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Defining Dementia-Friendly Communities From the Perspective of Those Affected

Iris Alexandra Wernher
Portland State University

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Defining Dementia-Friendly Communities From the Perspective of Those Affected

by

Iris Alexandra Wernher

A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy
in
Urban Studies

Dissertation Committee:
Paula Carder, Chair
Margaret B. Neal
Christina Sun
Greg Townley

Portland State University
2023

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Abstract

More and more communities across the globe are pledging to become more “dementia friendly,” yet many initiatives lack direction as to what this pledge might entail. The intent of this qualitative study, conducted in the metropolitan area of Portland and several other cities in Oregon, was to better understand how communities can increase their dementia friendliness – from the perspective of people living with dementia and their care partners. The study further aimed to clarify if and how age- and dementia-friendly efforts can be integrated.

Twenty-five community-dwelling individuals living with dementia and their 25 informal carers participated separately in semi-structured in-person interviews. The interview questions were centered on the participants’ day-to-day experiences, barriers to and opportunities for engaging in activities, and the interviewees’ thoughts on how communities might become more inclusive places for people affected by dementia.

The analysis of the interviews yielded eight common themes constituting a conceptual framework of dementia friendliness that proved largely congruent with the World Health Organization’s (WHO) framework of age friendliness which served as the theoretical foundation for this research: (1) public outdoor and indoor spaces; (2) transportation and travel; (3) housing and living environments; (4) participation in meaningful activities; (5) respect, inclusion, and spirit of support; (6) civic engagement and employment; (7) communication and information; and (8) community-based support and health services. “Technology” was added as an additional domain, and

“respite and peace of mind,” as well as “preserving self and identity” were identified as important aspects interwoven with the nine domains.

The results of this study can provide guidance for planning and implementing dementia-friendly initiatives and serve as foundation for a synergistic integration of dementia-friendly efforts into the greater context of age friendliness.

Dedication

For Mom. You are forever in my heart.

Acknowledgments

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Chapter 1: Review of the Literature

The Global Impact of Dementia

Definition, Etiology, and Available Interventions

As defined by the World Health Organization (WHO),

Dementia is a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation. (WHO, 2022, para. 1)

Symptoms can differ in their composition and extent depending on the underlying cause and the specific location of changes occurring in the brain. The most common cause for dementia is Alzheimer’s disease. Other causes for a progressive course of dementia include, but are not limited to: vascular disease, Lewy body disease, and frontotemporal degeneration (WHO, 2022).

Scientists agree that Alzheimer’s disease and similar conditions can be attributed to genetic as well as modifiable factors. In 2020, the Lancet Commission on Dementia Prevention, Intervention, and Care updated its previously published risk factor model to a life-course model of dementia prevention based on 12 modifiable risk factors: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact (Livingston et al., 2020). Similarly, a recent umbrella review of systematic reviews and meta-analyses undertaken by Zhang and colleagues (2022) found “convincing” statistical evidence for an association between

dementia and early-life education, BMI, plasma glucose levels, atrial fibrillation, gait speed, and benzodiazepine use. For education and plasma glucose, the relationship with Alzheimer’s disease was found to be causal. Less statistically compelling, yet “suggestive” modifiable factors identified in this review included, among others: smoking, alcohol consumption, blood pressure, hearing impairment, diet, sleep, physical activity, and social engagement.

While considerable strides have been made in recent years toward dementia risk detection and prevention, and although advances in clinical research have led to FDA approval of potentially disease-modifying drugs for the treatment of Alzheimer’s disease in the United States (Kantarci, 2022), there still is no curative treatment available. To date, for those living with dementia, pharmacological and non-pharmacological interventions can, in the best case, reduce symptoms, but they cannot protect or restore the neuronal connections that are irreversibly damaged and lost due to pathological processes in the brain. Interventions aimed at reducing what is commonly referred to as “caregiver burden¹” are typically limited to facilitated support groups or more formally structured psychoeducation or training to increase the carers’ coping and resourcefulness skills (e.g., Zauszniewski et al., 2022). While this lack of treatment and support options is alarming, there has been a shift from understanding dementia and dementia care as predominantly clinical problems toward rethinking and improving the

¹ In contribution to increasing efforts to combat dementia-related stigma through a more thoughtful use of language in research and practice, I will refer to “caregivers” as “carers,” “care partners,” or “supporters” throughout this document. Similarly, words with strong negative connotations, such as “burden,” will be avoided unless referring to other authors’ work or mentioned in a verbatim quote.

built, service-related, and social makeup of communities as a whole to increase the well-being of those living with dementia and their care partners.

Dementia in Numbers

According to the WHO, 55.2 million people around the world were living with dementia in 2019 (5.4% of men and 8.1% of women over the age of 65), and this figure is projected to rise to 78 million by 2030 and to 139 million by 2050 (WHO, 2021a). In the United States alone, 6.5 million people 65 years of age or older currently live with Alzheimer's disease, as stated in the Alzheimer's Association's most recent "Facts and Figures" report (Alzheimer's Association, 2022a). Black Americans are twice as likely, and Hispanics are one-and-a-half times as likely as White Americans to develop dementia, although they are less likely to be formally diagnosed. Studies suggest that genetic factors play a much lesser role in explaining these differences than an unequally distributed prevalence of health and socioeconomic risk factors (Alzheimer's Association, 2022b). Globally, about 60 percent of those living with dementia live in low- or middle-income countries (WHO, 2021a). However, Alzheimer's Disease International (ADI) suggested in its latest World Alzheimer Report that 75% of all people living with dementia, and up to 90% in low- and middle-income countries, are not officially diagnosed (Gauthier et al., 2021).

