sociodemographic Characteristics of the Sample at Baseline Interview

Characteristic	**N (%)** **M ± SD [Range]**
Caregiver age	63.8 ± 11.7 [40-88]
Caregiver gender (% female)	35 (71)
<u>Caregiver's race/ethnicity</u>	
African American/Black (%)	14 (28)
Asian American (%)	1 (2)
White (%)	32 (65)
Native American (%)	1 (2)
Chose not to answer (%)	1 (2)
Caregiver employed outside of home (%)	19 (39)
<u>Caregiver's education</u>	
High school (%)	5 (10)
Some college (%)	6 (12)
College (%)	13 (27)
Post-graduate/professional (%)	25 (51)
<u>Care recipient's relationship to the caregiver</u>	
Father (%)	4 (8)
Grandmother (%)	1 (2)
Mother (%)	17 (35)
Mother-in-law (%)	1 (2)
Spouse (%)	26 (53)
Care recipient's age	77.2 ± 8.7 [64-94]
<u>Dementia type</u>	

Alzheimer’s disease (%)	32 (65)
Frontotemporal dementia (%)	4 (8)
Dementia with Lewy bodies (%)	2 (4)
Vascular dementia (%)	1 (2)
Mixed dementia (%)	6 (12)
Other (%)	4 (8)
Number of chronic conditions[a] (besides dementia, as of the first IMCC encounter)	6 ± 4.2 [0-21]
Most common comorbidities	
Hypertension (%)	27 (55)
Musculoskeletal conditions (%)	24 (49)
Hyperlipidemia (%)	23 (47)
Depression (%)	16 (33)
Visual and/or hearing impairment (%)	13 (27)
Cardiovascular conditions (%)	12 (24)
Hypothyroidism (%)	10 (20)
Sleep problems (%)	10 (20)
Cancer (%)	9 (18)
Diabetes (%)	9 (18)
Gastrointestinal conditions (%)	9 (18)
Genitourinary conditions (%)	8 (16)
Caregiver lives with the PLWD (%)	43 (88)
Length of time PLWD needed attention and care because of dementia (years)	3.9 ± 2.9 [0.5-11]
Length of time caregiver personally provided care to PLWD because of dementia (years)	3.9 ± 3.5 [0.4-17]

Number of caregivers who receive help in caregiving duties (%)	40 (82)
Who helps caregivers with caregiving duties[b]	
Paid in-home assistance (%)	16 (40)
Daughter(s) (%)	14 (35)
Sister(s) (%)	10 (25)
Spouse/significant other (%)	9 (23)
Other relatives: cousins, grandchildren, aunt, PLWD’s sister, in-law relatives	8 (20)
(%)	7 (18)
Brother (%)	6 (15)
Son(s) (%)	2(5)
Other non-relatives: roommate, neighbors (%)	2 (5)
Children (%)	2 (5)
Adult day care (%)	1 (3)
Mother (%)	1 (3)
Father (%)	1 (3)
Friend(s) (%)	1 (3)
Church (%)	
Amount of help caregivers estimate they receive[c]	
A great deal of help (%)	21 (22)
Some help (%)	38 (40)
A little help (%)	24 (25)
Not much help (%)	10 (11)
Almost no help (%)	3 (3)
Caregiver indicates that he is responsible for caring for other individual(s) besides PLWD (%)	19 (39)

For whom the caregiver is also caring besides PLWD[d]	
Spouse/significant other (%)	6 (30)
Mother (%)	5 (25)
Children (%)	4 (20)
Sibling(s) (%)	3 (15)
Others (grandchildren, nephew, mother's sister) (%)	3 (15)
In-law parents or siblings (%)	2 (10)
Father (%)	1 (5)
Number of caregivers who reside with at least one other person(s) besides PLWD, for whom they provide care[d]	8 (16)
Amount of time caregivers estimate they put into caring for at least one other person(s) besides PLWD[e]	
A great deal of time (%)	8 (28.5)
Some time (%)	12 (42.9)
A little time (%)	3 (10.7)
Not much time (%)	3 (10.7)
Almost no time (%)	2 (7.1)
Number of the IMCC visits, from the first visit till the last visit before the last quantitative survey at 6 months post-baseline	3.2 ± 1.5 [1-7]

Note. [a]Chronic conditions were extracted from the electronic medical record. [b]Percentages are calculated out of 40 caregivers who indicated that they received help in their caregiving duties. [c]Percentages are calculated out of a total of 95 sources of help that 40 caregivers indicated (96 is the denominator, the numerator is the number of times a caregiver indicated each category of help – a great deal, some, etc.). [d]Percentages are calculated out of 19 caregivers who indicated that they were caring for someone else besides their PLWD. [d]Percentage calculated out of the total sample, 49 caregivers. [e]Percentages are calculated for 19 caregivers who indicated that they were caring for someone else besides their PLWD. The total number of persons for whom these 20 caregivers are caring, N = 27, is used as a denominator to calculate how much time caregivers put into this care.

Table 2. Comparison between Caregivers who Completed the Study with those Who Discontinued

Characteristic	Completed (N = 42) M ± SD [Range] N (%)	Did not complete (N = 7) M ± SD [Range] N (%)	Group Comparisons
Age	65.7 ± 11.2 [40-88]	52.7 ± 8.8 [44-68]	t (47) = 0.533, p = 0.005 95% CI [4.019; 21.933]
Caregiver gender (% Female)	28 (67)	7 (100)	X^2 (1) = 3.267, P = 0.071
Education (% ≥ college)	33 (79)	5 (71)	X^2 (1) = 0.176, P = 0.675
Race (% African American)	11 (26)	3 (43)	X^2 (1) = 0.602, P = 0.438
PLWD (% spouse)[a]	25 (58)	1 (14)	X^2 (1) = 4.93, P = 0.026
(% parent)	18 (42)	6 (86)	
PLWD age	77.1 ± 8.4 [66-94]	77.6 ± 10.9 [64-93]	t (47) = -0.126, p = 0.9

			95% CI [-7.65; 6.75]
Dementia type (% Alzheimer’s disease)	30 (71)	2 (29)	X^2 (1) = 4.864, P = 0.027
(% dementia besides Alzheimer’s disease)	12 (29)	5 (71)	
Number of comorbidities	6.1 ± 4.3 [0-21]	4.7 ± 3.5 [0-9]	U = 170, z = 0.661 p = 0.528
Co-residence with the PLWD (% co-reside with their PLWD)	37 (88)	6 (86)	X^2 (1) = 4.864, P = 0.027
Duration of time the PLWD needed care for dementia (years)	3.7 ± 2.6 [0.5-10]	5.1 ± 4.2 [0.6-11]	U = 126 Z = -0.604 P = 0.586
Duration of time the caregiver has been providing care to the PLWD (years)	3.7 ± 2.9 [0.5-12]	5.1 ± 6.3 [0.4-17]	U = 155.5 Z = 0.244 P = 0.812
Whether caregiver receives help in caregiving (% yes)	35 (83)	5 (71)	X^2 (1) = 0.567, P = 0.451
Whether caregiver is responsible for caring for at least one other person besides the PLWD (% yes)	16 (38)	3 (43)	X^2 (1) = 0.057, P = 0.811

Perceived Stress Scale[b]	18.9 ± 6.9 [3-30]	19.3 ± 7 [6-28]	t (46) = .135, p = 0.893 95% CI [-5.34; 6.11]
Zarit Burden Interview	21.1 ± 8.6 [3-37]	28 ± 11.3 [10-44]	t (47) = 1.884, p = 0.066 95% CI [-0.47; 14.28]
Center for Epidemiologic Studies – Depression	9.1 ± 4.9 [2-17]	10.5 ± 5.8 [1-17]	U = 123.5 Z = -0.673 P = 0.51
Patient-Reported Outcomes Measurement System - Anxiety	Raw mean: 17.1 ± 5.4 T-score: 56.3 Standard error: 2.2 95% CI [52; 60.6]	Raw mean: 17.7 ± 6.1 T-score: 57.6 Standard error: 2.2 95% CI [53.3; 61.9]	t (47) = 0.278, p = 0.783 95 % CI [-3.87; 5.1]
Short Form-36: Physical Component Summary	47.6 ± 10.4 [21.9; 68.2]	42 ± 8.1 [25.5; 51.4]	U = 197, Z = 1.429, P = 0.161
Short Form-36: Mental Component Summary	41.1 ± 13.3 [14.2; 62.5]	38. 7 ± 13.6 [19.2; 62.3]	U = 168, z = 0.6, p = 0.566

Healthy Aging Brain Care: PLWD’s cognitive symptoms	13.6 ± 4.4 [3-18]	11.3 ± 7.1 [2-18]	U = 152, z = 0.362, p = 0.737
Healthy Aging Brain Care: PLWD’s functional symptoms	15 ± 8.8 [1-33]	16.9 ± 9 [6-30]	U = 131, z = -0.458, p = 0.665
Healthy Aging Brain Care: PLWD’s behavioral and mood symptoms	11.9 ± 5.6 [4-30]	15.4 ± 9 [3-27]	U = 106, z = -1.174, p = 0.253
Healthy Aging Brain Care: caregiver stress	3.4 ± 2.9 [0-9]	5.6 ± 2.7 [1-9]	U = 81.5, Z = -1.887, P = 0.06
Healthy Aging Brain Care: total score	44.4 ± 16.1 [11-88]	49.1 ± 23.9 [14-73]	t (45) = 0.665, p = 0.509 95% CI [-9.57; 19]
Neuropsychiatric symptoms: total number of symptoms	5.9 ± 2.9 [0-11]	7.6 ± 2.5 [4-10]	t (43) = 1.251, p = 0.218 95% CI [-1; 4.4]
Neuropsychiatric symptoms: total symptom severity	11.7 ± 7.2 [2-29]	17.8 ± 7.3 [8-26]	U = 49, z = -1.695, p = 0.096
Neuropsychiatric Inventory (NPI): delusions - severity	1.9 ± 7.9 [1-3]	3 ± 0 [3 -3]	U = 3, z = -1.742, p = 0.132

NPI: depression/dysphoria - severity	2.2 ± 0.9 [0-4]	2 ± 0.8 [1 -3]	U = 58.5, z = 0.746, p = 0.505
NPI: apathy - severity	1.9 ± 0.8 [1-3]	2.6 ± 0.5 [2-3]	U = 32.5, z = -1.77, p = 0.096
Neuropsychiatric symptoms: total caregiver's distress	14.4 ± 11.7 [1-45]	23 ± 8.9 [15-33]	U = 34, z = -1.759, p = 0.079
NPI: delusions – distress	3.3 ± 1.4 [1-5]	4.5 ± 0.7 [4-5]	U = 5, z = -1.321, p = 0.264
NPI: agitation/aggression - distress	3 ± 1.3 [0-5]	4.5 ± 0.7 [4-5]	U = 6.5, z = -1.672, p = 0.116
NPI: anxiety - distress	2.5 ± 1.3 [0-5]	3 ± 1.4 [2-4]	U = 18.5, z = -0.562, p = 0.615
PLWD's quality of life	30.6 ± 5.1 [22-44]	25.5 ± 3.5 [19 – 29.3]	U = 237, z = 2.574, p = 0.008

---

[a] Individuals' PLWD were divided into only parents and spouses. If a caregiver indicated caring for an in-law parent or grandparent, they were counted as parents. [b] Values for these instruments are reported as of baseline assessment.

Table 3. Caregiver and PLWD outcomes

Variable	Estimate	Standard Error	*t*	*p*	95% CI
<u>Caregiver-Centered Variables</u>					
Perceived stress[a]	-0.24	0.22	-1.08	0.281	[-0.67; 0.2]
Caregiver burden[b,c]	-0.072	0.28	-0.25	0.800	[-0.63; 0.49]
Depressive symptoms[d,e]	0.097	0.17	0.56	0.577	[-0.25; 0.44]
Anxiety[f]	-0.18	0.18	-1.01	0.315	[-0.52; 0.17]
Short Form-36[g] Physical Functioning subscale	-0.19	0.67	-0.28	0.783	[-1.52; 1.15]
Short Form-36 Role Limitations due to Physical Health subscale	-1.53	1.35	-1.14	0.256	[-4.2; 1.13]
Short Form-36 Role Limitations due to Emotional Problems subscale	0.52	1.34	0.39	0.701	[-2.13; 3.17]
Short Form-36: Vitality subscale	0.7	0.67	1.03	0.303	[-0.64; 2.03]
Short Form-36: Mental Health/Emotional Well-being subscale	0.15	0.53	0.27	0.786	[-0.91; 1.2]
Short Form-36: Social Functioning	0.36	0.86	0.41	0.68	[-1.34; 2.06]
Short Form-36: Bodily Pain	0.13	0.77	0.16	0.871	[-1.4; 1.65]

Short Form-36: General Health	0.13	0.6	0.22	0.823	[-1.05; 1.32]
Short Form-36: Physical Component Summary	-0.27	0.34	-0.77	0.44	[-0.95; 0.42]
Short Form-36: Mental Component Summary	0.35	0.43	0.83	0.409	[-0.49; 1.2]
Healthy Aging Brain Care Monitor: Caregiver's Stress[h]	-0.085	0.091	-0.94	0.351	[-0.27; 0.095]
Neuropsychiatric symptoms:[i,j] delusions – distress (completers and non-completers included)	-0.14	0.067	-2.04	0.048	[-0.28; -0.0011]
Neuropsychiatric symptoms: delusions – distress (seven non-completers excluded)	-0.11	0.068	-1.64	0.111	[-0.25; 0.027]
Neuropsychiatric symptoms: hallucinations - distress	-0.03	0.1	-0.31	0.757	[-0.23; 0.17]
Neuropsychiatric symptoms: agitation/aggression – distress	-0.11	0.055	-1.93	0.058	[-0.22; 0.0038]
Neuropsychiatric symptoms: depression/dysphoria - distress	-0.026	0.043	-0.61	0.544	[-0.11; 0.059]
Neuropsychiatric symptoms: anxiety – distress (completers and non-completers included)	-0.13	0.055	-2.42	0.018	[-0.24; 0.023]
Neuropsychiatric symptoms: anxiety – distress	-0.41	0.19	-2.17	0.034	[-0.79; -0.033]

(only completers included)					
Neuropsychiatric symptoms: elation - distress	-0.2	0.14	-1.41	0.17	[-0.49; 0.095]
Neuropsychiatric symptoms: apathy - distress	-0.019	0.055	-0.34	0.733	[-0.13; 0.091]
Neuropsychiatric symptoms: disinhibition - distress	0.014	0.069	0.2	0.84	[-0.13; 0.15]
Neuropsychiatric symptoms: irritability - distress	0.027	0.077	0.36	0.722	[-0.13; 0.18]
Neuropsychiatric symptoms: motor disturbance - distress	-0.066	0.088	-0.75	0.459	[-0.24; 0.11]
Neuropsychiatric symptoms: sleep disturbance - distress	-0.081	0.071	-1.13	0.263	[-0.22; 0.062]
Neuropsychiatric symptoms: appetite and eating disorders - distress	-0.073	0.039	-1.89	0.063	[-0.15; 0.0042]
Neuropsychiatric symptoms: total distress	-0.58	0.4	-1.42	0.157	[-1.38; 0.23]
<u>PLWD-Centered Variables</u>					
Healthy Aging Brain Care Monitor: PLWD’s cognitive symptoms	-0.061	0.16	-0.37	0.709	[-0.39; 0.26]
Healthy Aging Brain Care Monitor: PLWD’s functional symptoms	0.19	0.26	0.72	0.472	[-0.33; 0.71]

