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An Exploration of Dementia Friendly Communities from the Perspective of Persons Living with Dementia

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A dissertation

presented to

the faculty of the College of Nursing

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Doctor of Philosophy in Nursing

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by

Catherine Ann Hebert

December 2017

Katherine Christine Hall, Chair

Kenneth D. Phillips

Teresa L. Stephens

Kezia Scales

Key Words: dementia, dementia friendly, content analysis, qualitative research

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ABSTRACT

An Exploration of Dementia Friendly Communities from the Perspective of Persons Living with Dementia

by

Catherine Ann Hebert

The growing global prevalence of dementia coupled with a shift in public perception from a hopeless disease to the possibility of living well with dementia has led to the formation of dementia friendly communities (DFC). DFCs are a new phenomenon in the United States, with a gap in knowledge on input from people living with dementia (PLWD). This study investigated DFCs from the perspective of PLWD in Western North Carolina. Eighteen older adults with reported dementia or memory loss were recruited from support groups or community organizations. Semi-structured interviews were conducted in participants' homes and analyzed using conventional qualitative content analysis.

Three major themes emerged from the transcribed interviews (a) transitions in cognition: vulnerable identities, (b) social connections, and (c) engagement in life activities. The dynamic experience of living with dementia revealed by participants suggested the following attributes of a DFC: (a) social inclusion, (b) support for role continuity, (c) availability of meaningful and contributory activities, (d) flexible support as cognition transitions, (e) community dementia awareness (to combat stigma), and (f) a supportive diagnostic process. The presence of care partners in the interviews was supportive, and the evaluation to sign consent tool assisted in determination of participant capacity to self-consent.

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The findings were interpreted through the theoretical frameworks of personhood, the social model of disability, human rights and citizenship, the environmental press model, and transitions theory. DFC development requires a contextual lens focused on well-being with input from multiple stakeholders including PLWD. Collaboration among community organizations supported by local, regional, and national policy supporting flexible service provision through cognitive transitions has the potential to provide a strong social network on which to build a DFC.

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DEDICATION

To my husband, Dan Waldman, together we persist in curiosity, love, and friendship.

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To the Dementia Friendly WNC team for their compassion, knowledge, and commitment toward the realization of a community where people living with dementia are included and respected. A special recognition to Dr. James Hyde, for his friendship, gentle guidance and unwavering encouragement as my muse in the world of dementia friendly and dissertations, a role model for living life fully and with an open heart.

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To my husband Dan, without him this endeavor would not be possible – the support, the dinners, the love, and the constant reminder that I’ve simply gone too far to quit now.

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ABBREVIATIONS

AA: Alzheimer’s Association

ADI: Alzheimer’s Disease International

CCRC: continuing care retirement community

DFC: Dementia friendly communities(y)

DFI: Dementia friendly initiative

DOH: Department of Health

DSDC: Dementia Services Design Centre

EFID: European Foundation’s Initiative on Dementia

ETSU: East Tennessee State University

IRB: Institutional review board

LTC: Long term care

NAPA: National Alzheimer’s Project Act

PI: Principal investigator

PLWD: people living with dementia

QCA: Qualitative content analysis

RCT: randomized controlled trial

UK: United Kingdom

US: United States

USDHHS: United States Department of Health and Human Services

WHO: World Health Organization

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CHAPTER 1

INTRODUCTION

The rising prevalence and cost of dementia has captured the attention of leaders world-wide. In the United States (US) alone, the number of persons living with dementia (PLWD) is projected to climb from the current 5.4 million in 2016 to 13.8 million in 2050 (Alzheimer's Association [AA], 2016). Internationally, dementia has affected 44 million people, growing to a predicted 135 million in 2050 (Alzheimer's Disease International [ADI]), 2016). The financial and social cost to individuals and families is far reaching (Schaller, Mauskopf, Kriza, Wahlster, & Kolominsky-Rabas, 2015). In these millions of cases of dementia, individuals and families are profoundly impacted by the cost of care, caregiver stress, the stigma of dementia, and social isolation (Bynum, 2014; Kenigsberg et al., 2015).

Without a cure or dependable treatment in the foreseeable future, researchers, policy makers, and citizens are searching for innovative, community-based solutions (European Foundations' Initiative on Dementia [EFID], 2016; Heward, Innes, Cutler, & Hambidge, 2016; Lin & Lewis, 2015). These responses are extending beyond the healthcare arena to social and community programming, viewing PLWD as holistic beings, not solely fragments of a former self due to cognitive loss (Dementia Friendly America [DFA], 2017). The narrative of dementia has shifted from one of deficit to inclusion and contribution. As the view of dementia has broadened from a single-minded medical approach, DFCs have emerged, promoting a comprehensive focus on healthcare, social support, well-being, and social inclusion for PLWD and their families.

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Background

Even with the shifting narrative, the word dementia is often met with a sense of unease. This is not surprising, as dementia stems from a Latin word for insane, mad, or ‘out of one’s mind’ (Chaufan, Hollister, Nazareno, & Fox, 2012). The use of the word dementia is culturally situated, with broad inferences that vary depending on the context. It often refers not only to a medical diagnosis, but incorrectly to normal age-related cognitive changes or mental illness (Miyamoto, George, & Whitehouse, 2011).

Depictions of Dementia

Medical professionals in the US have attempted to move away from the ill-defined term *dementia* without much success, although reports of successful changes in terminology in other nations, including Japan, exist (Miyamoto et al., 2011). In the most recent publication of the Diagnostic and Statistical Manual of Psychiatric Disorders (DSM – 5), the American Psychiatric Association (2013) introduced the term *neurocognitive disorder* (NCD) to replace dementia. It was hoped this would clarify the diagnosis, reduce misunderstandings, and elude the unnecessary stigma entrenched in the term; however, the term dementia still permeates the professional and lay public literature. In a comparison of the frequency of the terms dementia and NCD in the CINAHL search database, dementia appeared 47,755 times, and *NCD* appeared 1207 times, a 97:3 ratio. Narrowing the search to only the years 2016-17 to account for adaptation of new language, dementia appeared 10,887 times and NCD appeared 316 times, revealing a similar ratio of use, 97:3. The results were comparable in a Medline/Web of Science search, with ratios of the use of dementia to NCD equaling 98:2 for both the 2013 – 2017 and 2016-2017 time spans. Dementia will therefore be the term used in this study as it is most familiar to both healthcare professionals and the general public.

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In the healthcare domain, dementia denotes a syndrome or set of symptoms representing progressive cognitive, sensory, and functional decline (Kenigsberg et al., 2015). Many physical and cognitive tools exist, but no single test is available to diagnose dementia (American Psychiatric Association, 2013). Definitions for dementia have varied. The DSM-5 defines dementia as a major neurocognitive disorder that includes:

- a decline in memory;
- impairment in at least one of the following cognitive abilities (a) ability to generate coherent speech and understand spoken or written language; (b) ability to recognize or identify objects, assuming intact sensory function, (c) ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; (d) ability to think abstractly, make sound judgments and plan and carry out complex tasks;
- the decline in cognitive abilities must be severe enough to interfere with daily life (e.g., tasks at work; functioning in social situations).

Alzheimer's disease (AD) is the most common form of cognitive impairment under the dementia or major NCD umbrella (AA, 2016), therefore the terms *dementia* and *Alzheimer's disease* are often used interchangeably. Alzheimer's disease and related dementias (ADRD) is a term used to incorporate all dementias, often found in governmental reports. Therefore, for the purposes of this study, the term dementia will incorporate all forms of the condition. In this study, dementia is defined as a cognitive impairment significant enough to be identified by the individual as noticeable in their daily life but not reliant on diagnosis of specific deficits such as agnosia or apraxia.

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Stages of dementia. Dementia is characterized by defined stages (a) pre-clinical, where changes in the brain are present though not yet detectable by physical, cognitive, nor functional exam; (b) mild cognitive impairment (MCI); (c) early dementia; (d) moderate dementia; and (e) advanced dementia. MCI occurs in 10 – 20% of older adults (Albert et al., 2011). These individuals recognize a change in cognition, usually memory, but do not meet the criteria for dementia nor does the deficit significantly affect their everyday functioning (Albert et al., 2011). Approximately 10 – 15 % of MCI cases progress to dementia each year, while others never progress (Albert et al., 2011). In early dementia, only minor changes in memory or other symptoms are present. The individual retains the ability to verbally communicate sufficiently to remain independent, possibly requiring assistance for some instrumental activities of daily living such as managing finances and driving due to declines in executive function (AA, 2016). In moderate dementia, obvious symptoms of dementia are present in difficulty performing routine tasks and remembering common items such as the date and time. Increasingly levels of assistance are required for functioning (AA, 2016). Lastly, in advanced dementia, individuals have great difficulty communicating verbally and require assistance in nearly all activities of living due to severe cognitive losses. The loss of ability to swallow, communicate verbally, and ambulate develop (AA, 2016). Advanced dementia is a terminal illness.

Young-onset dementia is defined as dementia that has an onset in individuals under the age of 65. This includes approximately three to five percent of PLWD, totaling 100,000 to 300,000 individuals in the US, and 1.3 – 2.2 million individuals worldwide (AA, 2016; World Health Organization [WHO], 2012). The impact of dementia in the younger population is often intensified due to their active presence in the workforce and the demands of raising a family.

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Individuals with young-onset dementia have been active in sharing their perspective and advocating for recognition and respect (Millenaar et al., 2016).

Types of dementia. Dementia is also defined by its cause. There are over 70 causes of dementia; the most common causes and their rates include:

1. Alzheimer’s disease (55-80% of dementias): A loss of cognition caused by neurofibrillary tangles and amyloid plaques that interfere with normal brain function.
2. Vascular dementia (20% of dementias): A loss of cognition due to lack of blood supply to the brain. This lack of blood supply is related to vascular disease, involving either a series of small strokes or a reduced brain perfusion from narrowed or blocked vessels.
3. Dementia with Lewy body (10% of dementias): A loss of cognition from abnormal clumps of proteins building up in the brain. This type of dementia is characterized by hallucinations and coordination problems with a less prominent degree of memory loss compared to other dementias.
4. Frontotemporal dementia (5% of dementias): A loss of cognition due to atrophy of the frontotemporal regions of the brain. This is more commonly seen in young onset dementia, occurring before the age of 65, with prominent personality changes.
5. Mixed dementia: A loss of cognition stemming from a combination of two or more of the above dementias, often Alzheimer’s disease and vascular dementia. Mixed dementias are most common in people over the age of 85 (AA, 2016).

Survival and cost of dementia. The average time from diagnosis to death is four to five years, but some PLWD survive as long as 20 years post diagnosis. The weight of care for this chronic condition is overwhelming underprepared families, communities, and nations (ADI, 2016; Kenigsberg et al., 2015; Schaller et al., 2015). At number six, dementia is the only

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diagnosis in the top ten causes of death that has no cure or treatment (Kenigsberg et al., 2015). Societal burdens of dementia fall heavily on families. Of the $604 billion allocated to dementia worldwide, much of that funding is for social and personal care needs (e.g. adult day services, support groups, transportation), not healthcare (National Institutes of Health [NIH], 2016; WHO, 2015b). In the US, caregivers of persons living with dementia provided 18.1 billion hours of unpaid care in 2015 valued at a contribution of $221 billion (AA, 2016). The cost of Medicare payments for recipients with the diagnosis of dementia are more than two and a half times that of recipients without the diagnosis, often due to unnecessary hospitalizations (Schaller et al., 2015). These financial and social imperatives imposed by dementia are daunting and further heightened by pervasive stigma.

The Impact of Stigma

The historical context of stigma, social isolation, and inadequate care for persons living with dementia has been under scrutiny for several decades (Kitwood, 1997; Swaffer, 2014). Stigma refers to the "unwarranted stereotype, prejudice, and discriminatory practices against a social group that are widely shared by members of a society" (Cheng et al., 2011, p. 1433). Goffman (1963) first conceptualized stigma and its deleterious effects, noting the social discretization that occurs by members of society as an individual with characteristics outside of what is considered normal is seen as undesirable. Stigma disqualifies an individual from full participation in society, affecting the stigmatized individual, their family, and society (ADI, 2012). When an individual is denied full participation in society, the potential gifts that could have been contributed are lost. Stigma affects individuals in terms of relationships; that is the expectation for behavior or performance versus the actual abilities determines the assignment of

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stigma (Goffman, 1963). The high regard for cognitive prowess in present-day society accentuates stigma in the face of cognitive decline (Post, 2000).

The lack of universally effective medicines has led to the belief that nothing can be done for dementia (Bynum, 2014). In addition, health professionals may be reluctant to provide a diagnosis due to the uncertainty of how to test and treat, and the lack of available disease-modifying therapy (Stewart et al., 2014). For ethical, evidence-based dementia care to extend to all sectors of society, the stigma of dementia must be challenged (ADI, 2012). DFCs often address stigma through community awareness to correct misperceptions (DFA, 2017).

Social Responses to Dementia

Coupled with a disease-focused medical model, the philosophy of positivism has dominated dementia care throughout the past century with a strong focus on a search for a cure or effective treatment (Chaufan et al., 2012; Downs & Bowers, 2014; Kitwood, 1997). In a positivist view, knowledge "must be capable of examination, collection, ordering, in isolation from their context" (Rodgers, 2005, p. 89). This emphasis on an objective and value-free approach to dementia is slowly expanding from the medical model of care to include contextual social and community-based approaches (DFA, 2017; Innes, McCabe, & Kelly, 2012; World Health Organization, 2015b).

Globally, nations have responded to the dementia crisis with the enactment of national plans or strategies that extend beyond healthcare interventions to address the impending monetary and societal burdens (ADI, 2016; Lin & Lewis, 2015). Many European countries, including the United Kingdom, France, the Netherlands and Norway, have been early adopters having had dementia care strategies in place since 2009 or earlier (EFID, 2016; Fortinsky & Downs, 2014). In the US, President Obama signed the National Alzheimer's Project Act in 2012

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which is updated yearly by an advisory council to coordinate research, caregiver support, and education efforts (US Department of Health & Human Services [USDHHS], 2015). National plans, enacted in more than 27 countries worldwide, coordinate government social and healthcare initiatives, develop accountability systems for program outcomes, and perform strategic planning with evidence-based research agendas (ADI, 2016). National plans vary widely, but many include recommendations for DFCs or initiatives targeting social interventions rather than strictly medical (Lin & Lewis, 2015).

National policies are not the only force driving improvements in care and quality of life for PLWD. Grassroots efforts have taken hold nationwide in the US. States from coast to coast, led by Minnesota and Wisconsin, have created their own comprehensive reports to guide legislatures and community organizations to strategically plan for the impending growth of the number of people requiring assistance due to dementia (AA, 2016; Alzheimer's Disease Working Group, 2011; DFA, 2017). Regional organizations such as municipalities, the Alzheimer's Association, the Alzheimer's Society, and civic groups are collaborating to generate local community-based solutions and support that include programs such as accessible transportation, affordable adult day or home care, and increased community awareness (AA, 2016; Alzheimer's Society, 2015; Henwood & Downs, 2014).

Person-centered Dementia Care and Approaches

Since dementia was first recognized as a disease worthy of investigation and funding in the final decades of the 20th century, research has focused heavily, yet thus far unsuccessfully, on the search for a cure (Kenigsberg et al., 2015; Robinson & Corner, 2014). The medicalization of dementia served a purpose in that it provided legitimacy for policy creation and funding (Chaufan et al., 2012). Indeed, dementia became a household word, but many in the dementia

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social movement felt that in the scientific race for a cure, those living with the condition, their care partners, and families dealing with the daily challenges were left behind with little support (Innes et al., 2012; Robinson & Corner, 2014). In that a cure for dementia is not imminent, a shift in focus to improving care, social processes, and well-being is needed (ADI, 2016; Downs & Bowers, 2014).

Kitwood (1997) and Sabat (2001) pioneered the revolution in the recognition of a psychosocial perspective of dementia care. Sabat (2001) described the need for others to uphold the relationships and roles of PLWD to foster social inclusion and recognition (Innes et al., 2012). Similarly, Kitwood's theory of personhood was a ground breaking shift in his view of the person with dementia as a social being in context of a relationship, deserving of recognition as a unique, feeling, and responsive individual worthy of respect and trust, rather than a medical condition to be treated (Kitwood, 1997). Personhood is defined as, "A standing or status bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997, p. 8). Personhood is a broader, yet formative concept in person-centered dementia care.

A similar term, patient-centered care, came into favor in the US near the turn of the 21st century. This term reflects the viewpoint that patients must be intimately involved in healthcare decision-making and outcomes (Committee on Quality Health Care in 21st Century, 2001; Robinson & Corner, 2014). The term *patient* continues to imply a paternalistic relationship between the healthcare system and individual, along with a view of a person in terms of their illness rather than more holistically. Person-centered care, however, connotes an engaged presence of the individual within the system of care (Maslow, 2013).

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Person-centered care, and person-centered dementia care specifically, uphold a holistic focus on emotional, physical, social, and spiritual well-being, respecting the needs and preferences of the person rather than those of the system (Brooker, 2007; Downs, 2014). Personhood and person-centered care principles have formed a theoretical base in numerous dementia care studies to evaluate holistic approaches in dementia care (Brooker, 2007; Chenoweth et al., 2014). Person-centered care is frequently referenced in the dementia friendly initiative literature as a type of DFI undertaken in healthcare settings (Charras, Eynard, & Viatour, 2016; Innes, Kelly, Scerri, & Abela, 2016).

Person-centered care is used commonly within healthcare to simply indicate individualized care, often used without consistent or clear definition. For the purposes of this study, the definition identified in Brooker (2005), composed of four parts will be adopted:

- a value base that asserts the absolute value of all human lives regardless of age or cognitive ability;
- an individualized approach, recognizing uniqueness;
- understanding the world from the perspective of the service user; and
- providing a social environment that supports psychological needs (p. 13).

In the social movement toward supportive care and a humanistic rather than strictly medical approach to dementia, research on person-centered dementia care principles is robust and growing (Reuben et al., 2012). Furthermore, as with DFCs, the expanding focus on promotion of well-being in dementia beyond care settings into community settings, a person-centered *approach* is an increasingly common term, as promotion of well-being can occur both within and without the need for *care* (Lepore & Weiner, 2017).

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An example of the changing perceptions in dementia studies is the use of the term *care partner* to replace the term *caregiver* that signifies the individual responsible for ensuring the health, safety, and well-being of the person living with dementia. In that individuals with dementia are not merely passive recipients of care, particularly in the earlier stages of disease, the term care partner more aptly personifies the relationship as partners working together toward well-being while living with dementia. Care partner will be the term used in this study.

Dementia Friendly Initiatives

Dementia is both a health and social issue, requiring a comprehensive approach (Crampton & Eley, 2013; Wiersma & Denton, 2016). As prominent individuals such as Ronald Reagan, Glen Campbell, and Pat Summit have shared their dementia journey, the term has become increasingly familiar in everyday language. As familiarity and knowledge of dementia grows, the heightened awareness and understanding has the potential to reduce the associated stigma (Crampton & Eley, 2013). Awareness and education have served to chip away at stigma by creating a common understanding through dispelling myths, and thus assuaging fear, a key culprit in stigma (ADI, 2012; DFA, 2017; EFID, 2016).

The shifting of social perceptions allow individuals living with dementia the opportunity to normalize and experience well-being in society, despite the presence of a progressive cognitive decline (Downs & Bowers, 2014). While dementia can be viewed as a tragedy, an alternative more positive perspective is possible that provides hope, supports respect, and facilitates well-being (Rahman, 2014). European countries such as France have called this ‘living well with dementia in the community’ (EFID, 2016, p. 113), and “Living Well with Dementia” as part of the UK’s National Dementia Strategy (Department of Health [DOH], 2009; Rahman, 2014). Well-being includes emotional, physical, and social constructs (Orgeta, Sterzo,

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& Orrell, 2013). In PLWD, this requires attending to relationships, physical health, autonomy, and control (Rahman, 2014; Robinson & Corner, 2014).

Societies are addressing dementia at global, national and local levels with a range of health and social initiatives (ADI, 2016). Titles used to describe such initiatives commonly include dementia friendly, dementia capable, and person-centered dementia care (Lin & Lewis, 2015). This terminology is used interchangeably and therefore requires clarification. Lin and Lewis (2015) noted that *dementia capable* is used primarily within the US related to programs providing support for PLWD. *Dementia friendly* is used in numerous countries typically in terms of the lived experience of PLWD as a service user. *Person-centered dementia care* has a narrower focus on healthcare, rather than the broader experience of living in the community.

With 90% of the dementia friendly literature published after 2005, it is clear that dementia friendly is early in its conceptual evolution. While the term has been criticized as inexplicit and lacking definition, Henwood and Downs (2014) suggest that juxtaposing the words dementia and friendly implies a powerful meaning that balances a much feared syndrome with kindness and understanding.

Dementia friendly initiatives (DFIs) embrace an individualized approach to dementia, focused on promoting dignity, empowerment, engagement, and autonomy to enable well-being of PLWD through all stages of the condition (Crampton & Eley, 2013; Henwood & Downs, 2014). DFIs are varied and flexible enough to impact those in early stage dementia in which individuals are often still actively involved in their community, to end stage dementia, where an individual can no longer speak or walk, and requires total assistance with activities of daily living (ADLs). DFIs stem from the recognition that to live well with dementia requires a holistic approach incorporating social as well as medical interventions (Heward et al., 2016; Innes et al.,

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2012; Tranvag, Petersen, & Naden, 2016). Examples of DFIs include environmental adaptations, increasing awareness to dispel myths and stigma, support groups, community engagement activities for PLWD, and protocols to incorporate evidence-based practice in health and social care settings.

The definitions of DFIs within the conceptual literature resonate with the definition of person-centered dementia approaches. Similarities include cultivating an awareness and understanding of PLWD (Davis, Byers, Nay, & Koch, 2009; Downs, 2013; Henwood & Downs, 2014; Hirst, 2016; Swaffer, 2014), autonomy (Bartlett, 2016; Downs, 2013; Rahman, 2014), meaningful engagement (Henwood & Downs, 2014; Hirst, 2016; Lin & Lewis, 2015; Robinson & Corner, 2014; Swaffer, 2014), and a supportive social environment (Davis et al., 2009; Downs, 2013; Henwood & Downs, 2014; Jenkins & Smythe, 2013; Lin & Lewis, 2015; Rahman, 2014; Robinson & Corner, 2014; Swaffer, 2014). The principles and definitions of person-centered dementia care and DFIs share many elements, tempting authors and practitioners to use the terms interchangeably. Person-centered dementia care has demonstrated significant outcomes in a decrease in behavior symptoms and antipsychotic medication use in long term care (LTC) interventional studies (Li & Porock, 2014), and an increase in quality of life and decrease in agitation in residential care (Chenoweth et al., 2009; Chenoweth et al., 2014). As both concepts become more clearly defined and measureable through practice and research, their meanings will require evaluation for convergence or divergence.

DFIs are developing in countries across the globe, from the United Kingdom, to India, and Australia. Geographical areas undertaking DFIs as a coordinated effort are often labeled as a DFC (EFID, 2016). In July 2015, the White House Conference on Aging announced the inception of a Dementia Friendly America (2017), supporting "communities where all people

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can live, age, and thrive." As diverse regions create dementia friendly communities, the person-centered approach provides a fitting framework on which to build initiatives. Person-centeredness incorporates not only the health care provider and caregiver perspective, but that of the person living with dementia (Downs, 2013; Maslow, 2013). According to EFID (2016), "It is crucial that 'dementia-friendly community' initiatives situate people with dementia at the centre, maintaining a view of them as people, citizens, and equal members of society, not just service users or patients" (p. 6). DFCs expand the role of PLWD from receiver of care to community member.

While few evaluative criteria exist, organizations such as Innovations in Dementia (2015) and the Alzheimer's Society (2015) based in the UK have created guidelines to facilitate the creation of dementia friendly localities. These organizations incorporate the views of PLWD as core components of their programming. ADI (2016) has identified two core objectives of a DFC (a) reduction of stigma and (b) empowerment of people living with dementia. The concept of personhood provides an underpinning of PLWD assuming an integral role in DFC development. The Rowntree Foundation, through an extensive study of communities and views of PLWD similarly identified four cornerstones of a DFC (a) the people, (b) the places, (c) the networks, and (d) the resources (Crampton & Eley, 2013). Individuals and families found the most troubling aspect of living with dementia was the daily attrition of the ability to participate in everyday life (Crampton & Eley, 2013). Studies such as this highlight the social and interpersonal factors that influence well-being in dementia (Kitwood, 1997; Rahman, 2014). Further exploration is needed regarding the creation and evaluation of DFCs to develop consistent language and criteria based in the lived experience of persons with dementia.

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Statement of the Problem

As society becomes increasingly aware of dementia and its societal impacts, PLWD face continued challenges in receiving evidence-based healthcare, person-centered approaches, and social inclusion (Kenigsberg et al., 2015). The potent stigma of dementia has fostered lack of recognition, social isolation, and substandard care (ADI, 2012). The medical model of care still prevalent today fails to capture the complexity of the social, emotional, spiritual, and relationship-based aspects of living with dementia (Brooker, 2007; Chaufan et al., 2012). The social vulnerability of PLWD is present both in institutional and community-based settings (van Gennip et al., 2016). The rapidly growing population of PLWD has sparked the interest of governmental, non-profit, and private organizations to seek solutions to the impending financial and societal impact of need for care and social support (ADI, 2016; Kenigsberg et al., 2015). There is a growing sense of urgency to move dementia friendly principles forward to strengthen the capacity of communities to involve persons with dementia in ways that promote dignity and independence (DFA, 2017; EFID, 2016; Heward et al., 2016). As DFC initiatives take hold across the US, clear and measureable constructs must be identified to ensure adherence to personhood. While studies have examined the perspective of health care professionals and caregivers, a research-based perspective of PLWD is underrepresented in the common understanding behind DFCs (Robinson & Corner, 2014; van Gennip et al., 2016). The views of PLWD are inherently connected with the components of dementia friendly and therefore necessitate exploration to ensure implementation of meaningful initiatives.

Purpose of the Study

The purpose of this study is to explore the meaning of DFCs from the perspective of PLWD. This understanding, derived through qualitative conventional content analysis of

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interviews with PLWD, informs the use of the term as DFCs develop. By investigating the meaning of DFCs through the underrepresented viewpoint of primary stakeholders, the voice of people living with the diagnosis will enhance the credibility and dependability of DFC research. The results of this study inform policymakers, clinicians, and community members how to most effectively and intentionally engage PLWD in the community for sustainable, functional, and meaningful outcomes.

Significance of the Study

PLWD are the primary stakeholders of a DFC. Dementia friendly initiatives have not only the power to improve their lives, but to transform the way the world views dementia (ADI, 2016).

The voices of PLWD have been unnecessarily excluded from dementia related research (Dewing, 2002; Swaffer, 2014; Willis et al., 2009). Actively including PLWD in research creates a moral space acknowledging the joint endeavor between participant and researcher in interpretive inquiry (Brooker, 2007). Despite cognitive changes, PLWD have the right to determine their level of engagement in society, and to be recognized as a whole person with a full and meaningful life (Brooker, 2007; Kitwood, 1997; Swaffer, 2014). PLWD have contributed their perspective in multiple research studies, thereby illuminating previously undiscovered themes (Karlsson et al., 2015; Mazaheri et al., 2013; Resnick et al., 2007; Willis et al., 2009).

Dementia friendly health care settings and greater communities are being created across the world and are a particularly new phenomenon in the United States (ADI, 2016; DFA, 2017; Heward et al., 2016). By understanding the meaning of dementia friendly to persons living with the condition in a local US community, their perspective can be incorporated into initiatives

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reflecting the needs of the citizens. In their overview on the principles of DFCs, ADI (2016) stated, “Only by ensuring that initiatives are inclusive of people living with dementia at all stages of development, will we succeed in giving them the sense of respect, dignity, and purpose they seek.” (p. 10).

Philosophical Perspective

The purpose of inquiry and the subsequent research question serve as foundations for knowledge development (Weaver & Olson, 2006). In this study, the knowledge under exploration is a situated truth, based in the experience of living with dementia (Mazaheri et al., 2013). Such knowledge corresponds with a qualitative design, focused on exploring subjective experiences, understandings, and meanings rather than identification of discrete variables (Creswell, 2013). Research surrounding a holistic view of dementia “...involves assessing the consequences of a pattern of care practice taken as a whole without attempting to subdivide it minutely into separate variables” (Kitwood, 1997, p. 100). Research surrounding DFCs which involves more than only care, should therefore take the same approach, to seek an understanding of the individuals’ life pattern within their community without attempting to preemptively subdivide an emerging phenomenon.

Qualitative approaches search for an understanding emerging from the perspective of persons living in the phenomena (Vaismoradi, Turunen, & Bondas, 2013). The epistemological foundation emerges through open-ended questions rather than prescribed instruments that may limit the responses of the yet to be understood phenomenon (Richards & Morse, 2013). The interpretive paradigm is guided by socially constructed realities with multiple truths. PLWD had the opportunity to present their truth, based on their history, health, and social experiences.

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The choice of a research paradigm is additionally guided by the current state of knowledge in a discipline or practice area (Weaver & Olson, 2006). The philosophy of positivism and post-positivism with the scientist as supreme knower has dominated dementia research throughout the past century (Downs & Bowers, 2014; Kitwood, 1997). This perspective is valuable, however research is increasingly demonstrating that best practices in dementia is not limited to isolated interventions such as medications and LTC placement (Maslow, 2012). Contextualism affects the ontological and epistemological roots of inquiry, moving away from positivism and innate truth toward an interpretive philosophy focused on situated truths (Lincoln & Guba, 1985). An interpretive approach is congruent with the whole person focus of DFCs (Smith, Gee, Sharrock, & Croucher, 2016; Wiersma & Denton, 2016).

The course of dementia can be uncertain and difficult to predict, as an individual's history, health status, and both physical and social environment contribute uniquely to the course of the disease (Kenigsberg et al., 2015). Living with dementia, therefore, is a contextual experience by nature. Dementia must be understood through the lens of those who live it daily (Swaffer, 2014). This contextual nature endorses an interpretive framework for the analysis of DFCs. The inductive nature of qualitative research allows the examination of individual perceptions to detect common themes in an underexplored area with few evaluative tools. The person-centered paradigm with an underpinning of the interpretive standpoint has the power to broadly inform healthcare, social, and community practices (Kitwood, 1997; Li & Porock, 2014).

PLWD must be addressed compassionately and holistically, as beings worthy of acknowledgment, with consideration of the physical, social, and interpersonal implications of interventions (Davis et al., 2009; Swauffer, 2014). Alternative models of living in community with dementia have the possibility of embracing the principles that honor the personhood and

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individual perspective of PLWD (Davis et al., 2009; Kitwood, 1997). These models are situated in the interpretive philosophical framework for PLWD to be heard as valuable stakeholders worthy of acknowledgment despite cognitive disability.

The question of competence to participate in research naturally arises when involving persons with cognitive impairment in a study. Tools exist that assist with evaluation capacity for persons with limited cognition to participate ethically in research (Dewing, 2002; Resnick et al., 2007). The NIH (2009) has defined recommendations for conducting research with cognitively impaired individuals to provide protection for the participants, yet allow their voice to be heard (Resnick et al., 2007). Even with a progressive loss of cognition, the complexity of human experience is not lost in dementia, therefore researchers must expand contributions from PLWD to knowledge development (Dewing, 2002; Gill, White, & Cameron, 2011; Karlsson et al., 2015; Kitwood, 1997; Swaffer, 2014).

The goal of the present inquiry concerns developing an understanding of living with dementia, and the benefit this has on service development as communities strive to become dementia friendly. This research takes a standpoint that every life has value and every person has strengths to share. Through open-ended questioning, PLWD have the opportunity to share the complexity of their interpretation of DFCs to create new ways of seeing existing phenomena (Crampton & Eley, 2013; Richards & Morse, 2013). The emerging and underdeveloped concept of DFCs requires a qualitative inquiry to unveil the yet unseen constructs to be revealed PLWD.

Specific Aims of the Study

This study contains the following aims:

1. To provide an understanding of dementia friendly communities from the perspective of persons living with dementia.

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2. To uncover the attributes of dementia friendly communities for the purposes of evaluation of communities striving to embrace dementia friendly principles.

With these aims, PLWD will have the opportunity to contribute to the evaluation of DFCs.

Research Questions

The research questions are related to the specific aims of the study:

Aim 1: To provide an understanding of living with dementia in the community from the perspective of persons living with dementia.

  a. Research question 1: How are interactions and relationships experienced by persons living with dementia in the community?
  b. Research question 2: How is community engagement experienced by persons living with dementia?
  c. Research question 3: To what extent and in what way does stigma impact the experience of living with dementia in the community?

Aim 2: To uncover attributes of a dementia friendly community for the purposes of development and evaluation of communities or initiatives striving to embrace dementia friendly principles.

  a. Research question 4: What are the attributes of a dementia friendly community from the perspective of persons living with dementia?

Summary

While organizations such as Alzheimer's Disease International (2016) have examined and described key principles of DFCs, the concept of dementia friendly is yet to be discretely defined. As the meaning of dementia friendly emerges, rigorous research discerning the perspective of PLWD regarding dementia friendly is needed, particularly in the US. The

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interpretive philosophy, acknowledging the value of the multiple realities provides a framework to allow their voices to be heard.

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CHAPTER 2

LITERATURE REVIEW

The proliferation of the term dementia friendly in the past 10 years optimistically represents a movement "…from dementia fearful to dementia friendly" (Lin & Lewis, 2015, p. 1). Our understanding of dementia has advanced from an obscure and feared medical condition in the early 20th century known then as Alzheimer's disease (AD), to a public health priority in the 21st century (Chaufan et al., 2012; Kenigsberg et al., 2015).

The growing and multi-faceted effects of dementia on healthcare and society has led to the global evolution of a dementia friendly community (DFC) movement. The perspective of people living with dementia (PLWD) is gaining increasing attention with the advent of person-centered approaches in dementia studies and the acknowledgement of the basic rights of all humans despite cognitive or physical abilities. The perspective of PLWD therefore must be explored as principal stakeholders in the development of DFCs. The ensuing chapter will unfold the evolution of DFCs and need for contributions from PLWD. Through examination of the theoretical base, the developing components of DFCs, social and healthcare considerations, and the entrenched stigma, the imperative to drive this social movement forward will be evident.

Method of Literature Search and Databases Used

An online search of the CINAHL, Proquest, Medline, Google Scholar, and Dissertation and Theses Global databases was conducted using the search terms dementia AND friendly, dementia friendly, dementia friendly communities, dementia capable, Alzheimer's disease friendly, person-centered care AND dementia, stigma AND dementia, and dementia AND environment. The content and reference lists of secured articles were hand-searched for further findings.

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Inclusion criteria included (a) use of *dementia friendly*, (b) peer-reviewed literature or expert recommendation guideline, book chapter, or grey literature reports, (c) English language, (d) published in 2000 or later to include the emergence of person-centered dementia literature. While the process would be more streamlined to evaluate only peer-reviewed published literature and research studies, it would be negligent to ignore the vast amount of evidenced-based DFC reports written by recognized national and global societies, experts in the field of dementia. The collaborative nature of organizations such as The Alzheimer's Society, Innovations in Dementia, and Dementia Friendly America in the local and global sharing of their scrupulous work represents the generosity and inclusiveness sought in DFCs. LTC facilities function as small communities in a geographic location (Davis et al., 2009), and on average at least 50% of their residents are living with dementia (USDHHS, 2015), therefore dementia friendly studies based in LTC settings were included as a community focus.

Exclusion criteria included, brief summary articles of already included studies and reports providing no additional information or perspective, and literature produced before 2000. The concept of dementia friendly is newly and rapidly emerging but the seminal literature from the 1990s of Thomas Kitwood (1997) in the development of the concept of personhood is included in this review due to the foundation it provides for movement away from the medical model of dementia care.