Alzheimer's disease and other forms of dementia are the seventh leading cause of death worldwide, with 1.6 million deaths attributed to the disease in 2019 (WHO, 2020). According to the Alzheimer's Association's report for the United States,

Alzheimer's disease was the sixth leading cause of death among Americans of all ages in 2019, before falling to rank seven during the COVID-19 pandemic in 2020 and 2021. Among Americans in the 65+ age group, it remained the fifth leading cause of death with a steeply increasing number of deaths. In contrast, deaths due to other leading causes – namely heart disease, stroke, and HIV – have been decreasing (Alzheimer's Association, 2022a). It must be noted, however, that determining the cause of death for people with dementia is not always straightforward; new ways of approaching this issue are presently being explored (GBD 2019 Diseases and Injuries Collaborators, 2020).

Recent estimates suggest that, among people of all ages worldwide, Alzheimer's disease and related conditions are the twenty-fifth leading cause of disease burden, measured in disability-adjusted life years (DALYs) which represent the years of life lost due to disability or premature death (WHO, 2021a). Among people 75 years of age or older, this ranking changes to dementia being the fourth leading cause of DALYs (GBD 2019 Diseases and Injuries Collaborators, 2020). Moreover, DALYs due to dementia have more than doubled between 2000 and 2019, with a much steeper increase than other health conditions ranking highly in their contribution to the global burden of disease (WHO, 2021a).

The societal cost of dementia, including the cost of medical, social, and informal care, was estimated at \$1.3 trillion globally in 2019. Projections for 2030 range between \$1.7 and \$2.8 trillion as costs of care are expected to increase. Informal care makes up approximately half of the global cost of dementia with more than 89 billion hours of

support provided in 2019. Most of this informal support (70%) has been and continues to be provided by women (WHO, 2021a).

Social Implications of Dementia

Stigma, Negative Attitudes, and Discrimination. In addition to the stressful experience of adapting to their cognitive changes, people living with dementia as well as their carers are at a high risk of being marginalized, disenfranchised, and excluded from important areas of daily life in the community. Deep-rooted societal and individual misconceptions and negative stereotypes about being “out of one’s mind” (the literal meaning of the Latin word “de-mentia”) often lead to stigmatization and discriminatory practices. Social stigma can manifest in different, but interrelated, ways. According to Bos et al. (2013), it can take the form of public stigma, self-stigma, stigma by association, or structural stigma. Public stigma relates to people’s reactions – including thoughts, feelings, and behaviors – toward those who are perceived as living with a stigmatized attribute or condition. Self-stigma, on the other hand, describes the stigmatized person’s recognition of being stigmatized, the apprehension of the social and psychological implications of being stigmatized, and the potential internalization of the negative stereotypes connected with the stigmatizing attribute or condition. Stigma by association, also known as courtesy stigma, refers to people’s reactions to those associated with a stigmatized person (e.g., family members). Lastly, structural stigma emphasizes how stigma operates as a system; it describes how stigma is legitimized and maintained through societal ideologies and institutions.

The experience of dementia-related stigma, or fear thereof, can reduce a person's quality of life dramatically. It can delay diagnosis, treatment, and service provision and cause those affected by dementia, including family members, to withdraw from activities and social interactions that otherwise would have been supportive (ADI, 2019).

In ADI's 2019 World Alzheimer Report, the organization published the results of the to-date largest international study conducted on stigma and attitudes toward dementia and those living with it. Survey data from nearly 70,000 respondents in 155 countries revealed that 78% of the general public were worried about being affected by dementia at some point in the future. Along with these concerns went a sense of helplessness regarding the development of Alzheimer's or a similar condition: 75% of the same respondents did not believe that anything could be done to prevent it. Even more alarmingly, 62% of health professionals taking the survey considered dementia a normal part of aging, revealing a lack of training that corresponds with the impression shared by 40% of the general public that health professionals tend to ignore people with dementia or to treat them inappropriately (e.g., by discussing the diagnosis with a family member in their presence, without including them in the conversation). The majority (75%) of carers felt stressed because the demands of their role as supporters interfered with other responsibilities; many stated that being a carer had negatively affected their social life (62%), health (52%), and/or work (49%). More than a third (35%) of surveyed informal carers reported having hidden their family member's dementia diagnosis from

at least one person. At the same time, most survey participants (91%) agreed that people with dementia should not keep their condition a secret. Remarkably, however, 20% of the participants admitted that they would hide their own dementia from others. These respondents' caution might be grounded in everyday-life experiences shared by people with dementia: Among those survey participants living with Alzheimer's or similar conditions, more than 85% felt that their opinion was not taken seriously, and many had experienced other forms of unfair treatment, ranging from others making jokes about them to being deprived of their rights or responsibilities (ADI, 2019).

Startlingly, the experience of being excluded often starts at the doctor's office. A systematic review of qualitative studies on attitudes and practices among physicians showed that 89% of general practitioners and 97% of specialists usually informed family members about a dementia diagnosis while only 34% and 48%, respectively, shared this information with the person diagnosed (Low et al., 2018).

A systematic review of existing research on dementia-related stigma revealed that stigma and negative attitudes seemed especially strong among men, younger people, ethnic minorities and immigrants, people with little knowledge about dementia, and people lacking contact with someone affected by dementia (Herrmann et al., 2018).