Healthy Aging Brain Care Monitor: PLWD's behavioral and mood symptoms	-0.015	0.031	-0.49	0.627	[-0.076; 0.046]
Neuropsychiatric symptoms:[i,j] delusions – severity (completers and non-completers included)	-0.1	0.044	-2.23	0.032	[-0.19; -0.0091]
Neuropsychiatric symptoms: delusions – severity (seven non-completers excluded)	-0.079	0.045	-1.74	0.091	[-0.17; 0.013]
Neuropsychiatric symptoms: hallucinations - severity	-0.019	0.047	-0.42	0.68	[-0.11; 0.075]
Neuropsychiatric symptoms: agitation/aggression - severity	-0.045	0.033	-1.35	0.182	[-0.11; 0.021]
Neuropsychiatric symptoms: depression/dysphoria – severity (completers and non-completers included)	-0.12	0.029	-4.14	<0.001	[-0.18; -0.062]
Neuropsychiatric symptoms: depression/dysphoria – severity (seven non-completers excluded)	-0.12	0.03	-4.11	<0.001	[-0.18; -0.063]
Neuropsychiatric symptoms: elation/euphoria - severity	-0.076	0.063	-1.21	0.239	[-0.21; 0.055]

Neuropsychiatric symptoms: anxiety – severity	-0.036	0.029	-1.22	0.227	[-0.094; 0.023]
Neuropsychiatric symptoms: apathy – severity (completers and non-completers included)	-0.065	0.034	-1.91	0.059	[-0.13; 0.0026]
Neuropsychiatric symptoms: disinhibition - severity	-0.061	0.043	-1.41	0.165	[-0.15; 0.026]
Neuropsychiatric symptoms: irritability - severity	-0.012	0.044	-0.28	0.783	[-0.1; 0.076]
Neuropsychiatric symptoms: motor disturbance - severity	-0.075	0.047	-1.61	0.114	[-0.17; 0.019]
Neuropsychiatric symptoms: sleep disturbance - severity	-0.017	0.04	-0.42	0.675	[-0.097; 0.063]
Neuropsychiatric symptoms: appetite and eating disorders - severity	-0.058	0.032	-1.8	0.078	[-0.12; 0.0067]
Neuropsychiatric symptoms: total symptom severity (completers and non-completers included)	-0.093	0.037	-2.52	0.013	[-0.17; -0.02]
Neuropsychiatric symptoms: total symptom severity (seven non-completers excluded)	-0.082	0.038	-2.17	0.032	[-0.16; -0.0071]

Total number of neuropsychiatric symptoms	-0.048	0.085	-0.57	0.569	[-0.22; 0.12]
Quality of life[k,l]	0.069	0.18	0.39	0.697	[-0.28; 0.42]
Caregiver- and PLWD-Centered Variable					
Healthy Aging Brain Care Monitor: total score (PLWD's cognitive, functional, behavioral and mood symptoms, and caregiver's stress)	-0.1	0.55	-0.19	0.854	[-1.19; 0.98]

Note. CI = confidence interval. [a]Cohen, Kamarck, & Mermelstein (1983) [b]Zarit, Reever, & Bach-Peterson (1980) [c]Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001) [d]Radloff (1977) [e]Andresen, Malmgren, Carter, & Patrick (1994) [f]PROMIS (2011) [g]RAND Health (n. d.) [h]Monahan et al., (2012) [i]Cummings (1997) [j]Kaufer et al., (2000) [k]Logsdon, Gibbons, McCurry, & Teri (1999) [l]Logsdon, Gibbons, McCurry, & Teri (2002)

Table 4. Post Hoc Analyses for Outcomes that Changed Significantly over Time

Variable	Time point (I)	Time point (J)	Mean difference (I-J)	Standard Error	Significance	95% confidence interval
Delusions – distress	Time point 1	Time point 2	0.792	0.358	0.096	[-0.102; 1.687]
		Time point 3	0.829	0.546	0.358	[-0.535; 2.192]
	Time point 2	Time point 1	-0.792	0.358	0.096	[-1.687; 0.102]
		Time point 3	0.036	0.519	1	[-1.26; 1.333]
	Time point 3	Time point 1	-0.829	0.546	0.358	[-2.192; 0.535]
		Time point 2	-0.036	0.519	1	[-1.333; 1.26]
Anxiety - distress	Time point 1	Time point 2	0.353	0.295	0.554	[-0.369; 1.075]
		Time point 3	0.885	0.385	0.072	[-0.057; 1.826]
	Time point 2	Time point 1	-0.353	0.295	0.554	[-1.075; 0.369]
		Time point 3	0.532	0.369	0.396	[-0.372; 1.435]
	Time point 3	Time point 1	-0.885	0.385	0.072	[1.826; 0.057]
		Time point 2	-0.532	0.369	0.396	[-1.435; 0.372]
Delusions – severity	Time point 1	Time point 2	0.452	0.234	0.173	[-0.134; 1.039]
		Time point 3	0.671	0.354	0.184	[-0.214; 1.557]
	Time point 2	Time point 1	-0.452	0.234	0.173	[-1.039; 0.134]

		Time point 3	0.219	0.338	0.89	[-0.626; 1.065]
	Time point 3	Time point 1	-0.671	0.354	0.184	[-1.557; 0.214]
		Time point 2	-0.219	0.338	0.89	[-1.065; 0.626]
Depression/dysphoria - severity	Time point 1	Time point 2	0.717	0.167	0.000	[0.308; 1.125]
		Time point 3	0.65	0.204	0.006	[0.152; 1.148]
	Time point 2	Time point 1	-0.717	0.167	0.000	[-1.125; - 0.308]
		Time point 3	-0.067	0.201	0.983	[-0.559; 0.425]
	Time point 3	Time point 1	-0.65	0.204	0.006	[-1.148; -0.152]
		Time point 2	0.067	0.201	0.983	[-0.425; 0.559]
Total symptom severity[a]	Time point 1	Time point 2	0.123	0.216	0.921	[-0.401; 0.646]
		Time point 3	0.504	0.263	0.165	[-0.135; 1.142]
	Time point 2	Time point 1	-0.123	0.216	0.921	[-0.646; 0.401]
		Time point 3	0.381	0.261	0.381	[-0.253; 1.014]
	Time point 3	Time point 1	-0.504	0.263	0.165	[-1.142; 0.135]
		Time point 2	-0.381	0.261	0.381	[-1.014; 0.253]

Note. [a] Total symptom severity scores were transformed with square root transformation to attain normality.

The Experience of Informal Caregivers at an Integrated Memory Care Clinic

Introduction

In 2017, approximately 5.7 million Americans lived with Alzheimer’s disease – the most prevalent dementia type. Over 16 million unpaid informal caregivers helped persons living with dementia (PLWD) (Alzheimer’s Association, 2018). Unpaid caregivers assist 83% of PLWD in the U.S. (Friedman, Shih, Langa, & Hurd, 2015). Living at home for PLWD – compared to institutional settings – is associated with fewer depressive symptoms and better quality of life, cognitive performance, functional status, and social connectedness (Nikmat, Al-Mashoor, & Hashim, 2015). Caregiving may bring role fulfillment and personal and spiritual growth for the caregivers (Lloyd, Patterson, & Muers, 2014). Caregiving is also fraught with drawbacks: caregivers’ compromised physical health (Fonareva & Oken, 2014), health-related quality of life (Alfakhri et al., 2018), family relationships (Tatangelo, McCabe, Macleod, & Konis, 2018), social connections (Bass et al., 2012), and employment (Alzheimer’s Association, 2018).

Dementia care – in primary, emergency, acute, and long-term settings – is complex. Despite dementia prevalence, finding experts in dementia management is difficult, partially, because no evidence-based standards for dementia diagnosis and management or caregivers’ support exist. Specialists (e.g., neurologists) are scarce and, hence, may not care for all PLWD (Borson & Chodosh, 2014). Also, pharmacotherapy for PLWD and caregiver education and support are often suboptimal (Jennings et al., 2016).

Responding to the growing demand for expert outpatient dementia care, memory clinics have evolved worldwide (Jolley & Moniz-Cook, 2009) since the 1980s, originating in the UK (Bayer, Richards, & Phillips, 1990). They differ in location; personnel; services; coverage of non-dementia conditions; care coordination; interaction with primary care providers, specialists, and community agencies; and the commitment to education and research (Dreier-Wolfgramm et al., 2017; Jolley & Moniz-Cook, 2009). Several U.S. dementia care programs have been implemented (Boustani et al., 2011; LaMantia et al., 2015; Reuben et al., 2013). Most are physician-led. A few programs are led by advanced practice registered nurses (APRNs) (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014; Tappen & Valentine, 2014), including the Integrated Memory Care Clinic (IMCC). The IMCC is the only U.S. APRN-led dementia care program that, to our best knowledge, provides both primary and dementia care (Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018).

Investigators have explored caregivers' experience with dementia care programs by gauging their satisfaction with care through program-developed surveys (Barton et al., 2014; Fortinsky et al., 2014; Tan, Jennings, & Reuben, 2014) or via informal feedback (Verghese, Malik, & Zwerling, 2016). We found no qualitative studies analyzing caregivers' experience in these programs. This study qualitatively explored caregivers' experience at the IMCC.

Design and Methods

Setting. The IMCC at Emory Healthcare is a patient-centered medical home led by APRNs who provide dementia care and primary are simultaneously. Upon enrollment, patients transfer their primary care to the IMCC – the APRN becomes their primary care provider. The three APRNs at the clinic specialize in a combination of primary care, geriatrics, neurology, and palliative care. A geriatrician is the formal medical director who maintains a collaborative agreement with the APRNs and co-signs their orders. He does not see the IMCC patients. One APRN is the clinical director and the social worker is the administrative director of the clinic. The clinic also employs one registered nurse who conducts patient assessments before visits with APRNs, administers vaccines, runs electrocardiograms, advises clients on medication and treatment regimen, and performs other nursing care tasks. Additionally, the clinic employs a patient access coordinator who checks families in on arrival and schedules their follow-up visits on departure, prepares the “Welcome to the IMCC” packages, and answers the telephone during business hours. PLWD are referred to specialists within and outside Emory Healthcare. The clinic uses services in the Brain Health Center building that houses the clinic: neuropsychological testing, laboratory, and free parking with valet service.

The IMCC is designed according to principles discussed in-depth elsewhere (Clevenger et al., 2018). Here we provide a brief overview of the clinic.

Discussions are held between APRNs and families to understand clients’ care goals. The clinic staff aim to minimize unnecessary, avoidable, and redundant emergency and acute care use for PLWD. APRNs emphasize home treatment for ambulatory care-sensitive conditions (e.g., urinary tract infections, dehydration). Caregivers are instructed to first consult with APRNs when PLWD display worrisome symptoms. APRNs may recommend home management or same-day or next-day IMCC appointment, rather than emergency treatment when PLWD’s condition does not warrant it according to APRNs’ judgment. To facilitate uninterrupted access to an APRN before resorting to emergency or inpatient care, clients have round-the-clock and year-round telephone access to an APRN on duty, whom clients are encouraged to contact.

Likewise, families are advised on judicious use of diagnostic procedures, such that PLWDs’ dementia stage, comorbidities, advance care planning, goals, and preferences are considered. Additionally, safety is prioritized. Timing of driving cessation for PLWD is discussed. Caregivers are also advised on handling weapons (e.g., remove or disable guns).

Pharmacotherapy is managed using the most current geriatric prescribing guidelines. Medications that worsen cognition or produce adverse side effects especially pronounced for older adults are avoided. Behavioral and psychological symptoms of dementia, including depression, are managed aggressively – non-pharmacologically and pharmacologically. The IMCC social worker leads an evidence-based caregiver education program, the Savvy Caregiver Program, that increases caregivers' competence and capacity to manage the caregiving situation (Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007). The social worker also leads a class on late-stage dementia (Clevenger et al., 2018).

Design. Qualitative description (Sandelowski, 2000), the description of the phenomena using everyday terms of those who participate in these events, was used to guide the exploration of caregivers' experiences at the IMCC. This method fits studies with research questions that may be formulated as, "What are the concerns of people about an event? What are people's responses . . . toward an event? What reasons do people have for using or not using a service or procedure? Who uses a service and when?" (Sandelowski, 2000, p. 337). The primary goal in qualitative description methodology is to produce a descriptive resume of an event such that the data are relevant to the audience (Sandelowski, 2000), in this case, clinicians. Hence, this method supported our aim to report on caregivers' experiences within the APRN-led dementia medical home, the IMCC, such that the IMCC and analogous organizations may use this knowledge.

The principal investigator (PI), a registered nurse, recruited caregivers at the IMCC. Because of her knowledge of the IMCC, prior to data generation she wrote bracketing statements (Wall, Glenn, Mitchinson, & Poole, 2004) to account for her beliefs, preexistent knowledge about dementia caregiving, assumptions, and common concepts, such as caregiver burden (Zarit, Reever, & Bach-Peterson, 1980). These bracketing statements were shared with the last author who was less familiar with the IMCC but experienced in qualitative research.

Sampling. Eligible caregivers were at least 18 years old, English-speaking, providing unpaid care for a PLWD living in the community (not in institutional settings), and who had their first visit to the IMCC no more than 12 months prior to the date of the qualitative interview. The latter criterion enabled sampling caregivers who were relatively new to the IMCC.

The PI (first author) recruited caregivers using flyers at the IMCC. The PI also asked APRNs to inquire if newly enrolled caregivers might be interested in participating. As the main way of recruitment, the PI regularly reviewed the IMCC health records to identify new PLWD. The PI then provided the list of these individuals to the patient access coordinator who asked these PLWDs' caregivers about their interest in participation. If caregivers indicated interest, the PI called them or met with them at the IMCC and screened them for eligibility. If caregivers were eligible and interested in participation, they consented verbally. Recruitment occurred between August 2016 and July 2017. Emory University Institutional Review Board approved the study.

A convenience sample of 12 caregivers was recruited. This sample size was based on striving to achieve an appropriate and adequate sample (Morse, 1991), while accounting for time constraints to complete the study and unpredictable client enrollment into the clinic (which determined how many new clients would be potentially eligible for this study).

Data collection. The PI conducted interviews via telephone to minimize participant burden and decrease attrition. The PI administered a sociodemographic survey before each interview. The interviews began with a broad question, “Please tell me about your experience at the IMCC to date.” Subsequent questions focused on caregivers' expectations of the clinic and their wishes about dementia care; comparisons between the IMCC care and healthcare their PLWD received previously; and the strongest and weakest aspects of the IMCC care. Probes were used to draw further comments (King & Horrocks, 2010). The interviews lasted on average

29 minutes (range 13–54 minutes). Participants were reimbursed with $25 gift cards after interview completion.

All interviews were audio-recorded and professionally transcribed. The PI proofread transcripts for accuracy and removed identifying information. Caregivers were assigned pseudonyms (Poland, 1995). The PI wrote a reflexive statement (Malterud, 2001) and an analytic memo (Saldaña, 2016) for 10 out of 12 interviews upon interview completion. The PI wrote additional analytic memos throughout the analysis.

Analysis. Directed content analysis (Hsieh & Shannon, 2005) was used to focus the analysis on those data pertaining to caregivers' experiences of the clinic. A limitation of this approach is that it may overemphasize the selected area of inquiry, possibly blinding researchers to important contextual aspects of the studied phenomenon (Hsieh & Shannon, 2005). Yet, we aimed to learn about the caregivers' experiences of the clinic. Caregivers' accounts of other things important to them did not enrich our understanding of their experience of the clinic.

The analysis was undertaken in collaboration with the last author to ensure rigor. Initially, the interviews were read multiple times to get an overall sense of the data. Then the transcripts were coded inductively: the codes came from the data (Miles & Huberman, 1994). Textual elements ranging from a word to a phrase to one or several sentences were considered codes. Codes were discussed between the first and the last author. Then the finalized codes were applied to the transcripts. Whenever a text segment did not fit these codes, a new code was created and discussed between the co-authors. Then either this new code was added or an existing code was modified to incorporate the semantics of a textual segment that did not fit the preceding list of codes. This iterative process continued until all data were fit into a finalized list of codes.