A total of 108 articles and book chapters were reviewed in full through the electronic literature search. An additional 36 reports or white papers were retrieved through secondary sources or Google Scholar and reviewed in full. The recent explosion of literature in the past five years demonstrates the emerging nature of the concept. A search on CINAHL revealed dementia friendly literature beginning in 2012, and a search on Proquest Central revealed

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literature beginning in 2011, with 94% of the literature produced in 2013 or later. Additional references dated back to 2000 were found through secondary sources from articles reviewed and Google Scholar for use as a historical comparison in the DFC movement. In total, 32 articles and reports met the inclusion and exclusion criteria for this review (Appendix C). The preponderance of literature on DFCs has been produced in Australia, Europe, and in particular the UK, with a notable absence of literature from the US. This literature is discussed in detail under the Dementia Friendly Communities section.

Review of Literature

The Economic and Social Costs of Dementia

Looking beyond the dementia friendly specific literature, ADI and WHO (2012) jointly published, *Dementia: A Public Health Priority,* describing the striking epidemiologic and social imperatives stemming from the rising incidence of dementia. An urgent call was placed for nations and communities to collectively and quickly respond to the wide range of public health implications, including cost of care, caregiver burden, and the over-reliance on institutional care. The following excerpt summarizes the stance of ADI and WHO (2012):

> There is little doubt that dementia poses one of the greatest societal challenges of the 21st century that must be addressed internationally, nationally, and locally as well as at family and social levels. Dementia is exceptional in terms of size, cost and impact. (p. 90)

As noted, of the $604 billion in costs attributed to dementia worldwide, much of that expense is for social and personal care needs rather than healthcare, meaning the burden falls primarily on families and communities (Schaller et al., 2015; WHO, 2015b). Dementia is one of the most costly health conditions in the US, similar to estimates of health care expenditures for heart disease and higher than that for cancer (Hurd et al., 2013). Despite this cost, funding for

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dementia research reached only 14% of the cancer research budget (NIH, 2016). The financial and social cost to the healthcare system and to families is far reaching (Bynum, 2014). More than 15 million Americans provided 18.1 billion hours of unpaid care to PLWD in 2015, causing an average loss of 15,000 hours of work for caregivers from their paid employment. The financial insecurity from the cost of care and loss of work causes care partners to ignore their own health care needs, as evidenced by 74% reporting concerns about their own health and a 40% incidence of depression (AA, 2016). Caregiver burden results from the oft found scenario of a spouse or adult child managing work, child care, and dementia care (Long, Moriarty, Mittelman, & Foldes, 2014). WHO (2015b) found that dementia greatly surpassed other chronic diseases in the need for social support and care in low, middle, and high income countries. In low income countries, an even greater burden falls on families due to the lack of a public social safety net (ADI, 2016).

The Alzheimer's Society (2015) calculated that the economic benefit of programs supporting PLWD to live in the community rather than a facility would save at least £55 million/year for each year that institutionalization is delayed in the United Kingdom (UK). In the US, delaying long term care (LTC) placement by one month for PLWD would save $60 million a year (Hurd et al., 2013). These economic realities must remain in the forefront of policy discussions.

The number of older adults, particularly the number of PLWD that live alone is of great concern; current estimates are at one in seven PLWD living alone in the US (AA, 2016). In the UK, PLWD living alone were found to be at a significantly greater risk for unmet needs ($p < 0.01$) compared to PLWD living with others ($p < 0.001$), despite the fact that PLWD living alone having lower levels of dependency (Miranda-Castillo, Woods, Orrell, 2010). PLWD living alone

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had more unmet needs in the areas of looking after the home, food, self-care, and accidental self-harm (Miranda-Castillo et al., 2010).

The Stigma of Dementia

DFC literature regularly identifies the need to challenge dementia related stigma. The challenges embedded within a progressive loss of cognition and function are greatly affected by society’s response. Early definitions of stigma recognized the negative labels assigned to individuals with characteristics outside of societal norms (Goffman, 1963). The stigma surrounding dementia necessitates a clear definition to understand the importance of widespread initiatives in its eradication. Beyond the DFC literature, the WHO (2012) identified the grave presence of stigma in the lives of PLWD and their families, adhering to the following definition: “Stigma is an attribute, behaviour or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one” (p. 7). Stigma creates isolation and shame for those affected, and is a result of a superficial labeling and unjust exclusion of a group of individuals (Burgener & Berger, 2008).

Stigma is pervasive and well documented among PLWD (Benbow & Jolley, 2014; Robinson & Corner, 2014; Swauffer, 2014). In a mixed methods study, Katsuno (2005) examined the quality of life of 23 PLWD in the early to moderate stage of dementia per the Mini-Mental State Exam living in the US. Participants completed a Quality of Life Index (QLI) and several semi-structured interviews. QLI scores of the PLWD were comparable to the general population, and above scores common in individuals with common chronic illnesses (i.e. coronary artery disease, stroke, and cancer). In the semi-structured interviews, the researcher uncovered themes related to perceived stigma from the actions of both healthcare professionals

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and the general public including being devalued, feared, and the loss of friendship. Stigma can be internalized, leading to a negative self-image (Katsuno, 2005). In a methodological review of the literature and the authors' own experience in dementia research, Garand, Lingler, O'Connor, and Amanda (2009) identified numerous challenges to engaging PLWD in research imposed by stigma of the diagnostic label of dementia. Challenges included difficulty with participant identification due to the unwillingness of PLWD to seek evaluation of their cognitive symptoms, reluctance to learn about clinical studies, unwillingness to join a dementia study due to the stigmatizing label, difficulty retaining participants, lack of adherence to treatment protocols, and lack of support for the participants within their social circle. Recommendations for combating these barriers include general public education on dementia, use of non-threatening language and images in recruitment and study material, monitoring for participant burden, and conducting the study in the participant's home or location of choice (Garand et al., 2009). American society in particular places a high value on intellect, independence, and autonomy, making dementia and the loss of self-care abilities contrary to American ideals.

In a more recent study of 50 PLWD and 47 family members, Burgener, Buckwalter, Perkhounkova and Liu (2015) found complex relationships between stigma and quality of life outcomes using the Stigma Impact Scale, demonstrating that many personal and societal variable can impact stigma and quality of life. Due to the greater prevalence of dementia in older adults, the stigma of dementia often occurs in concert with ageism, a negative view of persons due to advanced age (Garand et al., 2009; Milne, 2010). Ageism is widespread, leading to beliefs that inadequacy in cognition and function are an assumption of aging. In an ethnographic study of 309 residents of assisted and residential living, several sources of stigma surfaced including ageism, stigma due to disability, and stigma of a residential living setting (Dobbs et al., 2008).

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When older adults are assumed to lack decision making capacity simply due to age or a change in function, autonomy and dignity are compromised (Katsuno, 2005). In an electronic cross-sectional survey of 616 healthy adults investigating attitudes of middle-aged (40 – 65 years of age) Australians on dementia, three reactions to perceived stigma were revealed: personal avoidance, fear of labeling, and fear of discrimination (Phillipson, Magee, Jones, & Skladzien, 2012). Examination of demographic factors identified men ($p = 0.001$) and individuals with lower levels of education ($p = 0.03$) scored higher on personal avoidance. The stigma that occurs in dementia is ageism in its most extreme form (Kitwood, 1997).

Stigma has many negative outcomes, most notable are the barriers to diagnosis and treatment, fragmented and poor care quality, and social isolation (ADI, 2012; Benbow & Jolley, 2012; Garand et al., 2009; Milne, 2010). In a nationally representative community-based cohort study of 845 older adults, 55% of the 297 individuals with dementia had not been screened for cognitive impairment by their primary care physician (Kotagal et al., 2015). In these situations, the lack of diagnosis denies families and individuals the autonomy of advance care planning for healthcare, financial decision making, and quality of life issues. Health professionals may hesitate to diagnose dementia due to the stigma associated with the illness, their lack of training in mental status testing, and the uncertainty of treatment options (Moore & Cahill, 2013; Vernooij-Dassen et al., 2005).

When a dementia diagnosis is provided, it often usurps decision making capacity and personhood from individuals even in the early and middle stages when capacity remains (WHO, 2012; Swaffer, 2014). The prevailing stigma leaves individuals and families reluctant to seek a diagnosis or assistance due to shame (Milne, 2010). The hopelessness that nothing can be done for dementia leads to a delay in seeking treatment until a crisis occurs. Individuals are then

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denied the autonomy to engage in advance care planning and healthcare decision making, exerting a strain on the healthcare system and individuals that must serve as proxies in crises (Benbow & Jolley, 2012). Low priority is given to dementia care services with funding far below that of less common conditions (Vernooij-Dassen & Jeon, 2016).

Courtesy stigma, family stigma, or stigma by association involves feelings of shame and disgrace of those in close relationship with PLWD (Werner, Mittelman, Goldstein, & Heinik, 2012). A correlational study of adult child caregivers in Israel examined the effect of caregiver burden as measured by the Zarit Burden Interview Short Form, on family stigma as measured by the Family Stigma in Alzheimer's Disease Scale. The investigators found that stigma of caring for a parent with dementia added 18% to the explained variance over and above the other covariates in caregiver burden (Werner et al., 2012). The stigma led the caregivers to distance their parent from others, and in doing so spent fewer hours providing care to their parent. By reducing stigma, caregiver burden may be lightened by increasing the likelihood of seeking and receiving help, and reducing the feelings of shame and isolation. Professional caregivers similarly suffer from negative stereotypes that they are unworthy of more competent healthcare roles (Benbow & Jolley, 2012)

Impacting Stigma. The first step in reducing stigma is awareness. Misconceptions perpetuate stigma (Milne, 2010). All sectors of society benefit from increasing dementia awareness including the healthcare community, schools, faith communities, social services, and businesses. Clearing up misconceptions through planned education is thought to combat stigma by elimination of persistent stereotypes (Duffin, 2014; Swaffer, 2014). In a randomized controlled trial (*n* = 504) in a Chinese community in Hong Kong, Cheng et al. (2011) measured the presence of stigma in participants after reading one of two separate brief dementia-related

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scenarios compared to a control group with no scenario. They found that dementia-related stigma was lower in both groups ($p < 0.002$) that read a dementia scenario before the stigma assessment, demonstrating that even brief exposure to basic information on dementia had a significant effect on stigma. Higher education levels were also significant for a reduction in stigma ($p < 0.03$). A community knowledgeable about dementia is better able to contribute to the well-being of persons living with dementia through substantiated interventions based in understanding rather than fear (McIntyre, 2003). Education on basic dementia information and positive ways to interact have proven effective in varied settings, from healthcare to community, and from formal to spontaneous (Kenigsberg et al., 2015; Henwood & Downs, 2014). Once the misconceptions are dispelled the fear underlying the stigma dissipates.

More positive conceptualizations about dementia are needed (Henwood & Downs, 2014; Innes et al., 2012). The media contributes to the stigma in dementia through the cultural creation of negative stereotyping (Gilliard, Means, Beattie, & Daker-White, 2005). Transforming the persona of dementia as a dark, dismal, and hopeless condition to a life with possibilities of well-being will help to manifest this change (Benbow & Jolley, 2012). Persons with dementia are often portrayed in the late stages, dependent in all activities of daily living and unable to communicate. Reframing dementia through positive media exposure is possible, such as publicizing literature picturing PLWD with affirmative phrases (Van Gorp & Vercruysse, 2011). Challenging stigma is of great importance to living well with dementia for all community members affected by dementia, not only those with the diagnosis (Benbow & Jolley, 2012; Van Gorp & Vercruysse, 2011). Stigma can be impacted by increasing knowledge and role modeling positive interactions.

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Creative and engaging ways to bring the topic of dementia to the public in a positive light are needed to normalize dementia. In community awareness endeavors, promoters of DFCs must impart not only how society can support PLWD, but what PLWD can contribute to society. PLWD can be found in every community continuing their careers, actively volunteering, and living life fully (WHO, 2012). Just as social media, billboards, and public service announcements highlight cancer survivors actively involved in life, PLWD can be featured in engaging promotional campaigns to dispel the prevalent stereotypes of PLWD as unable to interact with others or contribute to society. Inviting PLWD to speak at awareness events not only recognizes their expertise but also humanizes the experience of living with dementia (Henwood & Downs, 2014). Short videos of local PLWD sharing their both their challenges and their examples of living well can heighten awareness and stimulate a local response (DFA, 2017). These messages can be embedded within growing successful aging campaigns such as *Disrupt Aging* advocated by AARP, a discourse on living life fully and combatting unnecessary negative stereotypes of aging (Jenkins, 2016).

The reduction of stigma through awareness efforts has been included in the national dementia plans of many countries such as France, Australia, England, and the US. This is an important step in the use of policy as a pivotal player in the fight against stigma (Milne, 2010; WHO, 2012). For ethical dementia care to be extend to all sectors of society, the stigma of dementia must be challenged on many levels to enact a fundamental shift in societal attitudes (Milne, 2010; Watchman, 2016).

Dementia Friendly Communities

A growing global response to the wide range of needs of both aging and dementia has been the formation of DFCs to reach beyond best practice in a clinical setting toward an entire

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societal movement. The implementation of DFCs has the potential to ease what could amount to a public health crisis through a comprehensive societal response rather than an isolated medical intervention (Lin & Lewis, 2015). As Innes et al. (2012) reminds us:

> How we approach dementia, and what our starting point is, whether professionally and/or academically or as a policy maker, will have an impact on how we see the 'problem'; how we might try to approach it; and how we might try and respond to it or look for a solution. (p. 32)

DFCs emerged from the age-friendly community movement begun globally by WHO and adopted in the US by AARP, responding to the population growth of older adults through an active aging philosophy that focuses on quality of life as people age (AARP, 2016; Turner & Morken, 2016). Age-friendly principles have provided a structure from which to organize community dementia initiatives (DFA, 2017). The use of the term *dementia friendly* began as a vague and undefined concept in the first decade of the 21st century, focused on the physical environment in both national plans and academic literature, often directed at the healthcare setting (Bartlett, 2016: Lin & Lewis, 2015). When used in the more recent context of community, *dementia friendly* reflects a broader and more holistic approach. Current definitions of DFC reveal consideration of both the physical and social realms of individualized approaches. The DFC definitions in the reviewed literature are consistently comprehensive with use of positive terminology encompassing autonomy, dignity, empowerment, enablement, engagement, inclusion, independence, safety, support and understanding for PLWD and their care partners (DFA, 2017; EFID, 2016).

DFCs are emerging throughout the world, each corresponding to the needs, strengths, and unique context of their culture (ADI, 2016). National governments exhibit varied levels of

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involvement in DFCs, ranging from nationals plans with direct funding and oversight in the UK, to no national involvement, leaving individual communities to create local independent responses (ADI, 2016). Many countries fall somewhere in between the two strategies with regional and local governments and organizations providing leadership. Several robust reports have been generated from organizations with dementia expertise to examine the development of DFCs throughout Europe. These reports reveal a varied and extensive number of DFCs in countries ranging from Belgium to Sweden (Alzheimer Europe, 2015; EFID, 2016).

As dementia is increasingly recognized as a public health crisis in the United States, organizations such as Dementia Friendly America (2017) are developing toolkits for locally developed solutions. The backbone organization of Dementia Friendly America is the National Association of Area Agencies on Aging. Many of the solutions offered reflect person-centered approaches. While varied in focus, DFC initiatives strive to improve the quality of life for all people affected by dementia, those with and those touched by the condition (Lin, Becker, & Belza, 2015). Like any emerging social movement, a strong research base has yet to be established for DFCs (Bartlett, 2016). Theory is rarely mentioned in DFC studies or reports.

Theoretical Underpinnings of Dementia Friendly Communities. To determine a direction for practice and research, it is important to investigate the presence of a theoretical foundation for this quickly growing social movement. While DFCs do not currently have a consistent theoretical underpinning, four theories have been discussed as relevant to DFC literature (a) personhood and person-centered dementia approaches, (b) the social model of disability, (c) human rights and citizenship, and (d) the environmental press model.

Personhood and person-centered dementia approaches. A new perspective of dementia arose in the late 1980s. Kitwood (1997) and Sabat (2001) pioneered the revolution in the

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recognition of a psychosocial perspective of dementia care. Sabat proposed that the loss of cognition in dementia did not mean the loss of self or relationships, rather, PLWD have the need for others to uphold their relationships and roles to foster social inclusion and recognition (Innes, 2012; Sabat, 2001). Similarly, Kitwood's theory of personhood altered the common practice of viewing the person with dementia simply as a medical diagnosis. Personhood instead, positions PLWD as social beings in context of a relationship, deserving of recognition as unique, feeling, and responsive individuals worthy of respect and trust (Kitwood, 1997).

Personhood and person-centered principles are an integral and leading focus in university based dementia studies and research centers across the world, notably the University of Bradford (2017), home of the Centre for Applied Dementia Studies, the University of Stirling, home of the *Dementia Services Design Centre* (DSDC, 2013), and the University of Worcester (2016), home to an international organization, *Global Action on Personhood in Dementia*. Additionally, the Dementia Action Alliance (DAA, 2014), a global dementia advocacy organization, advocates for person-centered dementia support which they define as:

> …based on the fundamental belief that every person has a unique background, skills, interests, and the right to determine how to live his or her own life. Person-centered dementia support is focused on nurturing the person's emotional, social, physical, and spiritual well-being. This is achieved through reciprocal, respectful relationships by (a) valuing personal autonomy, choice, comfort and dignity, (b) focusing on the individual's strength and abilities, (c) enabling opportunities for continuation of normalcy and growth of self; and (d) enhancing individual purpose, meaning, enjoyment, and belonging. (DAA, 2014, p. 15)

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Li and Porock (2014) found through narrative analysis that person-centered care positively influences the behavioral and psychological symptoms of dementia (BPSD), thereby decreasing psychotropic medication use. Psychotropic medication use has dangers for older adults and is discouraged for treatment of BPSD (Kales, Gitlin, & Lyketsos, 2014). Many experts agree that a broadened understanding of dementia is slowly occurring, moving from a strict medical model to increasing recognition of social influences on health requiring a holistic bio/psycho/social/spiritual approach (Alzheimer Europe, 2015; ADI, 2016; Chaufan et al., 2012; DAA, 2014; Downs, 2013). The many disciplines involved in dementia and the knowledge required to improve the lives of PLWD are epistemologically strengthened when connected by the integrating nature of person-centered approaches (Innes, 2012; Maslow, 2013; Risjord, 2010).

Metrics have been created to evaluate improvement in outcomes of quality of life related to the use of person-centered care in dementia (Brooker, 2005; Passalacqua & Harwood, 2012). The first and most comprehensive, dementia care mapping, was designed by the School of Dementia Studies, a world-renowned center of excellence (Brooker, 2005; University of Bradford, 2017). In dementia care mapping, extensive observations identify contributors and detractors to quality of life and person-centeredness of dementia care (Brooker, 2005). Other less time consuming, yet valuable, guidelines to evaluate person-centered dementia care are being developed to allow facilities, healthcare practices and organizations to mark their progress and embed the principles into their culture (Downs, 2013). Randomized cluster trials have demonstrated significant reductions in resident agitation ($p < 0.002$) with staff training in person-centered care (Chenoweth et al., 2014). It is widely recognized that an organizational framework including managerial support and time for the development of relationships further ensures

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adoption and sustainability of person-centered care (Chenoweth et al., 2014). Person-centered care is increasingly being used as a conceptual measure of care quality in various settings. Personhood and person-centered approaches share common components with DFCs including a holistic and individualized approach, inclusion and empowerment, and engagement and relationships.

Social model of disability. In this model, society is viewed as contributing to disability by not providing adequate supports or compensation to fully accommodate for an individual's physical or mental impairment. Dementia is conceptualized not only as a medical or social condition, but also as a disability. When viewed as a disability, the lack of societal support offered to PLWD is viewed as accentuating or worsening the condition. This alternative approach provides hope beyond medicine's inability to 'fix' dementia. Society can instead elevate the status of PLWD by shifting attitudes and offering services to support their full inclusion and contribution (Milne, 2010). The Americans with Disabilities Act of 1990 (1990) was founded on this principal, with a focus on physical disability. Dementia advocates reason that cognitive impairment should be viewed as a disability similarly deserving of community support (Gilliard et al., 2005). Just as people with physical impairments are legally provided with wheelchair ramps and automatic doors in public places, so should PLWD be provided with accommodations for their cognitive impairments. Most of the needed assistance involves basic awareness and understanding to realize modest environmental and communication changes (DSDC, 2013; Mitchell & Burton, 2010). The social model of disability positions PLWD as valued members of their community. Henwood & Downs (2014) identify the expansion of DFCs as aligning closely with the social model of disability.

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Human rights and citizenship. In a review of recent citizenship studies, Bartlett (2016) examined the relationship between citizenship and dementia and stated, "…the notion of a 'dementia friendly community' is in its infancy and 'undertheorized', so the challenges of realizing it have yet to be fully scoped or invoked" (p. 456). The theory underlying a social issue often drives policy because theory forms how the issue is viewed (Innes, 2012). As the theory underlying expanding models of dementia care in community are examined and explored, basic rights of PLWD as citizens surface.

The conception of DFCs expands dementia models beyond the realm of medical and social care into a community responsibility surrounding rights to citizenship and well-being (Bartlett, 2016; Henwood & Downs, 2014). Downs and Bowers (2014) explain that without a focus on human rights and citizenship, living well with dementia is not achievable. Bartlett (2016) illuminates the connections between the concept of citizenship and the current climate in which DFCs are developing. The challenges include not only obtaining governmental support, but also the daily injustices of exclusion and loss of dignity faced by PLWD living within their homes and communities (Bartlett, 2016). Swaffer (2014), diagnosed with young onset dementia, advocates that PLWD have as much of a right to access services and to participate in the community as do other members of society.

The human rights framework holds a significant position in the DFC literature, demanding inclusivity and autonomy for PLWD (ADI, 2016; Charras et al., 2016; Mitchell, 2012; Swaffer, 2014). The *Charter of Rights for People with Dementia and their Carers in Scotland* (Alzheimer Scotland, 2009) clearly outlines the rights of PLWD to participation, accountability, legality, non-discrimination and equality, and empowerment based in an approach endorsed by the United Nations and approved by the Scottish Parliament (Alzheimer

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Scotland, 2009). The WHO (2015a) strongly advocates that PLWD and their families are worthy of the dignity of universal human rights so often denied through actions such as improper use of restraints and medication leading to lack of autonomy. PLWD have a right to information, basic community services, and to be heard in a meaningful way (WHO, 2015a). The concept of human rights appears in the US National Plan for ADRD under the goal of 'maintaining the dignity, safety, and rights of people with AD" addressing elder abuse, long term care resident rights, and supportive home and social programs (USDHHS, 2015, p 41). Human rights in dementia is widely supported from international to local community levels. All of the frameworks encompassing dementia care and potentially DFCs involve an individual's relationship with others and their environment.

Environmental press model. The environmental press model (EPM) provides a theoretical framework with which to evaluate the interaction of a PLWD within their environment (Lawton, 1985; Lichtenberg, MacNeill, & Mast, 2000). The personal competencies of an individual can be evaluated against the variables presented in the environment i.e., environmental press (Lawton, 1985). Physical, functional, affective, and cognitive abilities constitute personal competencies (Lichtenberg et al., 2000). When the demands of the environment are easily met by the individual's competencies, there is optimal fit (Charras, Eynard, Viatour, & Fremontier, 2011). When there is a mismatch of the environmental demands and the abilities of an individual whether physical or cognitive, maladaptation occurs (Charras et al., 2011). Both too little and too much stimulation and support in the environment can have negative consequences for PLWD (Charras et al., 2016). Similar to the social model of disability, EPM recognizes outside forces as supportive or inhibitive of well-being in dementia. A randomized clinical trial in France based on the EPM found that simultaneous changes in both

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the physical and social environment in eight special dementia care units (n = 63 PLWD) were significantly more effective in improving quality of life scores, rather than adapting only the physical or social situation (Charras et al., 2011). Although the authors reported findings were significant, they did not include numerical values (i.e. *p* values) to the statistical significance. Application of EPM in a residential care facility or the community has the ability to enhance dementia friendliness through systematic adaptation of the environment to meet the abilities and cultural standpoint of PLWD (Charras et al., 2011). Shifting the theoretical base of dementia away from the narrow medical model of care to these more inclusive and holistic social models supports the development of DFCs.

Components of Dementia Friendly Communities. Few research studies exist that specifically address the overarching concept of a DFC. In a study of the dementia friendliness of the city of York, Crampton and Eley (2013), identified core components of a DFC through qualitative interviews and observation. The framework of people (aware and supportive), places (clarity and familiarity), networks (professional and non-professionals working together to support PLWD), and resources (health, social care, businesses) summarize their findings on investigating a DFC, resounding with 'what is good for dementia is good for everyone" (p. 57). The interviews of community members included PLWD who reported a desire to remain engaged in their community in usual activities. Similar results were found in a qualitative study conducted during the post-earthquake rebuilding in Church Christ, New Zealand (Smith et al., 2016). Public officials sought broad input of PLWD self-identified as memory problems and dementia about their lives and how they wish to engage in community. Thematic coding of 26 interviews of PLWD produced themes of supporting connectedness and engagement, having services that understand and accommodate those living with dementia, and a community where

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the physical environment is accommodating and enabling for spending time in outdoor spaces. Their responses resounded with the importance of their inclusion in community life, supported by widespread desire for dementia awareness among local citizens.

While there is “no one recipe for success” (ADI, 2016, p. 5), leading dementia advocacy organizations recognize several key principles common to the formation of DFCs around the world. The emphasis on each component varies depending on the needs and resources of the local region (ADI, 2016). Organizations that have identified components or criteria for DFCs include (a) the Alzheimer’s Society foundation criteria for a beginning DFC, (b) the ADI/WHO (2016) collaboration on principles of a DFC, (c) the British Standards Institute (2015) in collaboration with the Alzheimer’s Society, created a Code of Practice for recognition of DFCs in England, (d) Dementia without Walls (Joseph Rowntree Foundation, 2012; Innovations in Dementia, 2015), (e) DFA with ACT on Alzheimer’s (DFA, 2017), and the European Foundation’s Initiative on Dementia (EFID, 2016). To become dementia-friendly, a community addresses the needs and aspirations of PLWD across several domains, which are addressed in detail below.

“Mapping Dementia Friendly Communities across Europe”, published as a white paper, was commissioned by the EFID (2016) and administered by the Mental Health Foundation in the UK. Communities across Europe were identified through the literature, national plans, and web searches to interview for their experiences in dementia friendly practices. The investigation resulted in an extensive compilation of diverse DFCs that serve as a hallmark to the contextual nature, yet consistent underlying themes supported in the following components.

Awareness and education. Clarifying myths and promoting understanding about dementia is a universal component of DFCs. ADI (2016) clearly states that reducing the stigma

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of dementia through campaigns to raise awareness is a primary objective of DFCs. Campaigns are underway worldwide, from India, Australia, across the US, Europe, and Asia (ADI, 2016). It is importance to convey that dementia is not a normal part of aging, therefore when an individual displays possible signs of dementia, community members should know how to enlist support for diagnosis and intervention. All sectors of society benefit from dementia awareness, not only the health care community, but schools, religious organizations, and businesses (DFA, 2017).

In an exploratory study of faith communities (*n* = 51), Plunkett & Chen (2015) used a Likert scale (response of 1 = strongly disagree; 5 = strongly agree) and an open-ended questionnaire via a postal survey to identify ways that churches supported PLWD and the resources they required to better support the social integration of PLWD and their caregivers. Faith communities self-identified a need for dementia education by answering the question, “Our staff has adequate preparation to work with dementia” (x = 2.64 urban; x = 2.73 rural setting). They also identified a need for education on the local resources available to help members with dementia on the same scale (x = 3.24 urban; x= 3.5 rural). Lack of resource awareness is common (DFA, 2017; DiGregorio, Ferguson, &Wiersma, 2015).

Page, Innes, & Cutler (2015) conducted a qualitative exploratory study using semi-structured interviews of business owners (*n* = 20) in a UK coastal tourist town to (a) identify the feasibility of developing dementia friendly products and experiences based on the business owners’ understandings about dementia, (b) identify barriers to dementia friendly practices that require attention of policy makers, and (c) examine the extent that the innovation of dementia friendly travel can exist within establishment of a DFC. The investigators found limited awareness and misconceptions on basic dementia facts influenced business owners’ attitudes and willingness to make adaptations for PLWD. They also found previous exposure to dementia

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softened attitudes toward a more understanding approach as opposed to those having no experience with PLWD. Pilot sites committed to dementia friendly tourism was recommended along with easy access to web portals for both education of businesses and referral sources for the public.

Many DFCs create information packets in hard copy or online to make resources more accessible. Communities have found that education clears up misconceptions and thus combats the stigma surrounding dementia to eliminate persistent stereotypes that assume all PLWD are unable to reason, enjoy conversation, and or participate in self-care (Swaffer, 2014). A community knowledgeable about dementia is better able to contribute to the wellbeing of PLWD through substantiated interventions based in understanding rather than fear (ADI, 2016; WHO, 2015a).

The Alzheimer's Society (2015) began an awareness program called *Dementia Friends*, which is utilized in many countries, with the UK and Japan reaching goals of more than one million dementia supporters trained (ADI, 2016). The program is offered both online and in person, and expanded to DFA in early 2017. This 60 minute program provides the learner with a basic understanding of brain changes in dementia, a glimpse into what it is like to live with dementia, along with helpful interaction skills to provide supportive yet not demeaning assistance (Alzheimer's Australia, 2013; DFA, 2017). Henwood and Downs (2014) state, "In our work, we have found that what matters most to people living with dementia is other people's attitudes" (p. 21). The Alzheimer's Society (2015) and others engaging in awareness programs have found even short sessions can have a profound effect on conceptualizations about dementia (EFID, 2016).

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Incorporating younger age groups in dementia awareness campaigns will contribute to DFC sustainability (Innovations in Dementia, 2015). Numerous European communities have intergenerational programs in schools and youth community initiatives receiving positive responses (Alzheimer Europe, 2015). Fewer caregivers will be available as our population ages, which demands that younger generations have the knowledge and skills to compassionately and effectively work within the DFC movement (WHO, 2012). In the UK, the city of York partnered with Plymouth University toward the dementia-friendliness. Other countries can similarly encourage universities to adopt service learning and educational programs to work toward municipal change (Crampton & Eley, 2013).

Increased awareness of dementia offers the opportunity for early diagnosis. Recognition of the common signs of dementia constitute an important part of awareness both in the healthcare sector and the community. An early diagnosis allows individuals the opportunity to obtain support and access to formal services (Iliffe et al., 2012). Education offered early in the diagnosis has been shown to reduce overly aggressive interventions near the end of life, saving moral distress for the family and health care staff, discomfort for the PLWD, and unnecessary costs to the health care system (Bynum, 2014; Kane & Cutler, 2015). Without awareness, the degrading and isolating stigma of dementia will prevail (Innovations in Dementia, 2015). Communities embarking on the DFC journey find that combining an engaging assessment process with awareness is successful by sharing signs and symptoms of dementia and myths, while evaluating dementia-related knowledge, attitudes, and resource awareness (DFA, 2017).

Adaptation of the physical environment. The physical environment has garnered significant attention in the development of DFCs, positioned as the most prominent and tangible attribute in the dementia-friendly literature. Environmental design research is demonstrating

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positive outcomes in the influencing the ability of PLWD to safely maximize independence in the face of cognitive decline (Marquardt, Bueter, & Motzek, 2014; Milton, 2012; Mitchell, 2012). Emerging empirical data suggests that design is an important consideration in a DFC (DSDC, 2013; Fleming, Bennett, Preece, & Phillipson, 2017; Mitchell, 2012). Evidence-based tools such as the Dementia Services Design Centre (DSDC, 2013) audit tool and the Dementia Friendly Community Environmental Assessment Tool (DFC EAT), discussed below, provide guidance for evaluation of indoor living arrangements and outdoor spaces (Fleming et al., 2017; Hadjri, Faith, & McManus, 2012; Mitchell & Burton, 2010). Numerous articles address the importance of safety and comfort in the physical environment (Boex & Boex, 2012; Davis et al., 2009). Design principles can be applied on several environmental levels, from function and maneuvering in indoor spaces, to neighborhood wayfinding to promote aging in place and community engagement (Mitchell & Burton, 2010). Safety features include attention to the visual-spatial changes that accompany dementia with elimination of door thresholds for fall prevention, color contrast for steps and doors, and movement sensitive lighting. Indoor design can be simply adapted by interventions such as clear or removal of cupboard doors to allow easy visual access of contents, easily visible toilets, and rooms with purposeful furniture to trigger recognition (DSDC, 2013).

In a scoping review, Parke (2017) found a lack of empirical evidence for dementia friendly design in acute care, demonstrating the challenge healthcare personnel face in providing safe and evidence-based care to PLWD. The DSDC criteria was used to assess the dementia friendliness of the physical design of nursing and care homes in Northern Ireland through completed questionnaires by facility staff (Hadjri et al., 2012). The 45% response rate from facilities ($n = 53$) found that nursing homes (68%) align better with DSDC design criteria than

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did residential care homes (32%). This may be due to the heightened regulations present in the nursing home industry. The main deficits in design features were (a) safe, accessible enclosed outside space, (b) signage, (c) toilet and bathroom design, (d) removable mirrors, and, (e) discreet storage space.

Maheniran and Dodd (2009) conducted an audit of care homes (n = 259) in the UK to determine their compliance with the DSDC checklist. They found 97% of care homes could be adapted to be dementia friendly with only minor changes for early stage dementia, 61% could be suitable for moderate dementia, and 14% could be suitable for late stages. Suggested changes included a secure outdoor garden, additional signage, and adaptation in furniture. By making the environment easier to navigate, the PLWD maintains independence and a sense of well-being (Robinson & Corner, 2014).

The design of the facility impacts the ability of PLWD to move independently with purpose within a LTC facility (Boex & Boex, 2012; Mahendiran & Dodd, 2009). Traditional LTC design composed of long hallways with similar doors, glaring floors, and difficult to reach outdoor spaces are contrary to current DF design principles (Mitchell, 2012). A setting that facilitates wayfinding with provision of environmental cues and reduction of environmental clutter clinically appears to facilitate independence (Marquardt, 2011). Important design features to facilitate wayfinding in LTC include a straight circulation system with no changes in direction ($p = 0.05$ in moderate dementia; $p = 0.001$ in severe dementia), one live-in kitchen rather than several ($p = 0.01$ in moderate dementia; $p = 0.001$ in severe dementia), and access to the outdoors through the living area ($p = 0.041$ in severe dementia) (Marquardt & Schmeig, 2009).

Four overriding principles of wayfinding in a dementia friendly LTC environment were identified as facilitative (a) do not require the use of new skills or complex interpretation,

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geometrically simple rooms and simple layouts, (b) allow visual access and overview so PLWD do not have to think abstractly, (c) reduce decision making by limiting cross road decision points, make environmental anchors obvious, and (d) increase architectural legibility (Marquardt, 2011). Additionally, fewer residents and a smaller-sized living area tailored to the interests of residents contribute to better wayfinding and well-being (Jenkins & Smythe, 2013; Marquardt & Schmeig, 2009). This occurs in Hogewey, a novel LTC "village" in Holland composed of small personalized homes of less than 10 residents each, with community amenities such as grocery shopping and a movie theater available to residents (Davis et al., 2009; Jenkins & Smythe, 2013). The founders valued the ability to honor individuals' unique personhood and dignity. A lower use of antipsychotic medication is reported although specific data are not available. Rethinking the culture of complete risk avoidance versus allowance of freedoms for well-being is necessary but creates a balancing act for caregivers (Jenkins & Smythe, 2013). Above all, the experience of PLWD should frame both the design and philosophy of care (Davis et al., 2009).

In qualitative studies, PLWD reported value in the ability to access outdoor spaces for physical and mental health (Crampton & Eley, 2013; Mitchell & Burton, 2010; Smith et al., 2016). Theoretical environmental design principles for neighborhood-based solutions include signage with photos, transport systems that allow easy and safe movement, child play areas mixed with elder focused areas to support intergenerational relationships, appropriate use of colors and contrast, and noise reduction to accommodate for sensory changes (DSDC, 2013; Mitchell, 2003; Mitchell & Burton, 2010). These environmental modifications, often quite simple, have the potential to allow PLWD to age in place and avoid the increased cost to families and societies of unwanted nursing home placement (Pantzartzis, Price, & Pascale, 2016).