According to a survey in the United States (Alzheimer's Association, 2021), Native Americans, Black Americans, and Hispanics were less concerned about developing dementia than White Americans, in part because around a third of the surveyed Native Americans and Hispanics did not expect to live long enough to

experience cognitive decline. One in five Hispanics and Blacks, which was twice as many as Whites, reported that they would feel “insulted” if a physician suggested a cognitive test. In addition to the high prevalence of dementia-related stigma within ethnic minority groups, the survey revealed that Black, Hispanic, Asian, and Native Americans experienced race-based discrimination by health care providers – such as being ignored or treated less respectfully than White patients – as a barrier to seeking and receiving dementia care. Between 84% and 92% of the respondents of color stressed the importance of culturally competent health care providers, but only between 47% and 63% of them believed they had access to such professionals (Alzheimer’s Association, 2021).

In a recent scoping review of the literature on stigma reduction interventions (Bacsu et al., 2022), the authors pointed out that, somewhat surprisingly, the reduction of stigma associated with dementia has only recently emerged as a research field. While over the last decade the awareness of dementia-related stigma and the evidence base regarding the detrimental effects of negative attitudes and stereotypes have notably grown (Herrmann et al., 2018), not much academic attention has been paid to stigma-reducing interventions. The interventions mentioned in the 21 publications reviewed by Bacsu et al. (2022) were categorized into (1) educational interventions (e.g., presentations, educational curricula, theater plays, films), (2) contact interventions (e.g., visual or performing arts such as intergenerational choirs), and (3) combinations of both. The review did not systematically assess the effectiveness of the interventions.

An often-overlooked reason for the stigmatization and marginalization of people living with dementia is the traditionally individual- and symptom-based approach to dementia that is still prevalent in many societies. This approach often falls short in recognizing the role of the community in addressing not only the physical, but also the social and emotional aspects of health, as noted in the WHO's definition:

[Health is] a state of complete physical, *mental and social* well-being, and not merely the absence of disease or infirmity... Health is a *resource for everyday life*, not the object of living. It is a *positive concept emphasizing social and personal resources* as well as physical capabilities. (WHO, 1998, p. 1; emphasis added).

Several theoretical frameworks used in the realm of public health, such as the social determinants of health model and the social model of disability (both explained below), are proposing a broader perspective on health in general. These frameworks are also suited for application in the more specific context of dementia.

Social Determinants of Health. The premise of health comprising physical, social, and emotional aspects of well-being supports an ecological perspective on health as proposed in the framework of the (social) determinants of health (WHO, n.d.-b). The model holds that health and well-being are influenced not only by an individual's predetermined characteristics (e.g., age, sex, and genetic factors) and lifestyle, but also by social and community networks as well as overarching societal, cultural, and environmental circumstances, all of which can theoretically be modified. The WHO defined these non-medical determinants of health as "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" and noted that up to 55% of health outcomes can be accounted

for by these social determinants as opposed to individual factors, including lifestyle choices (WHO, n.d.-b, para. 1). Living (well) with dementia can be understood as embedded in this multi-faceted framework.

The Social Model of Disability. The social model of disability was brought into existence by an activist group during the early disability rights movement in the 1970s and, in contrast to the medical, or individual, model of disability, postulates that people are not disabled by their impairments but by barriers encountered in society (e.g., Oliver, 2013). These barriers include “social, economic, attitudinal, physical, architectural and environmental factors” (Mental Health Foundation, 2015, p. 15), and while the social model of disability does not depreciate the relevance of medical approaches, it “contests the way in which policy is developed and services are delivered” (p. 16).

Whether dementia should be considered a disability or if it should be seen as merely a medical condition that, depending on the severity of the symptoms, can become “disabling” at some point, has far-reaching implications for policy and practice as well as the rights and everyday lives of those affected (Mental Health Foundation, 2015). Unarguably, individuals living with dementia, like people living with a disability, have been marginalized in many societies because of their perceived inability to meaningfully participate in community life. Instead of leaving it to the individuals to remain involved, the social model emphasizes the rights of people living with disabilities (or dementia) and the barriers their environments are posing to their pursuit (Mental

Health Foundation, 2015). The model, applied to dementia, encompasses features of a Kitwoodian approach in that it stresses the uniqueness of each person's experience, the existence and negative effects of stigma, and the importance of involving people affected by dementia in the process of designing, developing, and evaluating community and health services (Henwood & Downs, 2014) as well as efforts to facilitate their reintegration and participation in community life.

A Global Response to Address Dementia

As outlined earlier, dementia is a rising global health concern with devastating implications for the physical, emotional, and social well-being of those affected by Alzheimer's disease or similar conditions. Traditional support efforts tend to be narrowly centered on the individual and applied from the perspective of a clinically oriented mindset that neglects the greater context of people's everyday life. The following will explore alternative approaches that have been put forth in recent years with a broader understanding of dementia and what it means to live with it.

The WHO's Global Action Plan

In 2012, the WHO responded to the alarming demographic developments by declaring dementia a "public health priority" (WHO, 2012), stressing the urgency to attend to the issue globally and without delay. Five years later, the organization released a *global action plan on the public health response to dementia 2017-2025*, which was adopted by the 70th World Health Assembly (WHO, 2017). The plan outlines a set of action areas with specific targets which all of the WHO's 194 international

member states committed to addressing by developing, implementing, and/or renewing actionable national dementia plans or strategies.

To monitor progress toward meeting the plan's targets, ADI was tasked with compiling and publishing annual progress reports based on data submitted by member states to the WHO Global Dementia Observatory. In addition, the WHO published a separate report in September 2021. Based on these assessments, both the WHO and ADI concluded that, at the halfway mark of the implementation phase, most members had failed to fulfill their pledges to pursue the agreed-upon targets on national level (Benoist et al., 2022; WHO, 2021a). All action areas, global targets, and ADI status statements are depicted in Table 1.