The PI created data displays – tables with codes and corresponding quotations (or main ideas from quotations) for each participant. Additionally, documents were created with codes that pertained only to women, only to men, only to spouse caregivers, and only to children caregivers. These data displays were reviewed with the last author and used to "discover patterns and determine the presence, variation, or absence of patterns" in the data (Sandelowski, Holditch Davis, & Harris, 1989, p. 82) via constant comparison (Miles & Huberman, 1994). The PI posed the question, "How is one expression different from or similar to the other?" (Ryan & Bernard, 2003, p. 91) to guide the constant comparison of codes.

The data displays allowed for the observation of patterns across and within cases. For example, we observed patterns in the interviews from two caregivers who were nurses that may be attributable to their professional background. We noted differences between women's and men's narratives and between those who had been caregivers for one year vs. many years. The data displays supported grouping the codes into categories – "collection[s] of similar data," (Morse, 2008, p.727). Once the categories were agreed upon, they were re-arranged, yielding two main features that characterized caregivers' experience of the clinic. Quotation marks in the results signify participants' words as data.

Results

Sample. Twelve caregivers (mean age 65), completed interviews. Nine were women and 11 were White. Among women, three were spouse caregivers and six were daughters or daughters-in-law. All men participants were spouse caregivers.

Among the PLWD (mean age 79.7), nine had Alzheimer's disease, and three had other dementia types. Eleven caregivers lived with their PLWD. Caregivers reported caring for their PLWD for 0.75-12 years. Participants were clients of the IMCC for 6.5-12 months. On average, PLWD had seven chronic conditions besides dementia. Hypertension, musculoskeletal conditions, and dyslipidemia were the most prevalent comorbidities.

We discovered two major features characterizing the caregivers' experiences: (1) the IMCC as the wished-for model of dementia care; and (2) ways to enhance the IMCC. All but one caregiver were satisfied with the IMCC care, although most participants offered suggestions for improvement. The caregiver who claimed a predominantly negative experience represents an atypical case. This rival perception will be addressed after the prevailing opinion is reported.

The IMCC as the wished-for model of dementia care. Participants spoke about the IMCC providing care of higher quality compared to that their PLWD had received previously. Largely, the clinic met caregivers' expectations of dementia care. Comments conveying caregivers' impressions could be interpreted through the lens of caregivers' duration of caregiving, their support or lack thereof, and ways they approach dementia management. For example, a man who had been a caregiver for nine years stated that the IMCC is "as good as it can be." His tone did not convey discontent, but rather understanding that medicinal effect on dementia is markedly limited. This man expressed disappointment with lacking progress in finding pharmacologic cure for dementia. He also stated that since he had been a caregiver for nine years, he was a solitary caregiver with no support at the time of the interview as friends and family eventually stopped helping. By contrast, a woman with three years of caregiving experience who spoke about her work in organizations that educate and support caregivers described the clinic as "the only place you go to for dementia [care]," and called herself a "number one cheerleader" for the clinic. This woman's tone conveyed confidence in her ability to find better ways to manage dementia despite its terminal nature. Both the man and the woman expressed their willingness to be on the forefront of dementia research and practice, but, perhaps, the man’s longer experience caregiving created less “excitement” about the clinic. Finally, one woman who had been a caregiver for one year and who was satisfied with care but uncertain about the scope of practice of the clinic remarked that “there’s nothing you can really do for Alzheimer’s.” Such comment is potentially manifesting a presupposition that since dementia is incurable, it cannot be managed. Thus, caregivers’ contexts appeared to influence their impressions of the clinic.

Care was described as holistic – encompassing PLWDs’ physical, mental, and emotional well-being. This holistic approach was deemed “vital.” Participants’ narratives focusing on their appreciation of the clinic could be clustered into three characteristics of the clinic: patient-centeredness, human resources, and comparison of the IMCC to the mainstream dementia care.

Patient-centeredness. The clinic was designed to meet clients’ – PLWDs’ and caregivers’ – wishes, preferences, needs, and goals. Six characteristics of patient-centeredness were derived from caregivers’ narratives (Table 1).

Most caregivers described their sense of belonging to the IMCC healthcare team. Caregivers’ contributions to their PLWDs’ care were recognized: “They listen to my feelings . . . Because I’m with my mom, my input is important to get an understanding of what’s going on with her.” The APRNs inquired about caregivers’ physical and psychological well-being. Caregivers expressed their sense that the APRNs understand caregivers’ stress and treat the PLWD-caregiver dyad as a whole.

The concept of time prominently embodied patient-centeredness. This idea of time encompassed two aspects: minimal waiting before and sufficient time during the appointment. Short waits before appointments mattered because waiting could trigger PLWDs’ agitation. Adequate time during visits relayed a perception of the APRNs’ thoroughness and competence.

Unhurried pace of visits relieved pressure from caregivers to remember to ask all questions in a brief time slot, as they were certain they would eventually discuss all concerns in an unrushed manner.

Care access – unhindered ability to reach a clinician via telephone and convenient centralized location of other services in the same building with the IMCC – promoted patient-centeredness. Direct telephone access to clinic staff 24-hours/day was highly valued. During business hours, caregivers had a direct line to the patient access coordinator who could connect caregivers to other personnel. Caregivers appreciated having a direct line to an actual person – the patient access coordinator – not a voicemail. They compared this convenience to other healthcare settings where automatic prompts preceded leaving a voice message, such that caregivers never knew when the call might be returned. After hours, caregivers were encouraged to contact an APRN on duty with any questions. Many caregivers very strongly appreciated particularly the after-hours unhindered care access. They described using this service and benefitting from it (e.g., by adjusting medication dosage for their PLWD at home). They also described having peace of mind that this service gave should dementia- or non-dementia-related issues arise, citing previous stressful experiences of taking their PLWD to an emergency department on a weekend and without resolution of the issue that precipitated such visit. Finally, location of other services (e.g., laboratory) in the same building that houses the clinic also promoted care access, as it saved caregivers’ time and decreased trips for PLWD for whom commuting was difficult.

Time and access interacted during telephone calls. Whether caregivers called during or after business hours, they usually received immediate assistance. Because the APRNs rotated in their duty to answer the round-the-clock telephone line, caregivers appreciated the courtesy with which APRNs communicated and effectiveness with which they resolved caregivers' concerns even when they were not the APRN assigned to the dyad. Such reliability, regardless the APRNs' familiarity with clients, suggests clarity of purpose and shared vision among the APRNs on what dementia care and primary care should be.

Informational resources – the Savvy Caregiver (Hepburn et al., 2007) and the late-stage dementia classes – bolstered patient-centeredness. Caregivers who attended the Savvy Caregiver class noted how the class helped them modify their behavior, which affected their PLWDs' behavior, making PLWD more responsive and able to engage in feasible and meaningful activities. Participants expressed their regret that they had not attended these classes earlier.

Care coordination and care continuity contributed to patient-centeredness. Care coordination included promptly updating hospital staff on the PLWD's primary and dementia care before hospitalizations and coordinating pharmacotherapy with the personnel of an assisted living facility where PLWD resided. Because the clinic made referrals to specialty care, caregivers deemed the IMCC care comprehensive, meaning that APRNs, with their ability to connect with other clinicians, created a seamless, unified care for PLWD. Care continuity was exemplified by the staff establishing rapport with families: "They know mother. There's a strong connection that is established from the very beginning, particularly, when you see the same nurse practitioner, and that's part of the continuity."

Human resources. The IMCC had a unique combination of human resources that differed from other care settings. These human resources supported providing the wished-for care. Participants spoke about staff in three ways—the collective staff, staff other than APRNs, and APRNs.

Staff were recognized for their patience, caring and upbeat attitude, and cultural sensitivity. Regardless their role, the staff acted in unison to convey a sense of safety and understanding that caregivers valued. Often in their interviews, caregivers referred to all personnel in the clinic as “they,” making comments such as “they are very caring,” without specifying who “they” were: “They understand what needs to be done to care for the person with dementia.”

Staff besides APRNs added to the creation of unique experience at the clinic. Caregivers acknowledged the social worker, the registered nurse, and the patient access coordinator. The social worker effectively taught the Savvy Caregiver and the late-stage dementia classes. The registered nurse created a positive environment when she spoke with clients before the visit with an APRN and offered strategies for dementia management. The patient access coordinator was an important link in the communication between caregivers and clinic staff: caregivers described him as highly communicative, reliable, and competent.

Caregivers commented extensively on APRNs, possibly because the majority of visit time was spent with APRNs and care management was largely associated with them. The APRNs were described as professional, caring, committed, and supportive. Caregivers valued the rapport that APRNs established with caregivers and PLWD, dedicating time to the conversation with PLWD and creating a sense of familiarity and a welcoming atmosphere.

Women, but no men, mentioned the APRNs’ competence in managing PLWDs’ behaviors, skill in communicating with PLWD, and applying palliative care principles. APRNs offered advice on home environmental modification that helped ameliorate PLWDs’ symptoms. Also, women mentioned APRNs’ effective pharmacotherapy that streamlined medication regimen and achieved mood stabilization, decreasing depressive symptoms for PLWD.

Caregivers also appreciated APRNs' competence in the management of difficult conditions besides dementia. Situations where APRNs provided guidance included planning primary and cognitive care to accommodate for intensive cancer treatment for the PLWD and educating caregivers about ways in which cancer treatment may affect PLWD's cognition and quality of life.

Comparison of the IMCC care with mainstream healthcare. Although we directly asked caregivers to compare the IMCC healthcare to the care their PLWD had previously, such juxtapositions permeated the data as caregivers voluntarily contrasted the IMCC with mainstream healthcare. These data ran parallel to caregivers' accounts of how the IMCC was "one hundred percent different [compared to non-IMCC care]."

Caregivers expressed frustration with mainstream physicians' insufficient expertise in dementia, particularly in less prevalent dementias, and physicians' insisting on invasive diagnostic procedures despite palliative care goals. Caregivers also commented about previous pharmacotherapy mismanagement for PLWD: lacking explanation for medications and failure to pharmacologically stabilize PLWDs' mood.

Communication in mainstream healthcare was deemed suboptimal: "When I go to an outside physician . . . we're speaking different languages." The IMCC afforded an opposite experience: "When I go to the clinic . . . we speak the same language." Communication challenges with non-IMCC clinicians arose when other serious illnesses co-occurred with dementia (e.g., cancer). Caregivers reported how oncologists dismissed dementia because the PLWD "appeared fine." Additionally, caregivers noted how mainstream physicians avoided open-ended questions, believing this was done to shorten visits. This contrasted with caregivers' perception of adequate time during the IMCC visits. Likewise, caregivers perceived physicians' attitude towards caregivers' knowledge about dementia as condescending and expressed the sense of not being listened to. Caregivers also described their and their PLWDs' relationship with former clinicians as impersonal.

Ways to enhance the IMCC. Nine caregivers offered suggestions for improvement, and three participants stated that they had no such suggestions. These recommendations could be divided into two categories: enhancement of the variety and quality of resources at the clinic and improvement of care processes. Here we report caregivers' recommendations as they stated them without assessing feasibility of such requests.

Requests for resources encompassed medical and non-medical support. Some wishes stemmed from caregivers' finding non-IMCC resources on their own or from caregivers' past experiences, such as attending support groups and benefitting from a home visiting nurse. Caregivers wished to have all these "pieces of a puzzle" in one place – the IMCC. Hence, they recommended that the IMCC offer support groups, home visiting nurse, educational books for caregivers, transportation to the clinic, adult day care center at the clinic, help with applying for financial aid for PLWDs' care, and referrals to other clinicians (e.g., dentists who work with PLWD).

Emphasizing the dual role of the IMCC as the primary care and the memory care clinic, caregivers wanted to receive regular information on geriatric concerns (e.g., gait problems) and strategies to manage PLWDs' neuropsychiatric symptoms in the absence of external support (e.g., PLWDs' apathy when not in the adult day care center). Caregivers also wanted the IMCC to be "the best" in everything that concerns dementia, offering the best support groups and providing their expert opinion on adult day care centers in the area, rather than simply printing a list of such services from the internet – something that caregivers could locate themselves.

Specifically, caregivers were interested in adult day care centers that offer stimulating activities for PLWD. Caregivers also voiced their expectations (not concerns). Caregivers expected the clinic to continue maintaining PLWDs' quality of life, collaborate with other departments (e.g., palliative care), and continue effective pharmacotherapy.

Male and female participants had different views on resources. Men made a few suggestions: increasing opportunities for PLWDs' participation in clinical trials and offering updates on dementia research. Men mostly praised the resources at the clinic. But women's discourse was grounded in the viewpoint of what was lacking. For example, no women attended the Savvy Caregiver class, but they voiced their disappointment that they had not been notified earlier about it, that it was offered at an inconvenient time (weekday evening), and that it was not offered on-line.

Requests for the enhancement of care processes concerned overall care organization, physician involvement, and management of conditions besides dementia. Improvement of overall care organization included clarifying the IMCC scope of practice, responding to caregivers' calls and messages, and completing all follow-up requests in a timely manner. The scope of practice of the clinic remained unclear for several caregivers. The reasons why caregivers remained uncertain about it included uncertainty about what the clinic does because "there's nothing you can really do for Alzheimer's." The reasons for caregivers' uncertainty also included disappointment that occurred because referrals (done by non-IMCC healthcare professionals) to the clinic were sometimes accompanied by erroneous promises that the IMCC would address all healthcare for PLWD. Such inaccurately stated promises, likely meaning that all of primary healthcare would be done at the IMCC, led to caregivers' discouragement when APRNs referred

PLWD to specialists. Caregivers recommended that the clinic offer an in-person and/or on-line orientation to the clinic shortly upon enrollment.

Similar to the request to improve overall care organization was the request to enhance timeliness and thoroughness of follow-up and accuracy of completion of all steps in care. Although many caregivers praised the efficient care organization at the IMCC with prompt responses to questions, several women wanted faster follow-up. Also, caregivers indicated the need to improve thoroughness with which all steps in the care processes were completed. A few caregivers described their need to check and intervene – to assume more responsibility than they originally planned for tasks that they expected the clinic would fully address. This included ensuring that a correct laboratory analysis was drawn and making multiple calls to get answers from an APRN. Thus, several women were disappointed that they could not rely on the clinic for accurate and timely completion of all care steps (e.g., completing follow-up to specialists).

Multiple concerns fell into a pattern that could be described as caregivers' disappointment and stress arising from their unanticipated need to become more knowledgeable about and more involved in their PLWDs' medical management. This need to be more "in charge" of their PLWD's medical care was disconcerting because most caregivers lacked healthcare background. Even if they identified themselves as nurses, they were still displeased with their need to closely monitor accurate completion of all care steps. Thus, caregivers sensed that not all issues are being quickly resolved, yet they did not know what had to be done. Situations of greater uncertainty and less control over their PLWD's healthcare were anxiety-provoking to caregivers, making them question APRNs' competence and whether they themselves had to assume more responsibility. Potentially, as a way to ensure greater control over PLWDs' medical care and relieving caregivers from the need to assume greater control over their PLWDs' care, several caregivers requested a physician's engagement in care. Caregivers expressed their concerns about physicians' prompt availability in case of complications. Participants asked when the clinic medical director would see the PLWD. Caregivers were confused why the medical director never saw PLWD if he co-signed orders and prescriptions. Such absence of the physician was deemed especially problematic when PLWD had complex and rare comorbidities.