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Fleming et al. (2017) created the DFC EAT, a 37-item tool based on an extensive literature review, an iterative review process by interdisciplinary dementia experts, and field testing by experienced environmental auditors and PLWD in Australia. Preliminary results demonstrate an interrater reliability of 0.57 – 0.90, and an internal consistency of 0.59 – 0.82 ($p < 0.030$). The six building types evaluated followed by their total mean EAT scores included banks (66%), council buildings (44%), shopping malls (64%), medical clinics (65%), small shops (64%), and supermarkets (52%). Further use of the tool has not yet been reported. The tool could serve as a method for dementia friendly organizations to measure their success and communicate needed environmental changes to businesses.

Mitchell & Burton (2010) studied both PLWD ($n = 20$) and a control group of older people without dementia ($n = 25$) to determine how local neighborhoods could be adapted so PLWD could continue to get out and maintain a quality of life. The researchers interviewed the participants, accompanied them on walks for observation, and evaluated their neighborhoods with specially designed research instruments. Significant findings for PLWD ($p < 0.05$) included the importance of clarity of use and function in design of buildings, lack of use of public or personal transportation, and visiting only one place in a trip. Examples of suggested design modifications are signs with pictures, familiar cues such as mailboxes and benches, and minimal crossroads to decrease decision points. Open spaces with clear visual access to toilets and other common sites supported wayfinding (Mitchell & Burton, 2010). Distinct buildings that are familiar and recognizable are preferred over non-descript buildings without design variation (Crampton & Eley, 2013; Mitchell & Burton, 2010).

A dementia friendly building design can be functional for both PLWD and people without dementia, as investigated in a qualitative study by McCabe and Sim (2006). The

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dementia services program moved to a new facility constructed with dementia friendly design principles. The staff members interviewed were initially wary about a dementia friendly open floor plan but adapted successfully. An identified theme was the pride expressed by staff in having a dementia friendly building to serve their community. Similar results of pride were found by Crampton & Eley (2013) in interviews of the people of the York (England). The framework of people (aware and supportive), places (clarity and familiarity), networks (professional and non-professionals working together to support PLWD), and resources (health, social care, businesses) summarize their findings on investigating a DFC.

Dementia friendly environmental design has been studied in multiple settings. A notable 73% of environmentally focused dementia friendly studies have been published within the past five years. The instruments appear promising yet require psychometric testing in diverse settings. The recommended interventions must be more rigorously evaluated for effectiveness in improving function and well-being.

Environmental changes require an accompanied change in care processes (i.e. person-centered care) and interactive skills of caregivers and community members to create the holistic approach required in a DFC (Bartlett, 2016). When combined with an understanding and well-informed community, the built environment has the potential to enhance well-being of PLWD (Charras et al., 2016; Mitchell, 2012). The larger dementia friendly context must not be swept away in the environmental design efforts that concretely allow a quick fix rather than a more comprehensive paradigm shift in care.

Well-being in dementia. As society shifts away from a singular focus of dementia as an illness in need of cure viewed from the lens of the care provider, new dimensions in communities can be envisioned. Having the courage to view life from the lens of PLWD opens opportunities

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for novel approaches to dementia care (Innes et al., 2012). In an ethical examination of how people with Alzheimer's disease are treated by society, Post (2000) states, "Persons with AD count, and we should be devoted to the well-being of persons living with dementia throughout the course of their illness, including a natural and peaceful dying" (p. 3). This approach to well-being can be extended to caring in community (McIntyre, 2003). The components of a caring community focused on well-being are embedded within a DFC framework. DFCs are created not only to care for and support PLWD, they are created to empower individuals and their families to live well (ADI, 2016; Alzheimer's Society, 2015). PLWD live an average of eight years post diagnosis, with many living up to twenty or more (AA, 2016). The survival rate of PLWD post-diagnosis will likely only increase as chronic care management improves, therefore the opportunities to enhance well-being in PLWD must be further explored (Nyman & Szymczynska, 2016). The EFID (2015) study of DFCs across Europe, as discussed above, found that several projects embrace well-being as a programmatic goal. France, an early adopter of DFCs, uses the language of "living well with dementia" to describe their initiative (EFID, 2016). Robinson & Corner (2014) address the contribution of DFCs to well-being of persons living with dementia during cognitive decline. They describe a dementia friendly community as, "…assisting individuals living with dementia to maintain their independence by supporting inclusion and supporting people with dementia to remain active and included members of their community" (p. 46). As DFCs move forward, community-based measures of well-being will be considered in evaluation, creating more opportunities for the involving the perspective of PLWD (Innovations in Dementia, 2015; Topo, Kotilainen, & Eloniemi-Sulkava, 2012; Woods, 2012).

With the consistent identification of well-being as a component of a successful DFC, research on the construct of well-being is vital as a measure in DFCs. The cognitive changes in

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dementia affecting the ability to communicate present challenges for measuring well-being from the perspective of PLWD (Rahman, 2014). Quality of life measures are often used to measure well-being, including in dementia, although age-matched studies do not yet exist. Several dementia specific quality of life tools exist that come from the perspective of PLWD (e.g., Quality of Life in Alzheimer's Disease, Dementia Quality of Life Instrument and the DEM-QOL), with promising reliability and validity (Rahman, 2014). Dementia Care Mapping, of longstanding and widespread use, is an observational measure of quality of life in PLWD in residential care settings. A metasynthesis evaluating quality of life from the perspective of PLWD (*n* = 345) found major themes of connectedness and disconnectedness within four factor (a) relationships, (b) agency in life today, (c) wellness perspective, and (d) sense of place (O'Rourke, Duggleby, Fraser, & Jerke, 2015). Studies evaluating well-being and quality of life should be replicated in diverse geographical and cultural contexts to determine the most effective community resources to employ locally (Woods, 2012). Studies must address the differences in needs and resources in unique populations with dementia such as those with young onset, intellectually and developmentally disabilities, and minority populations. These assessments will support the development of an instrument with the sensitivity and specificity to provide valid, reliable assessment of dementia friendliness in disparate communities.

Inclusion and empowerment of persons living with dementia. ADI (2016) recognizes empowerment of PLWD as the second major objective of DFCs. With empowerment to make choices and have control of their lives, living fully with dementia is possible (Rahman, 2014). The inclusion of PLWD contributes to social capital, by maximizing the contribution and well-being of community members (Rahman, 2014). The perspective and active involvement of PLWD with rights to full citizenship, not simply recipients of care is a central tenet throughout

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DFC literature (Innovations in Dementia, 2015; Bartlett, 2016). In a DFC, PLWD must be supported to take an active role in development of programs and services as stakeholders (EFID, 2016; Nuffield Council on Bioethics, 2009). This includes meaningful participation in community life.

Engagement and relationships. The debilitating stigma of dementia leaves individuals and families isolated, as unjustified fear and social exclusion permeate their lives (WHO, 2012). DFCs seek to open the doors of the world again for PLWD. Building relationships within and among communities where PLWD can connect with others in a similar situation and with the greater community allows for meaningful participation in society, and has demonstrated an improvement in quality of life (Henwood & Downs, 2014; Hirst, 2016; Rahman, 2014; Woods, 2012). Davis et al. (2009) states, "Ongoing family involvement and community connections are essential for the creation and sustainability of a dementia friendly environment" (p. 193). Awareness training provides community members with the perspective that despite cognitive impairment, PLWD enjoy and benefit from engaging in relationships, and such relationships are key to their well-being (Robinson & Corner, 2014).

Neighborhood relationships are particularly important in rural environments where services are often limited (Wiersma & Denton, 2016). It is a social imperative that we find ways to thrive in relationship with persons with dementia (McIntyre, 2003). Community engagement fosters relationships, and through relationships PLWD are recognized as valuable members of society. Community engagement and relationships form the basis of important informal partnerships in DFCs.

Care partner and social support. Caregiver stress in dementia is well documented in the literature, along with the impact on other family members including children and young adults

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(Hughes et al., 2014). The emotionally and physically exhausting work of dementia care takes a toll on informal unpaid and formal paid caregivers alike (WHO, 2015b). The inability of the PLWD to remain employed, due to stigma and a non-supportive environment, despite retaining skills creates financial stress (Kelly, 2012). Family caregivers often suffer from reduced income or job loss due to competing demands (Schaller et al., 2015). Public support is currently inadequate to allow a caregiver to work or obtain respite to maintain strength (Hughes et al., 2014). Dementia friendly principles include evidence-based practices that support families and friends touched by the disease to live a balanced life, thereby extending their ability to provide care (Gaugler, Roth, Haley, & Mittelman, 2008).

The economic reality alone warrants a substantial improvement in informal caregiver support. Non-medical social support needs encompass the greatest percentage of costs of care in dementia, valued at more than $202 billion provided in free care (WHO, 2015b). The contributions of family caregivers are critical to sustaining quality care in the community, where it is most desired (Gaugler et al., 2008). Delaying LTC placement by even one month can save up to $1 billion per year in Medicare, Medicaid and personal costs (AA, 2016). The provision of enhanced support to caregivers of PLWD has not only demonstrated a reduction in caregiver stress, but also improved health outcomes for PLWD (Long et al., 2014). Prevention of hospitalization and delays or avoidance of institutionalization was estimated to have the potential to save the state of Minnesota $996 million in direct care costs through provision of the New York University Caregiver Intervention program (Long et al., 2014). Caregiver support programs often contain education on dementia and person-centered care, respite care, support groups, and stress reduction techniques. Caregiver support programs are a strong component of DFCs, and must continue to play a significant role.

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Partnerships. Partnerships exist at many levels in DFCs, extending from small businesses in local communities to international collaborations. Partnerships enhance the reach and effectiveness of clinical and social care, and community contributions by building on existing resources (Mills & Mills, 2016). Partnerships with strong coordinators have the potential to create a community network to expand successful services to additional regions (EFID, 2016). Partnership structures vary, and may begin with a top-down structure, often as a government mandate, or a bottom-up configuration, as a group of concerned citizens or civic organization. Organizations such as the Alzheimer Society have taken a strong role in European countries by serving as a coordinator with collaborating organizations in the creation of DFCs (Alzheimer Europe, 2015; ADI, 2016). In the US, a collective action framework has begun a state wide network of DFCs in Minnesota that has now reconfigured to a nationwide network under Dementia Friendly America (2017). Dementia Friendly America (2017) is housed under the National Area Agencies on Aging, and serves as a repository of best practices in DFC initiatives, striving to connect DFCs across the country. Dementia Friendly Western North Carolina similarly uses the local Area Agency on Aging as its backbone organization, and is composed of volunteers from various community organizations, along with PLWD and families.

Public-private partnerships for DFCs have been used successfully around the world (Alzheimer Europe, 2015; DFA, 2017). The World Dementia Council (n.d.) was established after the G8 Dementia Summit in 2013, where national experts gathered to unite in addressing this issue. While their top priorities are directed at financing and sharing data globally to enhance medical research for a cure, they have also added the goals of ensuring quality of life and delivery of quality care for PLWD and their caregivers (World Dementia Council, n.d.).

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In an initiative that relies heavily on volunteer support, partnerships are vital for DFC sustainability. It is unrealistic to expect a community movement to sustain without financial and leadership support from established organizations or governments (Innovations in Dementia, 2015; Heward et al., 2016). Working with local partnerships such as city council, public health departments, and civic groups will enhance networking and engagement with DFC efforts (Henwood & Downs, 2014). The Alzheimer Society of Ireland (2016) recommends the presence of a lead agency to work with local collaborators, with an identified coordinator. In their joint publication, WHO and ADI (2016) state that a sustained and coordinated effort from government at all levels, with all relevant stakeholders is necessary.

Resources. Many DFCs struggle with limited funding, therefore sharing of resources is essential (EFID, 2016). DFC resources are even scarcer in countries without a social safety net (ADI, 2016). The age-friendly movement currently spanning internationally via WHO and in the US via AARP provides a fitting alliance with DFCs. AARP has identified opportunities where the two initiatives can intersect for mutual benefit such as a joint engagement of political leadership in which DFC can broaden their focus, and age-friendly advocates can address the specific needs of PLWD as they age (Turner & Morken, 2016). Environmental design provides an ideal opportunity for an age-friendly community and DFC collaboration. Age-friendly communities promote universal design to create environments that are usable by all people regardless of ability or age (Institute for Human Centered Design, 2016). Sharing principles between universal and dementia friendly design strengthens the case for both (Dellamora et al., 2015). The involvement of city planners and architects, particularly those of LTC facilities or elder residences is important to operationalize the established dementia friendly design principles for indoor and outdoor settings (DSDC, 2013; Marquardt, 2011). As a cost effective and

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inclusive measure, dementia friendly design principles should be considered in the planning phase of community gathering locations such as faith services, recreation centers, and public parks (Pantzartzis, Price, & Pascale, 2016; Topo et al., 2012).

International Policy Responses to Dementia

Each nation, state, and community has a unique response to the public crisis of dementia based on their demographics, priorities, and resources (Kelly, 2012). Governments are addressing the rising tide of dementia needs through creation of public policy that revamps the outdated biomedical approach to dementia care (Kelly, 2012). The enactment of national dementia policies provides an opportunity to redirect the trajectory of dementia care from the current heavy emphasis on a finding a cure to a more balanced focus incorporating awareness and social support.

Many nations throughout Europe have a national dementia plan or strategy in place, with France creating the first in 2001. As one example, in 2009, England began its path with *Living Well with Dementia: A National Strategy* that outlined the programs, research, and social support that would be enacted to improve the lives of PLWD and their families (DOH, 2009). In 2012 this strategy was followed with a P*rime Ministers Challenge on Dementia 2015* (DOH, 2015), of which one goal was to create at least 20 DFCs by 2015. That goal was exceeded with over 100 communities committed to working toward becoming dementia friendly. Funding for research has since doubled to over £60 million (DOH, 2015). The most recent update, *the Prime Minister's Challenge on Dementia 2020* calls for even further improvements in social care and dementia-related research, with a goal to have over half of British citizens with dementia living in DFCs (DOH, 2016). The rest of the UK similarly have dementia plans, as do many countries across the world ranging from Asia to Australia, and Canada (ADI, 2016). It is important to note

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that national dementia organizations or societies such as the Alzheimer's Society are often in place either leading the effort in a country if there is no national plan, or collaborating with the government and other funders when a national plan is in place. If no national strategy is in place, regional plans often exist. There are two active regional plans in Belgium focused on dementia friendly cities, with Brussels leading the way (Alzheimer Europe, 2016). The Alzheimer's Society in England collaborated with the British Standards Institute (2015) to create a *Code of Practice for the Recognition of Dementia Friendly Communities* in England.

In response to the growing societal impact of dementia in the US, President Obama authorized the National Alzheimer's Project Act (NAPA) as Public Law 111-375 in January of 2011 (USDHHS, 2015). In doing so, the US launched a comprehensive response to dementia coordinated by the USDHHS in the creation of a National Plan to Address Alzheimer's Disease. Policy discussions that follow refer to NAPA and the National Plan together as NAPA. Funding has grown from $500 million in 2012 to $700 million in 2015, and $910 million in 2017 to fund research, awareness, caregiver support, and education (USDHHS, 2015, 2017).

NAPA provides a guiding framework to transform the care of persons with dementia. The plan broadly addresses the challenges of living with dementia through five major goals:

1. Prevent and effectively treat Alzheimer's disease by 2025.
2. Enhance care quality and efficiency.
3. Expand supports for people with Alzheimer's disease and their families.
4. Enhance public awareness and engagement.
5. Improve data to track progress.

With these goals, NAPA provides credibility and support for researchers to collect and interpret outcome data of PLWD in both public and private health care systems. In addition, NAPA has

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increased funding to organizations such as the National Institute on Aging and Health and Human Services which provide practice guidelines and dementia specific curricula that can be implemented at the health system and community level.

Equality plays into dementia policy as marginalized sectors of society such as African Americans have a higher incidence and therefore higher burden of this disease (Alzheimer's Association, 2016). NAPA addresses the social determinants research needed to combat this stark group-based inequality in the lives of minorities in America. Other countries such as England have embarked on similar studies and interventions that target minorities to reduce disparities and understand their unique needs and resources (EFID, 2016).

In the past twenty years, the search for a cure has dominated dementia research. NAPA continues to fund cure-focused research, but the program has broadened to include prevention, social issues such as caregiver stress, early diagnosis, and maintaining health care in PLWD (USDHHS, 2017). NAPA has coordinated the efforts of multiple public and private organizations through leadership of the USDHHS. Education of health care professionals and the public plays an important role in creating an efficient system, as dementia knowledge deficits are vast among America's health professionals (Iliffe et al., 2012). NAPA includes advocacy for nursing education curricula surrounding best practices in dementia.

NAPA advocates for both dementia capable systems, focused on helping PLWD, and DFCs in which PLWD are empowered with the ability to make choices and live life fully with support from caregivers (Kenigsberg et al., 2015). Currently, PLWD often have little voice in their care, constraining their individual freedom (WHO, 2015a). NAPA advocates for including the voice of PLWD in designing care models and living environments. Research demonstrates

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that the community-based care chosen by PLWD and their families is often less costly than institutional settings (Kenigsberg et al., 2015).

National policies have been supplemented with grassroots activism and local government support. Minnesota created a state plan with an extensive state-wide network of support, encouraging community needs assessments and volunteer action. Many other states have followed suit with a wide variety of state plans and community coordination (AA, 2016; Alzheimer's Disease Working Group, 2011; DFA, 2017).

The Perspective of Persons Living with Dementia

The advent of person-centered dementia approaches and acknowledgement of stigma recognizes the voice of PLWD as both necessary and valuable in service evaluation and program development (Maslow, 2013; Tooke, 2013). In a global report on stigma, WHO (2012) interviewed over 2500 PLWD and their families or care partners to grasp the global magnitude. The report had 127(6%) responses from PLWD, whom identified as living with stigma on a daily basis. Inclusion of PLWD is increasingly considered an essential element in development of a DFC, with 25 sources of literature reviewed acknowledging the value of their perspective. PLWD are primary stakeholder in DFCs, and should be meaningfully involved at all stages of the process (ADI, 2016; Alzheimer's Society, 2015). Swaffer (2014) described the "Prescribed Disengagement™" (p. 713) that occurs for PLWD post-diagnosis, as exclusion from society stifles their voice, leading to isolation, and the creation of services that are "about them without them" (p. 710). Marginalizing PLWD from contributing to the development of programs and services designated to assist them stands in stark contrast to the tenets of DFCs that profess the necessity of active involvement of PLWD (Alzheimer's Society, 2015; Corner, 2002). Studies with minimal or no PLWD as participants often acknowledged this limitation, such as an

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otherwise rigorous qualitative study that revealed a strong sense of social support for PLWD within a rural community, where the preponderance of participants were community members not living with dementia (Wiersma & Denton, 2016).

In consideration of the need to transform society's perspective on dementia, the Nuffield Council on Bioethics identified six components of an ethical framework for dementia (Nuffield Council on Bioethics, 2009). The first of these components supports a narrative ethics framework for dementia by advocating for a case-based approach. Excellence in dementia care and community interaction is person-centered based on the individual's unique history. Second, they acknowledge that dementia is a brain disorder, not normal aging. This proclamation serves to identify that although one can live well with dementia, decline is inevitable. Third, the council states the belief that it is possible to have a "good quality of life throughout their illness" as has been demonstrated by individuals receiving appropriate intervention and support (Nuffield Council on Bioethics, 2009, p. 2). Fourth, the council advocates for autonomy and well-being for the PLWD based in trusting relationships, with consideration of the interests of caregivers as well. Fifth, a group of people, whether it be a family or the greater community must treat one another as fellow citizens, and provide the support necessary for one another to live well, termed solidarity. Lastly, they encourage the recognition and respect of the personhood of all individuals regardless of cognitive ability.

Successful engagement of PLWD in community initiatives are expanding. Innovations in Dementia (2015) states, "We believe that with the right support and opportunities, people with dementia can communicate, engage, participate and continue to be part of relationships and communities, no matter how advanced their dementia." Innovations in Dementia (2015) collaborated with the Mental Health Foundation and the Joseph Rowntree Foundation (2012) in

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the UK to support the Dementia Engagement and Empowerment Programme (n.d.) which consists of PLWD collectively driving policy and services thrugh organized collective action. The support to meaningfully involve PLWD in DFCs is encouraging in its breadth and prospects for expansion.

While studies to improve dementia care have closely examined the perspective of health care professionals and caregivers, a research base on the perspective of PLWD is underrepresented in the common understanding behind DFCs (Dewing, 2007). The views of PLWD are inherently connected with dementia friendly components and therefore necessitate exploration to ensure implementation of meaningful initiatives (Innes et al., 2012; Rahman, 2014). To ensure the inclusion is continual and more than tokenistic, audits of DFC involving PLWD should be established (Innes et al., 2012; Swaffer, 2014). Rich and meaningful data have been gathered from PLWD even in the moderate and later stages of the condition (Dewing, 2007; Slaughter, Cole, Jennings, & Reimer, 2007). Methodologies of consent and research that honor the personhood of participants living with dementia must be more rigorously developed (Dewing, 2002; Palmer et al., 2017; Watchman, 2016).

WHO (2012) states, “People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them” (p. 4). Best practices for recruiting and interacting with PLWD in research should be disseminated to researchers and leaders of DFCs to facilitate rich data collection and participation (Dewing, 2007; Garand et al., 2009; Moore & Hollett, 2003). Institutional Review Board resistance to research with a vulnerable population can be overcome by adherence to strict participant protection practices including contextual consent processes for PLWD such as process consent and ongoing assent (Corner, 2002; Slaughter et al., 2007). Once

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the pervasive stigma of dementia is quelled, PLWD and their caregivers will be more readily identifiable and empowered to share their stories (Garand et al., 2009; Heward et al., 2016).

Summary

The traditional medical model for dementia care is clearly unsustainable as health and social care needs exert considerable impact on the quality of life and economic outlook in nations across the globe. The stage for DFCs has been set for over a decade as dementia friendly initiatives have evolved. Person-centered approaches along with a shift in dementia studies and programs from medical to social frameworks have contributed to this movement (EFID, 2016; Heward et al., 2016). Local organizations and leading nations are partnering to develop DFCs not only to mitigate economic catastrophe, but to transform the way dementia is viewed, from a hopeless condition of isolation and despair, to an opportunity for well-being and meaningful engagement.

It is important to incorporate the perspective of key stakeholders in the development of DFC. This perspective is absent regarding PLWD in the US. Their perspective will offer a sustainable and holistic framework on which to build opportunities for PLWD and their families to contribute, engage, and live well with dementia in communities across the US. Investigations of distinct components of DFCs has primarily occurred within studies of dementia friendly design and caregiver interventions leaving a gap regarding the other identified components such as relationships and community engagement. To solidify DFCs as a valuable policy and funding initiative in the US, rigorous research on the perspective of PLWD must occur to obtain a broader assessment of full community impact and thus sustainability.

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CHAPTER 3

METHODOLOGY

The purpose of this study was to explore the perspective of people living with dementia regarding dementia friendly communities. This investigation was based on the epistemological assumption that key stakeholders, those living with dementia, possess valuable information regarding the community in which they live and how they experience well-being. This epistemological stance, the underdeveloped research base in DFCs, and lack of consistent theoretical framework of DFCs guided the methodology of this study toward naturalistic inquiry. Research design decisions were based on these epistemological and methodological positions (Carter & Little, 2007). This chapter provides a detailed description of the methods undertaken to obtain the perspective of PLWD including participant inclusion criteria, recruitment methods, human subject protection, consent procedures, data collection, data analysis, and actions to ensure trustworthiness of study results.

Research Aims and Questions

The study aims and research questions below served as the basis for the research design.

Aim 1: To provide an understanding of living with dementia in the community from the perspective of persons living with dementia.

a. Research question 1: How are interactions and relationships experienced by persons living with dementia in the community?
b. Research question 2: How is community engagement experienced by persons living with dementia?
c. Research question 3: To what extent and in what way is the impact of stigma associated with dementia?

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Aim 2: To uncover attributes of a dementia friendly community for the purposes of evaluation of communities or initiatives striving to embrace dementia friendly principles.

a. Research question 4: What are the attributes of a dementia friendly community from the perspective of persons living with dementia?

Research Design and Data Collection Strategy

Research Design

Qualitative research provides a multitude of trustworthy interpretive approaches to explore the situated perspective of individuals living with a particular condition (Cho & Lee, 2014; Martin et al., 2015). This exploratory study, based in naturalistic inquiry, investigated the perspective of PLWD. Naturalistic inquiry involves the conduct of research in a natural setting (i.e. the community rather than a laboratory) to study phenomena in the real-world without a priori expectations (i.e. without hypotheses) through an interpretive process (Lincoln & Guba, 1985). Naturalistic inquiry recognizes the presence of multiple constructed realities (Bowen, 2008) and opens the door for the researcher to elicit the explicit and implicit meanings embedded in the interview data exploring their perspective (Cho & Lee, 2014; Hellstrom et al., 2007; Schreier, 2012).

The design for this study was based on the importance of ensuring the accelerated growth and creation of DFCs is enriched by the strengths and contributions of PLWD (Parke, Hunter, & Marck, 2015; Richards & Morse, 2013). Research in the field of dementia has traditionally excluded PLWD for reasons including assumptions of lack of capacity, the stigma of dementia, and well-meaning paternalism (Moore & Hollett, 2003). Valuing the voice of PLWD in the creation of DFCs in gaining momentum across the world (WHO, 2015b). As an emerging concept, evaluative constructs have yet to be identified for DFCs. The derivation of textual

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descriptions from interviews of PLWD allowed the attributes of DFCs to surface through naturalistic inquiry and qualitative analysis.

Data Collection Strategy

It is no longer tenable to view persons with dementia as incapable of sharing a valuable perspective, therefore their views must take a defining role as programs and communities strive to become dementia friendly. Inclusion of PLWD in the research process is both possible and necessary in a society attentive to personhood (O'Rourke et al., 2015; Smith et al., 2016; Swaffer, 2014). Therefore, the realities of individuals living with dementia were the source of data, obtained through semi-structured interviews to determine their perspective on living in the community with dementia. The information was obtained in one 39 – 90 minute interview session with each participant. Additional information about specific interview procedures is addressed below.

Sampling and Recruitment

Sampling

As is standard in qualitative studies, purposive sampling was used to acquire thick description of the phenomenon of living with dementia in the community to inform the concept of DFCs (Richards & Morse, 2013). Numerous studies seeking the perspective of PLWD have successfully included individuals with cognitive impairment (McKeown et al., 2010; Menne, Tucke, Whitlatch, & Feinberg, 2008; Mitchell, Burton, & Raman, 2004; Sherrat, Soteriou, & Evans, 2007; Smith et al., 2016). Evidence supports the ability of people with mild, moderate, and even severe dementia to meaningfully engage in open ended questions (Moore & Hollett, 2003). In this study, the principal investigator (PI) sought the perspective of individuals in the early to moderate stages of dementia per self-report. Individuals were evaluated for their

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decisional capacity to participate in the informed consent process through a series of questions as detailed under the *Consent* section.

Inclusion criteria. The temperate climate and natural beauty of Western North Carolina (WNC) has contributed to its appeal as a retirement destination. The number of adults over age 65 in WNC is significantly higher than in other areas of NC and the US. In the four central WNC counties of Buncombe, Henderson, Madison, and Transylvania, the average percentage of adults over age 65 is 22%, seven percentage points higher than the rest of the state at 15% (US Census Bureau, 2016). Using Alzheimer Association (2016) statistics of 11% (1 in 9) of older adults > age 65 having dementia (Hebert, Weuve, Scherr, Evans, 2013), this translates into 10,365 adults living with dementia in the above mentioned counties. Additional cases of younger onset dementia can also be considered, adding an additional 100 – 300 cases to this statistic, as 1 – 3 % of the population of PLWD are typically under age 65 (Alzheimer's Association, 2016). The accelerated growth of the population of PLWD in WNC warrants an examination of their perspective on living with dementia and their understanding of dementia friendliness. This study aimed to ensure community efforts related to social inclusion and engagement of PLWD are respectful of and incorporate rather than marginalize their views.

For the purpose of rich and detailed descriptions from participants living in WNC the following inclusion criteria were utilized. Participants (a) resided in WNC, (b) were living with dementia in the early or middle stage per self-report, (c) had the capacity to engage in a meaningful conversation as determined by the participant's ability to interact with the PI during the informed consent process, and to correctly answer the questions on the Evaluation to Sign Consent (ESC) questionnaire related to capacity to comprehend the informed consent document,

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as explained in the consent section (Cho & Lee, 2014; Hellstrom et al., 2007; Resnick et al., 2007), and (d) spoke English.

Participant Recruitment

Obtaining data from persons with cognitive impairment presents a number of ethical research challenges, in particular, participant recruitment and gaining meaningful consent (McKeown et al., 2010). A researcher must utilize a method of participant recruitment that most appropriately addresses the study aims, answers the research questions, and is sensitive to the autonomy, privacy, and confidentiality of community members (Moore & Hollett, 2003). The use of an inclusive approach that incorporates the multiple realities of living with dementia in a sensitive manner is ideal (Cowdell, 2006). In the exploration of the perspective of PLWD, common recruitment sites include memory assessment and care centers (Pearce et al., 2002; Steeman, de Casterlé, Godderis, & Grypdonck, 2006), primary care and neurology offices (Holst & Hallberg, 2003), hospitals (Cowdell, 2008; Innes et al., 2016), support groups, service organization newsletters, and public locations such as libraries (Cowdell, 2006; Smith et al., 2016).

The period of recruitment for this study spanned from June 15 – September 15, 2017. To foster a maximum diversity from the WNC community, numerous locations were used to recruit participants. The organizations listed below reach a diverse racial, socioeconomic, and rural versus urban population of community members and were approached about serving as a study recruitment site:

- local WNC dementia support groups,
- local adult day centers in WNC,
- local Area Agencies on Aging,

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- regional memory care clinics,
- primary care and neurology offices that care for older adults,
- memory cafés,
- local Alzheimer’s Association,
- local faith communities.

Gatekeepers at the organizations were approached by email or in person to serve as potential participant recruitment sites. Gatekeepers are those individuals that have access to PLWD that may serve as study participants. An example is a primary care physician that cares for older adults, or an adult day center manager. Using both newly developed and already established professional relationships with gatekeepers, the PI negotiated access to potential participants (Patton, 2015). The PI explained the purpose, aims, and method of the study to the gatekeepers and provided recruitment fliers (Appendix A) to post at their facility in a public area along with study information sheets (Appendix B) to provide to interested persons. The recruitment flier tested at 8th grade reading level, and the study information sheet at 7.5 grade reading level as determined by the Flesch-Kincaid grade level tool in Microsoft Word 2010. Gatekeepers posted the recruitment flyer or made copies available in the lobby or similar conspicuous location viewable by potential participants. They made a general announcement about the study at a group activity if appropriate. Gatekeepers are frequently involved in study recruitment processes involving PLWD (Hellstrom et al., 2007; Menne et al., 2008; Smith et al., 2016). Gatekeepers did not make any indication that participation in the study was required or expected, nor were the services provided to PLWD affected by participation or non-participation in the study. The gatekeeper did not provide a detailed explanation of the study to potential participants. The flier (Appendix A) and information sheet (Appendix B) had the phone number,

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email, and address of the PI as a means for the potential participant to independently inquire about participation in the study. The PI did not communicate participation of PLWD in the study or lack thereof with the gatekeepers.

Participants had the option to contact the PI through phone, email, or mail. All participant contact information was stored on a password protected computer in the possession of the PI, and was deleted at the end of the study as described in the Confidentiality section of this chapter. When the potential participant made contact by phone, the PI confirmed interest and gathered the name, phone number, address, and an email address. A password protected phone was used to contact and receive calls from potential participants. If the potential participant made contact by email, the PI responded by email to confirm interest and gather the name, phone number, and address and arranged an initial phone call. No participants made initial contact by regular mail. If the potential participant had made their initial contact by regular mail, the PI would made contact by phone if the phone number was included in the correspondence, and secondarily by email if included. If neither the phone number nor an email were included, the PI would have mailed an information sheet (Appendix B), sample consent, and a written request for the potential participant to contact the PI by phone or email (Appendix D) to the return mail address provided by on the original mail.

Regardless of how the PI was initially contacted by the participant, it is during the initial phone contact where the PI first reviewed the study and answered questions from the potential participant. If the potential participant was interested in continuing with the study, the PI offered to mail or email, based on participant preference, a study information sheet (Appendix B) and a sample informed consent document for the participant to review. All participants or care partners chose to have documents emailed. On this phone call, the PI and participant or care

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partner confirmed a date, time, and place for the face-to-face meeting at which the informed consent documents were signed and the interview conducted. The PI requested that if the PLWD had a legal authorized representative (LAR), they be present for the informed consent discussion along with their legal documents designating them as the LAR in the case that a proxy consent is required. Proxy consent is further explained below. This meeting occurred no sooner than five days after the initial contact to allow the potential participant ample time to review the study information sheet and informed consent documents before the interview.

Recruitment of participants continued until saturation of data was reached. Based on prior qualitative studies seeking the perspective of PLWD, 20 interviews were planned to obtain saturation (Martin et al., 2015; Mazaheri et al., 2013; Menne et al., 2008; Smith et al., 2016). Data analysis began after the first two interviews were completed, and continued throughout data collection. Saturation of data was reached at 15 interviews, with a total of 18 interviews completed.

Setting

The PI offered for the initial face-to-face meeting for informed consent and the participant interview(s) to occur at a location of choice for the participant that allowed for privacy for a thorough explanation of the study sensitive to the cognitive abilities of PLWD (Moore & Hollett, 2003) to include the participant's home, a mutually agreed upon community location, or the site from which the referral to the study originated. All participants chose to be interviewed in their home. The participant was offered to have a support person present for the consent and interview, such as the care partner (also known more commonly as a caregiver) or LAR. The term care partner is used in contemporary dementia literature to acknowledge the mutuality in a PLWD/support person dyad, with a bidirectional relationship rather than a strict

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receiver-giver structure (Alzheimer's Disease International, 2016). The terms care partner /LAR are used in tandem in this protocol as they are usually the same individual. A support person can provide cognitive and emotional support that enhances interviewing (Cridland et al., 2016; Moore & Hollett, 2003). The questions and data obtained however focused on the participant which was clearly stated at the beginning of the interview. Even with the care partner/LAR present, questions were directed toward the PLWD. Responses from the care partner/LAR were noted separately in field notes and interview transcripts for data analysis purposes. Per a conversation with personnel in the East Tennessee State University (ETSU) Institutional Review Board (IRB) office, the support person was not required to sign a confidentiality agreement (T. Cannon, personal communication, January 27, 2017).

Human Subjects Protection

This study was reviewed and approved by the ETSU Institutional Review Board to ensure adherence to human subject protection and ethical research guidelines. Addressing consent, confidentiality, and privacy are core components of rigorous qualitative research, and are discussed below (Holland & Kydd, 2015). The PI has completed human subject research training through the Collaborative Institute Training Initiative (CITI Program, 2016).

This study was of minimal risk, as it involved an oral interview process only, without the provision of services or intervention (US Department of Health & Human Services, 2010). The study involved at least one oral interview with a potential for a second interview. Specific interview procedures are described below. Although the study was of minimal risk, the consent process will be discussed in depth below as the issue is charged with ethical concerns due to the vulnerable status of persons living with cognitive impairment when participating in research (Resnick et al., 2007; Sherratt et al., 2007; Palmer et al., 2017).