Remarkably, the WHO's global call to action departs from viewing dementia primarily through a clinical lens; it brings into focus aspects of empowerment and inclusion and no longer regards those affected by dementia merely as patients impaired by an incurable disease but more holistically as individuals with a right to make decisions about the physical and social context they are and continue to be embedded in:

The plan calls for an approach to dementia that focuses on human rights and people. There is a need to create, or improve awareness of dementia. This will help educate society to better understand people affected by dementia, as well as their families and carers. This represents a shift from treating dementia as a purely medical condition that leads to impairment and dependence, to understanding it as an acquired progressive, cognitive and psychosocial disability. The shift brings with it the need to empower people with dementia to live their lives in a manner that they choose and value. This does not merely refer to the individual's physical and mental capacity, but also to the physical and social environments that they live in. (WHO, 2021b, p. 5)

Table 1*The WHO's Action Areas and Global Targets and ADI's Status Report*

Action Area (WHO, 2017)	Global Target (WHO, 2017)	2022 ADI Status Summary (Benoist et al., 2022)
(1) Dementia as a public health priority	“75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.” (p. 10)	“Five years on, member states are woefully lagging on the goals set for Action Area 1, with ADI positing only 39 national dementia plans and integrated plans in place out of a target of 146. While some countries face serious geopolitical or socioeconomic hurdles to prioritising dementia policy, it is imperative to accelerate efforts towards national plans while the momentum of the Global action plan is still there.” (p. 28).
(2) Dementia awareness and friendliness	<ol style="list-style-type: none"> 1. “100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025. 2. 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.” (p. 15) 	“Awareness is the essential first step to effective advocacy and dementia policy development, throughout the year. Raising awareness and challenging stigma through a variety of means are key to shifting the discourse surrounding dementia to one based on the values of equity and human rights. National associations and relevant health and care organisations are important actors in these campaigns and inclusion of the voice of people living with dementia and their carers is fundamental. States looking to raise awareness of dementia would do well to include grassroots organisations in these efforts, as well as seek out opportunities for regional or international cooperation.” (p. 38)
(3) Dementia risk reduction	“The relevant global targets defined in the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved for risk reduction and reported.” (p. 18)	“In the absence of disease-modifying treatment that is accessible to all, dementia risk reduction deserves more attention and investment from governments. While individuals can take steps to decrease their personal risks, large-scale, holistic initiatives are crucial to achieve a broader impact. The pandemic has highlighted the ties between social health and dementia, further emphasising that risk reduction should be approached from a societal rather than individualistic perspective. While the long-term effects of COVID-19 on cognition will take time to be more fully understood, states should see risk reduction as an essential and cost-saving tool to integrate in their national dementia plans.” (p. 45)

Action Area (WHO, 2017)	Global Target (WHO, 2017)	2022 ADI Status Summary (Benoist et al., 2022)
(4) Diagnosis, treatment, care and support	“In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.” (p. 23)	“The effects of COVID-19 continue to reverberate across the fields of dementia diagnosis and post-diagnosis support, although opportunities for more online or virtual services have emerged from the pandemic. Navigating the complexities of life after a dementia diagnosis can be a deeply challenging task requiring extensive networks of person-centred support based on a thorough understanding of dementia itself and the individuals affected by the condition. Post-diagnosis models will be explored in the World Alzheimer Report 2022, including treatment, care and support.” (p. 54)
(5) Support for dementia carers	“75% of countries provide support and training programmes for carers and families of people with dementia by 2025.” (p. 26)	“Informal carers bear the brunt of the responsibilities associated with dementia care, the impact of which is felt most acutely by women and those living in low- and middle-income countries. Care professionals by and large could also benefit from more specialised training when working with people with dementia, especially in areas where stigma remains high. Care needs to be coordinated with care pathways that are clear and accessible to all, regardless of their income or where they live. Efforts to provide support and resources to carers continue to be led by Alzheimer’s and dementia associations globally, especially in countries where national dementia plans are not yet implemented.” (p. 61)
(6) Information systems for dementia	“50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.” (p. 30)	“Knowledge sharing is essential in order to collect data on incidence of dementia, treatment, and management and monitor best practices across the world. Making such information easily available is crucial to improving the accessibility and coordination of care and support for those living with dementia. While there are many success stories, information-sharing platforms and dementia registries can be underutilised. Willingness to invest in these information systems must occur if we are to stand a chance of reaching the Global plan’s Action Area 6 targets.” (p. 66)

Action Area (WHO, 2017)	Global Target (WHO, 2017)	2022 ADI Status Summary (Benoist et al., 2022)
(7) Dementia research and innovation	“The output of global research on dementia doubles between 2017 and 2025.” (p. 32)	“The emergence of the first new dementia drug treatment in two decades, despite sparking debate, is far from the only development in dementia research in the past year. Research output still lags behind the goals set by the WHO, but innovations continue to abound. ADI persists in calling on governments to invest a minimum of 1% of the societal cost of dementia into research. While much attention is focussed on biomedical and pharmacotherapeutic research, there is also an urgent need to produce more qualitative research on care, and to make sure any discoveries made by labs or institutes can translate into real-world changes.” (p. 78).

Dementia-Friendly Communities

National and International Initiatives. Over the past decade, the concept of “dementia-friendly communities” (DFCs) has gained international recognition. Early activities began in the 1990s in Japan, where in 2004 the government supported a national campaign that lasted 10 years and delivered the groundwork for Japan’s current DFCs (Turner & Cannon, 2018). Smaller pioneer projects took place in Scotland, Belgium, and Germany (Henwood & Downs, 2014; Turner & Cannon, 2018). The UK – supported by government policy since 2012 (Prime Minister’s Challenge on Dementia) – spearheaded the implementation of dementia-friendly initiatives on a larger scale. To date, there are 351 officially recognized dementia-friendly communities in England alone (Buckner et al., 2022). While most DFCs are based on geographic location, some are identified by shared interests (Buckner et al., 2019). Since these early days, the

movement has gained momentum in Australia, the United States, and other parts of the world (Henwood & Downs, 2014).