Additionally, management of conditions besides dementia evoked doubts for a few caregivers. Caregivers expressed concerns about lacking progress at the IMCC in finding an efficacious treatment for PLWDs' conditions (e.g., arthritis). Lacking solution to a problem was especially anxiety-provoking for caregivers because PLWD could not precisely communicate their symptoms and needs. Similar to caregivers' wish for a physician's involvement as, possibly, a way to alleviate caregivers' doubts, was caregivers' bafflement with the succession of unsuccessful attempts to address their PLWD's musculoskeletal pain, without finding an efficacious treatment. This impasse was troublesome for caregivers because PLWDs' pain continued, but caregivers could not track treatments that were tried but were unsuccessful and still remaining treatment options. This stalemate with finding treatment for a non-dementia condition was anxiety-provoking to caregivers because they sensed lacking control over the a condition that was painful to the PLWD. This made caregivers doubt the APRN's ability to manage this issue. This confusion was similar to caregivers' need to be more proactive than they expected to get answers from APRNs and ensure accurate completion of all care steps. A similar concern was about the need to make in-person appointments only for medication re-fills, necessitating burdensome preparation and commutes for PLWD and time expenditure for caregivers.

We noted a trend in participants' experiences relative to the duration of their caregiving experience. For example, caregivers who appeared generally less satisfied with the clinic and offered numerous suggestions for its improvement had been caregivers between one and four years. By contrast, participants who were caregivers for 9-12 years conveyed an overall tone of satisfaction and thankfulness for the clinic with only few suggestions for improvement. This trend had exceptions, however, since several caregivers with substantial experience voiced concerns.

Caregivers' concerns for the present and the future indirectly highlighted how the IMCC might be improved. Women expressed more concerns about the present than did men. Caregivers' concerns for the present were related to the PLWDs' memory deterioration, more precipitous cognitive decline than caregivers anticipated, mood and sleep disturbances, behavioral and psychological symptoms of dementia, and health problems besides dementia. Concerns for the future signified areas that were troublesome to caregivers. Only three women spoke about concerns for the future. But they adamantly conveyed their anxiety, indicating that having even a bit more concrete information about dementia progression in the next months would help them plan, including making financial arrangements. Dementia thwarted caregivers' planning ability, bringing much anxiety about the future: "it is the unknown that is worrisome."

Atypical case. The woman whose interview represented the atypical case was very dissatisfied with the clinic overall. She deemed her husband's previous healthcare superior to the IMCC healthcare. She was disappointed with lacking APRN's follow-up and not making necessary referrals to specialists for her PLWD's multiple comorbidities after the first visit. After changing to a different APRN, this participant's opinion improved, but still she was undecided about staying at the clinic. The woman mentioned inadequate signage about the IMCC location in the building, which signified to her that the administration did not value this clinic. This caregiver stated that the clinic was named misleadingly, that it did not offer dementia care, but rather primary care for PLWD. In this remark she was similar to another woman who thought that nothing could be done for dementia, questioning what the clinic accomplished. Despite being overall mostly dissatisfied with the IMCC, this caregiver nonetheless mentioned several positive aspects of the clinic. Perceived strengths of the IMCC, according to this caregiver, were thoroughness of staff' explanations about medications, APRNs' interpersonal skills, and APRNs allowing for private conversation with PLWD without the caregiver present.

Discussion and Implications

This study adds to the literature on physician-led (Boustani et al., 2011; LaMantia et al., 2015; Verghese et al., 2016) and nurse-led dementia care programs (Barton et al., 2014; Tappen & Valentine, 2014). The findings enrich understanding of caregivers' experiences in such programs beyond caregivers' satisfaction and feedback reported in analogous programs (Fortinsky et al., 2014; Noel et al., 2017; Reuben et al., 2013). A major takeaway from caregivers' narratives is their experience of unique care at the IMCC. The IMCC has many opportunities for improvement, but it offers needed help in a way that is unprecedented to most caregivers. This care was achieved because the IMCC attained the goal of the Institute of Medicine for quality care — patient-centeredness (Institute of Medicine, 2001), partnering with PLWD-caregiver dyads in care provision. Patient-centeredness, manifested by attention towards the whole person ("holistic" approach) and engagement of clients in their care, is one of the defining characteristics of a patient-centered medical home (Agency for Healthcare Research and Quality, n. d.), confirming that the IMCC fulfills its mission (Clevenger et al., 2018).

Caregivers' accounts of what constitutes patient-centeredness in this study yields implications for the IMCC and other healthcare organizations that provide dementia care. The notion of caregivers’ sense of belonging to the IMCC is, to our best knowledge, unprecedented among dementia care programs. Potentially, it has not been reported in other accounts of American dementia care programs due to lacking qualitative explorations of caregivers’ experiences there, to our best knowledge. The idea of co-production of care (Realpe, Wallace, Adams, & Kidd, 2015) is close to the concept of the sense of belonging to the care team. It is especially important to recognize caregivers as clinicians (Hepburn, Kovaleva, & Clevenger, 2018) whose contributions are vital to formal dementia care and overall healthcare for PLWD. Incorporating caregivers into the care team is similar to the principle held at the Louis and Anne Green Memory and Wellness Center: PLWD and caregivers as experts in their lives and staff aim to build partnership relationships with clients (Hain, Dunn, & Tappen, 2011).

The concept of time was represented prominently in caregivers’ narratives. Minimal waiting before visits and sufficient time for the visits is essential. Minimized wait time is consistent with the patient-centered medical home design principles (Agency for Healthcare Research and Quality, n. d.). Other dementia care programs likewise emphasized time management. For example, facing constrictions that limited business hours and clinic space allowed for in-person clinic visits, the Healthy Aging Brain Care investigators developed the Aging Brain Care Medical Home, a mobile clinic where care coordinator assistants make home visits to clients (Callahan et al., 2011). Similarly, investigators of a telehealth-based dementia care program for Veterans reported on Veterans’ time saved commuting (Powers, Homer, Morone, Edmonds, & Rossi, 2017).

Unhindered care access to APRNs during and after business hours was one of the most notable and meaningful aspects of the IMCC for caregivers. Enhanced care access is one of the defining characteristics of the IMCC (Agency for Healthcare Research and Quality, n. d.).

Potentially, the benefit of this service is in the reduction of caregivers' sense of isolation – a common phenomenon among caregivers (Kovaleva, Spangler, Clevenger, & Hepburn, 2018). Although telephone access to an APRN is not meant for social support, it may provide support by alleviating caregivers' anxiety about the unpredictable changes in their PLWD's condition. Dementia care has been described as fraught with uncertainty and a "labyrinth," (Samsi & Manthorpe, 2014, p. 2055). Knowledge that an APRN could answer caregiver's questions at any time of the day year-round may partially alleviate such anxiety. Perhaps, such availability of a reliable, competent clinician somewhat compensates caregivers' social isolation because this APRN almost plays the role of a "surrogate family member" who is always available and provides competent care.

Additionally, auxiliary services in this clinic added to enhanced access, eliminating clients' need to commute to multiple places for various aspects of healthcare (e.g., laboratory, neuropsychological testing). This attribute is provided by a larger healthcare organization that houses the IMCC. Hence, potentially, solo practices without organizational endowment may be unable to provide for such services and may need to plan for them in the clinic design.

Availability of resources, including information, remain a big issue for caregivers. Although the caregivers appreciated the IMCC resources, they offered many suggestions for expanding the resources, indicating that their needs are still far from met (Jennings et al., 2015). The need for resources runs parallel to caregivers' appreciation of care access because it highlights that dementia care simply cannot be addressed via traditional in-person office encounters. Care happens during the visit, where it is critical to dedicate sufficient time to the visit. Care also happens when caregivers call the clinic or APRN on duty, when they attend the Savvy Caregiver class, and when the clinic coordinates care with other departments. The IMCC demonstrates how the very definition of care is expanded beyond traditional in-person encounters. This “spilling over” notion beyond the boundaries of an office visit is reflected in accounts of geriatricians in Germany who describe their work as a “Herculean task” due to the amount of clinical and non-clinical tasks required to provide quality care (Herzog, Gaertner, Scheidt-Nave, & Hozhausen, 2015, p.1).

Provision of informational resources (Savvy Caregiver and late-stage dementia classes) is consistent with activities that other dementia care programs do (Boustani et al., 2011; Noel et al., 2017; Reuben et al., 2013). Other programs offer more services, including counseling (Chodosh et al., 2015), psychoeducational intervention where caregivers may select topics of interest (Mavandadi, Wright, Graydon, Oslin, & Wray, 2017), support groups (Boustani et al., 2011), in-house driving evaluation for PLWD (Tappen & Valentine, 2014), and even provide caregivers with pharmacologic and non-pharmacologic prescriptions (Boustani et al., 2011). Even caregivers’ seemingly unrealistic request to provide an adult day care at the clinic is not impossible: Louis and Anne Green Memory and Wellness Center offers an adult day care center on site along with programs for caregivers (Tappen & Valentine, 2014). Thus, caregivers’ requests for a wider variety of resources that the IMCC could offer are not unreasonable, but would require extra workforce and financing. Caregivers’ requests for more resources are also similar to those reported in other studies, such as the need for home healthcare (Verghese et al., 2016). Caregivers’ willingness to attend the Savvy Caregiver class and to have an orientation to the clinic on-line rather than in-person is understandable due to time constraints. The University of California Alzheimer’s Disease Center (UCLA ADC) offers web-based education to caregivers (Tan, Jennings, & Reuben, 2014). Hence, the IMCC may offer these resources on-line in the future.

Care coordination is also one of the defining features of a patient-centered medical home (Agency for Healthcare Research and Quality, n. d.). Caregivers’ accounts demonstrated that the clinic personnel coordinated care, including with hospital and assisted living staff. Informing hospital staff about the PLWD’s condition prior to the PLWD’s admission exemplifies coordination of transitions between care settings. A potential opportunity to improve care coordination for the IMCC is to more actively coordinate care with community agencies. Traditionally, care coordination between medical and community services has been scarce (Tan et al., 2014). With caregivers’ suggestions to enrich the IMCC resources, a possible next compromising step is to strengthen partnerships with community agencies as is done at the UCLA ADC (Reuben et al., 2013), before the IMCC can offer more own resources. Thus, following one recommendation to provide expert opinion on adult day care centers, the IMCC could partner with adult day care centers that may be particularly beneficial for PLWD.

To our best knowledge, the IMCC is the only U.S. dementia care program where primary care and dementia care are provided simultaneously. This attribute is important given the high comorbidity burden observed in this sample: an average of seven chronic conditions besides dementia. APRNs’ expertise in primary care was recognized in caregivers’ accounts of how their questions about non-dementia concerns are answered and how their primary reason to transfer to the IMCC was to have an unhindered telephone access to an APRN who may help with concerns besides dementia. Potentially, worsening communicative ability in PLWD with dementia progression (Klimova, Marseova, Valis, Hort, & Kuca, 2015) makes it especially difficult to manage conditions besides dementia. PLWD may be unable to communicate their needs (Hughes, Lloyd-Williams, & Sachs, 2010) and symptoms, amplifying the caregivers’ need to be attuned to their PLWDs.

Caregivers’ concerns about the future extend the notion of uncertainty as a determinant of stress and anxiety (Grupe & Nitschke, 2013). Caregivers’ desire to know about dementia progression and what they may do to prepare for the future may mitigate concerns about the future. The findings here are consistent PLWDs’ own decision trajectories. Such decisions focus on typical dementia progression, daily life management, planning for support, and preparing for the future (Groen-van de Ven et al., 2017). Hence, caregivers’ concerns about the future in this study are similar to PLWDs’ concerns about their own future. Dementia care programs may dedicate time and resources to such discussions about the future, since possibly caregivers may not initiate these conversations unless asked or may erroneously believe that no future planning whatsoever is possible with dementia.

Caregivers’ differences in their overall evaluation of the clinic – more appreciative or more critical – could depend on caregivers’ gender and experience with caregiving. Specifically, women tend to score higher on neuroticism, which may manifest as anxiety (Weisberg, DeYoung, & Hirsh, 2011). Hence, clinicians may anticipate such anxious outlook from women and spend more time discussing their anxiety, stress, and fears. Here only women spoke about future concerns and their wish for a clearer understanding of dementia progression. This, however, does not mean that men do not suffer from uncertainty, but rather they may not express their anxiety as adamantly. Thus, all caregivers may benefit from clinicians initiating conversations about future planning.

Caregivers’ confusion about the scope of practice of the clinic and their belief that nothing can be done for dementia provide an essential practice implication: caregivers must be educated about what the clinic does and what can and cannot be done about dementia. Potentially, caregivers may not realize that while dementia is incurable, behavioral and psychological symptoms of dementia are manageable pharmacologically and non-pharmacologically. Nurses may educate caregivers about many environmental modifications they can make to manage dementia symptoms non-pharmacologically (Desai, Schwartz, & Grossberg, 2012). The theory of patient expectations (Laferton, Kube, Salzmann, Auer, & Shedden-Mora, 2017) may be relevant to caregivers' perception that dementia and non-dementia issues are managed insufficiently. Clarifying caregivers' expectations at the time of their enrollment – via an in-person or web-based tour of the clinic – may prevent such disappointment and equip caregivers with knowledge and skills about what *can* be done for dementia and other conditions.

Overall, caregivers' recounts of their experience of the IMCC consist with concepts of patients' expectations regarding medical treatment (Laferton et al., 2017). Specifically, patients typically have expectations from treatments and treatment-related behavior (Laferton et al., 2017). Here, caregivers commented on successful treatments, such as mood stabilization for PLWD, with consequent treatment-related behavior – improved mood for PLWD. Likewise, caregivers described unsuccessful treatments, such as inability to manage musculoskeletal pain for PLWD, with consequent treatment-related behavior – PLWD's continued manifestation of pain and caregiver's unease about this. Additionally, patients have process or structural expectations (Laferton et al., 2017). For example, several caregivers' request for a physician's involvement in care represents, most likely, their preexistent expectation about care process: a physician *must* be involved in care. Additionally, the common sense model of illness representation (Leventhal, Meyer, & Nerenz, 1980) helps to understand caregivers' presupposition that nothing can be done for dementia. Specifically, according to this model, individuals have subjective understanding of the illness (Petrie & Weinman, 2012). Individuals have perceptions about how illness may be managed by the person or by medical treatment (Cameron & Leventhal, 2003). Hence, caregivers' experience of the IMCC is likely shaped not purely by the IMCC success or lack thereof, but rather by the IMCC work in connection to caregivers' preexistent expectations. Understanding caregivers' beliefs about dementia by clarifying them at the outset and regularly gauging caregivers' expectations throughout disease management may be helpful to caregivers. For example, for clinicians it may be "common sense" that certain dementia symptoms are subject to control and may markedly improve PLWD's quality of life (e.g., decreasing PLWD's depression). Unless this is stated clearly, caregivers may continue to suffer from anxiety and false sense that they are not doing "enough," or believe that the clinic is not addressing anything.

Beyond clarifying expectations at the outset, it is important to regularly gauge caregivers' expectations during the course of disease management. This way, clinicians may either close the gap and better meet caregivers' expectations or admit that some expectations may not be met. Such ongoing evaluation of caregivers' expectations and corresponding performance of the clinic is consistent with the theoretical framework of a complex adaptive system that regularly evaluates its own progress and adjusts its workflow processes based on performance and program goals (Boustani, Alder, & Solid, 2018). Additionally, clarifying caregivers' expectations and explaining what is and is not modifiable in dementia course may decrease caregivers' sense of uncertainty, lacking control, and anxiety. Overall, it appeared that anything that made the situation less under caregiver's control (e.g., when no successful treatment for PLWD's pain was found, when insufficient resources were offered from caregivers' perspective), created for more anxiety and distress for caregivers. Thus, maximally streamlining, organizing, and simplifying care may be an antidote to uncertainty that characterizes dementia (Samsi & Manthorpe, 2014).