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Consent

The well-documented social injustices experienced by PLWD in which their views are discounted and disregarded (Benbow & Jolley, 2012) spills over into the research environment (Taylor et al., 2012; Wilkinson, 2002). Research *about* PLWD is plentiful, but lacking is the number of studies in which we learn *from* PLWD (Clark & Keady, 2002; Pesonen, Remes, & Isola, 2011). The exclusion of this perspective from research studies leaves an unfortunate gap in the empirical understanding of the experience of dementia from those who live it daily. The power inequities stemming from the stigma of dementia creates an assumption that the presence of cognitive impairment indicates the inability to reliably communicate, in essence creating a forced silence of the voice of PLWD (Wilkinson, 2002).

Traditional competence-based consent processes exclude PLWD from participation in research by assuming such individuals are not capable of comprehending consent material (Dewing, 2002; Jeste et al., 2007; Palmer et al., 2017). The exclusionary process of denying participation in research to persons living with dementia based only on the presence of cognitive impairment ignores the potential for meaningful contributions of their individual realities on living in community with dementia (Holland & Kydd, 2015; Menne et al., 2008; Menne et al., 2009). By ignoring their realities, we risk compromising their care, and their quality of life (Kenigsberg et al., 2015). Researchers have increasingly recognized the necessity of finding effective ways of meaningfully engaging PLWD in research to ensure that dementia-related programs and policies reflect consumer views (Clark & Keady, 2002; Cowdell, 2006; Span Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013).

The exclusion of PLWD from research has also arisen in response to the protection of human subjects based on seminal guidelines including the Declaration of Helsinki (World

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Medical Association, 2013) and the Belmont Report (US Department of Health & Human Services, 1979). The presence of cognitive impairment deems PLWD a vulnerable population, raising the question of how to determine the best process for safely managing their informed consent for research participation (Hellstrom et al., 2007; Jeste et al., 2007). Protecting PLWD from physically or psychologically harmful research is essential (Pesonen et al., 2011).

Consent capacity. Research has demonstrated that dementia is a risk factor for impairment in decisional capacity, but not all PLWD lose the capacity to make decisions about participation in research, especially due to the varied contexts and risk of research studies (Palmer et al., 2017). Because "… [Alzheimer's] dementia is not synonymous with incapacity" (Palmer et al., 2017, p. 33), a structured tool to assess capacity based on the context of the study was warranted (Jeste et al., 2007). A blanket protection from research participation without contextual considerations however has the potential to prevent PLWD from contributing their perspective even when the research is of minimal risk and has potential benefits, either to the individual, the population, or both (Black, Wechsler, & Fogarty, 2013).

Background of consent and capacity in dementia research. To protect PLWD, many research studies have required surrogate (proxy) consent, meaning the decision to participate in research was not made by the participant, but instead by a legally authorized representative, with the PLWD's best interests in mind (Hellstrom et al., 2007; McKeown et al., 2010). PLWD are increasingly being viewed as individuals with valid experiences and viewpoints worth investigating, with innovative approaches to consent developing to include more than simple assent (i.e. verbal or behavioral agreement to participate), but also their formal documented informed consent (Wilkinson, 2002; McKeown et al., 2010; Palmer et al., 2017). The consent process can be viewed as an integral component of developing trust between the researcher and

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participant (Dewing, 2007). As researchers value the perspective of all individuals, including those with cognitive challenges, consent methodologies are expanding to include rather than exclude PLWD (O'Rourke et al., 2015; Swaffer, 2014).

McKeown et al. (2010) noted, "…that given a relevant approach to consent, people with dementia are able to make decisions about whether to participate in research that may move beyond traditional approaches to consent" (p. 1937). The ability to make decisions is not immediately relinquished when an individual develops dementia, including the ability to understand the purpose and consequences for participation in a research study (Bartlett & Martin, 2002; Holland & Kydd, 2015; Palmer et al., 2017). Consent processes must move toward methods that fully engage the person lacking in what is considered full capacity in the research process (Dewing 2002; Hellstrom et al., 2007; McKeown et al., 2010).

Moye, Marson, and Edelstein (2013) explained that the study of capacity in older adults has evolved in the past 40 years, moving from the dichotomy of universal capacity to the framework that capacity is less rigid and contextual. In a collaboration between the American Bar Association and the American Psychological Association (ABA/APA; 2008), a task force was formed to address the issues regarding determination of capacity in older adults with cognitive impairment. The document states, "Capacity broadly refers to an individual's ability to receive and evaluate information and make and express a decision" (ABA/APA, 2008, p. 114). This extensive 180 page document provides guidance on the assessment for specific capacities in older adults with cognitive impairment including decisions about medical, driving, and financial concerns, along with the ability to live independently. Capacity to participate in research is covered only briefly, stating,

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> Capacity to provide consent for research depends on the complexity of the study in question. That is, a person may have capacity to make an informed decision about a simple low risk study, such as one that requires a paper and pencil interview, but not have sufficient capacity to make an informed decision about a study involving more complex procedures such as surgery. (ABA/APA, 2008, p. 133)

No specific tool was recommended to use for the evaluation of capacity to consent for research participation. The document clearly indicates however, that a diagnosis of dementia does not automatically exclude an individual from making an independent informed choice to participate in research.

A key issue to address in obtaining consent for research in PLWD is the determination of their capacity to understand the information provided in the informed consent documents (McKeown et al., 2010; Moore & Hollett, 2003; NIH, 2009; USHHS, 2010). Capacity is not dichotomous; it is contextual and dependent on the complexity and risk involved in the situation at hand (Cacchione, 2011; Moye, Marson, & Edelstein, 2013). Individuals can have capacity for some decisions of minimal risk, while lacking capacity for decisions with greater negative consequences (ABA/APA, 2008; Dewing, 2007; McKeown et al., 2010; Jeste et al., 2007). "[C]apacity is situational, capacity can be present even after the usual legal threshold has been crossed and it is often strengthened or even reinvigorate within an enabling and caring relationship" (Dewing, 2007, p. 13). The NIH (2009) concurs with this stance, as evidenced by their verbiage,

> …it is important to consider and determine whether a prospective subject's diminished decision-making capacity affects his or her capability to provide informed consent. Assessing consent capacity may involve asking prospective subjects to describe facets of

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> the research such as the purpose of the study, the components that are experimental, its associated risks and anticipated benefits, and the voluntary nature of, and alternatives to, study participation. (para. 2)

Little formal guidance exists regarding the determination of an individual living with dementia in the early to moderate stage to independently consent to research (Cacchione, 2011; Palmer et al., 2017). This is likely related to the stigma associated with dementia, where all individuals with the diagnosis are assumed to lack capacity for decision making, including the decision to participate in research (WHO, 2012; Swaffer, 2014).

Measures of consent capacity in dementia research. There is no consistently used measure to evaluate the capacity of a person with early to moderate dementia to consent for research participation (ABA/APA, 2008; Black, Wechsler, & Fogarty, 2013; Resnick et al., 2007).

Mental status testing. Mental status testing such as the Mini Mental State Exam (MMSE) does not reliably demonstrate the ability of a PLWD to communicate their views, nor evaluate the components to determine capacity to provide research consent (Cowdell, 2006; Heggestead et al., 2012; Palmer et al., 2017; Sherratt et al., 2007), therefore it has been excluded as a determinant of participation in numerous qualitative interview studies with PLWD (Cowdell, 2006). Multiple examinations of the utility of the MMSE in evaluating consent capacity in research for persons with Alzheimer's disease have shown it to be useful as a blunt predictor of incapacity below scores of 16 – 20 and a predictor of capacity above scores of 26/30 (Kim & Caine, 2002; Sturman, 2005). In a sample of 37 older adults with dementia, MMSE scores were correlated with the McArthur Competence Assessment Test - Clinical Research version as a benchmark, using receiver operating curves. The MMSE did not discriminate capacity well in

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the 21 – 25 score range representing individuals with mild to moderate dementia. It is important to consider that administration of a mental status test provokes anxiety in many individuals, and has the strong potential to erode the trusting relationship between researcher and participant necessary for substantive qualitative interviewing (ABA/APA, 2008; McKeown et al., 2010; Moore & Hollett, 2003). In addition to provoking anxiety, an extensive mental status evaluation could be nonconductive to research participation due to time and effort to administer and participant fatigue (Sherratt et al., 2007).

Evaluation to Sign Consent tool. Resnick et al. (2007) recognized the need to quickly and reliably determine the ability of cognitively impaired individuals to consent for research participation, and therefore appraised the five-item Evaluation to Sign Consent (ESC) instrument in a study of 346 residents involved in a randomized controlled trial (RCT) throughout six long term care facilities. The test takes less than five minutes to administer, is readily available, and easy to use (Resnick et al., 2007; Sturman, 2005). Questions include (a) What is expected of you in this study? and, (b) What if you do not want to continue? (Resnick et al., 2007). Interrater reliability measured with Rasch analysis demonstrated some evidence ($r = 0.81$) of reliability and validity. Item 1 (95% positive predictive value [PPV] and 81% negative predictive value [NPV]) and Item 2 (99% PPV and 78% NPV) listed on Appendix G were shown by logistic regression to have the greatest overall percentage of agreement with the overall ESC. The ESC has since been used in several studies involving long term care residents and individuals with schizophrenia to evaluate decisional capacity for research (Beebe & Smith, 2008; Resnick et al., 2009). Beebe and Smith (2008) found that individuals with schizophrenia taking two or more antipsychotic medications and those living in supervised housing were more likely that those taking one antipsychotic medication or living alone to require prompting on the ESC. This demonstrates the

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test's possible congruence with an apparent increased dependency as measured by the need for greater use of antipsychotic medications and supervised housing over living alone.

MacArthur Competence Assessment Tool. The MacArthur Competence Assessment Tool – Clinical Research Version (MacCAT-CR; Applebaum & Grisso, 2001) is another instrument used to assess the capacity of an individual to consent for research, taking approximately 20 minutes to administer. It must be purchased at a cost of $25. It contains 21 items measuring the abilities of understanding, appreciation, reasoning, and choice, applicable to capacity determination. Karlawish, Casarett, & James (2002) used this test with Alzheimer's disease (AD) research, judging it to be a reliable and valid tool for assessment of capacity for enrollment in a clinical trial. Of particular note is the ability of 55% of participants with AD in the mild to moderate stages deemed to have capacity to consent. The authors encouraged the use of capacity assessments, as "…the diagnosis itself does not constitute a label of incompetence" (Karlawish et al., 2002, p. 2023). In a study of capacity of 68 older adults with AD and 70 healthy controls for participation in an RCT, Palmer et al. (2017) similarly noted the importance of individualized assessments of capacity in consent for research participation due to their findings that multiple factors are associated with capacity, such as lower education, higher age, and lower mental status scores. They found that 31.3% of patients with dementia were capable of consent, congruent with other studies finding from 23.9% – 55.6% of persons with dementia capable of consent (Kim & Caine, 2002; Mueller et al., 2015; Palmer et al., 2017). Palmer et al. (2017) also found that a simple five item capacity test (similar to the ESC) significantly differed ($p < .001$) among patients with dementia that were deemed capable versus incapable on the more extensive MacCAT – CR. This demonstrates support for use of a simple capacity screen for participants with dementia in a low risk study.

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Tests of capacity in qualitative research. Extensive capacity tests are typically reserved for participation in randomized controlled trials involving a moderate to high risk physical intervention or for decisions regarding medical treatments, not involvement in low risk qualitative research. Many studies involving qualitative interviews of PLWD for research have not employed a formal capacity assessment beyond mental status testing that is often available from the referring agency. This study did not obtain medical record data including results of cognitive tests. Cowdell (2006) examined 22 research studies investigating the perspective of PLWD. A wide variation in consent processes was found, including both written and verbal approaches, "...although little reference was made to a confirmation of understanding" (Cowdell, 2006, p. 90). The author suggested a flexible approach to consent with PLWD, tailored to the needs and abilities of each study's participants, yet it was acknowledged that research governance regulations may require strict protocols, limiting flexibility.

Independent consent. Numerous studies exist in which PLWD provided independent consent to participate in research. An innovative yet meaningful ongoing consent process was used by Kelly (2010) in a qualitative observational study of PLWD in a long term care setting in the United Kingdom. In this longitudinal study occurring over six months, consent was verbally confirmed with participants at each research encounter without proxy consent. Martin et al. (2015) designed a self-management of chronic disease program for people with early stage dementia demonstrating positive outcomes in disease self-management. Independent provision of informed consent was obtained at the beginning of the intervention and again before the focus group, although the exact consent procedure was not described. Most recently, 26 PLWD were interviewed in Christchurch, New Zealand for their perspectives on what their community could do to help them live with greater well-being. Their responses to open-ended interview questions

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provided valuable information for the community as plans were made to rebuild after an earthquake (Smith et al., 2016). These participants self-identified as having memory loss issues (i.e. a term frequently used in place of dementia as it is less stigmatizing) and provided self-consent without proxy. If an enduring power of attorney was present, then that person was contacted for proxy consent.

Consent from both the PLWD along with a proxy consent is a common process in research of PLWD (Mazaheri et al., 2013; Phinney, 2013; Steeman, 2011). Obtaining written informed consent from participants with early stage dementia rather than solely relying on proxy consent supports personhood and the person-centered nature of qualitative dementia research (Cridland et al., 2016; Heggestead et al.; 2012; Kitwood, 1997; Menne et al., 2008). In a longitudinal study, Pesonen et al. (2011) obtained consent from both the PLWD in the early stage and their caregivers, as both views were being evaluated. Formal consent was obtained at the first meeting and verbal consent was obtained at each subsequent encounter. Both verbal and non-verbal signs of consent such as pacing or fidgeting were monitored during interviews. Mazaheri et al. (2013) first obtained family consent to gain access to the PLWD, then gained consent from PLWD to investigate experiences of living with dementia in Iran through semi-structured interviews. In a mixed methods study of the informed consent process for dementia research, Black, Kass, Fogarty, and Rabins (2007) obtained consent from PLWD. If the PLWD could not correctly answer four questions about what they were being asked to do for the interview, proxy consent was also obtained from the surrogate decision maker. A similar consent process was used for this study to obtain written informed consent.

Process consent. In addition to initial informed consent, Dewing (2002) recommends the use of process consent in which the researcher continually assesses for participant assent,

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meaning an expression of approval or agreement with research participation during the research interview involving PLWD. In this sense, consent is contextual and ongoing (McKeown, 2010). Signs of assent include readily sharing information without hesitancy, a relaxed posture, and an absence of a worried facial expression or other signs of discomfort. Signs of discomfort were also monitored for possible dissent, including a tense posture, hesitancy answering questions, fidgeting, and facial grimacing. None were exhibited. Process consent is commonly used in research with PLWD (Dewing, 2002, Dewing 2007; Holland & Kydd, 2015). Process consent is congruent with the ethic of care framework, valuing the connected and interdependence of relationships between participant and researcher (the PI in this study) (Hellstrom et al., 2007). Even persons in more advanced stages of dementia have been included in research through contextual consent processes which determine assent through ongoing behavioral and verbal responses (Cowdell, 2008; Menne et al., 2008). Process consent has been used successfully in multiple studies with PLWD in both community and LTC settings (Dewing, 2007; Kelly, 2010; McKeown et al., 2010; Parke et al., 2015; Sherrat et al., 2007; Smith et al., 2016). In addition to a signed informed consent document by the participant and/or care partner/LAR, process consent was used throughout this study. Adherence to process consent was noted in field notes during and after participant interviews.

Consent process for the current study. Extensive consent methods that are beyond the cognitive abilities of participants to comprehend have the potential to intimidate participants to prematurely withdraw from the study to avoid the frustration of testing (Cowdell, 2006; Resnick et al., 2007; Sabat, 2005). A full disclosure consent document for PLWD that is less complex than a traditional consent was used for this study. The informed consent document used simplified language from the recommended consent template at East Tennessee State University

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(Appendix E; Watchman, 2016). The PI contacted support personnel in the IRB office and received guidance in adaption and review of the current ICD (T. Cannon, personal communication, January 26, 2017). The ESC tool further ensured that the participant appropriately understood the content of the consent form by assessing their comprehension of the consent form through four questions, as explained below. Care partner/LAR surrogate consent was obtained if needed based on specifications below for adherence to human subject protection guidelines.

This study exploring DFCs from the perspective of PLWD was low risk in that participants were asked to participate in a semi-structured interview only. The individual had free choice of whether to contact the PI for participation. The interview meeting took place at a date, time, and location of the participant's preference. Meeting for the interview at a time best for the individual with dementia allowed the individual to choose to meet at a time and location of their greatest well-being to enhance communication (Dewing, 2007; McKeown et al., 2010; Pesonen et al., 2011). The PI requested that the care partner/LAR be available in the case that surrogate consent was required. If the participant did not have an LAR, the meeting occurred between the PI and participant only.

At the beginning of the face-to-face meeting and prior to asking interview questions, the PI reviewed the study process, including purpose, risks, and benefits. The participant had an opportunity to ask questions of the PI at any time. A paper copy of the informed consent document was available to the participant and the care partner/LAR (if present) during the review for reference. The PI also offered to read the consent and study information sheet aloud to the participant to aid in comprehension.

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The ESC (Appendix E) was incorporated into the consent process to confirm the participants' understanding of the research study before the interview commenced. As indicated above, capacity screening tools similar to the ESC have demonstrated congruency with the more extensive examination provided by the MacCAT-CR (Jeste et al., 2007; Palmer et al., 2017; Resnick et al., 2007). After the study procedure and the informed consent documents were explained, the PI completed the ESC (Appendix E) with the participant to evaluate their capacity to consent to the study. The capacity screen was performed after the consent was explained rather than before because the goal of the capacity screen was to determine their understanding of the consent document. The individual was required to answer all questions with an appropriate response as determined by the PI to independently consent to study participation. Correct answers were noted on the tool. The participant was asked to sign the informed consent document if they agreed to participate and answered all ESC questions correctly. If the participant required surrogate consent signature due to inability to answer all ESC questions correctly, they were offered the opportunity to sign the informed consent document but it was not required for study participation. Allowing the PLWD to sign the informed consent document even if they did not possess full capacity to make the decision to participate independently in this study acknowledged personhood and dignity of the individual. Even when full capacity to consent to research participation is not present, PLWD still possess capacities for determinations of how they spend their days, and their choice to participate in the study has value and is worthy of acknowledgement (Moye, Marson, & Edelstein, 2013; Phinney, 2013). If the participant was unable to answer all questions on the ESC correctly, the care partner/LAR was also was asked to sign the informed consent document to ensure protection of human subjects for a vulnerable population, those living with cognitive impairment. A copy of the informed consent document

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was provided to the participant and care partner/ LAR per recommendations from ETSU IRB personnel (J. Olive, personal communication, January 27, 2017) the care partner/LAR were requested to provide written proof of the legal documents designating them as the participant's legal representative if signing the informed consent document as a surrogate decision maker for research participation. The PI requested during the initial phone conversation that this legal document be available for the consent and interview process. This request was also present on the information sheet (Appendix B).

If the interview questions were not able to be answered within the first interview over a time period of 90 minutes due to time constraint or participant fatigue, a second interview would have been scheduled at the agreement and convenience of the participant within the study time frame. A second interview was not necessary in this study as all data was collected in one interview for all participants. If a second interview would have been indicated and if the participant answered all ESC questions correctly the first time, the ESC questions would have been repeated before the interview continued to confirm the participant's understanding of informed consent and to affirm participant assent to continue the study. They would not have been asked to sign another informed consent document. All participants would have been asked to verbally consent to participation in the interview before the second interview began. If the ESC questions were not answered properly at the second interview, the care partner/LAR would have been asked to sign the original informed consent document. If the care partner/LAR signed the informed consent document at the first interview based on inability of the participant to answer the ESC questions, no additional informed consent documentation would be necessary. This informed consent process was congruent with the body of literature representing

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investigations of the perspective of PLWD (Cowdell, 2006; Moore & Hollett, 2003). All consent procedures including provision of the ESC and verbal consent were audio-recorded.

Confidentiality and Privacy

All attempts to protect confidentiality were employed. All study data sent via email to the PI's faculty advisor or between the PI and the transcriptionist was encrypted with password protection. The password was communicated in person with those individuals only. The transcriptionist signed a confidentiality agreement (Appendix F). The study data was de-identified before analysis through use of a participant code on all documents (Appendix G). Once an individual consented to participate, they were assigned a participant code by the PI. After the informed consent document was signed, all electronic and written data for the study referred to the individual by their participant code only, not their legal name. The master sheet matching participant names and codes (Appendix G) along with all documents related to the study were stored as password protected documents, on a password protected computer accessible to the PI only, along with all electronic study data. If, during the interview, the participant used specific names of persons or places, they were redacted. Hand written participant data (e.g. field notes) is stored in a locked file cabinet accessible only to the PI housed within a locked building. All data is presented and analyzed according to participant code to reduce the chance of a breach in confidentiality. Presentation of demographic data is in aggregate. Although participant codes are used in the written report, due to the small number of participants, limited or altered participant information was provided to limit the possibility that the identity of participants could be revealed.

All consent procedures and interviews were audio-recorded with two digital recorders. Audio-recordings identified only the participant codes, not their legal name. Audio files were

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transcribed within ten days. The transcriptionist signed a confidentiality statement to ensure confidentiality of participant data (Appendix F). Audio-recordings were uploaded to a password protected laptop once the interview was completed. After the transcription was completed, both audio files were erase. At study closure, electronic data will be erased from the computer hard drive and saved on a travel drive only. Both the travel drive and hard copies of study documents will be stored in the East Tennessee State University, College of Nursing Center for Nursing Research office in a secure area for the duration as per university requirements. Privacy was protected as all interviews and informed consent processes for the study were conducted in a private location. While gatekeepers from referring organizations are aware of possible PLWD participating in the study, only the PI is aware of the identity of actual participants and their responses.

Risks and Benefits

Risks and benefits were shared with participants during the initial phone contact with the PI for interest in the study and again during the informed consent process. Benefits to participation in the study included the opportunity to express their preferences and experiences through a supportive encounter, and to influence the development of dementia friendly initiatives in their local communities. Each participant (PLWD) received a $10 Ingles gift card as appreciation for their time in the study, which was presented to them after the interview. The offer of the gift card was included on the recruitment flier and more importantly used to express gratitude for participation. Having the opportunity to share their perspective can be empowering for people living with dementia, particularly knowing their contributions have the potential to improve the lives of countless others in their community and beyond (Crampton & Eley, 2013;

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Palmer et al., 2017; Sherratt et al., 2007). There was no risk of displacing other interventions by participating in this study.

Risks included psychological distress from discussion of a progressive terminal illness, and participation in the consent process which posed questions related to comprehension. If a participant expressed psychological distress exhibited by worried expressions, hesitancy in answering questions, new onset of restlessness, crying, or directly stating their distress, the interview was paused to allow the participant to process the emotions in quiet support, and asked if they would like specific assistance. In addition, to comforting the participant, they were graciously thanked for their participation and allowed to express their concerns without judgement. All interviews continued after expressions of emotions due to participant preference; no interviews required termination due to participants' emotional responses. If readily available and the participant expressed agreement, the care partner/LAR would have been asked to join the interview setting if not already present. The expression of emotion when discussing sensitive experiences is a natural phenomenon, and PLWD have expressed the desire to continue interviews even in the face of emotion (Sherratt et al., 2007).

The participants were notified that although data is de-identified, a slight possibility of confidentiality breach in the publishing of findings exists, although the risk is minimal. All attempts have been made to minimize these risks through careful communication with gatekeepers and care partners/LAR, and anonymity of participants in publications.

Instruments

Demographic Data

The following demographic data was collected orally by the interviewer throughout the interview. If any data category listed has not been answered through the interview process, the

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interviewer asked the question directly (a) age, (b) marital status, (c) living arrangement, (i.e. alone, with spouse, with other family member/friends, assisted living), (d) gender, (e) race, (f) dementia diagnosis, (g) length of time since diagnosis (h) county of residence, and (i) rural or urban residence. The presence of demographic data enhances transferability for readers of research (Creswell, 2013). The interviewer recorded demographic data on a separate sheet (Appendix H), stored with other study documents in a locked file cabinet accessible only to the PI within a locked building. The participant was identified only by code at the top of the demographic form.

Semi-Structured Interview Guide

A PI-developed semi-structured interview guide (Appendix I) served as a guide during the interviews to explore the meaning of DFCs from the perspective of PLWD. The interview questions were based on the research questions driving this study. The emergent flexibility of qualitative research supports open-ended interview questions adapted as necessary based on participant responses and the context of the interview (Creswell, 2013; Patton, 2015). For this study, potential interview questions were presented to two persons living with early-stage dementia known to the PI, but not participants in this study. Those individuals provided feedback regarding the readability and understandability of the semi-structured interview questions. Interview questions began with generalities after warm-up introductory conversation to allow dementia friendly categories to emerge naturally through discussion of daily life in living with dementia. The word ‘dementia’ was not introduced initially in the questions as previous literature suggests this can be disconcerting for participants and focus on deficits rather than strengths (Cridland et al., 2016; Moore & Hollett, 2003).

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The interview questions were of an iterative nature, with refinement as the study progressed to identify effective questions to elicit themes and categories related to DFCs. If a certain interview question was difficult for several respondents to answer, the question was excluded from further interviews. Similarly, if certain contextual interview questions were particularly effective in eliciting a meaningful answer, the question was added to the questionnaire. Adaptations in the interview questionnaire were recorded and monitored through an audit trail and a reflexive journal kept by the PI whom was also the only interviewer. Changes to the interview questionnaire were discussed with another qualitative researcher for triangulation, contributing to the rigor of the study.

Data Collection

Semi-Structured Interview

Data were collected via open ended questions in semi-structured participant interviews. The interview guide (Appendix I) contained a list of questions to create a framework for respondents to express their understanding of living with dementia in WNC in their own words (Patton, 2015; Smith et al., 2016). Additional questions or probes were added as appropriate to each interview to elucidate further understandings about the participant's responses, e.g., *How did you feel when that happened?*

All sessions were audio-recorded with two digital audio recorders in the case that one audio recorder malfunctioned. Participant permission for recording was included in the consent process. Prior to interviews and as described above, the consent process was audio-recorded. One interview with each participant was conducted; a second interview was not needed as all interview questions were addressed during the first interview session. Interviews lasted between 30 – 90 minutes, with a maximum of 90 minutes at one time to prevent participant fatigue. If a

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second interview would have been necessary due to fatigue or the inability to address all interview questions within the allotted time, and if agreeable to the participant, the cumulative amount of time would not have exceed three hours, consistent with studies involving interviews of PLWD (Pesonen et al., 2011; Steeman, 2011; Smith et al., 2016). If the interview would not have been completed in the first encounter, and a participant declined to participate in a second interview, the data from the first interview would have been included in data analysis, providing the participant did not withdraw from the study. Interviews were confidential to encourage participants to express their views candidly and without hesitation, unless the presence of a support person was requested by the PLWD (Willis et al., 2009).

Additional Data Sources

In addition to the individual interview transcripts, three other sources of data were collected for use in analysis: field notes, a reflexive journal, and analytic memos. Field notes describing the environment, the participant's apparent response to the environment, and the PI's interpretation of the interaction were written during and immediately after each interview to capture contextual data including behavior of the participant indicating process consent (Patton, 2015). Field notes noted the degree to which the care partner/LAR prompted the participant to respond, as well as the amount of cueing the participant required from the PI to answer questions. Unnecessary cueing could impact the credibility of the finding by representing a perspective other than that of the PLWD. A reflexive journal was kept by the PI to notate thoughts and personal reactions to study events, as well as to note influences on methods as the study progresses (Lincoln & Guba, 1985). A reflexive journal can be compared to a 'diary' of the research study, in which a researcher (the PI in this study) writes reflections, thoughts, and information on decisions that influence the study process and methods. By capturing insights

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and methodological decisions made along the way, the reflexive journal provided a valuable audit trail to naturalistic inquiry (Lincoln & Guba, 1985). A reflexive journal served as a tool for the PI to maintain mindful self-awareness throughout the study. Reflexivity emphasizes "the importance of deep introspection, political consciousness, cultural awareness, and ownership of one's perspective" (Patton, 2015, p. 70). The researcher's perspective contributed to the context of the findings through self-awareness in knowing what shapes one's own perspective, sharpening fieldwork and analysis (Patton, 2015). A reflexive journal encouraged an examination of self and method, and thusly contributed to trustworthiness (Lincoln & Guba, 1985). Analytic memos were used as a separate conceptual tool to capture emergent patterns identified at any point in the study. These include patterns, choice of codes and their definitions, connections between codes, future directions of the study, related theories, and ideas for the study discussion (Miles, Huberman, & Saldana, 2014). Analytic memoing was more reflective of data synthesis than was the reflexive journal. All data sources were dated for a discernible audit trail.

Role of the Researcher

The researcher (i.e., the PI) served as an instrument for PLWD to express their perspective on DFCs including meaning, barriers, and facilitators within their community. Value-neutral language was used rather than pointedly assuming that the individual 'suffered' from dementia. The researcher was acutely sensitive to power imbalances that can occur with a vulnerable population subject to widespread stigma (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016; Swaffer, 2014). All efforts to equalize the relationship were made. This included but was not limited to side by side seating, the participant's choice of interview setting, allowance of the participant to ask questions, and observation for signs of discomfort (Cridland et al., 2016). An

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ability to respond reflexively both within the interview process and during data analysis was paramount to ensuring trustworthy qualitative research (Schreier, 2012). The PI was responsible for ensuring that participants consented to participation in the research with no undue influence or coercion. The PI ensured participants and the care partner/LAR understood the purpose of the research, their role in the study, and how the information would be used (NIH, 2009). Consent was ongoing throughout the study, therefore if a participant demonstrated discomfort, the PI provided necessary feedback and allowed the participant to stop the interview. Knowledge and experience in the stages of dementia, and communicating with persons living with dementia is necessary in conducting research of their views (Watchman, 2016). The PI, a gerontological clinical nurse specialist, has had 23 years of practice with older adults including extensive involvement in the care of PLWD. She conducted all interviews independently. Patience and empathy, crucial for any qualitative interview, is amplified in working with PLWD (Cridland et al., 2016). The interviewer spoke slowly and clearly, and acknowledged participant responses. Questions were direct and single-faceted to facilitate comprehension (Dewing, 2002; Cridland et al., 2016). The researcher reflected the participants' responses to ensure understanding when appropriate. The researcher provided written as well as verbal prompts for questions if needed. Photo or other prompts related to DFCs such as brochures, were not used to avoid risk of bias.

Data Analysis

Demographic Data

Descriptive statistics were used to summarize and report demographic data including means, standard deviations, and percentages. Microsoft Excel (2007) was used for analysis. The demographic data was used for informative purposes and reported in aggregate only with no identifying information present.

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Transcripts and Field Notes

Qualitative content analysis (QCA) was used to analyze qualitative data. QCA encompassed the analysis of both content and form, making the collection of *how* something was said as important as *what* was said in the interpretation of data (Schreier, 2012). The interview transcripts identified speech patterns such as pauses, laughing, and crying. Written field notes of observations taken during and after each interview contributed to these findings (Cho & Lee, 2012). The audio-recorded consent process and interviews of PLWD were transcribed verbatim. Accuracy of a random sampling of 15 minutes of three transcripts was verified by the PI.

While content analysis began as a quantitative research method in the first half of the 20th century, centered on an objective and theory-driven framework with use of numerical analysis, it has since evolved to a "research method for subjective interpretation of the content of text data through the systematic classification process of coding and identifying theme or patterns" (Hsieh & Shannon, 2005, p. 1278). QCA is often incorrectly interchanged with quantitative content analysis because the two methods exist in a continuum rather than as distinct methods (Schreier, 2012). QCA resembles other qualitative data analysis methods in its use of naturalistic inquiry for open coding and development of inductively derived categories (Cho & Lee, 2014). The framework provided by QCA enabled the researcher to access, describe, and interpret the views of PLWD.

The use of QCA required consideration of context in the search for latent meaning in the text (Elo & Kyngas, 2008; Vaismoradi et al., 2013). This contrasts with quantitative content analysis which is more concerned with the manifest meaning of data (Schreier, 2012). The goal of QCA in this study was to "arrive at socially shared, consensual meaning of material" (Schreier, 2012, p. 31), and to describe the way people in different settings understand and make

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meaning of their situation (Miles et al., 2014). The open-ended interview questions allowed participants to share their experience of living with dementia.

DFCs have gradually developed over the past ten years and are still in the formative phase in most regions (EFID, 2016). The concept of DFCs is emerging, and has yet to establish a strong theoretical base. In content analysis, "the aim is to attain a condensed and broad description of the phenomenon, and the outcome of the analysis is concepts or categories describing the phenomenon" (Elo & Kyngas, 2008, p. 108). QCA provided an inductive analytical framework to guide the identification of components of a DFC from the interview and field data stemming from the perspective of PLWD.

Conventional QCA, used to describe a phenomenon when extant theory is limited, was appropriate for the phenomenon of DFCs in their emerging conceptual state (Hsieh & Shannon, 2005). This contrasted with *directed QCA* which uses extant theory or categories to analyze data. The analysis of text from participant interviews served as a window into the phenomenon (Krippendorff, 2013) of living with dementia from the perspective of persons with the condition. Conventional QCA will provide a framework for structuring the unstructured data of the text of transcribed interviews and field notes (Krippendorff, 2013). As a qualitative method, conventional QCA has been used extensively to analyze interviews, including gerontological and dementia related inquiries (Charras et al., 2016; Cho & Lee, 2014; Elo & Kyngas, 2008; Hall, 2016; Mazaheri et al., 2013; Stephan et al., 2015). Conventional QCA served the exploration of DFCs by facilitating an organized description of participant views (Hseih & Shannon, 2005).

Conventional QCA was used to develop categories inductively within the text of the interviews (Richards & Morse, 2013, p. 90). A systematic coding process commenced with open coding to derive categories from the interview text in early readings. This form of data analysis

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began with immersion in the data by careful reading through the transcripts and field notes several times and highlighting units of meaning (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). During this immersion, codes were identified that represented the units of meaning, and they were written on the transcript (Elo & Kyngas, 2008). Similar codes were clustered on a separate sheet of large paper, and labeled to identify categories (Elo & Kyngas, 2008). Each labeled category and subcategory was explicitly defined for categories to be mutually exclusive (Schreier, 2012).

Building a coding frame. QCA as an over-arching qualitative analytic method seeks to systematically describe the meaning of data, therefore the development of a coding frame facilitates a systematic approach to data analysis (Mayring, 2000). The coding frame was developed and refined as interviews were analyzed. The coding frame consists of themes, categories, and subcategories.

A substantive coding frame entails several characteristics (Schreier, 2012). First, each category within the coding frame was unidimensional with each category referring to only one aspect of the data. The research questions guided but did not limit the development of categories (Elo & Kyngas, 2008). Second, each subcategory within the coding frame was mutually exclusive and clearly differentiated. Third, all relevant material was captured in the coding frame, meaning the coding is exhaustive. Fourth, data-driven categories and subcategories were saturated. Data-driven categories were inductively derived from the data (interviews, field notes, reflexive journals, and analytic memoing) as opposed to being derived from existing theories or concepts. “A data-driven strategy for building a coding frame is especially appropriate if your research goal is to describe your material in detail” (Schreier, 2012, p. 87). The PI was guided by the research questions in the development of a coding frame. The goal of QCA in this study

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was data reduction of interview text from PLWD into themes, categories and subcategories representing DFCs from their perspective. The steps that were followed in building a coding frame included:

1. Relevant material from the transcripts and field notes related to the research questions were selected.
2. Categories were structured and generated based their emergence from the data and research questions.
3. Each category was defined to make the rules for assigning data explicit.
4. The coding frame was revised and expanded to ensure categories were unidimensional, mutually exclusive, and saturated (Schreier, 2012).

Categories were generated through open coding, as used in the first step in grounded theory. This involved three steps of conceptualizing the data, defining categories by grouping similar concepts, and developing categories by creating a hierarchical structure (Schreier, 2012).

At a more specific level, the process of conceptualizing the data required segmentation in which the researcher must … "divide the material into units such that each segment /unit fits into one category of your coding frame" (Schreier, 2012, p. 129). This study utilized thematic criterion for segmentation as the categories were data driven, rather than formal criterion where data is concept driven and segmented by size such as by paragraph. The units of coding were marked by identification of when each concept started and ended.