In 2015, the White House Conference on Aging announced the launch of the Dementia Friendly America (DFA) initiative – a nationwide, cross-sectoral effort of more than 50 leading organizations (USAagainst Alzheimer’s, 2015). The setup of the initiative was guided by the long-standing work and experience of the “ACT on Alzheimer’s” group in Minnesota. Comparable to many of its international counterparts, the DFA initiative follows a cross-sectoral approach and provides a wealth of tools and resources for communities interested in joining the effort. The ecological nature of the DFA model aligns tightly with the previously discussed determinants of health. Sectors are understood as “areas for local action” (Alzheimer’s Society UK, 2022a) deemed particularly important to be involved in dementia-friendly initiatives. DFA’s materials are available online (<https://www.dfamerica.org>) and include community organizing and training tools as well as comprehensive “sector guides” to facilitate communication and collaboration among community partners and other stakeholders. Table 2 shows the sectors proposed by DFA (2022a) in comparison to those used in the DFC recognition process by the Alzheimer’s Society in the UK (Alzheimer’s Society UK, 2022a).

Between June 2017 and the time of this writing (September 2022), the number of cities and communities that have joined the DFA network has increased from 36 communities in 28 states to more than 150 in 41 states.

Table 2

Dementia-Friendly Community Sectors (USA & UK)

Sectors proposed in the United States (DFA, 2022a)	Sectors proposed in the UK (Alzheimer’s Society UK, 2022a)
<ol style="list-style-type: none">1. Airports2. Banks and financial services3. Neighbors and community members4. Legal and advance planning services5. Local government6. Health care throughout the continuum7. Libraries8. Faith communities9. Businesses10. Community-based services and supports11. Residential and specialty care12. Hospitals	<ol style="list-style-type: none">1. Arts, culture, leisure and recreation2. Businesses and shops3. Children, young people, and students4. Community, voluntary, faith groups and organisations5. Emergency services6. Health and social care7. Housing8. Transport

A plethora of definitions of DFCs exists, all similar in content and equally vague.

For instance, DFA describes a DFC as “a village, town, city or county that is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life” (DFA, 2022b). According to the Alzheimer’s Society in the UK,

A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported. In a dementia-friendly community people will be aware of and understand dementia, so that people with dementia can continue to live in the way they want to and in the community they choose. (Alzheimer’s Society UK, 2022b)

The WHO’s increased attention to the issue has further spurred the global DFC movement in more recent years. In 2021, to provide additional guidance on the implementation of action area 2 (“dementia awareness and friendliness”) in the

aforementioned global action plan, the WHO published a toolkit to advance “communities’ understanding of dementia and create dementia-inclusive societies where people with dementia can live meaningfully, safely and with dignity” (WHO, 2021b, p. vi). In line with the previously discussed social model of disability, the toolkit was built on the foundations of the United Nations Convention on the Rights of Persons with Disabilities (WHO, 2021b). Organized in four modules, it supports communities interested in developing new dementia-friendly initiatives, integrating the concept of dementia friendliness with existing initiatives, and expanding on an existing DFC.

DFC Research. While dementia-friendly initiatives had already seen a significant expansion when this dissertation was proposed, little systematic inquiry about these initiatives had been conducted at the time, let alone scientific research including the perspective of people affected by dementia.

One early DFC study involving people with dementia, albeit not academic in nature, was a project realized as part of the national “Ageing Well” initiative (2010 – 2012) in the UK which later informed the government-supported national launch of DFCs. A community interest company (Innovations in Dementia) was commissioned to “explore what developing a dementia-friendly community might mean in practice for local government and what steps a council would need to take to begin to bring it into being” (Local Government Association, 2012, p. 4). The project’s focus was explicitly defined as complementing, rather than encompassing, aspects of health and social care outlined in the National Dementia Strategy. Consequently, the project team was

primarily interested in people's daily experiences, with the goal of "supporting the wellbeing of those people with mild to moderate cognitive impairment in the early stages of dementia who are trying to live normal lives in the community" (p. 5). Interviews and online surveys were carried out with people living with dementia and their supporters in different locations (rural and urban), and the results were used as baseline information for a larger "think tank" convention on dementia. The project team found that respondents defined a dementia-friendly community as a place where they could safely find their way around, have access to the banks, shops, cafés and other facilities they were familiar with, and continue to be a part of their social networks. Pursuing hobbies, going out, using local facilities, and volunteering were mentioned as pleasant activities that people wanted to continue to engage in, and one-to-one informal support was recognized as a vital facilitating factor. Apart from feeling worried about their decreasing ability to cope due to cognitive difficulties, people living with dementia felt concerned about other people's lack of understanding and knowledge about the condition. The respondents recommended that communities should focus on raising awareness, supporting local groups, and securing continued access to facilities and to information about local support services (Innovations in Dementia, 2011).

In 2016, Karen Smith and colleagues carried out a qualitative study in the aftermath of the earthquakes in Christchurch, New Zealand (Smith et al., 2016). The study team interviewed 26 older adults living with dementia to collect their input on what a rebuilt, dementia-friendly Christchurch should look like. A thematic analysis of

the data showed that study participants envisioned their post-quake communities as places (1) where the people and services understand and accommodate those living with dementia (e.g., respectful and responsive businesses and services; increased awareness and understanding; accessible and accommodating transport options) and (2) in which the physical environments are accommodating and enable engagement in outdoor spaces (e.g., accommodating and safe physical environments, opportunities for engagement in outdoor spaces).