Supplying caregivers with strategies that they can implement may increase their self-efficacy. Self-efficacy and behavior outcome expectations are essential for volitional agentic activity (Bandura, 2001), which implies that caregivers may increase their sense of meaningful contribution if their expectations are clarified shortly upon the clinic enrollment and are continually assessed during disease management.

Caregivers testified about their satisfaction with improved pharmacotherapy for their PLWD that occurred at the clinic. Although only a few caregivers mentioned improved medication management at the clinic, this is an important finding. It contrasts with a larger examination of the quality of care rendered by the UCLA ADC where physicians partner with APRNs. At the UCLA ADC a wide variability in the treatment of dementia, including pharmacological treatment, was found. Specifically, while quality of care in the domains of counselling and assessments was high, it was considerably more inconsistent and poorer in the treatment domain that included pharmacological management (Jennings et al., 2016). It is impossible to evaluate the quality of treatment, including pharmacological management at the IMCC, based on a few caregivers' statements, but nonetheless this is an encouraging finding. The next step would be to conduct an evaluation of similar rigor as described by Jennings and colleagues (2016). Care quality at the IMCC could be assessed against dementia care quality indicators, such as the Assessing Care of Vulnerable Elders measurement set (Wenger, Roth, & Shekelle, 2007) and measurement developed by the Physician Consortium for Performance Improvement (American Medical Association, 2011). Furthermore, care quality may be evaluated in a randomized controlled trial that would enable to elucidate whether any positive outcomes for clients may indeed be attributed to the IMCC.

Non-clinical staff play an important role in families' experience. Caregivers' attention to workers besides APRNs, specifically the patient access coordinator, highlights the importance of non-provider staff in making the clinic work. The implication for other dementia care programs is to hire staff who are highly communicative, conscientious, reliable, and follow-up on families' questions and concerns. Since the patient access coordinator served as the "face" and the "voice" of the clinic when clients arrived for the visit and called during business hours, it is essential that an employee in this position does everything possible to create a positive, seamless experience for clients who are likely highly stressed and may indeed experience dementia care nothing short of a "labyrinth," (Samsi & Mathorpe, 2014, p.2055). Additionally, the fact that often caregivers referred to all staff as "they," signifies that regardless of their position in the team, clients perceived that the personnel had a shared mission of helping PLWDs and caregivers. Potentially, all employees put a united front, making certain that whomever the clients approached, they would be welcomed at the IMCC. The implication from this finding is that it is essential to hire all employees of a dementia care program who, regardless their credentials, are committed to delighting their clients. It is essential that these employees understand that a dementia care clinic is likely a place where clients may arrive having had much difficulty with healthcare and social services beforehand due to suboptimal performance of mainstream primary care for PLWD (Borson & Chodosh, 2014).

Limitations

This study has limitations. All interviews were conducted via telephone, affording greater flexibility to the PI and participants while trading-off the ability to appreciate visual and non-verbal cues, and environmental data (e.g., the person's appearance, living environment) (Novick, 2008). Use of silence and topics respondents may purposefully avoid (Ryan & Bernard, 2003) is likely lost with telephone interviewing because silence is difficult to assess on the telephone. Silences have to be "tolerated and assessed so that the interviewer could act appropriately," (Tausig & Freeman, 1988, p.424).

Sampling purposefully, although desirable, was not feasible. Convenience sampling yields information-poor cases (Patton, 2002). This, in combination with the telephone interviews, may have minimized the richness of data common in qualitative work. Convenience sampling limits generalizability of the findings (Polit & Beck, 2010). Additionally, the IMCC is under the jurisdiction of an urban academic center, not a safety-net healthcare system as the Aging Brain Care Medical Home (LaMantia et al., 2015) or a solo practice serving predominantly rural clients (Noel et al., 2017). Findings, therefore, may not pertain to caregivers with fewer financial resources.

Familiarity with the clinic may have predisposed the PI to gravitate to data that reinforced her expectations based on her IMCC observations and diminished her attention to data that may have run contrary to her ideas about the IMCC. This limitation, however, was counteracted partially by the last author who was minimally knowledgeable about the clinic and challenged data interpretations.

Conclusion

The findings from this study illuminate the experiences of caregivers within a nurse-led dementia patient-centered medical home. Accounts of these experiences and caregivers' suggestions for care improvement may be used by the IMCC and analogous dementia care programs. Overall, the findings show that programs such as the IMCC fill an important need.

That caregivers offered numerous suggestions for improvement speaks to the many needs that remain unmet for this population. The IMCC does not address every need of its clients, but it offers help. The fact that caregivers were mostly satisfied with this dementia care also speaks to APRNs' competence to deliver such care to the growing population of PLWD and their caregivers. Multiple remaining unmet needs for PLWD, both in medical and social domains, represent the field of serving PLWD as a growing area for jobs in healthcare and social sectors. With the projected increase of the population of PLWD in the next several decades in the U.S. (Alzheimer's Association, 2018), it is important that more dementia care programs become available. Potentially, APRNs may serve as leaders of programs similar to the IMCC, to contribute to closing the gap between the current supply of dementia care specialists and demand for them. These programs may centralize more services in medical and non-medical domains, streamlining care. Dementia brings much uncertainty into the lives of PLWD and caregivers (Samsi & Manthorpe, 2014), hence, programs such as the IMCC that offer streamlined, centralized care may at least partially alleviate caregivers' and PLWDs' suffering and enhance these individuals' quality of life notwithstanding terminal illness.

References

Agency for Healthcare Research and Quality. (n. d.). Defining the PCMH. Retrieved from https://pcmh.ahrq.gov/page/defining-pcmh

Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 14*(3), 367-429. doi: https://doi.org/10.1016/j.jalz.2018.02.001

Alfakhri, A. S., Alshudukhi, A. W., Alqahtani, A. A., Alhumaid, A. M., Alhathlol, O. A., Almojali, A. I., . . . Alaqeel, M. K. (2018). Depression among caregivers of patients with dementia. *Inquiry.* Advance on-line publication. doi: 10.1177/0046958017750432

American Medical Association. (2011). Physician Consortium for Performance Improvement (PCPI): dementia performance measurement set. Retrieved from http://neurofoundation.net/globals/axon/assets/9493.pdf

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology, 52*, 1-26.

Barton, C., Merrilees, J., Ketelle, R., Wilkins, S., & Miller, B. (2014). Implementation of advanced practice nurse clinic for management of behavioral symptoms in dementia: A dyadic intervention (innovative practice). *Dementia, 13*(5), 686-696. doi: 10.1177/1471301213519895

Bayer, A., Richards, V., & Phillips, G. (1990). The community memory project: A multi-disciplinary approach to patients with forgetfulness and early dementia. *Care of the Elderly, 2,* 236-238.

Borson, S., & Chodosh, J. (2014). Developing dementia-capable healthcare systems. *Clinics in Geriatric Medicine, 30*(3), 395-420. doi: 10.1016/j.cger.2014.05.001

Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M., . . . Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health, 15*(1), 13-22. doi: 10.1080/13607863.2010.49644

Boustani, M., Alder, C. A., & Solid, C. A. (2018). Agile Implementation: A blueprint for implementing evidence-based healthcare solutions. *Journal of the American Geriatrics Society, 66*(7), 1372-1376. doi: 10.1111/jgs.15283

Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, J., . . . Hendrie, H. C. (2006). Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: A randomized controlled trial. *JAMA, 295*(18), 2148-2157. doi: 10.1001/jama.295.18.2148

Cameron, L. D., & Leventhal, H. (Eds.). (2003). *The Self-Regulation of Health and Illness Behavior*. New York, NY: Routledge

Chodosh, J., Colaiaco, B. A., Connor, K. I., Cope, D. W., Liu, H., Ganz, D. A., . . . Vickrey, B. G. (2015). Dementia care management in an underserved community: The comparative effectiveness of two different approaches. *Journal of Aging & Health, 27*(5), 864-893. doi: 10.1177/0898264315569454

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Current Psychiatry Reports, 14*(4), 298-309. doi: 10.1007/s11920-012-0288-5

Dreier-Wolfgramm, A., Michalowsky, B., Austrom, M. G., van der Marck, M. A., Illiffe, S., Alder, C., . . . Hoffmann, W. (2017). Dementia care management in primary care: Current collaborative care models and the case for interprofessional education. *Zeitschrift für Gerontologie und Geriatrie, 50*(Suppl 2), 68-77. doi: 10.1007/s00391-017-1220-8

Fonareva, I., & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics, 26*(5), 725-747. doi: 10.1017/S1041610214000039

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J . . . Crumb, S. (2014). Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Research in Gerontological Nursing, 7*(3), 126-137. doi:10.3928/19404921-20140113-01

Friedman, E. M., Shih, R. A., Langa, K. M., & Hurd, M. D. (2015). U.S. prevalence and predictors of informal caregiving for dementia. *Health Affairs*, *34*(10), 1637-1641. doi: 10.1377/hlthaff.2015.0510

Groen-van de Ven, L., Smits, C., Oldewarris, K., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2017). Decision trajectories in dementia care networks: Decisions and related key events. *Research on Aging, 39*(9), 1039-1071. doi: 10.1177/0164027516656741

Grupe, D. W., & Nitschke, J. B. (2013). Uncertainty and anticipation in anxiety: An integrated neurobiological and psychological perspective. *Nature Reviews. Neuroscience, 14*(7), 488-501. doi: 10.1038/nrn3524

Hepburn, K., Lewis, M., Tornatore, J., Sherman, C. W., & Bremer, K. L. (2007). The Savvy Caregiver Program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing, 33*(3), 30-36. doi:10.1093/geront/43.6.908

Hepburn, K., Kovaleva, M., & Clevenger, C. (2018). (2018). Educational programs for informal dementia caregivers. In G.E. Smith (Ed.). *APA Handbook of Dementia* (chapter 31). American Psychological Association: Washington, D. C.

Herzog, A., Gaertner, B., Scheidt-Nave, C., & Holzhausen, M. (2015). "We can do only what we have the means for" general practitioners' views of primary care for older people with complex health problems. *BMC Family Practice, 16*, 35. doi: 10.1186/s12875-015-0249-2

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. doi: 10.1177/1049732305276687

Hughes, J., Lloyd-Williams, M., & Sachs, G. (Eds.). (2010). *Supportive care for the person with dementia.* USA: Oxford University Press.

Institute of Medicine. (2001). Crossing the quality chasm: A new health system for the 21st century. Retrieved from http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf

Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., . . . Wenger, N. S. (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of the American Geriatrics Society, 63*(2), 282-289. doi: 10.1111/jgs.13251

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., . . . Reuben, D. B. (2016). Quality of care provided by a comprehensive dementia co-management program. *Journal of the American Geriatrics Society, 64*(8), 1724-1730. doi: 10.1111/jgs.14251

Jolley, D., & Moniz-Cook, E. (2009). Memory clinics in context. *Indian Journal of Psychiatry, 51,* Suppl 1, S70-76.

King, N., & Horrocks, C. (2010). Interviews in qualitative research. London, UK: SAGE Publications Ltd.

Klimova, B., Maresova, P., Valis, M., Hort, J., & Kuca, K. (2015). Alzheimer's disease and language impairments: Social intervention and medical treatment. *Clinical Interventions in Aging, 10,* 1401-1407. doi: 10.2147/CIA.S89714

Kovaleva, M. A., Spangler, S. A., Clevenger, C., & Hepburn, K. (2018). Chronic stress, social isolation, and perceived loneliness among dementia caregivers. *Journal of Psychosocial Nursing and Mental Health Services*, *56*(10), 36-43. doi: 10.3928/02793695-20180329-04

Laferton, J. A., Kube, T., Salzmann, S., Auer, C. J., & Shedden-Mora, M. C. (2017). Patients' expectations regarding medical treatment: A critical review of concepts and their assessment. *Frontiers in Psychology*, *8*, 233. doi: 10.3389/fpsyg.2017.00233

LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G., . . . Boustani, M. A. (2015). The Aging Brain Care Medical Home: Preliminary data. *Journal of the American Geriatrics Society, 63*(6), 1209-1213. doi:10.1111/jgs.13447

Leventhal, H., Meyer, D., & Nerenz, D. R. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to Medical Psychology* (pp.17-30). New York, NY: Pergamon Press.

Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15* (6), 1534-1561. doi: 10.1177/1471301214564792

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *Lancet, 358,* 9280, 483-488. doi:10.1016/s0140-6736(01)05627-6

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia. *Psychological Services*, *14*(1), 102-111. doi: 10.1037/ser0000118

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook.* Thousand Oaks, CA: Sage Publications.

Morse, J. (1991). *Qualitative nursing research: A contemporary dialogue.* Thousand Oaks, CA: Sage Publications.

Nikmat, A. W., Al-Mashoor, S. H., & Hashim, N. A. (2015). Quality of life in people with cognitive impairment: Nursing homes versus home care. *International Psychogeriatrics, 27*(5), 815-824. doi: 10.1017/S1041610214002609

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality dementia care. *Journal of the Applied Gerontology, 36*(2), 195-212. doi: 10.1177/0733464815589986

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health, 31*(4), 391-398. doi: 10.1002/nur.20259

Patton, M.Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Petrie, K. J., & Weinman, J. (2012). Patients’ perceptions of their illness the dynamo of volition in health care. *Current Directions in Psychological Science, 21*, 60–65.

doi: 10.1177/0963721411429456

Poland, B. (1995). Transcription quality as an aspect of rigor in qualitative research. *Qualitative Inquiry, 1,* 290-310.

Polit, D. F., & Beck, C.T. (2010). *Essentials of nursing research: Appraising evidence for nursing practice* (7th Ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Powers, B. P., Homer, M. C., Morone, N., Edmonds, N., & Rossi, M. I. (2017). Creation of an interprofessional teledementia clinic for rural veterans: Preliminary data. *Journal of the American Geriatrics Society, 65*(5), 1092-1099. doi: 10.1111/jgs.14839

Realpe, A. X., Wallace, L. M., Adams, A. E., & Kidd, J. M. (2015). The development of a prototype measure of the co-production of health in routine consultations for people with long-term conditions. *Patient Education and Counseling.* Advance on-line publication. doi: 10.1016/j.pec.2015.07.005.

Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society, 61*(12), 2214-2218. doi: 10.1111/jgs.12562

Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods, 15*(1), 85-109. doi: 10.1177/1525822x02239569

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Thousand Oaks, CA: SAGE Publications Inc.

Samsi, K., & Manthorpe, J. (2014). Care pathways for dementia: Current perspectives. *Clinical*

Interventions in Aging, 9, 2055-2063. doi: 10.2147/CIA.S70628

Sandelowski, M., Holditch Davis, D., & Harris, B. G. (1989). Artful design: Writing the proposal for research in the naturalist paradigm. *Research in Nursing & Health, 12*, 77-84. doi: 10.1002/nur.4770120204

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334-340. doi: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

Tan, Z. S., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large, academic health system. *Health Affairs, 33*(4), 619-625. doi: 10.1377/hlthaff.2013.1294

Tappen, R. M., & Valentine, K. (2014). Building and sustaining a caring-based nurse-managed center. *Pennsylvania Nurse, 69*(2), 16-21.

Tatangelo, G., McCabe, M., Macleod, A., & Konis, A. (2018). I just can’t please them all and stay sane: Adult child caregivers’ experiences of family dynamics in care-giving for a parent with dementia in Australia. *Health & Social Care in the Community, 26*(3), e370-e377. doi: 10.1111/hsc.12534

Tausig, J.E., & Freeman, E.W. (1988). The next best thing to being there: Conducting the clinical research interview by telephone. *American Journal of Orthopsychiatry*, *58,* 418–427.