The analysis process involved reading the data as a whole for open coding, segmentation in which units of coding were identified, units of meaning were grouped to create well-defined categories and subcategories, followed by further abstraction for thematic development (Elo & Kyngas, 2008; Vaismoradi et al., 2013). The PI engaged in double-coding the first two

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interviews to evaluate the coding frame for consistency. To complete double-coding, the initial two interview transcripts were recoded after two weeks from a clean copy of the interview transcript to ensure the development of a consistent coding frame (Schreier, 2012). Two codes were initially inconsistent, therefore the codes were redefined. Subsequently, the third and fourth interviews were double-coded after two weeks with consistent coding. Inter-coder agreement between the faculty advisor and PI was also evaluated. The first four interviews were coded independently by both the PI and the faculty advisor. The researchers compared their interpretation of the transcripts and discrepancies were resolved through consensus to establish a reliable data-driven coding frame.

Once the coding frame was established, four additional reviewers evaluated the frame to enhance trustworthiness (Miles et al., 2014). The reviewers were (a) an individual doctorally prepared in social work experienced in dementia studies, (b) two study participants, and (c) one doctorally prepared PLWD. The individuals were provided with the coding frame by email, with subsequent confirmatory feedback by email from study participants, and in-person confirmatory feedback by the PhD prepared reviewers. No changes to the coding frame were suggested.

A data-driven (i.e. inductive) coding frame allowed codes to emerge naturally from the interview data and field notes (Vaismoradi et al., 2016). Dementia friendly literature based on the perspective of PLWD is derived primarily from research conducted outside of the US, therefore the researchers remained reflexive in both data collection and data analysis to allow new data to emerge representing the perspective of individuals living with dementia in the US.

Trustworthiness

The criteria for rigor in qualitative research differs from that of quantitative research due to a fundamental difference in their underlying assumptions (Creswell, 2013; Lincoln & Guba,

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1985, Patton, 2015). To describe the components of qualitative rigor, alternate evaluative criteria are used. Trustworthy is used in place of validity as an overall appraisal of soundness of the research (Creswell, 2013). Trustworthiness of data was ensured through adherence to these established qualitative evaluative criteria (listed next to the quantitative comparison), credibility (internal validity), dependability (reliability), transferability (generalizability), and confirmability (objectivity) (Cho & Lee, 2012; Creswell, 2013; Miles et al., 2014). By adhering to strict empirical standards of qualitative research, the components of trustworthiness (Lincoln & Guba, 1985) listed below ensured the coding frame captured the specific aims of the research (Schreier, 2012).

The goal of this study was to view DFCs through the eyes of PLWD. Credibility in qualitative research addresses the extent to which the data represents the views of the participants (Lincoln & Guba, 1985). Credibility was addressed through careful attention to the use of interview questions based on a literature review in their ability to produce attributes of DFCs from the perspective of PLWD (Crampton & Eley, 2013; Smith et al., 2016). The triangulation criteria first expressed by Denzin (1978) and later summarized by Lincoln and Guba (1985), was attended to through multiple sources of data, multiple investigators, and multiple methods. For multiple sources, participants from various backgrounds in WNC were sought through reaching out to sites with a broad range of socioeconomic statuses, race, and rural/urban settings for recruitment to obtain a variety of perspectives (Graneheim & Lundman, 2004). The need for multiple investigators was addressed through collaboration with two other researchers, the faculty advisor for interpretation of transcripts and review of the coding frame, and a researcher in the field of aging social work for confirmation of the coding frame. After interpretation of initial categories in the first several interviews, inter-coder agreement was employed by

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consultation with an impartial researcher, the faculty advisor. Peer debriefing is recommended in qualitative research as a method to ensure the researcher's interpretation is congruent with the participant experiences (Creswell, 2013). Multiple methods of data collection included the participant interview and participation observation through field notes. Field note analysis included attention to the amount of cueing the participant received from both the care partner/LAR and the PI. Credibility was enhanced by the use of a reflexive journal in which the PI carefully considered the environmental impacts on PLWD responses, and how this was interpreted during coding. Lastly, three PLWD (two were study participants, the third has research experience) reviewed the final coding frame for credibility to their experience of living with dementia. Having participants review study outcomes is a form of member-checking, recommended in qualitative research texts (Miles et al., 2014; Patton, 2015). No egregious themes or codes were reported by these reviewers. The above activities supported the PLWD as the source of data to enhance credibility of findings.

In qualitative studies, researchers run the risk of imposing their own assumptions onto the study results. For that reason, qualitative rigor included attention to confirmability; the results were corroborated by other researchers (Lincoln & Guba, 1985). Confirmability was enhanced in several ways. First, the PI engaged in double-coding, which involves re-coding part of the material (e.g., two interviews) after a period of 10 – 14 days to ensure consistent findings (Schreier, 2012). Double-coding of the first four interviews facilitated an assessment of the quality of the coding frame, with a subsequent revision. Inter-coder agreement as described above was also used to enhance trustworthiness. The review of the coding frame by a researcher outside of the discipline (social work) also contributed to confirmability.

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In addition, a detailed audit trail was kept for review by the PI. A reflexive approach to the research, including a reflexive journal, with sensitivity to participant and researcher responses further ensured confirmability (Lincoln & Guba, 1985). Similarly, analytic memoing provided an opportunity for the PI to synthesize information as the study progressed, beginning with data collection, through the coding process, and up until final reporting (Miles et al., 2014). A reflexive journal and analytic memos as a written narrative contributed to the trustworthiness of findings.

Interviews continued past saturation of data. The technique of saturation is defined as continuing to sample data (interview participants) until no new information emerges from the participants (Patton, 2015). Saturation is often ill-defined, therefore as recommended by Bowen (2008), sampling adequacy was sought by seeking out diverse participants that represent the topic well. Lastly, reimmersion in the data after analysis further confirmed results (Miles et al., 2014; Patton, 2015).

Obtaining trustworthy results in qualitative research also demands attention to the repeatability and consistency of finding. This is known as dependability, which takes into account the contextual nature of qualitative research, and thereby addresses the effect of a setting or other influence on the data outcomes. Dependability (reliability) was ensured through close adherence to the steps of QCA in the development of data-driven categories and subcategories which create the coding frame (Schreier, 2012). The PI clearly defined each category and subcategory to ensure mutual exclusivity and consistency in coding. In addition, an audit trail was maintained as well as a reflexive journal to note the consistency or non-consistency in the environment during the interviews.

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Transferability in qualitative research refers to the extent to which the results can be generalized or transferred to other settings (Lincoln & Guba, 1985). Qualitative research is contextual by nature and not intended to be readily generalizable, yet valuable information is more easily gathered and applied to new settings by readers when a study is well-conducted and well-written with transferability in mind (Creswell, 2013). Clear identification of the sample, setting, research design, and data analysis contributes to the transferability of this study in addition to rich description of data. Questions were similar for all participants while still allowing for an evolving interview process based on the context of the conversation (Graneheim & Lundman, 2004).

Conclusion

Conventional qualitative content analysis of individual interviews served as a foundation to answer the research questions surrounding the exploration of dementia friendly communities from the perspective of persons living with dementia. This study based in naturalistic inquiry supported the personhood of participants through their meaningful and respectful involvement in the consent and data collection process. With this emergent knowledge based in the voice of those living with dementia, attributes of DFCs have been identified. This provides information for planning and evaluation of dementia friendly communities both within the US and globally, furthering the opportunities for the well-being and engagement of PLWD in community life.

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CHAPTER 4

FINDINGS

Qualitative content analysis was used to explore dementia friendly communities from the perspective of 18 persons living with dementia or memory loss. The aims were to provide an understanding of living with dementia in the community, and to uncover attributes of a DFC for the purposes of evaluation of communities or initiatives striving to embrace dementia friendly principles. To recall, the research questions in this interview were:

1. How are interactions and relationships experienced by persons living with dementia in the community?
2. How is community engagement experienced by persons living with dementia?
3. To what extent and in what way is the impact of stigma associated with dementia?
4. What are the attributes of a dementia friendly community from the perspective of persons living with dementia?

This chapter describes the sample demographics, the emergent themes and categories, the interconnectedness of the themes, the participant meaning of dementia friendly and their perspectives on this study, the presence of care partners during interviews, and the use of the Evaluation to Sign Consent tool.

Demographics

Eighteen participants were recruited for this study, primarily from dementia support groups (*n* = 10; 55.6%) and community support organizations such as an Area Agency on Aging and a grassroots DFC organization (*n* = 8; 44.4%). Participant ages ranged from 65 to 94 years (*M* = 78.3; *SD* = 7.76). All live-in care partners were a spouse. Seventeen participants (94%) were White and one (6%) was Black. Additional recruitment was sought from the Black

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community to equal the census percentage of 13%, but efforts were unsuccessful. Three participants reported living in a rural community, and 15 identified themselves as living in an urban area. Eight participants were female and ten were male. Participants varied in their living situations. Seven lived in independent living or continuing care retirement communities (CCRC), with two of those living alone and five living with a spouse. Eleven lived in an independent home, either alone (*n* = 2) or with a spouse (*n* = 9). Table 1 presents participant demographics, including living arrangement, reported years since diagnosis, and dementia type.

Themes and Categories

The PI conducted semi-structured interviews with each participant, ranging from 33 to 93 minutes (*M* = 66, *SD* = 16.98). All interviews were conducted in the participants' homes. Twelve participants had a care partner present for the interview. Through data analysis, three themes and ten categories were uncovered. The three major themes are (a) Transitions in cognition: Vulnerable identities, (b) Social connections, and (c) Engagement in life activities. Themes, categories, and their definitions are listed in Table 2. Subcategories are described within the narrative of each category. Pseudonyms are used or participant characteristics have been changed to protect confidentiality.

Transitions in Cognition: Vulnerable Identities

"Transitions in cognition: Vulnerable identities" is defined as the process of undergoing a change in abilities or lifestyle due to cognitive decline. It includes the effects this has on how one views oneself, ones' role, purpose, meaning, and usefulness. The four categories submerged in this theme include (a) risk to personhood, (b) upholding personhood, (c) uncertainty toward the future, and (d) self-awareness.

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Table 1.

Socio-demographic characteristics of participants

Socio-demographic characteristic	Participant *n* (%)
Gender	
Male	10 (55.6%)
Female	8 (44.4%)
Age	
65 - 75	6 (33.3%)
76 - 85	8 (44.4%)
85+	4 (22.2%)
Living Situation	
CCRC/ILC	7 (38.8%)
Alone	2 (28.6%)
With spouse	5 (71.4%)
Independent Home	11 (61.1%)
Alone	2 (18.2%)
With spouse	9 (81.8%)
Years since diagnosis	
0 – 1	3 (16.7%)
2	5 (27.8%)
3	4 (22.2%)
4	4 (22.2%)
5+	2 (11.1%)
Type of dementia	
Alzheimer’s	9 (50.0%)
Vascular	2 (11.1%)
Mixed	1 (6.6%)
MCI	4 (22.2%)
Unknown type	2 (11.1%)

Note: CCRC = continuing care retirement community; ILC = independent living community; MCI = mild cognitive impairment

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Table 2.

Themes and Categories

Themes and Categories	Description or Definition
TRANSITIONS IN COGNITION: VULNERABLE IDENTITIES	The process of undergoing a change in abilities or lifestyle due to cognitive decline and the effects this has on how one views oneself, ones' role, purpose, meaning, and usefulness.
Risks to Personhood	Processes or situations that impede an individual's ability to experience well-being while living with cognitive impairment.
Upholding Personhood: Identity continuity	The processes or situations supportive of experiencing well-being while living with cognitive impairment.
Uncertainty toward the future	The unknown or indefinite understanding of how life will be in the future due to the unpredictability of dementia progression.
Self-Awareness	Conscious knowledge of oneself, one's feelings and one's abilities.
SOCIAL CONNECTIONS	Establishment of a meaningful contact or relationship with another person or persons.
Social Inclusion	The ability to freely participate and feel welcomed in groups or activities, with a welcoming attitude of group members.
Social Exclusion	The experience of being denied or feeling denied from access to groups or activities, leading to isolation and denial of human rights of participation.
Waning Conversational Ability	The ability of the PLWD to participate in conversations with others is compromised.

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Themes and Categories	Description or Definition
Sharing the Dementia Journey	The act of disclosing how one feels or acts related to living with dementia. This is different than a simple disclosure of the diagnosis, e.g., “I have dementia.”
ENGAGEMENT IN LIFE ACTIVITIES	A pursuit or process which a participant undertakes for pleasure or as part of daily living.
New-found Dependence	Requiring assistance with activities that were once done independently. This includes slowing down or avoiding an activity or engagement in light of safety or making a mistake.
Adaptation to Meet Current Abilities	Changing the structure of the activity or the participant’s degree of involvement to allow continued engagement in said activity

Risks to personhood. “Risks to personhood” is defined as processes or situations that impede an individual’s ability to experience well-being while living with cognitive impairment. The following subcategories are situated under risks to personhood, meaning these processes impede or potentially impede the participants’ ability to experience well-being while living with cognitive impairment (a) emphasizing losses of identity continuity, (b) sense of burden, (c) compounding health stressors, (d) the enigmatic dementia diagnosis, (e) pushing against introvert/extrovert personality tendencies, and (f) the stigma of a dementia diagnosis.

Emphasizing losses to identity continuity. Participants expressed their distress over lost memories, lost abilities, and lost involvement in activities, affecting how they view themselves and their ability to interact in the world as the person they once knew themselves to be. In essence, they experienced unmet expectations for themselves based on their past lived experiences.

For example, in referring to her current inability to use an iPhone, Participant 7 shared,

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"But you know, it wasn't that long, a month or so that I would look at it [the iPhone], and it wasn't a problem. I would just automatically do it. And that's so scary."

A retired professional who enjoys intellectual endeavors exemplified a threat to personhood through the statement, "The whole loss of the intellect, is just that's the hugest thing for me because that was so much of how I defined myself." (Participant 15)

A recently retired professional expressed his felt loss of agency as a PLWD:

> I see that whereas before, if I thought I had a valid foundation for a position, I would state it and I would go through the arguments and see if I couldn't prevail. Now there's too much drama in that effort so I don't do that. (Participant 11)

This same participant echoed the views of participants in being troubled with his determination that he leads an unproductive life:

> If I had my perfect day, it would be eight years ago or so, and I would really be doing something that meant something and something that not everybody could do. In other words, I guess accomplishing something has been really important to me. Now I'm in a position where what I'm accomplishing is getting up.

This participant also clearly articulated the challenge of being seen as an individual with a unique history and abilities. "My gripe with [medical system] is that you have dementia, they don't seem to recognize, at least in my view, degrees of dementia. It's one size fits all. (Participant 11)

A participant with an active professional life voiced his distress at the loss of his livelihood, "You know, I felt like this is not fair. This is not right, you know?...My life that was then taken away from me. And here I am. And I had to get out of that victim mentality." (Participant 1)

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In discussing her sadness at the inability to remember the details of significant events in her life, a participant shared:

> There's a little memory that flipped in and out and it's there and it's gone and maybe it could be something to say and maybe it couldn't. But at the same time it was a part of my past that made me an interesting person that it was a part of an interest… it was a part of my vitality. (Participant 10)

An accomplished writer sadly expressed, "So, you know… it's like one by one the attributes that used to define me are dropping by the wayside and I'm not sure what's left." He also stated:

> I have been accustomed to being a fairly accomplished person, and that's already beginning to change… and that's alarming because my self-regard is tied up in this, you know, and if I can't do that, then I don't know what I can do. ..the way I described myself was I was in transition to what I used to be to what I'm gonna [*sic*] be and I didn't like where I was going... And because it just seemed so confined. And I have never felt confined. I have had a million ideas and I have pretty much ranged freely in the world and I just feel really kinda [*sic*] hunkered down in a little place. (Participant 4)

The interviewer offered the observation of, "It seems as though you identify yourself as [name] the writer." The individual responded, "Yeah, it is. I mean, if I am not that, then who am I?" (Participant 4)

Sense of burden. Eight (44.4%) participants expressed guilt over the stress endured by their care partner(s) related to the participants' current and impending increase in care needs. Four of these individuals named their loss of driving privileges as a burden by leaving the care partner responsible for all transportation. This burden was recognized by a participant sharing,

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"[My wife] is doing it all. And very graciously but I try and limit the burden [by not asking her to drive him places]…She needs a break taking care of me." (Participant 3)

With the short term memory loss that occurs in dementia comes the need for the PLWD to have regular reminders of recent events and plans. "I think it's really becoming a difficulty for her to be constantly answering my questions about what's going to happen in the day and what I'm supposed to be doing and how… and I know, I know it's a burden for her. And that's something that bothers me a lot." (Participant 4)

For individuals without a spouse, the care giving responsibility often falls to adult children. A woman currently living alone described her reluctance to burden her daughters:

> I think any of them would be willing to have me come live with them. I would hope that would be workable at some point when I can't live alone, but there's a point at which I don't want to be at that point of having no mental capacity and just be a body and be in anybody's house. They've got young children. I mean this is just not a time in their lives when they need to be that level of caregiver. (Participant 15)

The enigmatic dementia diagnosis. Participants situated the diagnostic process of dementia as a significant life event. Several described receiving a murky diagnosis with little guidance on living with the condition, much less on how to live well. Participant 1 articulated this when he said,

> But when you go to a neurologist and they call you on the phone and say, 'you have an MRI that has cortical-atrophy and that that's consistent with dementia and have a nice day I hope that's helpful.' That's not real helpful. And then when they sit down and tell you 'Well you've got dementia. You've got five years of brain life left go live a good life and take Namenda and Aricept.' That's not real helpful, you know.

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This individual proceeded to describe employing stress reduction (retiring from long hours with heavy responsibilities), nutrition therapies, exercise, and alternative energy modalities with a resultant stabilization of his cognitive status.

Participants expressed frustration and weariness with the health care system in the multiple steps and "run around' of the diagnostic process. This includes the extensive medical workup, disclosure of the diagnosis, and the subsequent reactions of others when informed of their diagnosis. Several participants (*n* = 5) changed physicians due to dissatisfaction with their bedside manner or attention to their individual needs and questions regarding dementia. One participant expressed it this way, "I mean I just said to my own doc, 'I'm convinced he [the neurologist] doesn't like me and I don't want to get any part of my diagnosis to be done by somebody that doesn't like me.'" Participant 11 said:

> The PET scan showed a diminished glucose uptake. [My wife] identified behavioral changes, put those two together and then I went to [a neurologist] and he is the one that came up with the FTD [frontotemporal dementia] diagnosis. [Another neurologist] didn't reject it, but he didn't accept it either. He thought that there could be Alzheimer's. When I went to the new neurologist…he said my diagnosis will be mild cognitive impairment. I said, 'Okay. Whatever that means.'

Having gone through months of primary and specialty care visits, and then an academic center work up for a diagnosis, Participant 8 simply stated, "We went through an agonizing period trying to get a diagnosis."

While crying, Participant 7 shared, "And I was devastated…because I don't have Alzheimer's and it had just been recently that I have said I have dementia." She stated she

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discovered her dementia diagnosis by reading her medical records sent from one doctor's office to another. She reported she had not had a cognitive evaluation in over a year.

Participant 1, reporting the failure of western medicine to treat dementia holistically declared:

> I mean, that's the huge challenge with Western medicine is … there's not a pill, there's nothing to talk about. Well, that's a bunch of crap. I'm sorry…I basically think I got thrown under the bus by Western medicine, if you want me to be blunt about it.

In contrast, several participants expressed satisfaction with receiving their diagnosis and care from a center specializing in memory disorders. Participant 13 shared, "I got the best physical and care from my memory care doctor. They pull in the whole family."

Even with a definitive diagnostic process, participants expressed the incredible shock of receiving the diagnosis, as with Participant 1 in disclosing, "I was totally blindsided by this…I have a diagnosis that involved dementia. And so, the whole thing was beyond devastating and from that moment in time for at least two years I was extraordinarily depressed. I felt horrible."

Participant 4 similarly shared, "And while I was willing to be vascular-ly (laughter) impaired I wasn't ready to be demented and it kind of dealt a blow."

Reactions of anger toward their dementia diagnosis were also expressed, as with Participant 5, "I had this rage that's been at Alzheimer's" [when I was diagnosed]. He further discussed continuing to live life fully with a "kick-Alzheimer's butt attitude." Participant 17 shared a similar reaction with the statement:

> And I don't really swear, but one day I was sitting in here I said, "I just don't like this dementia, I hate it." And I had never said, 'fuck'. Never. And I said it. Because that's a hard word, and I made it sound hard…I felt better afterward.

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Compounding impact of health stressors. Physical or mental health problems that complicate or prevent the ability to engage in physical or social activities were reported by 13 (72.2%) participants. These health stressors prohibited participants from fully experiencing well-being, and thus threatening their personhood during transition of cognition.

Participant 12, desperate to continue a life-long activity of exercise and hiking said, “This chronic pain thing has really screwed up life. Chronic means, every day, all day; all day long.” He reported that he is not able to hike for more than a few minutes due to back pain, despite consultation with numerous specialists. He and his wife had been part of a hiking club for many years, and now this was another avenue of friendship and physical activity that had vanished. Comments about his pain were interjected multiple times in the interview.

Participant 1, dealing with chronic neck pain of unknown origin along with cardiac comorbidities said, “…I went into atrial fibrillation, which is a disaster. And it’s a disaster for me because I feel the worst…when I’m in a-fib [atrial fibrillation]… I already didn’t have energy, but I was worse.” He reported that his pain impacted his ability to participate in enjoyable activities, and detracted energy that could be devoted toward cognition.

Participant 7 expressed distress over the rapidity with which her cognitive status is worsening, and the exhaustion from dealing with numerous acute medical crises when she said, “And [my husband] has got cancer and ever since we’ve been here, it all started last year, we spent more time at the hospital than we did here [at home], so it’s terrible.”

Attention to warding off depression was mentioned by four individuals, such as “…with any sign of going into depression, we are right on it…” When asked what he has done to improve his well-being, Participant 1 responded, “Number one, getting off the stress bandwagon…I think this stress was a huge factor...” He also added, “How much the depression

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has contributed to [my cognitive challenges] I don't know. I think that was a huge factor in things."

Pushing against introvert/extrovert personality traits. Seven (38.9%) individuals, without prompting, noted the strain brought on by dishonoring of their introversion or extroversion personality traits. An introvert by nature noted the stress of the need to have people in his presence more frequently due to his cognitive deficits, against his natural tendency to prefer spending time alone:

> And I'm not naturally gregarious. And most of people are (laughter), because I've been to one session at [adult day center]…they all seem to be comfortable in that new role that they're in and it's hard for me to get comfortable with that because I'm a loner and always have been…And that's not going to work much longer I don't think…being a loner. I kind of need people around more with my inability to figure things out. (Participant 4)

Conversely, the impact of the social isolation that occurred after an individual's diagnosis was heightened by his natural tendency toward extroversion, as he explained:

> I am definitely much more of an extrovert than an introvert. And you probably know this, but, you know, extroverts gain their energy by being around other people. Introverts more just by being to themselves. And, you know, I became a recluse in this house. And for me, when I look back on it, that in itself was not a good thing. (Participant 1)

The stigma of a dementia diagnosis. While the word *stigma* itself was rarely used by participants, evidence of stigma surfaced regularly in the interviews. The word "dementia" conjured up negative images for participants even without prompting:

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> And there’s there is …negativity about dementia. And of course the word itself is just awful [laughter]. I mean, you’d expect people would expect to see me foaming at the mouth and be unable to express any kind of thought…dementia just has such as terrible connotation with the word. (Participant 4)

Stigma related to a dementia diagnosis was further evident when a participant was asked what “dementia friendly” means to him. He responded abruptly with, “…an oxymoron. The two words don’t compute.” When asked about “memory loss friendly”, he said, “I don’t think it’s friendly at all”. This same individual made it clear in the initial phone call that he does not use the “D word” [to indicate dementia], as he has only been diagnosed with MCI.

Participant 14 also identified the stigma in being diagnosed with dementia, as he stated:

> Well, I think, what I've felt, that we're not a full human person if we don't have all our faculties. And I think there is a lot of that, and the feeling that people have, if they don't have it [dementia]. And that's maybe why both --- and I felt we don't want to be called “dementia” for having “memory loss.”

The stigma of dementia can encompass an individual’s entire identity, as Participant 11 described, “…when you have a diagnosis, I've found that those who are aware of it attribute virtually everything to it.”

Stigma surfaced in a hesitancy of PLWD or others close to them to disclose their diagnosis. Participants reported family and friends countering their disclosure of receiving a dementia diagnosis with disbelief. When others minimized or denied the dementia diagnosis, participants felt others were unintentionally minimizing them personally and denying their reality. Participants reported feeling a dismissal of their truth.

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Participant 17 discussed the denial of her brother and sister-in-law being by saying, “They said ‘You can’t have that!’” She went on to say, “Well, it's sort of hurts. Yeah, because I know I have it.”

This denial from others was repeated by Participant 2 in relating her experience revealing her dementia diagnosis to the team with whom she volunteers:

> And I would tell the ones that I was closest to, that I had dementia, that I was having trouble with confusion, occasional memory lapses that kind of thing. And what I get from them is ‘Oh, I forget things all the time.’ For whatever reason, some of them didn’t want to accept it or they felt that I was being overly dramatic, that kind of thing.

Similarly, Participant 8, who is completely transparent with others about her diagnosis voiced, “Some people they try to slump it off with, ‘You're just imagining that.’”

Participant 11 stated his best friend, who lives in another state replied to him when told of his diagnosis, "Well, did you get a second opinion? No, you're not ... No, you don't have that. You should find another doctor." So now that’s something [he and I] don’t discuss, and that’s hard.”

Participants reported varied reactions to disclosing a dementia diagnosis to their adult children. In some cases (*n*=3) it was the participants’ children who pursued the diagnosis based on symptoms. In other cases, the children’s responses were analogous to those of friends and acquaintances. Participant 3 sighed as he related how his son reacted, “He said we need to get some real doctors, that this couldn’t be right. But he doesn’t live with us day to day.”

Participant 5 described it this way:

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> They're probably avoiding understanding (laughter). I don't really know. I think it's sort of for them an approach of avoidance. They don't really know how to talk to me about it or why should we. He's got it and that's it.

When asked whether her children were aware of her dementia diagnosis, Participant 7 stated:

> Well, evidently they are. And they were all here a week ago or for 4 or 5 days. And after they left I said to [my husband] 'Did they say anything to you about my memory loss?' And he said 'They didn't say a word.' So, I don't know what normal is or abnormal for children. You know, I know they're aware that I'm having problems.

Heartwarming responses of love were also mentioned, such as with Participant 16 who wrote his children a letter after his diagnosis. He shared, "But they aren't to my knowledge, they're not troubled by it [my diagnosis of dementia]…Because I'm not troubled by it." And Participant 6 shared, "They [his children] are 100% behind us."

In discussing his hesitancy to share his diagnosis with other church members, one individual stated, "When I tell people I have dementia it affects my speech…it's being cautious about turning people off." (Participant 3)

Participants described themselves or their family members avoiding disclosure of dementia to family and friends for fear of judgement. "I'd tell them 'Yeah, look I've got a dementia diagnosis and you know I've been very blessed and I'm doing well with it, you know.'…[my spouse] doesn't want to discuss it, but for me I'd rather be out in the open and people just accept it and that's part of life." (Participant 1)

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Non-disclosure of the diagnosis appears to insinuate the condition is deserving of shame. “The [family] had a little bit of a problem because we had certain things in the family they wanted to protect... but we just came on out and this is what it is...” (Participant 8)

Two participants specifically stated they wished they had never had a brain scan, as having the diagnosis has led to their being devalued in all areas of life. They felt that if they did not have the diagnosis, their daily actions would not be judged so harshly. “My views become invisible when they hear my diagnosis.” (Participant 11)

When asked, “Do you ever find that people treat you differently when you disclose you are living with dementia?” Participant 8 replied, “Oh, oh yeah. It drives me bananas, people come up and say, ‘Are you okay?’ And pat my hand. You know that kind of thing. It's like you're different now and you're not you.” She expressed a sense of paternalism that she found degrading to her identity and she added, “There are certain people that look at me differently and I am very aware of that than I was before…After a while they relax and realize that I'm not going to do anything coo-coo.”

In a similar situation of lost agency, Participant 7 described an offending interaction when her daughter was visiting from out of town:

> But she [daughter] started telling me what to do. And how to do it. ..And that was very difficult for me. She said ‘We’re going to do this.’ She never said ‘Can we do this?’ or ‘Should we do it this way?’ She didn’t… even my own husband said to me, which is very unusual of him to say, he said ‘She treated you like a mouse.’

Participant 7 later expressed a wish to be more open with her diagnosis. “I hear other people around here [the CCRC] say ‘I’ve got dementia.’ That’s the people I would really like to be like.”

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In this study, covert stigma was not limited to revealing a dementia diagnosis. Additional discussion about stigma is found under the Social Connections theme.

Upholding personhood: Identity continuity. While many instances of threats to personhood surfaced in the interviews, participants also demonstrated ways in which they or others sustain their personhood, allowing a continuity of their identity. Even in the face of cognitive decline, personality traits continue, as expressed by a former college professor who describes why he is a leader in his dementia support group, “I feel that I’ve been a leader since grammar school and I’m just living up to my experience.” Sub-categories that emerged under this theme include (a) reframing toward acceptance of living with dementia, (b) living a contributing and engaged life, (c) knowledge or experience of dementia, (d) tapping into coping skills and resilience, and (e) presence of support.

Reframing toward acceptance of living with dementia. By changing the perspective of how they view living with dementia from a terminal chronic disease to ‘just something else to deal with,’ participants were able to find contentment and joy in their lives. Dementia is a part of their lives, but does not control it. One participant who successfully lives alone stated:

> I really don’t think about dementia, my having dementia, in my day-to-day life. I just know I’ve got it, but it’s just a part of me. If I can’t find something, I don’t think ‘Well, that’s my dementia or that’s Alzheimer’s.’ I just don’t worry about it, because worrying about it is going to create stress. (Participant 2)

“I think acceptance of who you are is the big thing and I think [my spouse] has been great in helping me do that.” (Participant 8)

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Some individuals expressed relief from the anxiety of not knowing the cause of their symptoms when they received a diagnosis, “We were thrilled to have an answer as to what was going on.” (Participant 8)

An aspect of this acceptance is sharing the diagnosis willingly with others, without fear of negative reactions. Participants attending a local memory care medical clinic are encouraged to share their diagnosis with their friends and family, as several participants noted:

> One of the guidelines they suggest is that you tell people that you have dementia. So I did. I suspect so they’ll be there to help if you need help. If you start acting weird they’ll understand what the problem is and be more accepting of you. (Participant 2)

Even in casual encounters, the issue of cognitive loss can be approached with kindness and understanding. “I will say to some people, if they ask me, ‘Do you remember such and such?’ I say, ‘No, I don't, but then, I have a memory problem.’ I'll say that…Because I don't mind telling people.” (Participant 10)

Similarly, when asked how things go for her when she is at the library, Participant 8 responded, “Yes. I don't mind asking if I get confused.”

The diagnosis of dementia did not result in an abrupt end to involvement in professional life for study participants. Continuation of past professional endeavors supports continuity of identity, as Participant 4 explained when talking about writing:

> So I’m making efforts, consciously…to try to reestablish some of these contacts and to try to again have goals. And I’ve just recently made some efforts to get this sequel back on my radar and try to push it. I guess I felt like I was kind of, like going in circles or getting lost. And as soon as I decided ‘Well, I’m going to do this sequel.’ Everything

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> clarified and I feel, maybe stupidly, but I feel like I'm involved in something that is going forward.

Reframing one's identity in a new light also involves refocusing from a professional life to new roles and purposes. One participant shared how a therapist brought this to light for him:

> Here I am, all I know is I'm Dr. *Green*...this is hugely helpful to me, he sat me down…and he says '*Jerome*, I need you to know this. You are not Dr. *Green*, you are *Jerome.*' [no Dr. in front of his name] And you know that meant a lot. I had no idea who *Jerome* was.

This alternative way of viewing himself allowed *Jerome* to seek out new experiences and activities beyond the professional role that had dominated his life pre-diagnosis.

Similarly, Participant 10 noted, "I really do feel like it's a different person. I don't… I don't associate the person who ran that [business] as me, now. I feel like it took a totally different kind of ability. And that's gone in a way. And… I don't know." She had earlier stated, "It's a good time. It's a good time in my life right now. I'm…in a time of contentment." She had successfully reframed her identity to be congruent with her current reality. Participant 1 also described the notion of refocusing purpose when he reported becoming highly engaged in health promotion after his diagnosis said, "The diagnosis of dementia has been the best and worst thing that has ever happened in my life by a long shot…this has opened up my life to so many different things that I would have never experienced."

Participants took an active role in choosing how they will view their life going forward. For example, Participant 5 said, "And I'm aware that I'm maybe just making that up to comfort my own self-image [sharing his experiences to help others to cope with dementia] or the image

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for the public to see. And it's worked so far." Both gratitude and humor were described by several participants as part of their reframed perspectives.

Gratitude. Many participants (*n* = 14; 77.8%), despite their cognitive and physical decline, expressed gratefulness, for the life they have lived, the support they receive, and for each day that comes. The phrases they used included, "I like my life." (Participant 2, 15 & 17), "We have a good life." (Participant 3, 12, & 14), and, "Every day is a good day." (Participant 16)

Participant 18 more specifically said, "God is good and I give thanks every day for what I have. To have a roof over my head and my daughter who takes care of things. I can't complain. I am so blessed."

Humor. Several participants present their strategies for living well with dementia at public awareness events, and with that, share their ability to find humor in the situations living with dementia brings. For example, Participant 5 said:

> When she [another PLWD] and I show up it is constant laughter…She and I put those people at ease and they open up. At the same time for me that's a gift that I have to give and I'm glad to do so. And it makes me feel that I still have some worth. And just that I can make people laugh.

As part of her involvement in a local DFC, one participant designed t-shirts that read, "I have Alzheimer's; what's your excuse?" She sees this as a way to bring dementia awareness to the community in a fun-loving manner.

Another participant explained that when he runs into a memory problem during a conversation or activity, he jokingly says, "There goes Alzheimer's again!" Similarly, another participant calls his condition, "My pal, Alz." And simply put, a woman living in a CCRC stated with a smile, "I can laugh at things that I do."

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Living a contributing and engaged life. Participants viewed themselves as possessing the ability to be a productive member of society; serving as more than a passive care recipient, but as a person with agency to impact their community.

Several participants readily shared their experiences living with dementia so that the journey of others may be lightened. In this light, they are giving back to their community:

> I actually thought that maybe as a person who has been somewhat successful in the literary world and is beginning to lose some of my abilities that maybe my experience would be useful for other people in my similar situation…I want what I have to say to be useful…even if to say, 'You're not alone.'…And I thought, 'Well, if I can give voice to that situation well maybe somebody will benefit.' (Participant 4)

As one man explained his anger at being diagnosed with dementia, he had an epiphany, "…it dawned on me…that I got chosen because I'm strong enough that I can help other people." (Participant 5) He also added:

> I've made appearances with all kinds of folks to help people who are caregivers or professionals in the field to give to them information or some impressions of what would be helpful. I try to be very open. Ask me whatever you want…I'm an open book… I may not know what the word is for it… Just, I want, if there's something to be learned, okay, I want to be helpful.

When asked what she enjoys about support groups, Participant 8 replied, "I sometimes think that there are people, friends that have the same problem, who are very uncomfortable with it. I can help them. I think that I do help them."

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Having endured over a year of a challenging diagnostic process and subsequent depression, a participant said, “I want to do good. I want to help people. If there’s anything I can do to help people with my experience I want to do that.” (Participant 1)

Acknowledging his life-long and continued passion as an activist, having served as a protester in the 1965 Selma civil rights march, a participant vehemently stated, “I fight for a whole lot of things. I am anti-racism…” He recently attended the 2017 Women’s March that occurred throughout the United States. In this way, he continues his agency as a social advocate and long-time “bully buster”.