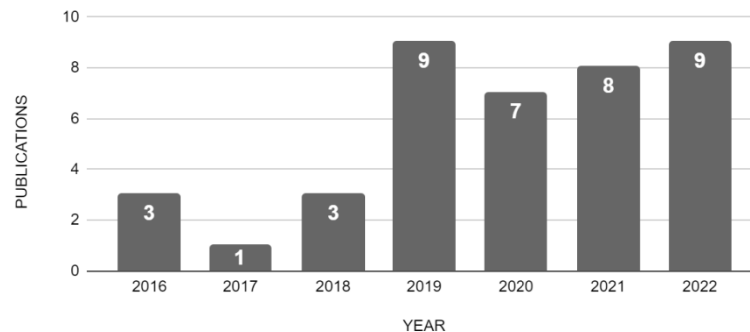
Since these early papers were published, the scientific landscape has changed significantly. “Dementia-Friendly Communities” as a special subject term first appeared in 2016 to index academic publications on the topic in electronic databases. A search within AgeLine and Medline revealed that, since 2016, forty peer-reviewed articles have been published under that subject term alone. Moreover, the number of publications showed a steep upsurge in 2019, then a temporary stagnation during the COVID-19 pandemic (see Figure 1). It is worthy of note that the Medline database contained all 40 articles while AgeLine contained only 20, which is likely reflective of the traditional view of dementia as a medical rather than community or societal concern.

Recent publications include several review articles synthesizing the state of scientific research on DFCs in general or on particular aspects of them (e.g., Diaz et al., 2022; Gan et al., 2022; Hebert & Scales, 2019; Shannon et al., 2019). Other recently published work has addressed, among other topics, the involvement of people with dementia in DFC initiatives (e.g., Mathie et al., 2022; Liu et al., 2022; Wu et al., 2019),

systematic approaches to measure a DFC’s effectiveness (Buckner et al., 2022), and barriers to/facilitators for creating DFCs (e.g., Parkinson et al., 2022).

Figure 1

Number of Publications Indexed Under Subject Term “Dementia-Friendly Communities” by Year (Medline)



The growing number of DFC initiatives and related research activities has been accompanied by an increasing and explicit recognition of the importance to engage people with dementia and their supporters in the planning and evaluation of these initiatives, following a general trend toward participatory approaches in dementia research (Kowe et al., 2022).

In ADI’s aforementioned status report on the fulfillment of the targets in the WHO’s global action plan, the organization underscored that “inclusion of the voice of people living with dementia and their carers is fundamental” (Benoist et al., 2022, p. 38). Similarly, a Dementia Research Blueprint developed by the WHO explicitly points to the “involvement of people with lived experience” as a central driver for research activities (Cataldi et al., 2022, p. 691). Further, active engagement of people affected by

dementia in the early planning stages of a DFC is a key requirement for joining networks such as DFA, and their input and expertise continues to be instrumental for the development of a DFC framework aiding both the design and continuous evaluation of DFC initiatives (Buckner et al., 2022; Hebert & Scales, 2019; Mathie et al., 2022).

While Mathie et al. (2022) underscored that “the success of DFCs are [sic] determined by how the needs of people living with dementia are identified, discussed and reviewed by those within the community who are most affected” (p. 1251), the authors pointed out that the level of inclusion varies widely among DFC initiatives. In many cases, intentions to involve those affected by dementia do not go beyond the rhetoric used in planning documents. Mathie et al. (2022) also differentiated between involvement and engagement, where the former refers to active participation in the shaping of the DFC and the latter to merely describing the dissemination of information, for instance, at town hall meetings.

Including people with dementia in DFC activities encompasses involving them in the discussion of what constitutes a community’s dementia friendliness. Wu et al. (2019) conducted a qualitative study with people living with dementia and family carers and identified seven indicators of a community’s dementia friendliness: (1) dementia-friendly care services; (2) dementia-friendly hospitals; (3) dementia-friendly community environment; (4) dementia-friendly transportation; (5) dementia-friendly stores and shops; (6) dementia-friendly people; (7) integrated dementia-related information and community contribution; (8) and involvement opportunities for people with dementia.

These indicators, with minor modifications, later served to develop a Perceived Community Dementia Friendliness scale used by Liu et al. (2022) to survey people living with dementia, carers, service providers, and the general public in Taiwan.

As more DFC initiatives are starting to develop and evolve, an emerging line of academic work is centered around measuring their effectiveness. To develop useful evaluation tools, it is necessary to specify areas in which change is intended to occur, yet no universally applicable definition of DFCs exists to date that could provide actionable assessment categories or indicators of success (Buckner et al., 2022; Diaz et al., 2022).

ADI (2016) introduced four key principles essential for DFC success: (1) people, including the involvement of people with dementia; (2) communities, including their physical and social environments; (3) dementia-friendly organizations and access to appropriate health care; and (4) cross-sectional partnerships (ADI, 2016, p. 10 f.). To measure success, ADI further suggested focusing on five outcomes of DFC efforts: (1) increased awareness and understanding of dementia; (2) increased social and cultural engagement for people with dementia; (3) legal and other measures in place to empower people with dementia to protect their rights; (4) increased capability of health and care services to develop services that respond to the needs of people with dementia; and (5) actions to improve the physical environment whether in the home, residential care, hospitals, or public places (ADI, 2016, p. 7).