Verghese, J., Malik, R., & Zwerling, J. (2016). Montefiore-Einstein Center for the Aging Brain: Preliminary data. *Journal of the American Geriatrics Society, 64*(11), 2374-2377. doi: 10.1111/jgs.14473

Wall, C., Glenn, S., Mitchinson, S., & Poole, H. (2004). Using a reflective diary to develop bracketing skills during a phenomenological investigation. *Nurse Researcher*, *11*(4), 20-29.

Weisberg, Y. J., DeYoung, C. G., & Hirsh, J. B. (2011). Gender differences in personality across the Ten Aspects of the Big Five. *Frontiers in Psychology, 2*, 178. doi: 10.3389/fpsyg.2011.00178

Wenger, N. S., Roth, C. P., & Shekelle, P. (2007). Introduction to the assessing care of vulnerable elders-3 quality indicator measurement set. *Journal of the American Geriatrics Society, 55 Suppl 2,* S247-252.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655. doi:10.1093/geront/20.6.649

Table 1

Characteristics of Patient-centeredness at the Integrated Memory Care Clinic

Characteristic of patient-centeredness	Defining feature
Caregiver belonging to the healthcare team	The IMCC healthcare team recognizes the importance of caregivers and caregivers' contributions to their PLWDs' health.
Time	The clinic manages time well. Waiting/non-productive time is minimized. Sufficient time is dedicated to the visit. Clients never feel rushed during the visit.
Access	Care is not limited by the time constraints of an in-person visit. Caregiver has direct telephone access to the patient access coordinator during business hours and to an APRN after hours. Access to healthcare is simplified because other essential services (e.g., laboratory, neuropsychological testing) are located in the same building as the IMCC.
Interaction of time and access	When caregivers call the patient access coordinator or an APRN on duty, their calls are answered

	immediately or responded to in a timely manner. Care is accessible and caregivers get help quickly.
Informational resources	IMCC offers the Savvy Caregiver class and a class on late-stage dementia.
Care coordination/care continuity	APRNs update hospital staff on the PLWD’s condition if a PLWD is hospitalized. APRNs coordinate pharmacotherapy with the staff at the PLWD’s assisted living facility. APRNs refer PLWD to specialists.

Note. IMCC= Integrated Memory Care Clinic. PLWD = person living with dementia. APRN = advanced practice registered nurse.

Characteristics of Patient-centeredness at the Integrated Memory Care Clinic

Note. IMCC = Integrated Memory Care Clinic. PLWD = patient living with dementia. APRN = advanced practice registered nurse.

Conclusion

This dissertation study was undertaken to quantitatively and qualitatively explore the experiences of caregivers of persons living with dementia (PLWD) and PLWD, as reported by their caregivers, at the Integrated Memory Care Clinic (IMCC) at Emory University in the first year since clients' enrollment into the clinic. This section briefly summarizes the results of this dissertation study and points to possible future directions. In this section, the results are re-capped largely in the order of the dissertation sections (scoping review, quantitative section, and qualitative section), but connections between these sections are made when appropriate to present a cohesive conclusion.

The first section of this dissertation was a scoping review of the literature on the U.S. dementia care programs. This scoping review explored outpatient dementia care programs in the U.S. since 2011: how these programs are built and how they operate, what they accomplish, their similarities and differences, and knowledge gaps in research on dementia care programs. Such a broad overview of dementia care programs allows us to consider the IMCC in context with analogous programs. This scoping review allows us to conclude about the ways in which the IMCC is similar to and different from other American dementia care programs. Additionally, information gained from the scoping review allows us to see how the IMCC advances the field of dementia care programs and what knowledge gaps remain.

The scoping review enabled identification of several commonalities among the dementia care programs and the IMCC. The IMCC (Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018) is similar to other dementia care programs in several ways. Dementia care programs are frequently described as collaborative models, implying their use of interdisciplinary personnel (Geldmacher & Kerwin, 2013). IMCC is an interdisciplinary team comprised of advanced practice registered nurses (APRNs), a social worker, a registered nurse, and a patient access coordinator (Clevenger et al., 2018). All models described in the scoping review are interdisciplinary, pointing to the breadth of concerns and needs that PLWD and caregivers have: no single specialty can meet all concerns of their clients. This scope of concerns that caregivers and PLWD deal with is manifested by the fact that medical and nursing personnel do not meet all the needs of this population. Non-medical social concerns are essential too. These concerns require many resources for caregivers, such as help with advance care planning, education about dementia, counseling, and support. IMCC offers classes for caregivers, the Savvy Caregiver class (Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007) and a late-stage dementia class. Similar educational initiatives – although not in the form of a stand-alone evidence-based intervention – are offered by the Healthy Aging Brain Care program (Boustani et al., 2011), Aging Brain Care Medical Home (LaMantia et al., 2015), Partners in Dementia Care (Bass et al., 2015), Behavior Management Clinic (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014), and others. Only one program did not report on any interventions for caregivers, the Montefiore-Einstein Center for the Aging Brain (Verghese, Malik, & Zwerling, 2016).

The role of context in shaping the dementia care program became evident in the scoping review. Context includes resources that the program can rely upon and its population. For example, some programs operate under the jurisdiction of a larger healthcare organization that may sponsor the clinic space and electronic health records software (Boustani et al., 2011; Reuben et al., 2013). It is logical to assume that recruitment to a clinic that shares the brand name with a larger, known healthcare organization would be simpler than recruitment to a stand-alone clinic not affiliated with a larger health system. The IMCC is similar to the Healthy Aging Brain Care (Boustani et al., 2011) and the University of California Medical Center (Reuben et al., 2013) in that it operates within a larger healthcare system. Being a part of the Emory

Healthcare likely allows clients to associate the IMCC with one of the leading healthcare systems in the nation. In fact, in qualitative interviews caregivers revealed their high expectations from the IMCC, underscoring that they wish the IMCC to offer “the best” of each resource because it is a part of Emory Healthcare. As programs affiliated with a larger healthcare system, the IMCC uses the same electronic health records system as Emory Healthcare, and uses auxiliary services provided by the Brain Health Center where the IMCC is located: neuropsychological and laboratory services, free parking with valet services, and main lobby check-in. Such services would not be available in, for example, a solo practice that serves a rural population (Noel, Kaluzynski, & Templeton, 2017). Initiatives that are planning to start up a dementia care program need to account for these factors.

The IMCC differs from other dementia care programs in several major aspects. First, the IMCC adds to the minority of programs that are led by APRNs as opposed to physicians (Barton, Merrilees, Ketelle, Wilkins, & Miller, 2014; Tappen & Valentine, 2014). APRNs have the necessary expertise to provide primary care. This has been demonstrated by previous studies that found that APRNs’ performance is similar to that of physicians in a number of metrics, including satisfaction with care, health status, functional status, and number of emergency department visits and hospitalizations (Stanik-Hutt et al., 2013), quality of life, and mortality (McCleery, Christensen, Peterson, Humphrey, & Helfand, 2014).

Another major aspect in which the IMCC differs from other dementia care programs is that primary care and dementia care are provided in the IMCC simultaneously, by the same clinicians. The scoping review began after the principal investigator had done multiple preliminary, non-systematic literature reviews, where she found that no U.S. dementia care programs provided dementia care and primary care simultaneously. The same conclusion holds after the scoping review was conducted. In this way, the IMCC stands out from physician- and nurse-led memory care programs. Notably, primary care was mentioned in multiple programs in the context of the importance of collaboration between dementia care and primary care. Dementia care programs are built in outpatient settings and vary in their degree of collaboration with primary care, ranging from primary care physicians referring PLWD to a dementia care program (Noel et al., 2017) to physicians in the dementia care program consulting with primary care physicians on dementia care plans (Boustani et al., 2011). The Aging Brain Care Medical Home strove to maximally close the gap between dementia care and primary care, such that APRNs worked in the suite of offices of primary care physicians to facilitate dementia care and primary care (Callahan et al., 2011). Several programs conveyed dementia-specific care plans to primary care physicians (Barton et al., 2014; D’Souza, Davagnino, Hastings, Sloan, Kamholz, & Twersky, 2015; Mavandadi, Wright, Graydon, Oslin, & Wray, 2017). But no programs went as far as to offer primary care and dementia care by the same clinicians. This dissertation study cannot attribute positive PLWD and caregiver outcomes in the IMCC to the APRN leadership, since no comparison group was used. Nonetheless, it provides descriptive data on what the experience is like at the IMCC under the APRN leadership, further supporting the notion of APRNs’ competency and fit to render primary care and dementia care.

IMCC operates as a patient-centered medical home (Clevenger et al., 2018). According to the scoping review, only the Aging Brain Care Medical Home also operates as a patient-centered medical home. Thus, the IMCC differs from most dementia care programs in the principles of its design, since a patient-centered medical home is a concept of healthcare delivery model with its defining characteristics (Agency for Healthcare Research and Quality, n. d.). This designation is important because it implies certain aspects that the IMCC must encompass to comply with its definition of a patient-centered medical home: comprehensive care, patient-centeredness, coordinated care, accessible services, and quality and safety (Agency for Healthcare Research and Quality, n. d.). The ways in which the IMCC meets these defining characteristics is described elsewhere (Clevenger et al., 2018). The IMCC is a Level 3 patient-centered medical home, denoting the highest level of recognition given by the National Committee of Quality Assurance (NCQA) (Clevenger et al., 2018; NCQA, n. d.). Arguably, adherence to national recommendations is not only more labor-intensive for the personnel who run the dementia care program, but also makes this care program more standardized. Thus, the IMCC stands out from other dementia care programs in its adherence to the requirements of the patient-centered medical home certifying body.

The scoping review demonstrated that most dementia care programs reported on various parameters that characterize the work of the program from a clinical perspective – metrics that are traditionally used in the evaluation of healthcare programs and that convey productivity of programs. Such measures included the number of hospitalizations and emergency department visits that the clients made (Bass et al., 2015; Boustani et al., 2011; Chodosh et al., 2015); total number of clinic visits, home visits, and telephone or email contacts with clients (Boustani et al., 2011; LaMantia et al., 2015; Noel et al., 2017); adherence to dementia care quality indicators (Chodosh et al., 2015; D’Souza et al., 2015; Jennings et al., 2016); economic outcomes (Chodosh et al., 2015; French et al., 2014; Noel et al., 2017); and institutionalization rate (Choodosh et al., 2015; D’Souza et al., 2015; Noel et al., 2017). The IMCC also reported on similar outcomes, including clinical quality indicators for the management of comorbidities (e.g., hypertension, diabetes); and hospitalization and emergency department use rate (Clevenger et al., 2018). This dissertation, however, extends the exploration of the IMCC to the perspective of PLWD and caregivers. In this scoping review, it became evident that most programs reported outcomes that described the workflow of the model and its clinical outcomes stated above. Fewer programs reported on PLWD and caregiver outcomes. This dissertation aimed to better understand outcomes from consumers' perspective, as opposed to more frequently reported clinical productivity outcomes. Largely, the question that guided the dissertation was, "what is it like to be a client of the IMCC?"

In sum, the scoping review portrayed the field of the dementia care programs in the U.S. between 2011 and 2017. Comparing the IMCC to other programs, it is evident that the IMCC, under the APRN leadership, combines several strengths of previously reported programs and is unique in its simultaneous provision of primary care and dementia care. With the increasing population of PLWD in the next several decades in the U.S. (Alzheimer's Association, 2018), it is essential that more dementia care programs such as the IMCC become available. The scoping review demonstrates what attributes make for a viable program and it also demonstrates what outcomes may be studied in the future, ranging from clinical to PLWD- and caregiver-centered to economic outcomes. Potentially, assuming a more research-intensive approach may position such APRN-led dementia care programs as leaders in geriatric research and help secure funding that would enable their further growth. Clearly, the area of service to PLWD and caregivers is very far from being saturated. This scoping review reported on 14 programs that have been reported between 2011 and 2017, with nine of them operational and open to the public (five others have only been tested and there is no evidence that they have been implemented into practice beyond research phase). Given the projected increase of PLWD in the U.S. up to 16 million by 2050, 14 programs will never meet the increasing demand for dementia care delivered by collaborative programs. Due to such demand and difficulties of implementing such programs, including organizational and financial challenges (Callahan, Sachs, LaMantia, Unroe, Arling, & Boustani, 2014), APRNs are in the prime position to address this unmet need and serve as leaders who may tackle commonly encountered problems intrinsic to translation of evidence into practice (Callahan et al., 2014).

The quantitative section of this dissertation contributes to the literature by reporting on three PLWD-centered outcomes (severity of neuropsychiatric symptoms; quality of life; and cognitive, functional, and behavioral and mood symptoms, evaluated by the Healthy Aging Brain Care Monitor measure (Monahan et al., 2012)), and six caregiver-centered outcomes (stress, caregiver burden, depressive symptoms, anxiety, health status, distress relative to their PLWDs' neuropsychiatric symptoms). Since many of the previous studies reported on PLWD and caregiver satisfaction with the dementia care program (Fortinsky et al., 2014; Reuben et al., 2013), this dissertation broadens understanding of clients' experience in the setting of a dementia care program. Such broader exploration is important because it allows us to position the study of dementia care programs in context with commonly reported outcomes in geriatric and caregiving research. For example, measures that are commonly represented in dementia caregiving research (Belle et al., 2006; Griffiths, Whitney, Kovaleva, & Hepburn, 2016; Griffiths, Kovaleva, Higgins, Langston, & Hepburn, 2018; Kovaleva et al., 2018; Mittelman, Roth, Coon, & Haley, 2004) include caregiver burden (Zarit, Reever, & Bach-Peterson, 1980), depressive symptoms (Radloff, 1977), and perceived stress (Cohen, Kamarck, & Mermelstein, 1983). The scoping review found that only four programs reported on caregiver burden (Chodosh et al., 2015; Fortinsky et al., 2014; Mavandadi, Wright, Graydon, Oslin, & Wray, 2017; Powers, Homer, Morone, Edmonds, & Rossi, 2017). Only three programs reported on caregivers' depressive symptoms (Chodosh et al., 2015; Fortinsky et al., 2014; Judge t al., 2011). Only one program reported on caregiver stress (LaMantia et al., 2015). The program that reported on caregiver stress, the Aging Brain Care Medical Home (LaMantia et al., 2015), used a validated instrument created by the investigators of the Aging Brain Care Medical Home (Monahan et al., 2012), as opposed to any instrument that had been used in geriatric and caregiving research previously. By contrast, the quantitative portion of the dissertation study used instruments that have been used in dementia caregiving and geriatric research previously, enabling comparison in outcomes using the same instruments.

Behavioral and psychological symptoms of dementia, or neuropsychiatric symptoms, are considered some of the most challenging aspects of dementia (Desai, Schwartz, & Grossberg, 2012). But the scoping review found that only three programs reported on these symptoms (Chodosh et al., 2015; Fortinsky et al., 2014; Mavandadi et al., 2017). Neuropsychiatric symptoms are essential in dementia management because, while the underlying reason for these symptoms is neuropathology, frequently co-existing and reversible factors exacerbate these symptoms and behaviors (Desai et al., 2012). In other words, while dementia is a terminal incurable illness (Kumar, Singh, & Ekavali, 2015), neuropsychiatric symptoms are modifiable and reversible (Desai et al., 2012). This dissertation study, therefore, contributes to the literature by reporting on neuropsychiatric symptoms – their severity and caregivers' distress regarding these symptoms (Cummings, 1997; Kaufer et al., 2000) – in addition to other caregiver- and PLWD-centered variables.