Another participant describes how joining exercise classes has contributed to his well-being, emphasizing his agency in taking an active involvement in life:

> I do…aerobics class, I do pump, which is a strength training. I do flow…a combination of Pilates and yoga…I do Shabam…I do Zumba, which is a dance step. And I do hip-hop…I do all that stuff, which I think has really helped me a lot. It’s given me a purpose. It’s helped me feel better. (Participant 1)

Knowledge and experience of dementia. Having up to date knowledge of dementia literature, whether from online sources or local experts, provided participants with a tool to better manage and develop a strategy for this overwhelming diagnosis. Participant 2 said, “When I was diagnosed with dementia I…. I read a lot on the Internet. I look things up. Everybody does.”

Another participant responded similarly:

> Once I was diagnosed with Alzheimer’s...I read everything I could about it and how the symptoms and what to expect and be conscientious and careful and I have been very successful and comfortable…I have made appearances with all kinds of folks to help

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> people who are caregivers or professionals in the field to give them some information or impressions of what would be helpful. (Participant 5)

Several participants had a comfort level with the condition before their diagnosis due to experience caring or associating with a PLWD, often a family member. This seemed to bring as sense of calm and self-assurance when discussing their own situation. Participant 16 shared his comfort in caring for his mother when he said "Mama had Alzheimer's. I understood it enough that it was Mama and I took a lot of care of her during her time."

Time with family members going through the journey provided a sense of understanding. "I had an advantage. I had a beloved cousin with Alzheimer's…and I spent time with her…so I knew what it was going to be like when I was diagnosed… I could be prepared for it …to do it gracefully." (Participant 5)

Tapping into coping skills and resilience. The long life span of individuals in this study provided well-developed strategies for them to employ in the life challenges of living with cognitive impairment. Many participants identified and applied lessons learned from previous life situations in their adaptation to the experience of living with dementia. Prior experience with acute or chronic illness can prepare individuals for the dementia trajectory. One participant's experience with a stroke and subsequent temporary cognition problems stirred her to plan for the memory loss that will occur with dementia:

> I learned…to take the pictures I wanted to because, I knew that after having a stroke…I might not remember this life. Specific places, specific things about how it looked. And because I had gotten to where looking back on a memory was really fuzzy. So, I figured if I took pictures that would bring it back to me. And it has. But it has also helped me

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> think back on it and remember. So, focusing on the camera focused my brain, for want of a better phrase. (Participant 2)

In contrast, another participant spoke regretfully of her discarding old photographs and memorabilia that could have helped her remember events in her life that are now difficult to recall.

A participant who had demonstrated resilience through surviving a difficult childhood cheerfully stated, “Well, very early in my life I adopted the phrase, ‘Smile. It makes people wonder what you've been up to.’ It worked.” (Participant 8)

Living a life of leadership requiring problem-solving skills and attitude, whether in a personal or a professional role also provided skills to uphold personhood, as described by Participant 3:

> I guess because of my life experience, my business experience, I’m dealing with changes and challenges all the time. It’s just something I deal with. If something comes up, and I have, I feel, an ability to influence making things better or seeking changes, I’ll do it. (Participant 3)

The presence of support. Support for living with dementia in community presented in multiple ways for participants, through family, friends, other PLWD, community members, and professionals. Participants expressed a continuity of identity through the acceptance and support of friends such as, “They laugh with me and that's who you are, and you are still you…that's the thing that I want to say to people, "I'm still me. I haven't changed. I'm not a different person… I feel like I have an incredible support system and I am very thankful for that.” (Participant 8)

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When asked how she would prefer people respond when disclosing her dementia diagnosis, one participant stated, “My favorite ... My friend who's a child therapist, when I told her…she just leaned over, put her hand on my arm and said, "I'm so sorry." (Participant 15)

When asked to identify sources of support, one participant responded, “Just people in general that I’m with, that I like, that I enjoy their company.” (Participant 3) The mere expression of unconditional warm regard in casual contact felt supportive in identity continuity.

In another case, the participant shared appreciation for a colleague’s response after sharing his diagnosis with him. “He acknowledged that it’s going to be hard. And I have a sequel to the book…that I’ve been working on…and he was encouraging me to try and submit it again…it was good to have that nourishment.” (Participant 4)

Care partners in their intimate knowledge of the individual demonstrated the ability to foster continuity of identity with person-centered support. “She [care partner] bolsters my confidence. She encourages me not to give in to despair and that’s just wonderful. With my last book she helped quite a bit with some…you know the requirements of scholarly writing.” (Participant 4)

Family members, both children and parents contribute to keeping their loved ones safe at home. “I know that my parents are always right there and I can call them whenever and they respond.” (Participant 8) Her adoptive parents, in their 90s, serve as a source of support and supervision when her care partner has other obligations. She also stated, “For the people that you can [be yourself] ... you're still you, what is it about them that makes you feel better and more yourself? “They're not judging me.” When asked what she likes to do with her friends, a response was, “Hang out. That's what you do with friends. You know when people are genuinely concerned and worried about you and you accept you…”

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This supportive warm regard from others also occurs with informal community encounters such as retail shops, as several participants reported. When grocery shopping, a participant noted, “But it’s easy [there] because you can go up to the desk and ask them ‘I’m looking for such and such.’ And somebody will take you down and show you where it is.” (Participant 7) A male participant similarly noted this about a local shop, “…they are friendly and willing to answer my questions.” (Participant 6)

Professional support in the form of a compassionate informative diagnostic process was appreciated. “And I don’t know if I felt relief, but I felt that… this is overstating it, but that maybe I saw a way forward...It’s always better, no matter how bad it is, to know one way or another, than not to know.” (Participant 2)

In discussing how he emerged from a deep depression that set in after his dementia diagnosis, a participant shared further support from the healthcare community:

> [What]…changed my life in a very positive way, is that I started going to an acupuncturist… I honestly attribute him to partly saving my life…I think had it not been for him and [my spouse], that I wouldn’t be talking to you. (Participant 5)

Uncertainty toward the future. In this study, nine (50%) participants discussed freely their feelings of uncertainty about what was to come, in light of living with a diagnosis of dementia or MCI. The unknown or indefinite understanding of how life will be in the future due to the unpredictability of dementia progression in both severity and length of time seemed to create a perplexity, for which there was no compass to guide them. For example, one participant, who is still driving stated the following about his views on volunteerism:

> I don't see a future in it, in trying to get involved in an organization and then having to drop out because I'm not able to contribute. I have no idea how long or what the slope of

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> the curve is on this progression. I don't know whether I would be able to do something for half a year or six years or whatever. (Participant 11)

The progressive nature of dementia also brings uncertainty as expressed about the ability to drive and remain independent:

> I'm hoping when I have to pass the test next time, and I think at that, in 2019, I can look at that day to remember signs. You know how you have to pass the thing, where you recall what the sign says? And I keep wondering, will I be able to do that? (Participant 14)

In a simple but poignant response to how he is living his daily life with dementia, a participant responded, "I'm bewildered somewhat by it [dementia] and want to know kind of what the future is going to look like." (Participant 4) He also stated, "And when all this came up I felt like the quality of my life and my interests was going to be degraded and eventually destroyed and that was awful."

Uncertainty was also expressed with a patience and acceptance of unknown impending change. "…I'm in what's a fairly dramatic change and I'm sort of sitting and waiting to see what happens next." (Participant 5)

In contrast, when asked how her activities have changed since her diagnosis of dementia, a participant living with her spouse in a CCRC stated:

> I think it's about to maybe change, I don't know…well, the feeling that I'm getting, and [my spouse] knows it too, is how fast it's going. Weeks, I mean days. From one day to the next or one week to the next I'm not… I'm different. (Participant 7)

After spending great effort in regaining physical and mental health, with a subsequent improvement in his cognition, a participant shared his continued experience of uncertainty.

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> I honestly think that my cognitive challenges are real. And, yes I think I'm doing much better, but, you know I cannot tell you that I don't think about the fact that I could go back down the tubes at another point. (Participant 1)

A hesitancy of approaching healthcare providers about their dementia prognosis was evidenced by a participant relating his interaction. "And even today I haven't asked him [physician] what the long-term prospect is as far as life span. I don't have an answer for that. Maybe you have an answer on that. I mean it's not a simple answer." (Participant 3) Although asking providers for a prognosis was not directly asked by the interviewer, eight (44%) participants raised the question of their unknown prognosis and lack of conversation about it with their physician during the study interview.

Self-Awareness. Conscious knowledge of oneself, one's feelings, and one's abilities varied with the participant sample, including their ability to recognize their own cognitive decline and subsequent impact on their ability to function in daily life. In this study, all participants readily discussed a level of recognition of progressive cognitive changes occurring within themselves, accompanied by emotions ranging from fear to calm acceptance.

Participants also described experiences out in the community at restaurants, shopping, and events, for which they often reported that things go well and denied any challenges in those encounters. It appeared however, the participants did not regularly recognize the contributions made by care partners to ensure events went smoothly, in their compensating for the participants' lost abilities. For example, one participant described having difficulty with numbers, such as making change and using a credit or debit card. But when asked how things go at restaurants he said he had no challenges, not acknowledging his care partner is managing the financial aspect of

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their life together now. Similarly, three participants did not recognize they are never alone. These individuals had a varying ability to recognize their changing roles within the home.

In all cases, participants recognized at some level the neurocognitive changes (deficits) happening within themselves, both as compared to previous levels of function and as compared to older adult peers. "And I take a lot a classes. And then in classes, I am the slowest one. But that's okay." (Participant 15)

The participants' degree of deficit in driving ability appeared to be in question in three cases, with the participant taking a stance that they are safe to drive when family and professionals believe otherwise. "I know I could drive if I had the chance, but they took my keys away." (Participant 17)

Participant 12 was adamant in his belief that his driving restrictions are unnecessary and overcautious. He stated:

> I think they're being very careful since I went there [driving evaluation center]. They have to be very careful and so they're going to overstate it and therefore punish the people who come to get the help. But I couldn't count all the stops. To me it was, they're protecting their ass, excuse me. That's what they're doing as opposed to helping the people.

The issue of driving cessation is discussed further under the "Life Engagement in Activities" section.

In discussing his pre-diagnosis cognitive decline that others at work also began to notice, a participant shared, "I was finding that I was less capable of really accomplishing what I used to be able to accomplish. You know, I was aware…" (Participant 1) He also stated later in the

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interview, “And, you know, this all made sense to me, because I kind of was aware of it. I just thought, ‘well, that’s how it is with getting older’ and that I’m under a lot of stress and so on.”

Another shared, “But when I'm tired, that's when, of course, the dementia sets in…so I come up here [room at an independent living facility] which is my haven.” (Participant 17) This individual recognized the impact of fatigue on cognitive ability in living with dementia.

When asked what led him to seek a diagnosis, Participant 4 responded, “I knew I was slowing down I guess I would put it.” Even though he had recognized the presence of cognitive deficits, he reported his dementia diagnosis came as a surprise.

Cognitive abilities and function were noted to fluctuate daily in dementia, as described by one participant. “I just have to be open to recognizing where the limits are. I’m very different today than I was three or four days ago.” (Participant 5)

The following quote is from a participant lamenting the recognition of his declining abilities to continue in his profession:

> It’s harder to grasp things and put them in order and you know, assign priorities and all that…I had the diagnosis but I didn’t like it because I’m accustomed to being fairly organized and able to organize thoughts and express them… form opinions and express those, but it’s harder now. And well, [my spouse] is having to help me quite a bit, because it’s just not coming to me like it should, like it used to.” (Participant 4)

Participants related recognition of their own cognitive decline and the resultant emotional distress. “The last month…or so it just seems like my memory is getting worse. And I feel it. I know that it’s just bad.” (Participant 7).

Living in the early stages of dementia was presented as though participants were carrying around a secret. The secret is not readily apparent to others, but the individual working extra

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hard cognitively to keep up with society is well aware of their deficits. "You know, most people that would talk to me would not have a clue that I have a diagnosis of dementia. And so, but I know I do." (Participant 1)

Social Connections

In this study social connections is defined as the establishment of meaningful contact or relationship with another person or persons. A participant simply but eloquently stated this as he described the reduction in social contacts he has experienced since his dementia diagnosis. "Connect is a word I think about a lot." (Participant 3) Four categories emerged in this theme (a) social inclusion, (b) social exclusion, (c) waning conversational ability, and (d) sharing the dementia journey. Subcategories will be discussed under each category.

Social inclusion. Social inclusion is defined as the ability to freely participate and feel welcomed in groups or activities, with a welcoming attitude of group members. Inclusion did not need to be highly organized; the everyday social events that made up their lives presented opportunities to be inclusive. Participants often responded that they enjoy the simple acts of getting together with others for a meal or a casual chat. Social inclusion also involves the nurturement of relationships, as illustrated by a participant's description of why he enjoys the early stage dementia adult day program he attends:

> And every person in it I like. It's not just that I can bear to be with, or I will ignore. It's just really fine people that I like and it's not so much the common Alzheimer's that we share. It's just that these are people that I'd love to be friends with the rest of my life. (Participant 16)

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In recalling time at a recent Memory Café event, where PLWD and their families get together for lighthearted socialization, a participant stated, “It's kind of nice. I took the opportunity to play Scrabble with my friend and whoever else would play.” (Participant 9)

One participant noted the improvement in her cognition when she socializes, “And it is… since… especially since I’ve been diagnosed with dementia I have noticed that when I’m out and around people, either at meetings or just sitting and talking to people, it’s good for me and it makes my brain work better.” (Participant 2)

Similarly, another participant noted, “It helps my mind to have conversations [with others]. It makes me sharper when I am out talking to other people. Makes me think better.” (Participant 18)

Going out to a restaurant was a nearly universal activity with the participants interviewed. A participant described how this activity has created social inclusion for him by sharing, “There are a lot of people in our Sunday school class taking me out for lunch. I’m enjoying it- meeting other people better.” When asked how he would like people to respond when he shares that he is living with dementia, one participant stated, “Well, to have an interest in where I am, what I am feeling, and how it is affecting my life.” (Participant 3)

The feeling of unconditional positive regard by other people allows for social inclusion and feeling connected. Participants smiled as they recounted recent gatherings with friends and welcoming encounters with people in the community. Participant 8 shared what this means to her, “That's the thing that I want to say to people, "I'm still me. I haven't changed. I'm not a different person, I just find things difficult sometimes. When people relax, I relax... I'm still me.”

When asked what he finds supportive about his community, a participant responded, “I appreciate the chance to develop friendships and be with people.” (Participant 5)

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When asked what made a certain store more preferable than others at which to shop, a participant noted, "I hadn't thought in depth about that, but people there are friendly, always been helpful when I couldn't find something." (Participant 6)

In explaining how he feels welcomed at the local YMCA, Participant 12 shared, "They always know us by name, I don't know how. Although, we've got a card that you scan and they always calls us by name as we come by…the people there are very, very nice."

When asked what the term 'dementia friendly' meant to him, a participant replied, "I can relax when I go to a place that's dementia-friendly. And I don't know, might be a euphemism but it's a chance to relax and just be myself." (Participant 9)

Social exclusion. Participants also mentioned social exclusion, the experience of being or feeling denied from access to groups or activities. They described feeling themselves being distanced from others.

"There are some people who ... that I was friends with, not close I guess, that find it difficult to be around me. That it's like I'm a different person and I am a different person but, I'm not." (Participant 8)

In describing his experiences with fellow church members, Participant 3 stated:

> They seem to have a fear that they don't know what to say to me so they're not as friendly to me as they used to be…They're fearful that they'll say something wrong…people I used to talk to more readily don't approach me like they used to…that's a feeling I have that they're cautious. They don't know what to say to me.

Shrinking social circle/ isolation. Participants reported friends and community interaction fading into the background as their dementia or memory loss became apparent. This

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was not always viewed as a negative occurrence; one participant saw this time of her life as an opportunity to be alone:

> Having a few hours during the day to read and be by myself. I find this time of life, for the first time in my life being alone… I've never had time alone and I'm enjoying the aloneness of it. (Participant 10)

When talking about how he spends his days, Participant 13 stated:

> I don't know what the reason is that I don't enjoy other games. It's not that I don't enjoy other games. It's that there's never an opportunity to play games with people, other than [assistant], who we pay extra for to get her to spend time with me**.**

While this participant was not directly shunned, he appear to be voicing an unmet desire to spend time with others.

When discussing how friends no longer want to be in her company, Participant 8 stated, "Most people ... people like that I'm not around that much…. It's awkward for them to communicate with me."

Participant 12 shared, "I don't have friends anymore and that's because I don't go to any groups." He also stated later, "I've always been private to myself, I guess. I'm just not a good chatter, communicator I guess…Yeah, like I said I don't have friends and I don't know where to go to get friends."

Participants described how past friendships often disappeared after their dementia diagnosis. "We're just not doing that [socializing together]. So if she doesn't want to see me, that's fine. Maybe she's afraid she's going to get dementia." (Participant 17).

Participant 4 described why he finds conversations and relationships with prior colleagues intimidating to pursue nowadays, and usually avoids them. "The kinds of

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relationships…I had when I was an active novelist, I don't know they were just more intense, more sophisticated, and more sort of demanding in some ways."

The social world of several participants (*n* = 4) was limited to people involved in their support group or those understanding of the changes that accompany dementia. "We spend time around mostly with dementia people that we know." (Participant 9)

Similarly, Participant 6 shared, "…I mainly socialize with others in the same situation anyway…from our [dementia] support group. (Participant 6)

Residing in a continuing care retirement community can be a supportive environment through the provision of opportunities to meet both socialization and health care needs. Despite this support, as new residents, a participant struggled with social isolation, as further described:

> …it's hard to be in a new place and not have many friends and there are a lot of old people here that are sort of isolated, they kind of just stay in their houses and, you know, there are others that get out there more and bond, there's both kinds of people…so we really don't have any people we see in this area, neighborhood." (Participant 7)

Self-exclusion from social opportunities specifically because of the limitations imposed by dementia was also reported, by both male and female individuals. "The main thing is that there are times when I don't want to get out because of it [dementia], and I don't like that, especially when I'm tired, just plain tired." (Participant 17)

The shrinking social circle and self-exclusion appeared to be connected to the stigma associated with dementia in the response of Participant 1 when asked about his interactions with others in response to his dementia diagnosis. He stated, "I never gave them the chance [to respond]…I couldn't go out in public. You know, so I would lay in bed. I mean, there were days

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where I would not get out of bed." He isolated himself by ceasing all social activities once he was diagnosed, and slowly reentered the social world with positive results.

Stigma. While once again participants did not use the word "stigma" outright, they described social scenarios indicative of stigma. The felt stigma of PLWD rang loudly in descriptions of social isolation, as evidenced by the following statement:

> I just felt like, you know, I mean, it was embarrassing. I was extraordinarily embarrassed. And I just felt like, you know, how can I go out and see people I'm just embarrassed about what's going on… I mean, there's almost as much of a stigma from my standpoint about dementia as there is death. I mean we just don't deal with death well in this country at all. (Participant 1)

Participant 5 had a similar view describing the fear associated with dementia, stating, "…newcomers are frightened by it. They don't know how to deal with people who have it. They don't know how to deal with themselves about it. And what… they can't deal with is their own fears about it."

Individuals insinuated instances where they would attempt to hide their cognitive decline from others in social situations:

> How open you want to be about it, obviously. I don't go out broadcasting it say, but I have on occasions said to people 'I just don't remember.' But hopefully that merely means that they recognize that I'm at such an age where you just don't remember everything, without having it be a particular problem. (Participant 6)

Similarly, Participant 17 shared trying to cover it up in public, "…when other people start talking … I can fake it a bit… but I know I won't be able to for long."

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Stigma surfaced again in this conversation with Participant 18 when asked how other people respond when they know she has memory loss:

Participant 18: They don’t know. I can hide it.

Interviewer: Why do you want to hide it?

Participant 18: Well, nobody wants to be thought of like they not thinking right.

Another participant stated she feels no stigma, yet she described her friends denying the possibility she had dementia and stated, “I think they are afraid if I have it, they might have it too.” (Participant 2)

Participant 11 echoed this sentiment with his stating, “It’s going to be a long road [to having awareness in the community.] In some respects, some people I think believe you could catch dementia.” He described a poem that his dementia support group uses to help them cope with the negative responses of others toward PLWD:

> See me as I am now, not as I was and not as you are afraid I'm going to be. That's almost like a mantra to me because what I see is that that is not what people do…They see you as ... as I was or that she [wife] remembers I was, but mostly as she fears I will be.

Two participants presented a more optimistic perspective. Participant 16 distinctly denied the presence of dementia stigma in his life. “If dementia were something that would be embarrassing I wouldn’t like it because… I understand after [attending an adult day program]…that dementia is an okay word in the world.”

Participant 5 offered hope of one day eliminating stigma with his interpretation of the current social culture. He stated, “…the negativeness that has accompanied the word Alzheimer’s has declined I think, significantly, noticeably toward opening the door to understanding for the public; comprehension of what it means and what is involved.”

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Waning conversational ability. Early, yet subtle emergence of conversational difficulties was noted to present communication challenges by 13 participants in this study. These individuals were still quite functional in daily living and wanting to be conversant despite having a diagnosis of dementia.

In discussing her memory loss, Participant 10 shared:

> I feel my age socially. I feel less adept. I feel less able to participate conversationally than I once would have… I feel less able to think of things to say and I feel more like pulling back and staying in a corner so I feel self-conscious, more self-conscious.

She also teared up as she described how her memory loss impacts the way she relates to others in conversation, "It's that I've no longer… It's [the memories and stories] gone from me so I'm a zero. It's gone from me because I can't grasp it anymore."

In discussing his struggles in spending time with friends and acquaintances, another participant noted:

> Well, yeah. I've had memory problems forever. I've never been able to remember a name. It's worse now than ever. I get to talking with people and I want to talk about something very similar to me. I can't pull the words up to do it. I have to admit that I can't go on. (Participant 13)

This individual also stated his wife lets him know when he is off track in the conversation, such as when the group has moved on to a new topic but he is still making references to the previous topic. When asked how others could facilitate his inclusion in conversations to compensate for his memory loss, he stated, "I suppose it would be helpful if people would ... If they knew that I had a problem, and were wanting to say, 'Just to remind you, I'm Bobby,' or, 'I'm Jackie,' or something like that. They could tell me, and that'd be fine."

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A participant shared how she felt attending a discussion group about the morning sermon at church, "…they'd start talking about the sermon...and they had all heard and remembered and could discuss [the sermon], but I was at sea." She could not remember the sermon well enough to contribute to the conversation. She stated she felt like she was, "…losing IQ points." (Participant 15)

Difficulty following the sermon during faith community services due to memory loss also arose in an interview with a participant whom stated:

> It's gotten hard for me to understand the Pastor's sermons, because my brain seems to be… have difficulty remembering what I've heard. And even what I read… like I talk about political books or political essays and things like that. I have a hard time remembering what I read. (Participant 3)

A participant described how her declining conversational ability has led her to reduce her interactions that require a conversation. "I don't talk as much to people as I used to…I guess because I'm afraid I'm going to have a mishap, which of course I'm going to have them." (Participant 17)

A participant described his struggle to engage in conversation with his professional peers, and his hesitancy to attend professional events. He spends most of his day home alone as his wife works full time. "So it's rough to not be able to do the back and forth that I used to do, because you're just slowed down and it's not there anymore." (Participant 4)

In attending community political events, a participant who was active in this arena in the past described his reluctance to join in now. "Where, I mean, I don't know how to respond because I wasn't able to gather what I hear and put it in any kind of a form." (Participant 3)

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Word finding challenges were mentioned by several participants. For example, Participant 7 shared, “Sometimes I’m thinking when I say words I’m not sure I’m saying the right thing… Sometimes I think I’m saying something else.” An illustration of this occurring for her during the interview is as follows: “Well, my thing over here was not working right…my thing that makes music [the speaker]”, and “I can’t go there because I can’t remember the words.” when referring to explaining her last hospital admission to the interviewer.

Similarly, Participant 9 stated, “... I lose words. Although, I think lately, less often. I can't think of the word that fits…I used to be fairly articulate. That's a frustration.”

The presence of hearing loss, noted during the interviews of eight participants further accentuated conversational challenges. For these individuals, their conversational challenges were not only cognitive, but also physical. Two participants informed the interviewer of their hearing challenges before the interview began to arrange the seating to maximize their hearing; in other cases it was noted by the interviewer as the interview progressed.

Sharing the dementia journey. Participants described supportive relationships in which they were able to share their concerns and struggles in living with dementia. This sharing was demonstrated to occur in both informal and formal settings among study participants.

Informal sharing. Ten participants discussed sharing their dementia journey in a casual conversation with friends or family. Participants noted that their care partners often provide a warm and understanding place to vent feelings related to issues that arise in living with dementia.

One of the participants openly shares experiences of living with dementia with interested parties, wearing an Alzheimer’s, T-shirt and pin. She expressed being received warmly by community members when the topic of dementia surfaces. She also shares her experiences of

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living with dementia in dementia awareness sessions in her community said, “I want to do good. I think my experiences can help other people, and I want that.” (Participant 2)

Another participant discussed a conversation he had with a long-time friend, “…we talked about my dementia, and what it meant. It was good to have that sharing.” (Participant 4)

Participant 7 praised a neighbor in their CCRC who openly shares that she is living with dementia. “But she doesn’t know yesterday or today. She doesn’t know anything. She hardly knows her children’s names, but she’s just really delightful to be around…. It’s not like she’s out of it, you know.”

Formal sharing. Formal sharing such as in dementia support groups was both more commonly mentioned by participants, and noted as occurring on a consistent basis rather than sporadically as with informal sharing. The two sites acknowledged for formal sharing of experiences related to living with dementia occurred in sessions with a therapist (n = 6 participants), and in dementia support group meetings (n = 10 participants) which met at varying frequencies from weekly to monthly. Three participants discussed being involved in both therapy and a support group. Overall responses to support group participation were positive.

“It’s hard to find places where I can share. That’s why we are going to these [support] groups. They are a touch of what I have been missing for a long time.” (Participant 3)

Support groups are a welcomed source of kinship in the face of living with dementia, especially when family is not nearby. “I lost some friends in the New York area… although going to these groups has opened up new doors. I don’t know who else I would know unless I’m going to these groups here.” (Participant 6)

When asked what drew her to attend a memory loss support group, one participant expressed, “That I can be me and share with other people, and I learn and they learn.” When

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asked how she helps others in the support group, she replied, "By being honest and open and they relax and can be the same way." (Participant 8)

Another participant explained the value of sharing how to access resources to improve living with dementia. "I think it's a good thing to be doing…this kind of thing…they'll give you ideas of how to find out about things that you can't remember, because they tell you things that they've done." (Participant 14)

One participant not currently in a support group but interested in attending stated, "I would think that dementia meetings, like al-anon, like I went to for years, would be good for people." (Participant 17) Another participant not currently attending meetings was looking forward to a dementia support group being started by a church member that had recently attended a dementia awareness session.

The comradery and openness within a structured support group was a welcome activity for many participants as expressed by participant 6:

> Participant 6: And I find those [support group] meetings… we go every Thursday. And I really enjoy going through. I'm not sure if I feel like it's because I'm hiding [elsewhere].
>
> Interviewer: Hiding?
>
> Participant 6: I'm not hiding there [at the support group], I never talk about it [dementia] with strangers, but these are folks on the same issues that we have, that I have. And I really enjoy those weekly sessions.

When asked what is gained from attending a dementia support group, a participant replied:

> Just hearing from other people and what they're going through and how they're dealing with it. Going back to what I've been sharing, I enjoy being around people who share

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> openly who share who they are and then I can connect with a lot of those people. (Participant 3)

Conversely, support group leadership was critiqued by four individuals for not appropriately directing the conversation to meaningful topics. “Well, we are facing dementia. We share our dementia, but they want to talk about animals or homes or vacations or stuff like that. It’s superficial stuff.” (Participant 3)

Participant 12 reflected a similar view when he stated, “It [support group for PLWD] had absolutely no benefit other than a complaint area or a yak area, but there's no benefit for me.”

The study interviews provided an opportunity for sharing, much appreciated by several participants, such as, “I feel better having the chance to talk … I am glad you came.” (Participant 7)

Sharing the dementia journey brought an opportunity for friendship and mutual support for those living with dementia, amidst an often ill-charted path.

Engagement in Life Activities

The manner in which participants spent their time, either for pleasure or as part of their daily activities of living was discussed during the interviews. Most individuals reported continued engagement in long-standing interests including intellectual pursuits such as political meetings, senior college, writing, and reading, and physical activities such as running, exercise classes, biking and walking. Other activities in which participants continued to engage included: pottery, faith community gatherings, pet care, child care, volunteerism, and eating out at restaurants. Participants shared the importance role of continued engagement in their lives.

“I’m big on stimulation and I just, now I’m kind of a homebody. Because I can’t drive and [my care partner] can’t take off every evening.” (Participant 4)

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When discussing going out to eat at a restaurant Participant 4 stated, “While I’m a little advanced in age to share that [downtown nightlife], it’s good to be around it.”

In discussing his desire to go grocery shopping and cook, Participant 13 stated, “I need some of these things to keep me alive.”

New-found dependence. Participants reported the need for assistance or supervision and the inability to complete activities previously done independently, including the inability or limitations on going places alone. They also reported a heightened sense of caution by intentionally slowing down or avoiding an activity or engagement in light of safety or avoidance of making a mistake:

> “..I’ve been learning, relearning the most dramatic things physically, loss of confidence that something is going on…just issues like maintaining balance, not falling down...avoiding mistakes and once I got the diagnosis I started, you know I got alert to these things and…don’t take for granted that you’re going to be able to function like you’ve always been able to do. (Participant 5)

Participant 11 described the heightened sense of safety precautions since his diagnosis. "I was being safe before [my dementia diagnosis], but now I am, fancy word, trepidatious.” The caution exhibited by their care partners was viewed by two participants as an impingement on their ability to engage in activities, as the same participant further shared:

> There have been a few times when she has jerked something out from under me, that I don't know where that's coming from. I can't think of a specific anymore. She gets very discouraged, very easily. She's a worry wart. She tells me, ‘Look, you've got to have someone with you all the time.’ That means all the time she's not with me.

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Participants shared their frustration at being unable to continue activities they previously mastered. Participant 4 demonstrated this by stating:

> The… interference with my logic, and my creativity, and how I see the written material progressing. My imaginative life is just as strong as it ever was, but the transference of what I think I see in my imagination to the page is just… there's an interference there that I'm not familiar with, or used to. Because I always felt pretty sure about where I was taking the story, or event, or whatever. And now it's like I don't even know how to do that…I can feel it. And there's this tremendous frustration.

He summed this up with, "I'm not able to do what I like to do…That's writing. Write effortlessly. Now, you see, it's all labor."

Participant 7, a long time quilter, expressed remorse at her loss of ability to complete a quilting project:

> I had just a little bit left to do and I put the binding on it and [husband] came in and said 'That binding looks awful. You better take that off and make it look better.' And I just, I just don't think I can make a quilt anymore.

Participant 12 explained that he had to cease his long-standing 27 year involvement in karate with his spouse after developing memory loss. "We did it for years, we taught it for years and then I started forgetting…the forms that you do and the weapons. I mean there were a bunch of them." When asked how it was for him giving up karate he replied, "It was disappointing, highly disappointing." He compensated for this lost activity by joining the YMCA where he uses exercise equipment to stay physically fit.

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When discussing how she has forgotten how to use some features on the iPad, Participant 7 stated, “I told [husband] this morning I said ‘I just wanna [sic] do that [iPad] every day because if I don’t do something every day I’m going to lose it.’”

Twelve participants reported difficulty reading. This involved either a loss of interest in reading, and/or difficulty comprehending written material. For example, Participant 12 noted, “I don't read as much as I did. I got a whole stack of stuff that I still should be reading.”

The change in reading habits, with a newly developed lack of initiative or motivation to read was also described like this by Participant 15,

> Okay, I used to be an addicted reader. I'm just not interested in it. If I have something, that, for one reason or another, sometimes I have to read books for a class, I can read them, I can enjoy them on some level…I've been partway through it [a book] for a very long time. That is so incomprehensible to me.

Participant 3 described a frustration with the inability to remember what he had just read, making the material difficult to follow:

> I used to be a veracious reader. I still read some, but I don’t remember a lot of what I read…And now I don’t, because I feel like I’m not getting the value out of it that I used to.

Reading menus at restaurants was also reported as challenging as one participant noted, “I don't like to look through pages of menus anymore, and I just scan to get what I want.” Several participants noted that they frequent familiar restaurants, where the menu is consistent and the choices are not overwhelming. Participant 18 shared her strategy in ordering at a restaurant, “Well, I usually right know [sic] what I am going to get before I get there.”

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In discussing the activities they could no longer be involved in, those that involved driving to events arose commonly. For example, difficulty getting to music events such as local concerts was reported by two participants. Participant 17 stated, “I loved Shindig, I went to Shindig and did it all the time. And I'm going to find a way to get to it…That was a joy to me.”

The painful loss of independence felt by participants was greatly intensified by loss of driving privileges. “And of course, when you have something like that {driver’s license restriction] happen on top of everything else… that was just another nail in the coffin. I mean it was horrible.” (Participant 1)

As with many rural regions in the United States, Western North Carolina even in its most urban areas has limited public transportation, leaving people without driving privileges dependent on others for transportation. When asked about not being able to drive, his frustration became evident as a participant exclaimed, “Terrible. It's very hard. I still go to the driver's seat once in a while when I'm getting in the car. I've been doing this for over a year I guess, two, two years.” (Participant 13)

In sharing the broad limitations imposed on him by driving cessation, Participant 4 shared, “I don’t know…it’s hard to be stuck in the house, it’s frustrating. I feel trapped in this dementia sometimes.” He also stated, “Because I have so many interests, there are so many things I want to do that by not being able to drive I can’t do.”

Simply put, Participant 3 shared his frustration with, “It complicates my life a lot more. I used to be able to get so much more done so much efficiently when I could drive.”

Although he has an attentive care partner providing transport, Participant 6 simply stated, “Essentially I’ve accustomed myself to the fact that I can’t go anywhere.”

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"The sense of independence has pretty much gone. And that is a void that troubles me. I can't just get an idea and go do something. And I can't even get to a library, because I can't drive. And it's just infuriating. And then that sort of impedes all the other sort of things that I would like to do because you can't get there easily." (Participant 4)

Five participants reported they still had driving privileges at the time of their interview, but drove with caution, as communicated by Participant 15, "I don't drive unfamiliar places, much. I'm grateful for GPS. It'd be a lot harder without that." She also stated she informed her daughter, "I said if there's ever any concern….have me go get that evaluation and then it's not in your hands to make the decision, because it was horrible making that with both of my parents."

Several individuals reported giving up their driver's license willingly for the protection of themselves and others, although succumbing their independence was difficult. For example:

> It was my standing up and acknowledging that it was the right, safe thing to do…my recognition that I still had some more mileage in me and I didn't have to quit, but I did. And never once, did I whine about it. (Participant 5)

Adaptation to Meet Current Abilities. While cognitive impairment was reported to interfere with some activities, it did not automatically prohibit participants from engaging in activities, rather they often instead changed the structure of the activity or the participant's degree of involvement to allow continued engagement. For example, instead of hiking trails alone, several participants reported they went for walks in local parks with a companion:

> She [hired companion] takes me out to…the only soft surface park that has a trail, soft surface for those of us that don't like hard surfaces. I've learned not to do with this hard surface stuff out here because I broke two toes on this hard surface out here. (Participant 13)

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Two participants, both living alone, reported making lists as a helpful strategy in living with memory loss. For example, Participant 2 stated, **“**And then I’ll make a list of what I need or want to accomplish that day…that’s the only way I can remember it.”

Several participants reported continuing to volunteer by taking on a role specific to their abilities. A participant that previously organized a large book sale for a library now serves as a volunteer on the team transporting the books. Another participant volunteers at a pottery co-op store and shared how she approached her team about appropriate involvement. “Yeah, I have told them that I would not… when we started this, like three years ago… that I would not be comfortable running the Square [sales device] during sales. So, and that was okay with them.” (Participant 2) She also stated, “I like my life. I like my life. The way I live. I like what I do. I pretty much don’t do anything I don’t want to do. And it… so I’ve kind of designed it for me.”