In a scoping review of the recent literature on DFCs, Diaz and colleagues (2022) examined the use and adequacy of quantitative tools to evaluate the dementia friendliness of communities. The authors identified 40 tools, only six of which were found in peer-reviewed publications; the others were extracted from grey literature such as reports, toolkits, and websites. The researchers noted that none of the tools adequately assessed DFC features and concluded that “a comprehensive DFC framework is needed to support a systematic approach to the development and assessment of DFC initiatives” (Diaz et al., 2022, p. 1847).

Most recently, Stefanie Buckner and colleagues (2022) developed an evidence-based collection of DFC evaluation resources based on a mixed-methods study conducted in the UK (Buckner et al., 2018). The study was aimed at addressing the lack of systematic approaches to measure the effectiveness of DFCs and included the conceptualization of a DFC evaluation framework, a “Theory of Change” with input and output measures, and a matrix to determine a DFC’s level of maturity. Based on workshops that included participants living with dementia, the authors suggested seven evaluation domains: (1) leadership and governance (including political support); (2) basis of DFC (e.g., baseline and needs assessments, use of existing frameworks, evidence-based interventions); (3) resources (financial and human); (4) involvement of people affected by dementia; (5) activities and environments provided by the initiative; (6) collaboration; and (7) monitoring and evaluation (Buckner et al., 2022).

Age- vs. Dementia-Friendly Initiatives. While, over the last decade, the UK has been pioneering the global dementia-friendly movement, the United States has been among the international leaders in exploring ways to increase the *age* friendliness of local communities or, more recently, entire states. Consequently, the question has been raised if and how age-friendly and dementia-friendly initiatives can be integrated to avoid their development as two separate movements competing for resources and attention.

The most widely used framework of age friendliness was introduced by the WHO in 2007 to define and describe the features of age-friendly communities (AFCs) in response to the global demographic trends of population aging and urbanization. The framework is centered around eight domains, or focus areas, of age-friendliness (see Table 3). The domains, along with a guide and checklist to help cities and communities identify age-friendly features, resulted from an initial focus-group study conducted simultaneously in 33 cities around the world in 2006 (Neal & DeLaTorre, 2009; Plouffe & Kalache, 2010; WHO, 2007a,b).

This framework has since found international acclaim (Fitzgerald & Caro, 2014): Since the WHO's Global Network of Age-Friendly Cities and Communities was established in 2010, 1,363 cities and communities in 47 countries have joined as members to date (WHO, n.d.-a). In the United States in particular, the WHO model has been utilized to plan, implement, develop, and evaluate various efforts on state and community level. Many of these local initiatives are members of the national AARP

Network of Age-Friendly States (formerly: Cities) and Communities (AARP, n.d.) – a network formally affiliated with its global counterpart.

Table 3

The WHO's Age-Friendly Domains

Age-Friendly Domains (WHO, 2007b)	Description (Turner & Cannon, 2018, p. 10 f.)
<i>Built environment</i>	
Outdoor spaces and buildings	“The accessibility of parks, streets and public buildings significantly impacts the mobility, independence and quality of life of older people.”
Transportation	“Accessible and affordable transportation supports older people to get out and about and stay active and connected, including, to community and health services.”
Housing	“The availability of appropriate and affordable housing for different life stages is key to staying safe, healthy and in control as we age.”
<i>Social environment</i>	
Social participation	“Offering a range of opportunities to participate in leisure, social and cultural activities. Allowing older people to continue to learn, stay active and build and maintain relationships throughout life.”
Respect and social inclusion	“Creating places where older people are respected, recognised and included in the community and family life.”
Civic participation and employment	“Ensuring opportunities to continue to contribute to their communities through paid work or volunteering and to be engaged in the political process.”
<i>Service environment</i>	
Communication and information	“Supporting older people to stay connected with events and people and have ready access to relevant information in a variety of forms.”
Community support & health services	“Having access to health and support services that are affordable, of good quality and appropriate is vital for older people to maintain health and independence in the community.”

Research on the integration of AFCs and DFCs does not currently exist. A special issue of the *Journal of Aging and Social Policy*, published in March 2022, featured recent research reports focused on advancing age-friendly initiatives and illuminating mechanisms of sustainable community change at the intersection of policy and practice. None of the 10 articles in this issue mentioned dementia, let alone DFCs.

Based on the previously mentioned model of modifiable risk factors for dementia (Livingston et al., 2020), a qualitative study with older adults (without dementia) in Germany investigated what features of urban environments might be conducive to maintaining brain health and hence reducing the likelihood of developing dementia (Röhr et al., 2022). The authors identified three general themes (social participation and inclusion; proximity and accessibility; local recreation and well-being) showing a strong resemblance with the WHO AFC framework.

Buckner et al. (2018) adapted an assessment tool originally developed to evaluate AFCs and applied it to a DFC, but apart from acknowledging that there is a continuing “debate on the nature of the relationship between both” (p. 49), the authors did not provide any further insight regarding this relationship. However, in a blog post created in the context of a related study in the UK, Buckner (2017) reflected on the question what additional aspects DFCs would call for that were not already encompassed in an age-friendly community. Buckner proposed that everything that is dementia friendly is also age friendly, and that everything that is age friendly benefits

everyone, with the added caveat that “in reality, the boundaries are blurred” (Buckner, 2017, para. 11).

Only two publications, both by Natalie Turner and two different colleagues, have thus far explored the relationship between age-friendly and dementia-friendly initiatives. The first paper is a non-academic comparative analysis carried out by AARP International Affairs which compared the WHO AFC framework with the DFA approach and included four international case studies of cities that were simultaneously working toward becoming more age and dementia friendly (Turner & Morken, 2016). The second publication is a UK-focused summary paper addressing the history of both movements and ways in which they can be aligned, including three case studies from the UK (Turner & Cannon, 2018).