The quantitative section of this dissertation study demonstrated significant improvements in two outcomes for caregivers and three outcomes for PLWD when time was used as the only predictor in the model. For caregivers, their distress relative to their PLWDs' delusions (Delusions-distress) (Cummings, 1997; Kaufer et al., 2001) decreased over time significantly (p=0.048). Importantly, with seven non-completers removed, the significant decrease in Delusions-distress was no longer observed. When the model accounted for the total number of visits the clients made to the IMCC during the study period, time no longer significantly predicted change in Delusions-distress. But when we accounted for the PLWDs' total number of comorbidities at baseline, time still significantly predicted decrease in Delusions-distress (p=0.036). Overall, these results indicate that caregivers' negative reaction towards their PLWDs' delusions decreased significantly over time, when total number of visits was not taken into consideration.This is a positive finding because it indicates potentially effective pharmacologic and non-pharmacologic management of delusions at the IMCC, effective education about this symptom done by the IMCC staff (likely APRNs and social worker, if the caregiver attended the Savvy Caregiver class taught by the social worker), or both.

Delusions are psychotic symptoms most common in moderate stages of dementia (Desai et al., 2012), that may be manifested by delusions of stealing, infidelity, persecution, and delusions of reference (belief that a common neutral event, such as a TV program, has a special message and meaning intended only for the PLWD) (Bassiony & Lyketsos, 2003). Possibly, caregivers' distress relative to these symptoms may be lessened if APRNs educate caregivers about this symptom as an expected manifestation of dementia that the PLWD cannot control. For example, delusions of stealing, such as if a PLWD accuses the caregiver of stealing the PLWD's belongings, may be very hurtful to the caregiver. Understanding that the PLWD does not verbalize such delusions out of spite may lessen caregivers' distress. If APRNs' and/or social worker's explanations and reassurance indeed lower caregivers' distress, this may support the role of the elements of the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) that has been used as the theoretical framework for this study. Clinicians' reassurance and education may change caregivers' appraisal of the situation (PLWD engaging in delusional behavior), which in turn may improve caregivers' emotional context (lessen distress regarding PLWDs' symptoms).

Likewise, caregivers' Anxiety-distress significantly decreased over time (p=0.018). This significant effect of time was maintained when seven non-completers were removed from the analysis (p=0.034). Similarly, accounting for either the total number of visits to the IMCC that the PLWD-caregiver dyad made or the total number of comorbidities that the PLWD had at baseline besides dementia did not cancel the significant effect of time on the decrease of caregivers' Anxiety-distress.

Two PLWD-centered outcomes decreased significantly over time when time was used as the only predictor in the model: severity of delusions (p=0.007), depression/dysphoria (depression) (p<0.001), and total symptom severity (p=0.013). All significant quantitative changes in the quantitative section of this dissertation study were observed using the Neuropsychiatric Inventory (Cummings, 1997; Kaufer et al., 2001).

For depression severity, significant drops occurred both between the baseline and the 3-month interview and between the baseline and the 6-month interview (p<0.001 and p=0.004, respectively). Improvements in depression severity were the most robust among all significantly changed outcomes. For total symptom severity, despite the fact that there was an overall decrease in total symptom severity over time (p<0.001), post hoc analyses failed to demonstrate significant changes between the three time points. Potentially, this may be explained by the small sample size and missing data.

These improvements in symptom severity are an encouraging finding because they demonstrate what was improved for PLWD in a relatively short amount of time – the interview date that was furthest from baseline was 9.2 months after that PLWD-caregiver dyad's first visit to the clinic. Hence, these improvements occurred rapidly, which is highly beneficial for PLWD and caregivers. The relatively short duration of this study is in a way a potential advantage of its design because, although a repeated measures study, it shows what happens in a "snapshot" of time relative to typical duration of dementia (mean survival time from onset is 3.3 to 11.7 years (Todd, Barr, Roberts, & Passmore, 2013)). While longer study duration is typically a strength of any study design, this study demonstrated what happens in a brief period of time. Had there been no evaluation at the three-month benchmark, it would have been impossible to conclude that several positive changes occurred relatively quickly after clients' enrollment into the IMCC.

In the quantitative section of this dissertation study we did not account for the number of calls/email messages that clients made to the IMCC during the study. This may be an important measure to include in the future study because it is directly linked to the key element of the clinic design and the way in which the clinic accords with the definition of a patient-centered medical home: enhanced care access. In fact, caregivers may have avoided visits precisely because their questions were answered via telephone or email, so reliance on clinic visits is an insufficient measure of intensity with which clinic services were used.

Another important covariate is the number of comorbidities – PLWDs' chronic conditions besides dementia. Comorbidities are very prevalent among PLWD (Bunn et al., 2014). Significant changes over time were maintained in the severity of delusions, depression, and caregivers' distress relative to their PLWDs' anxiety, regardless PLWDs' total number of comorbidities. These are important relationships because they demonstrate that significant improvements occurred over time regardless of comorbidity burden for PLWD. If these changes could be attributed to the clinic in the next study with a comparison group, this signifies that the clinic, in essence, is working “against the gradient,” overcoming the comorbidity burden. This is especially relevant because individuals with depression tend to have a higher comorbidity burden (Kang et al., 2015).

Beyond changes that occurred over time, descriptive data characterizing the sample of caregivers deserve mention. At baseline, caregivers were highly stressed, as demonstrated by their mean on Perceived Stress Scale (Cohen et al., 1983) of 18.9 for completers and 19.3 for non-completers. While this scale does not have clinical cut-off values, it has population norms. Mean perceived stress in population norms does not exceed 12.6 for all age strata (Cohen et al., 1983). Similarly, for caregiver burden (Zarit et al., 1980), completers had a mean score of 21.1 and non-completers had a mean sore of 28 at baseline. Score of 17 and above indicates severe burden (Stagg & Larner, 2015), so these baseline values underscore how burdened this sample was. For depressive symptoms (Andresen et al., 1994; Radloff, 1977), completers had a mean score 9.1 and non-completers had a mean score 10.5. Scores 10 and above indicate depression (Andresen et al., 1994). Therefore, according to these three essential measures, this sample showed highly unfavorable indicators of psychological well-being. This points to the fact that caregivers’ needs continue to be unmet (Jennings et al., 2015), which makes caregivers a population that is in much need of interventions, particularly, translation of research into interventions that reach caregivers (Gitlin, Marx, Stanley, & Hodgson, 2015).

The majority of PLWD- and caregiver-centered outcomes did not have significant changes over time. For caregivers, this is likely explained by the fact that IMCC does not offer a direct intervention for caregivers (Savvy Caregiver and late-stage dementia classes are exceptions, but caregivers attend these classes based on their own choice). While it is plausible that by virtue of being in the clinic, caregivers’ psychological well-being may improve, it is equally likely that it either may not improve or it may need longer time to improve. Potentially, more specific efforts may need to be directed towards caregivers. These may include dedication of time to discuss PLWDs' symptoms and changes in these symptoms over time. It may be especially helpful to regularly meet with caregivers and show them graphs of how their PLWDs' symptom severity changed over time. Then caregivers' performance on measures of their distress relative to their PLWDs' symptoms may be shown. This way, if improvements occur for PLWD (decreased symptom severity), but not for caregivers (no changes in caregivers' distress and other measures of psychological well-being), an APRN may point to the positive changes for PLWD, underscoring that some progress has been made.

Possibly, caregivers simply may not recognize those changes even though numeric reports demonstrate them. Potentially, such "reality check" delivered by an authority figure (APRN) and with reassurance that symptoms are to be expected and are indeed some of the most challenging aspects of dementia, may help decrease burden, stress, and anxiety for caregivers. This discrepancy was especially evident when total symptom severity was compared between PLWD whose caregivers were men vs. women. Caregivers-women reported significantly higher baseline total symptom severity for their PLWD compared to what caregivers-men reported. PLWD whose caregivers were men experienced a non-significant decline in total symptom severity over time, but PLWD whose caregivers were women experienced a significant decline in total symptom severity over time, and it was significantly faster in these PLWD compared to PLWD whose caregivers were men. No changes in distress relative to the total symptom severity were noted for the whole sample. But it is possible to assume that since PLWD whose caregivers were women experienced a significantly faster decline in total symptom severity compared to PLWD whose caregivers were men, women caregivers should have also demonstrated a significant decrease in their distress regarding total symptom severity. This, however, was not observed.

Potentially, showing caregivers a decline in the total symptom severity in the form of a graph and discussing numeric results vs. caregivers' perceptions may alleviate caregivers' distress at least partially. Possibly, since women reported a significantly higher baseline total symptom severity, they may remain "stuck" in their perception of symptoms as highly severe, even though they report them as less severe in the questionnaire. Thus, regular consultations with APRNs and discussion of caregivers' concerns specifically about symptom severity may be both an efficient use of time (since symptoms are modifiable (Desai et al., 2012)), and also help caregivers "get unstuck" from their baseline perception of symptom severity, ultimately relieving, to a degree, caregivers' burden and stress. Potentially, breaking down symptoms into 12 categories that the Neuropsychiatric Inventory assesses (Cummings, 1997; Kaufer et al., 2001) and discussing each symptom may already somewhat lessen caregivers' distress. This may occur because the very presentation of commonly occurring symptoms as something that has been researched and is well-known among dementia experts, may make such symptoms less burdensome, frightening, and overwhelming to caregivers. Simply putting a symptom on a piece of paper and seeing that it is well-known to the APRN and medical and research community may already make this symptom less difficult to deal with for the caregiver. It may in a sense, "normalize" the symptom, presenting it as something to be expected and not the fault of the caregiver or the PLWD, but rather an extremely common occurrence in dementia that is, unlike cognitive deterioration, modifiable to a certain extent.

Significant improvements in total symptom severity (when time was the only predictor in the model) are also encouraging because a 1-point increase in the Neuropsychiatric Inventory score is associated with an increase in healthcare costs in the range of $247-409/year (Murman & Colenda, 2005). Therefore, the fact that no measures on the Neuropsychiatric Inventory increased significantly is also a positive finding, in light of the progressive nature of dementia and the fact that symptoms such as agitation, aggression, sleep disturbances, and apathy increase in prevalence with severity of cognitive impairment (Desai et al., 2012). In other words, it is logical to expect exacerbation of the severity of these symptoms with the course of the illness. Thus, findings in the quantitative section of this dissertation study point to possible healthcare savings, but most importantly, a likely decrease in suffering for PLWD and caregivers at least to a degree.

One aspect of the IMCC context makes it different from previously reported programs. While no formal analysis of the socioeconomic status of the IMCC clients was done, the fact that 78% of caregivers had college degrees or professional/post-graduate education implies a likely higher socioeconomic status of this sample. This makes the IMCC different from, for example, the Healthy Aging Brain Care (Boustani et al., 2011) and the Aging Brain Care Medical Home (LaMantia et al., 2015), both of which are situated within a safety-net healthcare system. Hence, findings on the IMCC may not be applicable to other settings where clients are likely to have lower socioeconomic status.

A notable characteristic of this sample was that 39% of caregivers received help in caregiving duties, which is likely connected to their higher socioeconomic status (with college degree or higher educational attainment considered as a proxy for socioeconomic status). Potentially, having extra support is conducive to the improvements in caregiver- and PLWD-centered outcomes that are described in the quantitative section of this dissertation. Also, it is possible that individuals with higher educational attainment are more “coachable” and accepting of APRNs’ instruction, and hence, more likely to benefit from non-pharmacological management strategies that APRNs share with caregivers. Additionally, caregivers with higher educational attainment may be more open to an innovative care model led by APRNs. From qualitative interviews, it became evident that some caregivers were strongly interested in opportunities to participate in clinical trials for their PLWD. Hence, this sample may have been a self-select group of caregivers who are actively searching for better ways to provide care for their PLWD and who are thus more likely to notice improvements in PLWDs’ condition (decreased symptom severity as demonstrated in the quantitative section). Potentially, caregivers who do not seek enrollment in dementia care programs may have the greatest need for help and education, as they may not realize themselves their degree of need, may not have resources or opportunity to enroll in the program such as the IMCC, or may erroneously believe that nothing can be done for dementia management. Hence, findings from this dissertation study may not generalize to caregivers of lower socioeconomic status and in settings other than an urban academic health center.

While this dissertation study extends the research on dementia care programs by reporting on a wider variety of PLWD and caregiver outcomes, the scoping review points to several variables that the IMCC may address in future studies. They include institutionalization rate of PLWD; more detailed characteristics of clinical management as reported by the Healthy Aging Brain Care (e.g., number of various tests and orders completed, length of hospital stay, 30-day re-hospitalization rate, emergency department return one-week return rate, etc.) (Boustani et al., 2011); staff’ satisfaction with and opinion on the care program; adherence to dementia care quality outcomes; and economic evaluation of the IMCC.

Findings in the qualitative section of this dissertation study point to caregivers' overall positive experience at the IMCC, with the exception of one caregiver who represented the atypical case. However, even that caregiver found several positive aspects at the IMCC, including patient-centeredness, thoroughness of explanations that she received regarding her PLWD's medication management, and APRNs' interpersonal skills.

Overall, caregivers found their experience positive and valuable. In many ways it was unprecedented to anything that caregivers experienced before. Characteristics of this unprecedented experience included competence of APRNs in terms of management of dementia and other conditions. They also included unhindered access to care, which caregivers compared not only to a difficult care access experience that their PLWD had previously but even to their own suboptimal access to care. Additionally, the sense of belonging to the care team was both surprising and helpful to caregivers. Caregivers strongly valued their ability to access an APRN on duty year-round with any questions. This was important not only for dementia management, but also for other serious conditions that have caused severe health deterioration for PLWD previously. Even without actually calling the APRN on duty, the availability of such help in time of need appeared to create greater certainty and stability in caregivers' lives. Arguably, it may be possible to find clinicians outside of the IMCC who are experts in dementia care and primary care and have outstanding bedside manner that allows caregivers to feel welcomed, respected, and listened to. But unhindered access to care is a system feature of the IMCC – most likely no provider, unless it is stipulated in the practice regulations, may choose to be available year-round to clients simply because it is helpful to caregivers. Hence, unhindered access to care is a reliable characteristic of the IMCC that does not depend on any one individual but rather describes the IMCC as a whole. Such stability may be especially vital for caregivers whose overall experience is marked by uncertainty (Samsi & Manthorpe, 2014) and the need to plan for the future (Mastwyk, Dow, Ellis, & Ames, 2016).

Besides describing positive experience at the IMCC, caregivers expressed ways in which the IMCC may improve its services. Clearly, such recommendations imply avenues for improvement not only for the IMCC but also for any dementia care programs and mainstream healthcare that serves PLWD and their caregivers. The very fact that caregivers named so many resources that they found lacking at the IMCC but necessary for their caregiving duties underscores again that caregivers' needs are far from being met (Jennings et al., 2015). It is impossible to ascertain which of these recommendations the IMCC may implement in the near future as each addition of a resource necessarily comes with financial expenditure and organizational challenges that accompany any change in an established workflow. But the fact that caregivers wish for all resources to be organized at the IMCC – from the adult day care center to a home visiting nurse that the IMCC would sponsor – also signifies that the more certainty and predictability a clinic may bring, the more it will help caregivers. It appears that caregivers' preference to have all resources centralized at the IMCC indicates their desire for more order and structure. This is consistent with much uncertainty that dementia brings into PLWDs' and caregivers' lives (Samsi & Manthorpe, 2014). But also the many suggestions for improvement, including that of greater physician's presence in care, and the narrative of the caregiver who represented an atypical case mean that the IMCC may not meet every need of every client, and that is an expected finding.