Two participants reported they received support from their employers to continue to work despite a diagnosis of cognitive impairment. One participant shared, “I had a fabulous supervisor. Fabulous. And it was hard because she pretty much was pretty good about leaving it up to me to try to make a decision about retiring.” (Participant 15)

Participant 11, who worked for two years post-diagnosis stated, “…even though I had the diagnosis of mild cognitive impairment, the functionality that was related to my work didn't seem to be affected it all.”

Pet care also emerged as an important source of socialization and engagement in life activities. Six (33.3%) participants happily reported fully or partially contributing to the care of dogs, cats and a rabbit. For example, Participant 13 shared, “Well, a typical day starts with me and my dog walking around the circle here.”

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Increasing dependence and adaptation occurred with the use of a computer. Sixty percent of participants still used a computer at the time of the interview, however several reported increasing challenges. One participant noted, to the surprise of the care partner present for the interview:

> I *was* able to function pretty well on a computer…that is something that bothers me, because it takes more time, I make more mistakes when I'm writing an email, and I have to be very careful, and do a spellcheck, and all that kind of stuff, because I'm hitting the wrong keys, and things like that. (Participant 14)

Similarly, Participant 15 explained how her daughter regularly assists her with computer glitches, "…that I probably should, at another time in my life, might of figured out myself. Sometimes it's as simple as I didn't know, I didn't remember I needed to double click, or even think to try double clicking." Soon after this statement she exclaimed, "But I love my iPad!" Three participants expressed their preference for a tablet as opposed to a standard computer, as evidenced by another preference statement: "I have quit going to the library. I find it is easy to read on my tablet, because I can change the size of the font and that's easier for me. The font at the library was too small." (Participant 2)

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Conceptualization of Living with Dementia in Community

As seen in Figure 1, the three major themes emerging from the perspective of persons living with dementia in community demonstrated overlap, and are therefore graphically situated surrounding the individual as an interconnected experience. The themes are independent, yet have the ability to influence how the other theme is experienced by the PLWD. The relationship between the PLWD and the themes are bidirectional. The complex social and health history of the person living with dementia affects the manner in which that person experiences their cognitive transition, social connections, and engagement in life activities. Likewise, the experiences the individual encounters in the community through the realms of their transitioning cognition, their social connections, and engagement in life activities in turn shapes their experience of living with dementia.

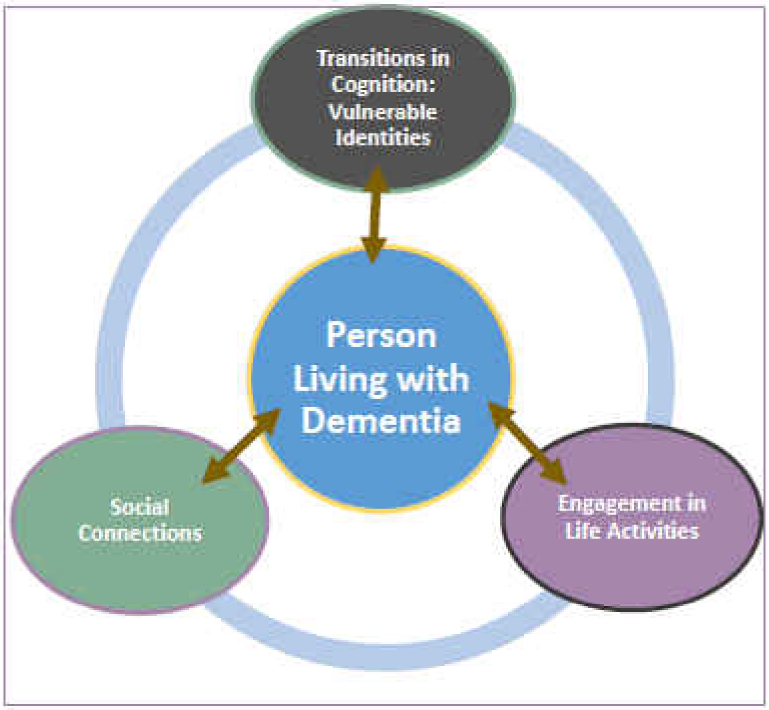

Figure 1. Living with Dementia in Community

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Additional Findings

Dementia Friendly: What Comes to Mind

As part of the semi-structured interview, the final structured question asked, “When you hear the term, ‘dementia friendly’, what comes to mind?” This question was placed last, so as not to bias the prior interview responses toward ‘dementia friendly’ answers. Many participants hesitated slightly when answering this question, as it appeared to be a new concept and required some thought to articulate a response.

Participant 13 clearly articulated that a dementia friendly community goes beyond the provision of healthcare; it involves social inclusion:

> Well, I'll tell you, it means people don't treat you kindly and then they walk off. It means that I have community out there who aren't necessarily involved with me around my ailments, to take care of me. They are with me because they appreciate spending time with me.

Participant 15 reiterated this in her focus on quality of life. “It's a very intriguing term. But it's very inviting, I think I would say…the main concern doesn't need to be health and safety, it needs to be quality of life.”

Participants reported dementia friendly implies an ability to openly use the word, “dementia” without stigma, as Participant 3 shared:

> Dementia Friendly. Well, what comes to mind is that… people that are open about talking about dementia and sharing and that want to hear from others about dementia… I think that would be… that’s where I learn. I learn things about myself when people share where people think they’re growing or not growing.

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The feeling of being understood, and open about living with dementia was also evident as with the response of Participant 8, “People that understand. I think that the friendly community is going to be one that you can talk about it.”

This feeling of understanding was also exhibited with, “Dementia-friendly I guess would be your friends who already know about it and are used to it.” (Participant 17)

Self-acceptance was mentioned in one reply, “I feel it’s a stage in my life that I’m in and I accept that this is me.” (Participant 10)

Being treated with warm regard without having to perform at a certain cognitive level was insinuated with the next several responses, “I guess it means an atmosphere that still regards persons with dementia positively in some way.” (Participant 4)

“I can relax when I go to a place that's dementia-friendly. And I don't know, might be a euphemism but it's a chance to relax and just be myself.” (Participant 9)

Raising community awareness about dementia was identified as well with:

> Dementia friendly would be clearly… and again, I don’t know if I’m right or not, I feel like I am. I feel that there needs to be a better understanding by the general population that dementia is an illness just like heart disease, or like diabetes, or like anything else. (Participant 1)

Participant 2 reiterated this focus:

> Well, when I hear the phrase I think of our group and all the wonderful things that are happening because of all the energy we’re putting into it [raising awareness]. And I think we’re having a real positive effect on the community.

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Participants shared valuing a recognition of personhood, as with this response, "The one-size-fits-all approach is as disruptive to my peace of mind as anything. In a dementia-friendly community, that would not be the case." (Participant 11)

The importance of relationships was evident in this response, "And, you know, just because I have dementia doesn't mean that I can't go out and do stuff and relate to people. You know, I mean, maybe I can't talk like I used to." (Participant 1)

Lastly, one participant responded with a social yet an exclusionary focus, where the PLWD would need to be separate from the rest of society. "I have not heard that before. Well, I suppose that is when people with dementia can all get together and socialize." (Participant 18)

This is Important Work

In addition to the major themes discussed above, participants exhibited a sense of pride in contributing to work they felt important in improving the lives of PLWD. The study was presented to the participants on the recruitment flier and information sheet with the goal that their perspective would contribute to the creation of meaningful DFCs both locally and nationally. Participant 3 stated in the introductory phone call, "I would like to be a part of this – it is important work. I think I am going to get something out of this myself." This participant asked questions about his role in improving community dementia awareness throughout the interview and thanked the PI for broadening his perspective.

Similarly, when told the interview would most likely last 60 – 90 minutes, depending on how much she had to say, a participant replied, "Oh, I have a lot to say!" During her interview she expressed gratitude for having a chance to contribute to "something that needs more attention."

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After his interview, Participant 6 shared his positive interview experience with his support group, specifically the conversation that entailed and the empowerment he experienced. This inspired four other support group members to join the study. Most participants asked for follow-up on the findings. Participant 1 stated, "If even one person could be helped by my contributing to this study it is worthwhile. I am so grateful you are doing this work."

The Presence of Care Partners during Interviews

Six individuals did not have a care partner present for any part of the interview, and three of those individuals lived alone. Regarding the other individuals interviewed alone, their care partners were either at work, at an appointment, or out of town. Through mutual decision between participant and care partners, 12 (66.7%) participants had a care partner present for the interview. In two interviews, the care partners left part way through to attend to other commitments.

Care partner presence appeared to enrich the interview process for several reasons (a) creating a safe space for participants in the interview, (b) clarifying information for participants to respond with confidence, and (c) and respectfully inserting information. Several care partners came prepared to take notes, viewing the interview as an opportunity to learn. Most care partners sat across the room at a distance to limit their involvement in the interview. Many respectfully requested permission to contribute before responding to a question from the participant. It was not uncommon for a participant to look to or ask their care partner for word finding difficulties, confirmation of, or to clarify their response to an interview question but participants appeared to consult their care partners less often as the interview proceeded.

In several instances however, care partners offered clarifying information after the participant gave what would appear to be a complete answer but from the care partners'

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perspective was not. Discrepancies between participants and care partners included reporting the length of time a deficit had been occurring or the frequency with which an event occurred (e.g., care partners stated the participant had not been driving for two years instead of only one year reported by the participant). These factual discrepancies posed little importance for coding and data analysis, rather the meaning derived from the participant's narrative was the focus for this study. There were no final disagreements on study data between participants and care partners. The view of the PLWD served as the data for the study.

Use of the Evaluation to Sign Consent Tool

The evaluation to sign consent (ESC) tool (Appendix E) was completed with each participant after the consent was explained in person. A copy of the consent had been emailed to either the participant themselves or to their care partner to share with the participant. Each dyad had access to email, therefore no postal mailing was necessary. Seventeen participants passed the ESC without the need to have a care partner sign the consent document. One care partner was required to sign the consent as surrogate due to inability of the participant to answer questions one and three. The tool required approximately three minutes to complete.

The first question, "What are the risks to participating in this study?" was in 16 cases initially answered by the participant as "None," or "I do not see any risks for me." Participants appeared to personalize the risks and provided that answer rather than repeating the study risks back to the PI as stated on the consent and in the conversation. Once the question was clarified to ask for the general risks of the study rather than which risk they were personally concerned with, the participant was able to answer the question.

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The second question, “What is expected from you in this study?” was easily answered by most participants, with responses such as, “to tell you my view on having dementia,” and “to speak my truth.”

The third question, “What would you do if you do not want to be part of this study?” was answered with short sentences, such as, “I would stop,” or “I will not want to stop.” The PI clarified with participants that even though they did not plan to stop their participation before the study, it must be clear they understood they were aware of their ability to decline to participate at any time, even after the interviewer had left their house.

The final question, “What if you experience discomfort during the study?” was commonly answered as, “I will tell you,” or “the same as I just said”, as the third and fourth questions appeared repetitive to the participants.

Conclusion

Through qualitative content analysis of 18 interviews of people living with dementia or memory loss, the interrelated themes of transitions in cognition: vulnerable identities, social connections, and engagement in life activities emerged. Participants enjoyed contributing to the study as they considered it important work. In addition, the term ‘dementia friendly’ was identified by PLWD as containing aspects of acceptance, openness, personhood, and awareness. The presence of care partners in the interviews was supportive, and the evaluation to sign consent tool assisted in determination of participant capacity to self-consent.

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CHAPTER 5

DISCUSSION

This study set out to explore dementia friendly communities from the perspective of persons living with dementia, with the specific aims of providing an understanding of living with dementia in the community, and uncovering the attributes of a dementia friendly community for the purposes of evaluation of communities or initiatives striving to embrace dementia friendly principles. Through QCA of 18 semi-structured interviews, three themes and ten categories emerged.

The intersection of themes in this study opens a window into the complex nature of living with dementia. The themes and categories weave together through participant narratives, intersected by long standing physical, mental, emotional, and social histories, and the type, stage, and location of dementia within the brain. The themes and categories are discussed in light of the research questions and extant literature. Theoretical, practice, policy, and research implications follow. The use of "participant(s)" refers to individuals in this study, unless otherwise noted.

The Experience of Identity, Interactions, and Relationships in Community by Persons Living with Dementia

The participants in this study bravely revealed social and personal dimensions of living with dementia that otherwise remain concealed. Their accounts confirmed the non-binary nature of dementia (Bartlett & O'Connor, 2010); living with dementia is not simply a "you have it or you don't" existence. The popular depictions of dementia in the media would have us believe otherwise, often portraying PLWD in later stages with little awareness or abilities, to the chagrin of participants (Johnson, Harkins, Cary, Sankar, & Karlawish, 2015). Participants described

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dementia as a stigmatized label threatening to their personhood (Benbow & Jolley, 2012; Swaffer, 2014).

The experience of community interactions and relationships in this study were influenced by individuals' expression of self. Participants described living with dementia as a gradual transition of cognition impacting their sense of identity. The progressive transition of living with cognitive impairment and memory loss opens many potential paths with which to negotiate identity (Hedman, Hansebo, Ternestedt, Hellstrom, & Norberg, 2012). These paths present opportunities and situations that either risk or support personhood. Even with the uncertain experience of a changing cognition, participants described a continuity to their selfhood. Hedman et al. (2012), through QCA of interviews investigating expression of self in 12 PLWD, also found a continuity in selfhood despite the onset of dementia. In both studies PLWD recognized stigmatizing behaviors and in response tried to 'act normal", that is adapt, to the social condition.

There is a growing interest in resilience, the ability to adapt despite adverse life events, within dementia studies (Bailey et al., 2013; Williamson, & Paslawski, 2016). Participants in this study tapped into coping and resilience skills to meet the demands of living with cognitive impairment. The discussion of resilience facilitates moving the standard dementia narrative of sufferer to one of survivor (Clarke, Bailey, O'Connor, & Nedlund, 2016). Resilience traits identified by PLWD include (a) active and purposeful living with social participation and physical activity, (b) an open perspective to change, and (c) the presence of education, support, and strategies as resources (Williamson & Paslawski, 2016). The trait, "an open perspective to change," sets the stage for reframing toward acceptance, which influences whether the PLWD views themselves as a burden, which in this study impeded personhood. How a PLWD is

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situated with respect to agency and dignity in their community can support or negate resilience (Clarke et al., 2016).

Participants in this study and others astutely noted their conversational difficulty and subsequent self-exclusion from social situations due to fear of "making a mistake" (Salva, Wang, Roberto, & Bleiszner, 2016). Relational interactions have the potential to preserve or threaten dignity in exchanges with family, the community, and healthcare providers (Tranvag et al., 2016). A preserved sense of self can be facilitated by compassionate communication expressing love, confirmation, social inclusion, and understanding (Tranvag et al., 2016). Formal and informal care partners perform these actions multiple times each day as they mitigate risks to personhood for care recipients. Participants described care partners keeping them on track in conversations as a presence of support and encourager of active life engagement.

Many of the participants spent a great deal of time with their care partners, typical of this relationship, and often a source of caregiver stress (Nay et al., 2015). They reported pleasure in participating in planned activities together. Through interviews of 27 PLWD and 28 care partners, Keller et al. (2010) found mealtimes as an opportunity to strengthen connections, adapt to their evolving life, and honor identity through being face-to-face, giving and receiving support, and psychological participation. Dyadic programs that include both the care partner and the PLWD hold promise in building on and strengthening this important yet often strained relationship. In the "Reducing Disability in Alzheimer's Disease" program, trained interventionists provided in home training and education on a three component program of exercise, dementia education, and behavior management training for the care partner. In a large scale replication study (*n* = 508 dyads), significant improvements in function, activity level, and depressive symptoms for PLWD were realized (Menne et al., 2017). Guided interaction

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facilitated positive health outcomes. Positive outcomes such as normalizing and enhancing relationships have been realized in community arts programs for families with dementia (Eakman, Carlson, & Clark, 2010). In this way, the broader community is supporting the development of relationships in PLWD.

Identity is tied to what we do, therefore engaging in meaningful activities can support a sense of identity (Phinney, Chaudhury, & O'Connor, 2007). Activity that is meaningful to the individual supports personhood (Kitwood, 1997). Losing the ability to maintain a focus in or grasp lengthy reading material (e.g., novels, journals, and essays) was mentioned by participants; they acknowledged this as a loss of identity, as well as a meaningful activity. Meaningful activities provide a way to remain connected to everyday life (Mazaheri et al., 2013). Social inclusion in turn plays a role in the ability to remain engaged in meaningful activities (Cantley & Bowles, 2004), demonstrating the bidirectional influence among the themes and the PLWD (Figure 1).

The Experience of Community Engagement by Persons Living with Dementia

This study examined not only interactions and relationships, but the broader context in which PLWD live within their community. The presence of social connections involving relationships that support personhood are increasingly recognized as a crucial component of successful aging and an intervention that can prolong the functional phase of the dementia trajectory (Douglas, Georgiou, & Westbrook, 2017).

Community engagement for PLWD is not a simple act of receiving from community, it involves reciprocity (Clarke et al., 2016). PLWD in this study valued the opportunity to contribute. Continuity with past roles and activities was important to participants. Consistent

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with other studies, care partners often facilitated role continuity, and instilled that personhood is not dependent on productivity, rather only on being (Steeman, 2011; Ward et al., 2017).

In discussions of community, PLWD report a shrinking social world, as did participants in this study (Crampton & Eley, 2013; Ward et al., 2017). The number of activities are reduced, and PLWD often report wanting to attend events but do not having the ability, access, or invitation to do so. In addition, seemingly casual acquaintances encountered in daily life become important relationships to PLWD, i.e., housekeepers, bankers, coffee shop attendants. They provide important social connections with unconditional warm regard; a smiling face with eye contact and no expectation of return other than a smile seemed to fulfill a sense of belonging. This highlights the importance of dementia awareness trainings in community settings to foster meaningful social connections.

A narrative review of social participation determined the three components of social participation (social connections, informal social participation, and volunteering) are each individually associated with positive health outcomes for older adults (Douglas et al., 2017). Instrumentation has yet to be standardized to measure this concept, as it is often ill-defined (Douglas et al., 2017). Social participation has been demonstrated to benefit PLWD and care partners as in this study, with an adaptation by both in how they engage in life activities (Nay et al., 2015). Ward et al. (2017) found that the quality of relations were individualized, and there were a "diverse cast of connections" in the community that fostered social inclusion.

Participants enjoyed access to the outdoor world as part of their engagement in life activities, even within their new-found dependence. In a study of outdoor activity experiences, 22 PLWD in the UK were interviewed (Duggan, Blackman, Martyr, & Van Schaik, 2008). The investigators found spending time outdoors to contribute significantly to the quality of life of

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PLWD for several reasons which include being in the open air, connecting with other people, and having an opportunity to exercise, reasons also mentioned by participants in this study. Community engagement may consist of greater observation rather than active participation for the PLWD as their executive function skills decline, but this change should not be considered a reason to end the activity, only to adapt it.

Participants preferred to choose their level of social participation based on not only their interests, but also on their preference of degree of introversion/extroversion engagement. While extant studies recommend providing an individual with the agency to determine their level of participation (Ward et al., 2017), the influence of introversion or extroversion preferences on personhood in dementia is a new finding.

Living in a continuing care retirement community as did 38.8% (*n* = 7) of participants, appears to ease, yet not eliminate the problems of exclusion, lack of support, discontinued life engagement, and stigma that can be overbearing to PLWD in rural or isolated locations (Blackstock et al., 2006; Clarke et al., 2016). In retirement communities, residents have access to regular activities for meaningful engagement and social inclusion, along with social supports that typically accommodate the needs of PLWD. Access to activities was more limited or non-existent for those individuals living in independent homes, particularly if the PLWD no longer had the ability to drive.

Driving cessation is implicit as dementia progresses (Bennett, Chekaluk, & Batchelor, 2016). The ability to engage in community depends greatly on availability of transportation. Driving cessation is a new-found dependence in living with dementia impacting the ability to engage in life activities, and therefore contributes to the risk of social exclusion and isolation in the presence of limited alternate sources of transportation. Community engagement is

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additionally hindered by comorbid health stressors that disallow PLWD to engage in activities due to hearing loss, pain, and functional challenges.

In a survey of older adults' views on cognitive impairment, social isolation along with forgetfulness and repetitive speech were identified as expected outcomes of cognitive impairment (Ladtika et al., 2013). The participants in this study also identified their experience of social isolation as a result of living with dementia and the loss of conversational skills. Social isolation is a well-identified phenomenon in dementia studies (Innes, Archibald, & Murphy, 2004). Participants in this study enjoyed adult day programs, where planned activities and warm regard from staff and other members provided safe opportunities for engagement and inclusion.

Participants and their care partners found solace from social exclusion by bonding with other PLWD and their families, often within organized support groups. Groups specifically designated for PLWD to share their concerns and strategies are growing with a strong evidence base (Logsdon et al., 2010; Young, Kwok, & Ng, 2014). Supportive relationships in which individuals can share their concerns and struggles have demonstrated a contribution to coping with impending life changes (Logsdon et al., 2010). Support groups for PLWD have shown reduced isolation, depression, improved coping skills, and self-efficacy (Young et al., 2014). The outcomes of joint support groups for PLWD and their care partners are mixed, with a trial demonstrating significant outcomes for carepartners but not PLWD (Gaugler et al., 2010) and a trial demonstrating significant improvement in family communication, quality of life, and depression in PLWD, but no improvement in care partner outcomes (Logsdon et al., 2010).

A single blind RCT with 20 treatment group participants (10 support group sessions) and 16 control group participants (written information only) demonstrated significant reduction in depression in the treatment group (Young et al., 2014). An integrative review found positive

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outcomes for PLWD support groups including acceptance, meaningful activity, and self-help (Jao, Epps, McDermott, Rose, & Specht, 2017). Sharing the dementia journey in a formal setting to allow meaningful exchanges of support and information is supported in both qualitative and quantitative studies.

Stigma: Insidiously Embedded in Living with Dementia

Stigma figured prominently within two of the three major themes (a) as a risk to personhood within "transitioning cognition", and (b) as a contributor to "social exclusion" within "social connections". Stigma surfaces in both blatant (obvious social distancing, discounting the opinion of PLWD based on diagnosis) and subtle (denial of the diagnosis by others; hesitancy to discuss dementia with providers) ways, leading to a loss of social connections and risks to personhood (ADI, 2012; Batsch & Wortmann, 2017; Burgener et al., 2015). Loss of social connections occurs for both PLWD and families (Nay et al., 2015). Participants, similar to other PLWD, self-exclude themselves from social situations to avoid embarrassment, withdrawing from social conversations and reducing involvement in activities (Burgener et al., 2015). Such self-exclusion from activities and conversations is recognized as internalized stigma, also identified as internalized shame as a component of the Stigma Impact Scale. In the use of this scale, Burgener et al. (2015) found internalized shame in PLWD was associated with negative outcomes related to anxiety, personal control, health, self-esteem, social support understanding and assistance, and social participation. These associations are relevant to the findings in this study as several overlap with study categories including social support, health, social participation as social inclusion, and anxiety related to an uncertain future.

The reticence exhibited by participants to discuss dementia with health care providers sadly signifies the continued influence of stigma even within the medical community (Walmsley

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& McCormack, 2016). This stigma extends to reduced research participation, also experienced in this study (Garand, Lingler, Conner, & Dew, 2009) in difficulty recruiting from settings other than support groups and DFC activities.

Johnson et al. (2015) found the perceived dismal prognosis of dementia more strongly contributed to the negative reaction to dementia than the disease label itself. When dementia was presented as a stable condition, without the links to unrelenting decline, stigma lessened. This reframing toward acceptance was evidenced as upholding personhood in study participants whom focused not on prognosis, but living well. This provides hope that as the cultural framings of dementia adapt to meet the current reality of PLWD as functional and contributing citizens for many years, stigma will lessen.

The Attributes of a Dementia Friendly Community from the Perspective of Persons Living with Dementia

The intertwined, mutually reinforcing themes and their categories emphasize social dimensions of living with dementia and present a basis on which to discuss emerging attributes of a DFC. Participants did not readily use the term “dementia friendly” within the interviews due to an unfamiliarity with the term, even though they were introduced to the concept through the study information sheet and informed consent process. This is not surprising as DFCs have emerged just within the past five years in the US. Additionally the PI did not use the term until the end of the interview in order to allow the concept to emerge naturally in discussions of living with dementia. The attributes of a DFC from the perspective of PLWD in this study include (a) social inclusion, (b) support for role continuity, (c) availability of meaningful and contributory activities, (d) flexible support as cognition transitions, (e) community dementia awareness, and

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(f) a supportive diagnostic process. Research in these concepts has been primarily qualitative therefore evaluative tools have yet to be developed.

A DFC promotes social inclusion (ADI, 2016; Lin, 2017). Inclusion supports role continuity for PLWD within a spirit of unconditional positive regard and acceptance during their transition in cognition. Quantitative measurement of social inclusion can begin with social participation instruments which have been used for care partners of PLWD (Nay et al., 2015); their relevance to PLWD is not yet determined. Community connectedness scales also hold promise for DFC evaluation, as this construct has been measured as part of well-being, and in older adults and student cohorts, but not yet in PLWD (Culley, Herman, Smith, & Tavakoli, 2013; Forjaz et al., 2011; Mashek, Cannaday, & Tangney, 2007).

Participation in meaningful activities including those that contribute to society promote connectedness and belonging, autonomy, and identity for PLWD (Phinney, Kelson, Baumbusch, O'Connor, Purves, 2016). The opportunity for engagement in meaningful activities alongside, not necessarily separate from the community is an important consideration (ADI, 2016). Occupational therapists found the Aid for Decision Making in Occupational Choice tool on an iPad useful in choosing meaningful activities with PLWD in the moderate stage (Tomori et al., 2015). More specifically, a Satisfaction with Meaningful Activity Program Scale was used to measure a Daily Enhancement of Meaningful Activity intervention (education and exercise) in PLWD/care partner dyads (Lu & Haase, 2011). Metrics on scale reliability and validity were not available for either tool. Interdisciplinary collaboration with recreational therapy and occupational therapy for tool development is recommended.

For community acceptance of PLWD, reduction of stigma must occur through increased dementia awareness (Alzheimer's Society, 2015; DFA, 2017; EFID, 2016). Programs for

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community dementia awareness are wide-spread, but valid and reliable dementia awareness scales are needed. Generic satisfaction scales and knowledge tests have been used to measure dementia awareness (DFA, 2017; Galvin et al., 2010). Such tools should be further tested and applied to an evaluation of the dementia diagnostic process, as an attribute of a DFC.

Evaluation of DFCs is in its infancy. Due to the local contextual nature of DFCs, evaluative measures may need to differ among communities depending on resources and priorities. Qualitative evaluation therefore may be necessary to capture this contextual nature. The inclusion of PLWD in the evaluative process is imperative. Views of community members on their successes and challenges meeting DFC criteria are an important step in the sustainability of DFCs as well (Heward et al., 2016).

This study both supported current concepts in DFC literature and illuminated concepts not yet addressed. Living with dementia in the US in a rural and semi-urban area has many parallels with literature from other countries. This includes the presence of stigma, the desire for inclusion, the need for flexible support throughout their decline including a timely and informative diagnosis, and a desire for a stronger presence of community dementia awareness. These similarities confirm the applicability of DFC guides developed abroad to be used in the US (ADI, 2016; Crampton & Eley, 2013; Smith et al., 2016).

Although physical design holds prominence in contemporary dementia friendly literature, participants in this study did not mention challenges in this realm, even when asked specific questions about problems encountered in the community. This aspect of living with dementia may be more readily evaluated in an observational study where challenges would be more obvious during in situ community interactions.

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As a new finding, the participants in this study expressed the importance of identity continuity as a means of dignity during their decline, focusing not only on opportunities for inclusion, but activities that are personally meaningful and contribute to society. The struggle participants experienced in attempting to actively participate in conversations was notable, and this highlights the importance of teaching skills to engage PLWD in conversations as a dementia friendly intervention in awareness sessions. The strain participants felt from moving outside of their natural introvert and extrovert personality traits within the realm of living with dementia is another new finding. The implications of these findings, including the potent impact of driving cessation on community engagement in areas without public transportation are discussed below.

Implications

Theoretical Implications

In this section, the study findings are interpreted through the framework of theories identified in the literature review (a) personhood, (b) the social model of disability, (c) environmental press model, and (d) human rights and citizenship. Additionally, transitions theory is discussed and applied to the study as an emergent finding.

Personhood. Kitwood's theory of personhood established the understanding that dignity and worth do not depend on cognitive abilities, rather, each person by virtue of being human inherently possesses these qualities through meaningful relationships with others. Kitwood (1997) identified inclusion, attachment, comfort, identity, and occupation (i.e., "engagement in activities") as important needs of PLWD. The needs identified by Kitwood 20 years ago surfaced in this study as risks to personhood and factors that uphold personhood for PLWD in the community. Eleven subcategories emanated from the concept of personhood (both risks and facilitators) situated under the major theme of "transitions in cognition: vulnerable identities",

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evidence that personhood played a dominant role in the perspective of participants, even though a specific question concerning personhood or identity was not directly asked.

Personhood has been identified as an important component in the continued identity, or selfhood, of PLWD (Skaalvik, Fjelltun, Normann, Norberg, 2016). The terms selfhood, identity, and personhood are often used interchangeably. Living with dementia places selfhood in a vulnerable position as cognitive abilities decline (Hedman et al., 2012; Kitwood, 1997; Skaalvik et al., 2016).

Participants in this study identified numerous risks to maintaining their personhood in living with dementia, consistent with the literature that upholding personhood becomes a joint venture of the individual and the community. This partnership is most prominently displayed in the care partner - PLWD relationship but extends to community as well. The community facilitated personhood, as illustrated by participants maintaining their identity through engaging in paid work, continuing their careers, volunteering, and taking part in recreational activities. In a DFC, community members embrace the role of upholding personhood through allowing the individual to reframe living with dementia with a wellness perspective through meaningful activities (Smith et al., 2016). This study illustrates the relevance of the theory of personhood based on the complexity of maintaining identity and dignity in the face of dementia, and the many opportunities that exist for community intervention.

Social Model of Disability. The social model of disability illuminates societal contributions to disability experienced by individuals, based on the supports present or lacking in communities to facilitate independence. In this mode of thinking, society bears a responsibility to compensate for physical or cognitive deficits of individuals to facilitate as much independence and engagement in society as possible.

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Numerous instances in this study exposed ways in which cognitive disability was heightened through the social models on which the communities were built. The failure of society to yet provide a medical cure or an effective treatment for dementia appears to provoke an insensitivity in healthcare providers. With no pill or procedure to offer, participants reported great emotional distress when they were only, and at times dismissively provided a diagnosis and dire prognosis. Conversely, participants using dementia care models providing comprehensive family care and access to knowledge and peer support experienced less frustration with the diagnostic process.

As a community-based social service, dependable and flexible transportation was flagrantly lacking for individuals needing transport for non-medical needs. In a small urban town surrounded by many rural regions in WNC, public transportation does not meet the needs for PLWD to maintain social connections, a key component of a DFC (Crampton & Eley, 2013; Wiersma & Denton, 2016). The lack of transportation for PLWD can be viewed as passively allowing disability to occur.

The skills of community members to recognize cognitive impairment and intervene in a supportive manner are a key part of a DFC (ADI, 2016). Individuals living in CCRCs found this support, however outside of this setting, knowledgeable and understanding community members in WNC were inconsistently found outside of dementia specific support groups.

Environmental Press Model. The EPM evaluates an individual's competencies against the requirements present in the environment for functioning (Lawton, 1985). An evaluation of the degree of fit between PLWD and an environment providing just the right amount of support to both promote independence and maintain safety has relevance to the findings of this study. There were situations where participants expressed frustration in which their deficits were

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overcompensated by ‘hovering’ care partners, limiting their independence, and alternatively withdrawing in a self-limiting measure from activities due to inability to ‘keep up’, that is not having the proper support.

Ward et al., (2017) used a constructivist paradigm to evaluate the ways in which neighborhoods support PLWD and their care partners to remain socially and physically active. Neighborhood environments played an active role in the everyday lives of PLWD, with varying degrees of person-environmental fit. Identified barriers included busy roadways that impeded walking, and lack of public spaces for place-making. Conversely, dementia awareness among shopkeepers provided a more appropriate fit with the environment by the availability assistance and an open floor plan. Participants likewise identified navigating their neighborhood, and helpful staff at grocery stores as facilitators of feeling socially connected to and engaged in their community as a mode of person-environment fit.

Human rights and citizenship. In a human rights and citizenship model, PLWD are viewed as having the same rights as other citizens to be treated with respect, to lead autonomous lives, and with agency to have their voices heard (Bartlett, 2016). The empowerment of PLWD does not figure prominently in this study, rather individuals focused more strongly on the losses they were experiencing, their risks to personhood, and the shrinking of their social circle leading to isolation, even among the presence of support.

The narrative of support and inclusion identified by participants would expand to that of empowering and enabling under a human rights and citizenship model (Bartlett & O’Connor, 2010). A climate in which the voices of PLWD are regularly heard and actively involved is the goal in a DFC, but does not yet exist for the participants in this study. The desire of PLWD to maintain agency in various social settings was evident. The importance of agency within the

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home was noted, as participants both benefited from engagement in, and lamented lost involvement in instrumental activities of daily living such as cooking and housework. Agency was demonstrated in a broader community perspective through two participants engaging in a contemporary social movement by attending the 2017 Women's March, and one participant attending community political meetings. Permission to continue living with established community roles is essential to citizenship in dementia (Clarke et al., 2016). These rights are addressed in US national policy (USDHHS, 2015) and by the WHO (2015a). A DFC provides a place for such agency and an opportunity for these voices to be heard and acted upon.

Transitions theory. Individuals living with a progressive neurocognitive condition such as dementia are essentially in a progressive course of cognitive loss, a transition impacting physical, mental, spiritual, and emotional aspects of life. A transitions framework can be useful for conditions in which individuals experience progressive complexity in a disease state (Meleis & Trangenstein, 1994).

Transitions theory has a long history of use in the discipline of nursing (Meleis, 2010), and has been applied to a framework for gerontological nursing for the purpose of guiding nurses to facilitate older adults moving through developmental, situational, and health/illness transitions (Schumacher, Jones, & Meleis, 1999). The primary risk factor for dementia is age, therefore a gerontological framework has potential for application to a dementia transitions model.

In this framework, contributors to healthy and unhealthy transition processes are identified, along with process indicators to facilitate measurement of adaptation, and interventions to facilitate a healthy transition. Multiple congruencies exist between the gerontological nursing transitions framework and the study findings. The framework suggests a redefining of meaning /awareness of the event to promote the experience of a healthy transition,

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similar to the subcategory of "reframing toward acceptance" that emerged under "upholding personhood" category in the "transitions in cognition" theme of this study. The gerontological nursing transitions framework also identifies the importance of maintaining role continuity, checking unmet expectations, and developing new knowledge and skills, all concepts contained under "transitions in cognition" in this study.

In a transitions framework, living with dementia can be viewed as dynamic state requiring ongoing adaptation to new cognitive losses for effective transitioning and identity continuity. Enduring a significant transition, such as the development of cognitive impairment, places ones' identity in a vulnerable state (Hedman et al., 2012). Robinson, Ekman, Meleis, Winblad and Wahlund (1997) applied a transitions framework to the experience of early memory loss based on a phenomenological study of eight individuals. Once again, congruencies exist between the concepts in the transitions framework for early memory loss and this study. Participants in both studies experienced a recognition that 'something is wrong' (self-awareness), waning conversational skills, and avoidance of social situations and thus isolation. The striking difference between the transitions in early memory loss study and the dementia friendly movement is the portrayal of persons with memory loss as 'sufferers', placing the participants in a situation of victimhood rather than as an individual with agency and empowerment in a DFC (Bartlett, 2016; Clarke et al., 2016).