While the IMCC may be unable to implement all recommendations in the near future, some of the recommendations point to potential partnership opportunities. For example, caregivers recommended that the IMCC could provide a list of adult day care centers that the

APRNs and the social worker recommend. In the future, the Brain Health Center where the IMCC is located might sponsor its own adult day care program. For caregivers who wished for an on-line tour of the clinic upon enrollment, computer programmers and videographers might create such on-line orientation. The online Tele-Savvy caregiver program (Kovaleva et al., 2018) would likely be highly appreciated by many caregivers who cannot attend the in-person class. Caregivers' willingness to have more resources centralized at the IMCC points to the topic that the scoping review revealed: dementia care programs must be interdisciplinary because no single specialty can fulfill all that PLWDs and caregivers need. From an economic standpoint, such an area of need points to the demand for professions who can serve PLWD and their caregivers. APRNs, with their demonstrated competency, knowledge, and skill in managing the IMCC, may serve as leaders of such interdisciplinary collaborations.

This dissertation study yields several implications for research and for practice. To re-cap implications for research, they stem from the design of this dissertation study: a descriptive longitudinal cohort study without a comparison group, with small sample size (N=49 at baseline), and of relatively short duration (the longest duration between the first IMCC visit and the last interview was 9.2 months). Finally, all positive findings may not be conclusively ascribed to the IMCC in the absence of a comparison group in this study design. A future study with a comparison group, with randomized controlled trial as a gold standard, may elucidate the mechanism whereby significant changes in PLWD- and caregiver-centered outcomes occur. While this dissertation study extends the research on dementia care programs by reporting on a wider variety of PLWD and caregiver outcomes, the scoping review points to several variables that the IMCC may address in future studies. They include institutionalization rate of PLWD; more detailed characteristics of clinical management as reported by the Healthy Aging Brain

Care (e.g., number of various tests and orders completed, length of hospital stay, emergency department return one-week return rate, etc.) (Boustani et al., 2011); staff' satisfaction with and opinion on the care program; adherence to dementia care quality outcomes; and economic evaluation of the IMCC. It may be best to conduct the next qualitative section of a larger study with in-person interviews, rather than telephone interviews, due to the many limitations of telephone interviews, such as loss of participants' non-verbal cues, including intentional use of silence, and inability to appreciate participants' surroundings (Novick, 2008).

The most important practice implication, beyond the ones mentioned above, is that APRNs with expertise in primary care, neurology, psychiatry, and palliative care, can lead dementia care programs such as the IMCC. There is a shortage of primary care physicians (Hackey, Grasso, LaRochelle, & Seaver, 2018), and hence, APRNs specializing in primary care may contribute to closing the gap between the supply and demand in primary care. In fact, relatively recent advancements in education and certification of nurse practitioners manifest the increased need for nurse practitioner workforce in geriatrics. The Advanced Practice Registered Nurse Consensus work group eliminated a separate certification in gerontology for nurse practitioners, such that nurse practitioners began to graduate with a specialization in adult care and gerontology (Warshaw & Bragg, 2014), starting 2013 (American Nurses Credentialing Center, n. d.). This enables all adult-gerontological nurse practitioners to work with older adults, including PLWD, since all nurse practitioner students in the adult-gerontological track get gerontology content in their curriculum (Warshaw & Bragg, 2014). Additionally, geriatricians are scarce, and nurse practitioners may fill the need for geriatricians (Golden, Silverman, & Issenberg, 2015).

While positive changes cannot be attributed to the IMCC in the absence of a comparison group, it is likely that they do occur due to clients' enrollment into the IMCC. The rationale for this reasoning is that it has been shown that in the absence of any intervention, for caregivers and PLWD who are enrolled into a memory care clinic, psychological well-being (depression and anxiety) remains stable (Clare, Wilson, Carter, Breen, Berrios, & Hodges, 2002). Hence, absence of significant negative changes and presence of important positive changes, as demonstrated in the quantitative and qualitative sections of this study, suggests that these changes may be due to the IMCC. Further evidence is essential to determine the efficacy of APRN-led dementia care programs. But previous research, demographic projections of the increase in the PLWD population (Alzheimer's Association, 2018), and clearly demonstrated in this dissertation study caregivers' and PLWDs' need for help are substantial grounds for APRNs to lead more dementia care programs similar to the IMCC. As new APRN-led programs are founded, it is important that they assume a research-intensive approach and disseminate knowledge they discover. This commitment to research is likely to bring funding that would sustain these programs and make such programs active contributors to research and, potentially, leaders in the education of the next generation of healthcare professionals (Jolley & Moniz-Cook, 2009).

References

Agency for Healthcare Research and Quality. (n. d.). Defining the PCMH. Retrieved from https://pcmh.ahrq.gov/page/defining-pcmh

Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 14*(3), 367-429. doi: https://doi.org/10.1016/j.jalz.2018.02.001

American Nurses Credentialing Center. (n. d.). Consensus model for APRN regulation FAQs. Retrieved from https://www.nursingworld.org/certification/aprn-consensus-model/faq-consensus-model-for-aprn-regulation/

Andresen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventive Medicine, 10*(2), 77-84.

Barton, C., Merrilees, J., Ketelle, R., Wilkins, S., & Miller, B. (2014). Implementation of advanced practice nurse clinic for management of behavioral symptoms in dementia: A dyadic intervention (innovative practice). *Dementia*, *13*(5), 686-696.

doi: 10.1177/1471301213519895

Bass, D. M., Judge, K. S., Maslow, K., Wilson, N. L., Morgan, R. O., McCarthy, C. A., . . . Kunik, M. E. (2015). Impact of the care coordination program “Partners in Dementia Care” on Veterans’ hospital admissions and emergency department visits. *Alzheimer’s & Dementia, 1*(1), 13-22. doi: 10.1016/j.trci.2015.03.003

Bassiony, M. M., & Lyketsos, C. G. (2003). Delusions and hallucinations in Alzheimer’s disease: Review of the brain decade. *Psychosomatics, 44*, 388-401.

Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., . . . Resources for Enhancing Alzheimer’s Caregiver Health (REACH) II Investigators. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, *145*(10), 727-738. doi: 10.7326/0003-4819-145-10-200611210-00005

Boustani, M. A., Sachs, G. A., Alder, C. A., Munger, S., Schubert, C. C., Guerriero Austrom, M., . . . Callahan, C. M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health, 15*(1), 13-22. doi: 10.1080/13607863.2010.49644

Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine, 12,* 192.

Callahan, C. M., Boustani, M. A., Weiner, M., Beck, R. A., Livin, L. R., Kellams, J. J., . . .

Hendrie, H. C. (2011). Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging & Mental Health, 15*(1), 5-12. doi: 10.1080/13607861003801052

Callahan, C. M., Sachs, G. A., LaMantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs, 33*(4), 626-632. doi:10.1377/hlthaff.2013.1260

Chodosh, J., Colaiaco, B. A., Connor, K. I., Cope, D. W., Liu, H., Ganz, D. A., . . . Vickrey, B. G. (2015). Dementia care management in an underserved community: The comparative effectiveness of two different approaches. *Journal of Aging & Health, 27*(5), 864-893. doi: 10.1177/0898264315569454

Clare, L., Wilson, B. A., Carter, G., Breen, K., Berrios, G. E., & Hodges, J. R. (2002). Depression and anxiety in memory clinic attenders and their carers: Implications for evaluating the effectiveness of cognitive rehabilitation interventions. *International Journal of Geriatric Psychiatry, 17*(10), 962-967.

Clevenger, C. K., Cellar, J., Kovaleva, M., Medders, L., & Hepburn, K. (2018). Integrated Memory Care Clinic: Design, implementation, and initial results. *Journal of the American Geriatrics Society.* Advance on-line publication. doi: 10.1111/jgs.15528

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24,* 385-396.

Cummings, J. (1997). The neuropsychiatric inventory: Assessing psychopathology in dementia patients. *Neurology, 48*(Supple 6), S10-S16.

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Current Psychiatry Reports, 14*(4), 298-309. doi: 10.1007/s11920-012-0288-5

D’Souza, M. F., Davagnino, J., Hastings, S. N., Sloane, R., Kamholz, B., & Twersky, J. (2015).

Preliminary data from the Caring for Older Adults and Caregivers at Home (COACH) program: A care coordination program for home-based dementia care and caregiver support in a Veterans Affairs Medical Center. *Journal of the American Geriatrics Society, 63*(6), 1203-1208. doi: 10.1111/jgs.13448

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J . . . Crumb, S. (2014). Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers. *Research in Gerontological Nursing, 7*(3), 126-137. doi:10.3928/19404921-20140113-01

Geldmacher, D. S., & Kerwin, D. R. (2013). Practical diagnosis and management of dementia due to Alzheimer's disease in the primary care setting: An evidence-based approach. *The Primary Care Companion for CNS Disorders, 15*(4). doi: 10.4088/PCC.12r01474

Gitlin, L. N., Marx, K., Stanley, I. H., & Hodgson, N. (2015). Translating evidence-based dementia caregiving interventions into practice: State-of-the-Science and next steps. *The Gerontologist, 55*(2), 210-226. doi: 10.1093/geront/gnu123

Golden, A. G., Silverman, M. A., & Issenberg, S. B. (2015). Addressing the shortage of geriatricians: What medical educators can learn from the nurse practitioner training model. *Academic Medicine, 90*(9), 1236-240. doi: 10.1097/ACM.0000000000000822

Griffiths, P. C., Whitney, M. K., Kovaleva, M., & Hepburn, K. (2016). Development and implementation of Tele-Savvy for dementia caregivers: A department of Veterans Affairs clinical demonstration project. *The Gerontologist*, 56(1), 145-154. doi: 10.1093/geront/gnv123

Griffiths, P. C., Kovaleva, M., Higgins, M., Langston, A. H., & Hepburn, K. (2018). Tele-Savvy: An online program for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 33*(5), 269-276. doi: 10.1177/1533317518755331

Hackey, R. B., Grasso, V., LaRochelle, M., & Seaver, K. (2018). Rethinking the shortage of primary care physicians. *Journal of the American Academy of Physician Assistants, 31*(6), 47-50. doi: 10.1097/01.JAA.0000533662.88073.15

Hepburn, K., Lewis, M., Tornatore, J., Sherman, C. W., & Bremer, K. L. (2007). The Savvy Caregiver Program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing, 33*(3), 30-36. doi:10.1093/geront/43.6.908

Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., . . . Wenger, N. S. (2015). Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of the American Geriatrics Society, 63*(2), 282-289. doi: 10.1111/jgs.13251

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., . . . Reuben, D. B. (2016). Quality of care provided by a comprehensive dementia co-management program. *Journal of the American Geriatrics Society, 64*(8), 1724-1730. doi: 10.1111/jgs.14251

Jolley, D., & Moniz-Cook, E. (2009). Memory clinics in context. *Indian Journal of Psychiatry, 51 Suppl 1,* S70-76.

Kang, H.-J., Kim, S.-Y., Bae, K.-Y., Kim, S.-W., Shin, I.-S., Yoon, J.-S., *& Kim, J.-M. (2015). Comorbidity of depression with physical disorders: Research and clinical implications. *Chonnam Medical Journal, 51*(1), 8-18. doi: 10.4068/cmj.2015.51.1.8

Kaufer, D. L., Cummings, J, L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., . . . DeKosky, T. (2000). Validation of the NPI-Q, a brief form of the Neuropsychiatric Inventory. *Journal of Neuropsychiatry and Clinical Neuroscience, 12*(2), 233-239.

Kovaleva, M. A., Bilsborough, E., Griffiths, P. C., Nocera, J., Higgins, M., Epps, F., . . . Hepburn, K. (2018). Testing Tele-Savvy: Protocol for a randomized controlled trial. *Research in Nursing & Health, 41*(2), 107-120. doi: 10.1002/nur.21859

LaMantia, M. A., Alder, C. A., Callahan, C. M., Gao, S., French, D. D., Austrom, M. G., . . . Boustani, M. A. (2015). The Aging Brain Care Medical Home: Preliminary data. *Journal of the American Geriatrics Society, 63*(6), 1209-1213. doi:10.1111/jgs.13447

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer Publishing Company.

Mastwyk, M., Dow, B., Ellis, K. A., & Ames, D. (2016). Why attend a memory clinic? What do patients and their families want and/or expect? *Australasian Journal on Ageing, 35*(3), 220-224. doi: 10.1111/ajag.12257

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia. *Psychological Services, 14*(1), 102-111. doi: 10.1037/ser0000118

Mittelman, M. S., Roth, D. L., Coon, D. W., & Haley, W. E. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer’s disease. *American Journal of Psychiatry, 161*(5), 850-856. doi:10.1176/appi.ajp.161.5.850

McCleery. E., Christensen, V., Peterson, K., Humphrey, L., & Helfland, M. (2014). Evidence brief: The quality of care provided by advanced practice nurses. In *VA evidence-based synthesis program evidence briefs.* Washington, DC: Department of Veterans Affairs (U.S.). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK384613/

Monahan, P. O., Boustani, M. A., Alder, C., Galvin, J. E., Perkins, A. J., Healey, P., . . . Callahan, C. (2012). Practical clinical tool to monitor dementia symptoms: The HABC-Monitor. *Clinical Interventions in Aging, 7,* 143-157. doi: 10.2147/CIA.S30663

Murman, D. L., & Colenda, C. C. (2005). The economic impact of neuropsychiatric symptoms in Alzheimer's disease: Can drugs ease the burden? *Pharmacoeconomics, 23*(3), 227-242. doi:10.2165/00019053-200523030-00004

NCQA. (n. d.). Program structure: ACO accreditation. Retrieved from https://www.ncqa.org/programs/health-care-providers-practices/accountable-care-organizations-aco/structure/

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality dementia care. *Journal of the Applied Gerontology, 36*(2), 195-212. doi: 10.1177/0733464815589986

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health, 31*(4), 391-398. doi: 10.1002/nur.20259

Powers, B. P., Homer, M. C., Morone, N., Edmonds, N., & Rossi, M. I. (2017). Creation of an interprofessional teledementia clinic for rural veterans: Preliminary data. *Journal of the American Geriatrics Society, 65*(5), 1092-1099. doi: 10.1111/jgs.14839

Radloff, S. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401. doi:10.1177/014662167700100306

Reuben, D. B., Evertson, L. C., Wenger, N. S., Serrano, K., Chodosh, J., Ercoli, L., & Tan, Z. S.

(2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *Journal of the American Geriatrics Society, 61*(12), 2214-2218. doi: 10.1111/jgs.12562

Samsi, K., & Manthorpe, J. (2014). Care pathways for dementia: Current perspectives. *Clinical Interventions in Aging, 9*, 2055-2063. doi: 10.2147/CIA.S70628

Stagg, B., & Larner, A. J. (2015). Zarit Burden Interview: Pragmatic study in a dedicated cognitive function clinic. *Progress in Neurology & Psychiatry, 19*(4), 23-27. doi: https://doi.org/10.1002/pnp.390

Stanik-Hutt, J., Newhouse, R. P., White, K. M.., Johantgen, M., Bass, E. P.. Zangaro, G., . . . Weiner, J. P. (2013). The quality and effectiveness of care provided by nurse practitioners. *The Journal for Nurse Practitioners, 9*(8), 492-500.e13. doi: https://doi.org/10.1016/j.nurpra.2013.07.004

Tappen, R. M., & Valentine, K. (2014). Building and sustaining a caring-based nurse-managed center. *Pennsylvania Nurse, 69*(2), 16-21.

Todd, S., Barr, S., Roberts, M., & Passmore, A. P. (2013). Survival in dementia and predictors of mortality: A review. *International Journal of Geriatric Psychiatry, 28*(11), 1109-24. doi: 10.1002/gps.3946

Verghese, J., Malik, R., & Zwerling, J. (2016). Montefiore-Einstein Center for the Aging Brain: Preliminary data. *Journal of the American Geriatrics Society, 64*(11), 2374-2377. doi: 10.1111/jgs.14473

Warshaw, G., & Bragg, E. J. (2014). Preparing the health care workforce to care for adults with Alzheimer’s disease and related dementias. *Health Affairs, 33*(4), 633-641.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655.

doi:10.1093/geront/20.6.64