The liminality of transitional states, moving from one place or role in society to another, resonates with the experiences of participants questioning their identity (Birt, Poland, Csipke, & Charlesworth, 2017). In the trajectory of dementia, an individual's identity transitions from an independent adult to an individual experiencing increasing dependence due to cognitive impairment. The stages of dementia are rarely distinct or predictable, leading to the liminal

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quality of uncertainty, an emergent category within “transitions in cognition” in this study.

Uncertainty toward the future appears to limit engagement in community activities, specifically volunteerism which has been shown to improve depression and self-efficacy (Chen, 2016). Birt et al. (2017) recommended dementia studies take on a sociological lens to promote agency of PLWD to overcome the liminal state of uncertainty as individuals move through the dementia diagnostic process, as experienced by participants within the enigmatic dementia diagnosis category. Frustration with the health care system in the multiple steps and “run around’ of the diagnostic process negatively impacted personhood and continuity of identity.

Five theories were identified as resonant with the experiences of PLWD in community. Moving forward, personhood, human rights and citizenship, and transitions theory provide comprehensive constructs with which to advance the study and application of DFCs.

Practice Implications

Non-pharmacological interventions are the mainstay of community practice approaches in dementia. Unfortunately, Maslow (2012) found that much of the evidence for non-pharmacological interventions has not been translated into practice. The following recommendations pull together findings from this study and the literature for practice applications.

Address stigma through awareness programs. Dementia continues to be viewed as an immediate sentence to a dark and dismal life in the broader community, including the healthcare sector (DFA, 2017; Benbow & Jolley, 2012). Awareness trainings have demonstrated an impact on stigma (Batsch & Wortmann, 2017). Popular dementia awareness programs such as Dementia Friends (Alzheimer’s Society, 2015) should be evaluated for their effects on stigma. The Stigma Impact Scale (SIS) has been tested in PLWD with acceptable reliability ($\alpha = 0.87$)

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and validity ($p < .05$ for measurements of depression [$r = 0.59$], self-esteem [$r = -.47$], and personal control [$r = -.50$]) (Burgener & Berger, 2008, Burgener et al., 2015). Communities could test stigma impact of an awareness program through use of the SIS with PLWD, which could prove to be an empowering collaboration. This would highlight both external and internalized stigma.

The faculty in healthcare disciplines, including nursing, should incorporate current dementia knowledge into their curriculum; faculty with geriatric expertise provide the backbone for the integration of dementia content into courses. Programs such as the ‘buddy program’ that match a PLWD with a healthcare student for interaction throughout the semester have proven valuable for enhancing dementia awareness and a person-centered approach (Morhardt, 2006). Dementia content in medical curricula could contribute to the realization of a more compassionate and efficient dementia diagnostic process (Morhardt, 2006).

Dementia friendliness occurs in every day actions involving relationships with community members. Crampton and Eley (2013) report that the effort to make a community dementia friendly must go beyond health and social care. They found PLWD wanted to go everyday places that they have frequented for years, as did participants in this study. The attitude with which services are provided is as important as the service itself, therefore communication strategies and fostering relationships through supportive conversations should be part of dementia awareness. This includes compensatory measures for hearing loss.

The language used in dementia literature and presentations influences how we think and construct reality about dementia, therefore we must choose words carefully. The Frameworks Institute (2017) and leaders of aging organizations created guidelines to raise awareness of the

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ageism that permeates our society through language. This can be incorporated into DFC language, such as eliminating the word, “demented”.

A dementia transitions model in healthcare. Transitions theory has been applied in a healthcare context to older adults with multiple comorbidities through a holistic transitional care model demonstrating improved outcomes of health, cost, and quality of care (Naylor, 2010). A dementia transitions model that incorporates dementia chronic disease management processes in community with care partners and relationship-based approaches could serve as a framework for holistic dementia care (Noel, Kaluzynski, & Templeton, 2017; Porok, Horgan, & Seitz, 2013). The model would include cognitive screening guidelines in primary care, with referral to memory centers as needed for a supportive diagnostic process (Borson & Chodosh, 2014; DFA, 2017). Reframing the views of practitioners from medication as the only intervention to the value of social interventions and resource provision is crucial. Successful management of co-morbidities that impact dementia symptomatology and personhood could also be realized with a collaborative interdisciplinary approach (Borson & Chodosh, 2014).

A focus on well-being with flexible service provision. To address well-being, the complexity of dementia requires community-based solutions residing both within and beyond the health and social care sector. Living well with dementia focuses on remaining abilities rather than deficits, requiring an individualized approach. When capabilities are not acknowledged participants are rushed into submission, losing their agency (Chung, Ellis-Hill, & Coleman, 2017).

Engagement in meaningful activities promotes well-being in older adults (Roland & Chappell, 2015). Prescribed programs created with the intention of engaging PLWD and their care partners in community have demonstrated successful outcomes for social participation and

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health, particularly in the arts (Beard, 2012). In a grounded theory analysis of interviews of 21 care partners and 13 PLWD related to their views on participating in a community arts program, Burnside, Knecht, Hopley, & Logsdon (2017) found positive impacts not only for themes such as socialization, engagement, and mindfulness, but also for positive effects on the care partner/PLWD relationship. These program outcomes should be replicated in other types of activities based on the known impact that meaningful activity engagement, social participation, and respect for personhood have on reducing caregiver burden, improving health, and increasing well-being and quality of life for older adults, including those with dementia and memory loss (Crampton & Eley, 2013; Douglas et al., 2017; Eakman et al., 2010). Multiple programs have reported positive results in the use of electronic tablets by PLWD (Crampton & Eley, 2013), as did participants in this study. Opportunities abound for improving community access and engagement with tablets and other technology such as the use of audio books to address the challenges PLWD face with reading comprehension, yet little is known about the interface of PLWD and technology (Gibson, Dickinson, Brittain, & Robinson, 2015).

Transportation. The nearly ubiquitous mention of driving cessation as socially isolating, tragic, and as a source of care partner burden in this study illustrates the dire need for communities to enact transportation services to promote well-being. The lack of public transportation in rural areas is detrimental to PLWD in their inability to engage in essential aspects of well-being including meaningful activities and community contributions. The *Clinician's Guide to Counseling and Assessing Older Drivers* developed by the American Geriatric Society (2015) serves as a comprehensive guide in reducing and removing driving privileges, as this task often falls to healthcare providers. Innovative community transportation

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models using volunteer transport, emerging transport businesses, and internet-based communication systems with policy support are needed.

Policy Implications

The recent shift of Dementia Friendly America (2017) to Washington DC as a subsidiary of the National Area Agencies on Aging supports a national movement toward strengthening community-based approaches to dementia. The "National Plan to Address Alzheimer's Disease 2017 Update" now includes DFCs as one component in a dementia capable system of supports. Funding for such initiatives are limited, however, with dependence on volunteer efforts and the expectation that non-profit organizations will absorb DFC programming. The bulk of federal financing is directed toward medical research (Alzheimer's Association, 2016), risking sustainability of DFCs (Heward et al., 2016).

Policy at the national, state, and local levels must shift the dementia discourse from a focus on deficits and passive support, to one of strengths and agency toward wellness for PLWD (Birt et al., 2017). Person-centered approaches must expand to social interventions that engage PLWD as agents in living well through active community involvement. Based on the current science demonstrating limited efficacy of pharmacological interventions, evidence-based non-pharmacological services should be more quickly evaluated for reimbursement (e.g., exercise, adult day, and social engagement programs). The growing evidence for the effects of social participation on health outcomes including depression and quality of life warrants an examination for a policy and funding shift toward community engagement programming. Such programming must include availability of flexible transportation services for non-medical transport that promote the ability of PLWD to age in place in the community, rather than in long term care. Aging in place offers increased quality of life at a reduced cost to society (Office of

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Policy Development & Research, 2013). Collaboration with age-friendly communities on this initiative is occurring globally and should continue (Turner & Morken, 2016).

State governments, through the departments of health and human services should coordinate dementia friendly efforts across counties and cities, to serve as a repository of best practices for sharing ideas and resources. Coordination with agencies such as the Alzheimer's Association and local dementia friendly advocacy groups can enable a collective action approach (DFA, 2017). A common agenda to share resources and reduce duplication of efforts will create stronger social networks on which PLWD and their families can rely to live fully and well.

Local community action has proven to be an important determinant in the development of DFCs (Heward et al., 2016). Stakeholders that include PLWD, families, and local policy makers (e.g., city council members, county commissioners) should be educated and convened. Local government entities such as Area Agencies on Aging and community health coalitions have the ability to gauge local needs and strengthen social networks and social capital to sustain DFCs. Most importantly, communities must not only listen to the voices of PLWD, but must demonstrate the willingness to act.

Implications for Future Research

As a nascent concept, DFC development will benefit from a strategic research approach based on current knowledge and emerging constructs for meaningful measurement.

Inclusion of persons living with dementia in research. This study demonstrated both the feasibility and value of involving PLWD as research participants and major stakeholders in a DFC. Recruitment must occur through diverse channels, as PLWD are a difficult to access population. Alternative consent options to effectively protect and include PLWD, such as the

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ESC instrument used in this study should continue to be evaluated in diverse settings and populations.

Community observation and participatory research. In this study, the interviews took place in the participants' homes, which effectively increased their comfort level, convenience, and agency. The PI and participants did not actively engage in the community together. It appears that PLWD do not always appreciate the extent to which their care partners or others support them in the community. To evaluate dementia friendly attributes of the physical environment and interactions outside of the home, an observation study is necessary for a fuller understanding of the challenges that PLWD experience (Mitchell, 2012). Actively walking the neighborhood, or in-situ interviewing will offer a greater breadth for understanding daily living in various community settings (Crampton & Eley, 2013; Ward et al., 2017). Methods incorporating visual techniques such as photo mapping could diminish verbal communication challenges for PLWD.

To enhance confirmability, PLWD can be included not only as the observed but as an 'expert' consultant on the experience of receiving dementia friendly initiatives in communities (Carmody, Traynor, & Marchetti, 2015). Ward et al. (2017) suggests "mobile methods of assessment and interviewing as a route to deepening our understanding of the person as a foundation to person-centered practice" (p. 11). Bartlett and O'Connor (2010) recommend researchers not stop at subjective experience but determine the other factors at play and "disentangle their influences" (p. 116). Social network mapping of PLWD could support a community-based evaluation of dementia friendly practices, just as dementia care mapping evaluates person-centered care practices in long term care facilities. Community-based participatory research would support the dementia friendly principle of providing PLWD with

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agency to not only serve as a research participant, but to actively engage in the research process. An investigation of interventions to promote resilience in PLWD would benefit from such a design.

Analysis of dementia friendly guides and descriptions. Online and printed materials from organizations such as the Alzheimer's Association, ADI, and other dementia advocacy groups provide valuable insight into the enactment of DFCs across the globe (EFID, 2016). QCA should be applied to this text data for the purposes of describing and organizing written phenomena to generate new understandings of DFCs (Krippendorff, 2013). Document analysis would provide insight to supplement current empirical knowledge with a contextual understandings of diverse community practices (Schreier, 2012).

Instrument development. Several constructs emerging from this study and the literature review offer opportunities for quantitative measurements to contribute to DFC evaluation. These include scales for social participation, community connectedness, meaningful activities, well-being, and resilience in dementia. As components of these constructs are clarified, the development of tools will support communities in creating meaningful dementia friendly initiatives. Additionally, the Environmental Assessment Tool (Fleming et al., 2017) developed to assess physical aspects of dementia friendliness and the SIS scale for stigma impact should be evaluated further for applicability in dementia studies.

Limitations

Given the small sample of primarily white non-marginalized individuals living in Western North Carolina, this study does not claim to represent the perspective on DFCs for all PLWD. A more diverse sample of participants in terms of ethnicity and geography would further extend the applicability of findings to broader communities. Additionally, those

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individuals with younger onset dementia may have views that differ from this sample representing older adults.

Individuals who decline to participate in research or qualitative interviews may have views on DFCs that differ from those that choose to participate. This study examined the views of persons that both admitted to having significant memory loss and in most cases, dementia, and were willing to expose their narrative. Those experiencing stigma or isolation without community access to social support services or agencies used for recruitment may not have had the opportunity or the desire to participate. Their stories of living with dementia in community remain untold.

This research relied on the use of language during interviews to understanding the perspective of PLWD. Challenges in the use of spoken language such as word finding difficulties are often part of the dementia trajectory therefore it is possible some information was not communicated (Bartlett & O'Connor, 2010). This study did not observe PLWD interacting in the community which may be necessary to fully understand the experiences and nuances that occur for PLWD in community.

Finally, a DFC is not simply a community of PLWD, but of all people. Care partner observations could enrich the data by filling in gaps of information of which PLWD might not be aware. Community members that interact with PLWD also have a valuable perspective to share for more robust and community-based definitions of DFC constructs.

Conclusion

DFCs are being implemented globally as a response to the increasing dementia prevalence and shift in societal views on dementia from despair to optimism. This study sought to include voices of PLWD to broaden the understanding of living with dementia in community

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in the US and to uncover attributes of a DFC. QCA of interviews of 18 individuals living with dementia or memory loss in WNC produced three major themes (a) transitions in cognition: vulnerable identities, (b) social connections, and (c) engagement in life activities.

Their shared experiences were collectively linked to the broader social and political context of DFCs. Theoretically, DFCs have five obvious applications (a) personhood, (b) the social model of disability, (c) the environmental press model, (d) human rights and citizenship, and (e) transitions theory, with personhood, transitions and human rights and citizenship most congruent with DFC constructs. The dynamic experience of living with dementia revealed by participants suggested the following attributes of a DFC: (a) social inclusion, (b) support for role continuity, (c) availability of meaningful and contributory activities, (d) flexible support as cognition transitions, (e) community dementia awareness (to combat stigma), and (f) a supportive diagnostic process.

DFC research is primarily exploratory and qualitative. Current instruments holding promise for DFC measures include community connectedness, social participation, and meaningful activity scales, along with quality of life scales for well-being, Stigma Impact Scale, and the Environmental Assessment Tool. The contextual nature of DFCs requires local community input which includes PLWD as key stakeholders. Initiatives to improve dementia friendliness of communities must target more than health and social services, rather broad community perceptions of dementia must be challenged to eliminate stigma and ignite social change. Collaboration among community organizations in a collective action framework supported by local, regional, and national policy with flexible service provision provides a strong network on which to build a DFC.

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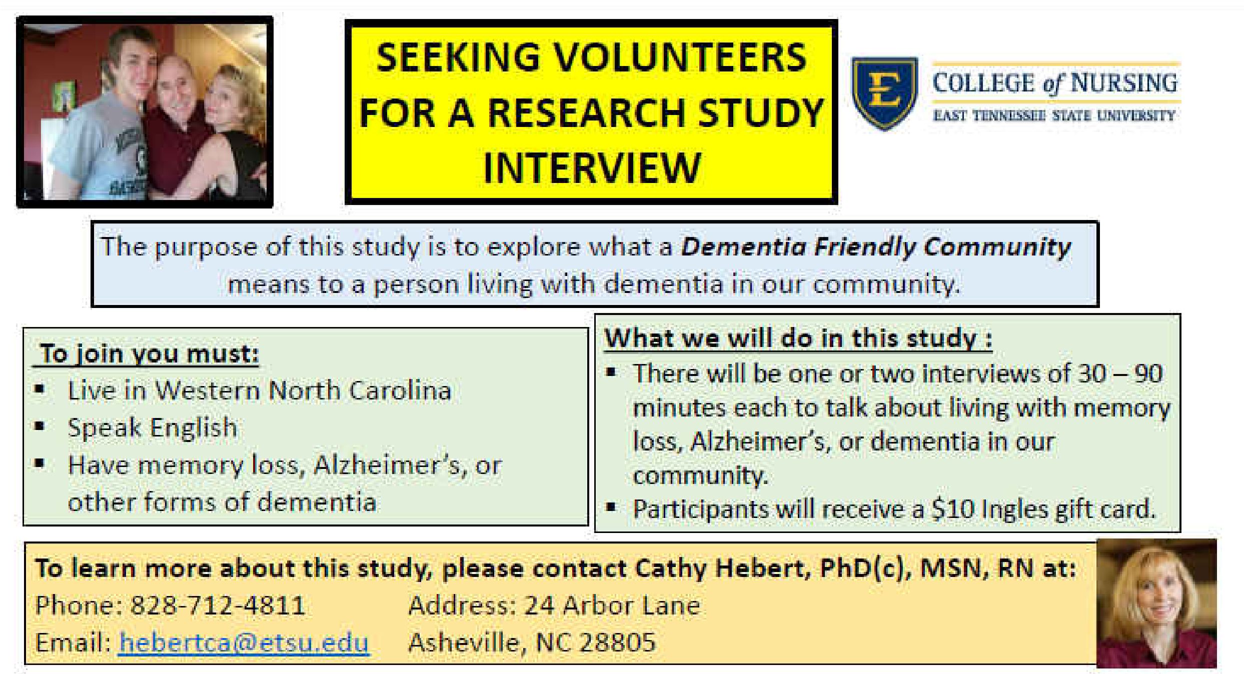
APPENDICES

APPENDIX A

Recruitment Flier



SEEKING VOLUNTEERS FOR A RESEARCH STUDY INTERVIEW

COLLEGE *of* NURSING
EAST TENNESSEE STATE UNIVERSITY

The purpose of this study is to explore what a ***Dementia Friendly Community*** means to a person living with dementia in our community.

To join you must:

- Live in Western North Carolina
- Speak English
- Have memory loss, Alzheimer's, or other forms of dementia

What we will do in this study :

- There will be one or two interviews of 30 – 90 minutes each to talk about living with memory loss, Alzheimer's, or dementia in our community.
- Participants will receive a $10 Ingles gift card.

To learn more about this study, please contact Cathy Hebert, PhD(c), MSN, RN at:

Phone: 828-712-4811
Email: hebertca@etsu.edu

Address: 24 Arbor Lane
Asheville, NC 28805

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APPENDIX B

Study Information Sheet

Research Project Studying Dementia Friendly Communities in Western North Carolina
Information Sheet

Introduction and Study Description

I am a geriatric nurse working on a PhD in nursing. I am researching Dementia Friendly Communities. I would like to learn more about the how people feel about having memory loss or dementia, how they live in their community, and how their community supports, or does not support them.

What you will be asked to do if you agree to participate

We will arrange a time and place to meet convenient for you, in your own home or another quiet place. I will interview you to ask you questions about your views on living with dementia and things you do in your community. Examples of questions I will ask are:

- What is a typical day like for you?
- Who are the important people in your life?

You may have a support person with you during the interview. The interview will be audio recorded unless you prefer it not be recorded.

How much of your time will participation involve?

We will have one or two meetings. At the first meeting I will explain the study and get your consent to participate. I may need to get consent from your legal representative also. A copy of the consent is included with this information. Please have a copy of the legal document (power of attorney) stating your care partner is your legal representative for our meeting. We will begin the interview at that meeting. It will last anywhere from 30 - 90 minutes. If you get tired and would like to continue the interview on another day, we can schedule another time. There will be no more than two interviews, for a total of no more than 3 hours over 2 meetings.

Will your participation in the project remain confidential?

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If you agree to take part, your name will not be recorded on the questionnaires and every effort will be taken to keep your information confidential. Your responses to the questions will be used for the purpose of this project only and I will not have access to any of your medical records.

What are the advantages of taking part in this study?

You may enjoy being interviewed about your views, things you like to do, and what is important to you in your community. Once the study is finished, you views may be useful in making Western North Carolina more dementia friendly.

Are there any disadvantages of taking part in the study?

It could be that you are not comfortable talking about living with dementia and the things you do in your community. That could cause you psychological distress. You also may become tired from being interviewed. There is also a small risk of a breach in confidentiality, but all efforts will be taken to prevent this by keeping study documents on a computer with a password or in locked file cabinets.

Do you have to take part in the study?

No, your participation in this project is entirely voluntary and will not affect any services you receive. If you do agree to participate, you are free to withdraw at any time.

What happens now?

We will meet on to meet on ______________________
Date/time
at _____________________ for you to sign the informed consent document
location
and be interviewed. I will contact you two days before this to confirm our meeting. If you decide you would rather not participate, you can contact me to let me know or tell me when I call you.

I appreciate your taking time to be a part of this study.

Warm regards,

Cathy Hebert, PhD(c), MSN, RN, GCNS-BC

www.manaraa.com

Phone: 828-712-4811 Email: hebertca@etsu.edu
Address: 24 Arbor Lane, Asheville, NC 2880

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APPENDIX C

Dementia Friendly Research Literature

Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
Charras, Eynard, Viatour (2016) *France*	QLR Ethnographic/	Observation of three special care dementia units	To develop a framework to understand the effects of environment on PLWD	Observation of use of space by PLWD based on human rights dimensions; QCA	Six dimensions identified as key elements of dementia community service settings: Provides a framework for evaluation of human-environment DF design
Crampton & Eley (2013) *UK*	QLR: Interview and ethnographic/	The City of York/ *N* not noted;	What are the components of a dementia-friendly community?	Observation and open-ended interviews of community members and organizations	Four key findings: People, places, networks and resources. Focus on PLWD and their experiences. Attrition from everyday life is devastating for PLWD.
Fleming, Bennet, Preece, Philipson (2017) *Australia*	Literature review, tool design, draft tool reviewed by experts/	community buildings, *n*= 60	Create DFC environmental assessment tool	Tested by PLWD and city planners on 37 items in six types of buildings	Substantial interrater reliability of 0.652 minimum; average absolute agreement on items = 83% demonstrating acceptable internal consistency.

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
Galvin et al., (2010) *USA*	QN	Hospital Staff (*n* = 540)	Determine the effect of a DF educational program on knowledge, attitude, and confidence	Demographic Confidence level Knowledge level Attitude level Measure with Likert scale items Open ended questions	From pre to post test, significant increase in knowledge (*p* =.001), confidence (*p* = .001), and attitude (*p* = .001). A delayed posttest (120 days) demonstrated slight decrease in knowledge and confidence at 3 hospitals, and a significant loss of knowledge (*p* = .01) and confidence (*p* = .02) at 1 hospital.
Hadjri, Faith, & McManus (2012) *UK*	Mixed Methods: correlational survey; open-ended survey	All Northern Ireland nursing homes & care homes (*n* = 119)	To assess level of compliance of dementia nursing & residential care homes using the DSDC dementia friendly design essential criteria.	Non-probability sampling; Mailed survey for self-reported compliance with DSDC Audit Tool (yes/no checklist)	45% response rate (n = 53). Nursing homes (68%) align better with DF design criteria to create a DFC than do residential care homes (32%). Main deficits are safe and accessible enclosed outside space, signage, toilet and bathroom design, removable mirrors, and discreet storage space.

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
Heward, Innes, Cutler, & Hambidge (2016) *UK*	QLR/ interview and focus groups	DF project worker 14 individual & 1 group interviews	Assess the challenges and strategies for achieving involvement in DFCs.	Directed QCA	• Challenges to stakeholder involvement are unpredictable • Establish networks representative of local community • Involve PLWD
Innes, Kelly, Scerri, & Ablea (2016) *Malta*	Multi-method/ Theory: PCC	Staff on 2 hospital wards, $n = 34$ (response rate 47%); PLWD $n = 16$ for DCM	Investigate the attitudes, knowledge and experiences of staff, and the observation of PLWD. Identify good practice, provide recommendations to improve practice and physical design of the wards	Four tools: 1. EAT 2. DCM (IRR 70%) 3. PCAT (Staff questionnaire) 4. Person Centered Climate (Staff) Questionnaire Measured October 2011 (T1) & October 2012 (T2) Descriptive statistics only analyzed along with	Feedback on necessary DF changes provided to management after T1. EAT scores very low at T1 with slight improvements at T2 but still low as noted below: W1 at T1 = 22/112 W1 at T2 = 28/112 W2 at T1 = 30/112 W2 at T2 = 40/112 DCM: (qualitative) slight improvement in attention to dignity & awareness of pt. experience PCAT: for both wards, overall positive response to environment at T1 & T2; slight

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
				QLR data from DCM	decrease in perception of having time for PCC
Marquardt (2011) *Germany*	Literature review/	Empirical studies of wayfinding studies in LTC	What is the impact of the floor plan in supporting the wayfinding abilities of PLWD?	Literature review, Inclusion/exclusion criteria not noted	Both floor plan design and environmental cues are essential or wayfinding in PLWD. Four main guidelines discovered
Marquardt & Schmeig (2009) *Germany*	Descriptive correlation-al; person-environ-ment fit	30 German nursing homes; 450 residents in mild (*n* = 91), moderate (*n* = 183); severe (*n* = 176) stages	What is the impact of architectural characteristics on wayfinding abilities of PLWD?	Nurses rated ability of residents in each stage of dementia in wayfinding of 5 separate places measured on a scale of 0 (does not find the way), 1 (wayfind with help), & 2 (independent)	A smaller number of residents increases way finding abilities. Straight circulation routes enhance wayfinding (*p* =.001); one live-in kitchen enhances wayfinding (*p* = .001); an outside space easier to find when near the living room (*p* = .041); a continuous path decreases orientation (*p* = .002); People with mild dementia had no wayfinding issues (*p*=.001).

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
McCabe & Sim (2006) *UK*	QLR exploratory Post-occupancy evaluation	Interview of staff $N = 18$ (13 female, 5 male)	Academic office building of the DSDC	First interview: Explored hopes for the building; Second interview explored experiences	Pride in serving as an exemplar of DF design; open floor plan risks noise and confidentiality; people work together more in open plan; a building can serve both PLWD and staff of an office building
Milton (2012) *UK*	QLR: Narrative interview	PLWD (26); CG & supporters (62) $N = 86$	What does the idea of a dementia-friendly community mean to PLWD and their supporters and caregivers?	Open ended questions via one-on-one, telephone and online surveys	Implemented by Innovations in Dementia; funded by Department of Health in UK. Attitude of others is most important criteria; make local mainstream services more accessible: support local groups for PLWD and caregivers; include PLWD in normal life activities
Mitchell & Burton (2010) *UK*	Correlational; QLR: narrative and ethnographic	$n = 20$ PLWD $n = 25$ control	How can local neighborhoods be adapted so that PLWD can use them to enhance quality of life?	Open-ended questions; then accompanied PLWD in neighborhoods and assessed community characteristics	Created *Neighbourhoods for Life* focused on DF design principles: a.) familiarity, b.) legibility, c.) distinctiveness, d.) accessibility, e.) comfort, and f.) safety.

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
Mitchell, Burton, & Raman (2004) *UK*	Multi-method: qualitative Interviews of PLWD/	Older adults > age 65; *N* = 20 PLWD; *n*= 25 without dementia	1. Establish the importance of legibility of older people with dementia 2. Identify the design factors that affect legibility	Textual analysis of narrative interviews of PLWD; environmental assessment comparisons between PLWD and those without dementia in patterns of use on accompanied walks and ability to way find.	PLWD rely on a legible environment to find their way; 1/3 of PLWD lost their way, no people without dementia did so; Street layout: Disorientation at road junctures and in places with poor visual access; Building: distinguishing features for recognition; open, multiuse spaces; Signage: dark letters on white, perpendicular to building, simplicity; Environmental cues more effective than signs
Page, Innes, & Cutler (2015) *UK*	QLR Exploratory/	*N* = 20 interviews of tourism industry providers	Identify feasibility of DF tourism; Highlight barriers for policy; Examine DF tourism	QLR thematic analysis	a.) Awareness and understanding of dementia is limited, b.) Cost concerns of businesses c.) Experience with PLWD improves attitude, d.) Recommend pilot site & partnership; include in policy development
Parke et al. (2016) *Canada*	Scoping review;	*N* = 28 documents	Identify design elements in acute care that	Atskey and O'Malley scoping	Little empirical data exists regarding DF physical design for acute care settings. Current

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
			maximize function, safety and independence of PLWD	literature review methodology	state of evidence is at expert opinion. More intervention studies needed.
Plunkett & Chen (2015) *Canada*	Mixed methods explor-atory descriptive	Ontario *N* = 51 Church leaders; rural and urban (34% response rate)	Identify ways that churches currently support PLWD. Identify resources for churches to better support the inclusion	Mailed postal survey with Likert scale and open ended questions. Measures: descriptive statistics and QCA	Presence of dementia symptoms in members, and demonstrated interest in DF initiatives. Need for education, physical infrastructure and maintaining social connections. Unawareness of community resources.
Smith, Gee, Sharrock, & Croucher (2016) *New Zealand*	QLR; narrative and apprecia-tive inquiry theory	PLWD in Christ-church; *N* = 26 PLWD; age range 60 - 95; 14 male & 12 female	"Gain insights from Christchurch PLWD about what would make it possible for them to live better in their post-quake communities" (p. 188).	Semi-structured interview; Thematic qualitative analysis	Emergent themes of a DFC: 1. Supports PLWD to be connected and engaged; 2. People and services understand and accommodate those living with dementia; 3. A community with accommodating physical environments

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Authors (Year) Country of Origin	Design	Setting/ Sample	Research Questions/ Aims	Measures/ Instruments	Results/ Comments
Wiersma & Denton (2016) *Canada*	QLR; interpret-tivist construc-tionist paradigm	Northern Ontario/ *N*= 71; (37 HCP; 15 CG	Purpose: to explore and understand the context of dementia and DF	In-depth interviews analyzed via open and thematic coding	Emergent themes: 1. Culture of Care: Looking out for the PLWD 2. Remaining connected 3. Limits of rural social support require exploration

Note. CG = caregiver; DCM = dementia care mapping; DF= dementia friendly; DFC = dementia friendly community; DSDC = Dementia Services Design Centre; EAT = environmental audit tool; GDS = global deterioration scale; HCP = health care provider; QoL in AD = Quality of Life in Alzheimer's disease; PCAT = person-centered assessment tool; PCC = person centered care; PLWD = people living with dementia; pt. = patient; QCA = qualitative content analysis; QLR = qualitative research; RCT = randomized controlled trial

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APPENDIX D

Request for Contact

Date:

Dear ________________,

I have received a letter from you about joining a research study called “Exploring Dementia Friendly Communities from the Perspective of Persons with Dementia”.

If you want to be interviewed for this study, please contact me:

By phone at 828-712-4811, or

By email at hebertca@etsu.edu.

There is an information sheet about the study, and a sample consent form with this letter.

Thank you for taking the time to answer this letter and be a part of the study.

Best regards,

Cathy Hebert, PhD(c), MSN, RN, GCNS-BC
PhD Candidate
College of Nursing
East Tennessee State University

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APPENDIX E

Evaluation to Sign Consent

Exploring the Dementia Friendly Communities from the Perspective of Persons Living with Dementia

EVALUATION TO SIGN CONSENT FORM

To be completed by the interviewer (PI)

Participant Code: _______________ Date: ________________________

1. **What is a potential risk to participating in this study?**

   ____

   ____

   (Possible correct answers: emotional or psychological stress or fatigue, physical fatigue, loss of confidentiality)

2. **What is expected from you in this study?**

   ____

   ____

   ____

   (Possible correct answers: to answer the questions from your own perspective; to speak truthfully; to attempt to complete the interview)

3. **What would you do if you do not want to be a part of the study?**

   ____

   ____

   (Correct answer: decline to participate further with no consequences)

4. **What if you experience discomfort during the study?**

   ____

   ____

   ____

   (Correct answers: share this with the researcher; ask to take a break or discontinue the interview)

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All questions must be answered correctly for the participant to independently consent for research participation. If the participant does not answer all questions correctly, both the participant and the legally authorized representative will sign an informed consent document before the participant is interviewed.

Name of individual completing evaluation: ____________________________

Reference

Resnick, B., Gruber-Baldini, A., Pretzer-Aboff, I., Galik, E., Buie, V., Russ, K., & Zimmerman, S. (2007). Reliability and validity of the evaluation to sign consent measure. *Gerontologist, 47*(1), 69-77.

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APPENDIX F

Transcriptionist Agreement

TRANSCRIBER CONFIDENTIALITY AGREEMENT

An Exploration of Dementia Friendly Communities from the Perspective of Persons Living with Dementia

[Insert IRB log number when assigned]

I, ________________________________, agree to transcribe data for this study. I agree that I will:
Name of transcriber

1. Keep all research information shared with me confidential by not discussing or sharing the information in any form or format (e.g., disks, tapes, transcripts) with anyone other than Catherine A. Hebert, the researcher on this study or Katherine C. Hall, the faculty advisor on this study;
2. Keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession. This includes:
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    - keeping all transcript documents and digitized interviews in computer password-protected files;
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3. Give all research information in any form or format (e.g., disks, tapes, transcripts) to the primary investigator when I have completed the research tasks;
4. Erase or destroy all research information in any form or format that is not returnable to the primary investigator (e.g., information stored on my computer hard drive) upon completion of the research tasks.

____ __________
Signature of transcriber Date

____ __________
Signature of principal investigator Date

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APPENDIX G

Confidential Participant Code Sheet

CONFIDENTIAL

Exploring Dementia Friendly Communities from the Perspective of Persons Living with Dementia

Participant Name	**Phone Number**	**Email**	**Address**	**Participant Code**
				P1
				P2
				P3
				P4
				P5
				P6
				P7
				P8
				P9
				P10
				P11
				P12
				P13
				P14
				P15
				P16
				P17
				P18
				P19
				P20
				P21
				P22

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APPENDIX H

Demographic Form

Exploring Dementia Friendly Communities from the Perspective of People Living with Dementia

To be completed by the interviewer

Participant code:______________ Date:______________________________

1. **Age** ____________

2. **Marital status:**

   SINGLE MARRIED WIDOWED

3. **Living arrangement:**

   ALONE WITH SPOUSE WITH OTHER FAMILY WITH FRIENDS

   INDEPENDENT LIVING FACILITY

4. **Gender identity:**

   MALE FEMALE NEITHER NOT DISCLOSED

5. **Race**:

   WHITE BLACK HISPANIC MIXED
   OTHER__________

6. **Dementia diagnosis:**

   ALZHEIMERS VASCULAR LEWY BODY

   MIXED PARKINSONS DO NOT KNOW

7. **Length of time since diagnosis** _______ years ___________months

8. **County of residence:** ____________________

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9. **Rural or Urban** (circle)

10. **Who is your primary source of support? (care partner)**

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APPENDIX I

Interview Guide

An Exploration of Dementia Friendly Communities from the Perspective of Persons Living with Dementia

1. What is a typical day like for you?
2. What kinds of things do you enjoy doing, or what sorts of things do you like to do?
3. What would be a perfect day for you?
4. Would you tell me about a recent time when you went out and things went really well?
   a. What do you think helped it go so well?
   b. Is there a time when you went out and things did not go so well?
5. What about a typical week, can you describe what type of things you do?
   a. Where might you go? (List places such as church, grocery store, restaurant if needed for prompting)
   b. What's that like for you?
6. Have your activities changed in the past few months/years since you developed memory loss or since your diagnosis of dementia?
7. Are there things you used to go out and do but have stopped doing?
   a. Tell me more about how this has happened.
   b. What is different?
   c. Is there a way you could continue this activity?
   d. What have you continued to do?
   e. Have you stopped doing things you enjoy?
   f. Are there things that you wish you could do?

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8. Who are the important people in your life?
    a. What makes this person important to you?
9. What do you find supportive about your community?
10. Is there anything you would change about your encounters in the community or how things go when you are out and about?
11. How do you think other people think about you when they know you have memory loss or dementia?
12. When you hear the term, *dementia friendly,* what does that mean to you?

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VITA

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Hebert, C. & Scales, K. (in press). Dementia friendly initiatives: A state of the science review. *Dementia.* Accepted for publication August 2017.
Hebert, C. (in press). Evidence based practice in perianesthesia nursing: Application of the American Geriatric Society Clinical Practice Guideline for Post-Operative Delirium in older Adults. *Journal of Perianesthesia Nursing.* Accepted for publication February 2016.
McConnell, E., Lekan, D, Hebert, C, Leatherwood, L. (2007). Academic practice partnerships to promote evidenced based practice in long term care: Oral hygiene care practices as an exemplar. *Nursing Outlook; 55*(2), 95-103.

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