As for similarities stated by Turner and Morken (2016), both concepts share the objectives of creating supportive physical and social environments to enable people to remain in their communities as long as possible and of building partnerships with a variety of stakeholders, including older people/people with dementia themselves whose lived experience is valued. Turner and Cannon (2018) added that both initiatives (1) focus on local structures and decision making (DFCs being more diverse in scope), (2) involve a group of cross-sector stakeholders (DFCs being more flexible regarding the representation of sectors), (3) emphasize the importance of involving older adults/people with dementia (the latter being less able to participate at higher levels), and (4) address the physical, social, and service environment (attitude change and

understanding having a particular importance in DFCs when cognitive changes in community members can no longer be accommodated by adaptations of the physical environment).

On the other hand, AFCs and DFCs differ in that AFCs (1) avoid the identification of people based on illness or disability (one reason being the avoidance of age-related stereotypes), (2) focus more on prevention, (3) are less centered on raising awareness and reducing stigma, and (4) require formal political commitment (Turner & Cannon, 2018). Turner and Morken (2016) also pointed out that AFCs are less prescriptive in their guidelines than the DFA approach (e.g., regarding the inclusion of specific sectors), but follow a more strictly defined timeline (five-year cycle). Further, as opposed to DFCs, informal carers are not explicitly considered key stakeholders in the WHO framework of age friendliness: Although care partners were included in the initial AFC study (WHO, 2007), their primary role in the study was to complement the information collected from the older adults they were caring for.

Both papers stressed that dementia- and age-friendly efforts can and should be integrated, especially in the face of limited funding resources. For communities starting both initiatives at the same time, the authors recommended that they be integrated from the onset to benefit from the coordinated efforts. For instance, in this coordinated model, DFCs could be included in AFCs' political engagement. For communities already working toward becoming more age friendly, the authors suggested reviewing existing plans to ensure the inclusion of dementia-specific aspects. This review could be

organized by domain and ideally be realized in consultation with people affected by dementia. Alternatively, DFC initiatives could be added to existing AFC efforts as a separate domain. For communities already engaged with becoming more dementia friendly, on the other hand, it may be helpful to broaden the conversation to incorporate the needs of *all* people as they age (Turner & Cannon, 2018; Turner & Morken, 2016).

Despite the absence of scientific research on integrating the two initiatives, an increasing amount of grey literature has become available as more communities pledge to become both more age and more dementia friendly and undertake the effort to create and share guidelines and other resources. To name just one example, the Commonwealth of Massachusetts is hosting a governmental website describing the characteristics of age- and dementia-friendly cities and providing an “age- and dementia friendly integration toolkit,” along with a step-by-step implementation guide (Massachusetts Executive Office of Elder Affairs, 2019, 2022).

Conclusion

Population aging and rising numbers of people living with Alzheimer’s disease or related conditions have brought dementia into the focus of public health initiatives on a global scale. When declaring dementia a public health priority in 2012, the WHO set the stage for various efforts to engage countries, cities, and communities around the world in the development of dementia-focused policies, campaigns, initiatives, clinical practices, prevention strategies, data collection, support structures, and research

funding (WHO, 2017). While the WHO's call to action did not immediately lead to a satisfying international response, an upward trend in research and intervention activities can be observed, especially over the past five years.

The international DFC movement is a part of this recent development, and it marks a noteworthy shift from individual-level approaches toward community-focused concepts to support people living with dementia and their carers. Replacing a predominantly medical understanding of dementia, DFCs “focus instead on broader concepts of well-being, human rights, and social inclusion, prompted through social and environmental solutions” (Hebert & Scales, 2019, p. 1859).

While it is encouraging to see community-focused models move to the forefront of dementia-related initiatives, the evolution of DFCs appears to have outpaced the efforts to supply them with appropriate theoretical concepts or accompany them with evaluative research. As demonstrated in this review of the literature, an actionable definition and conceptual framework of DFCs is missing. While a multitude of models for DFC approaches exists in the grey literature, the meaning of dementia friendliness and the means to achieve it have been insufficiently examined. More data for the development of evidence-based guidelines is needed. To advance knowledge on developing, maintaining, and evaluating DFCs, research grounded in the daily lives of individuals living with Alzheimer's or a related disease is of paramount importance. Further, to date, no scientific attention has been devoted to a possible integration of age- and dementia-friendly initiatives, partly due to DFCs being a relatively new

phenomenon. Competition for resources and public attention as well as concerns among proponents of either DFCs or AFCs about blurring one initiative's mission by adding the other might also be contributing to the scarcity of integrative work.

Building on theoretical models emphasizing an ecological understanding of living with dementia – namely the social model of disability, the social determinants of health model, and the DFA model of dementia friendliness – this dissertation aimed at contributing to the small, yet rapidly emerging scholarship on DFCs. Based on the perspectives of individuals living with dementia and their informal care partners, the study's goal was to develop a conceptual DFC framework. Since the data collection was guided, in part, by the WHO AFC framework, the dissertation also aimed at providing insight into areas in which dementia- and age-friendly initiatives could synergistically collaborate.

Chapter 2: Research Design and Methods

Purpose of the Study

The purpose of this qualitative study was to gain insight into the everyday experiences of individuals living with dementia and their care partners and, based on these accounts, to identify desirable characteristics of a DFC from the perspective of those directly affected by Alzheimer' disease or other forms of dementia. Specific aims regarding these insights were:

- actively involving people living with dementia in the discussion;
- developing a framework of dementia friendliness to inform and support community-based planning efforts, for instance, in the context of joining the DFA network; and
- understanding how this dementia-friendly framework compares to the framework of age friendliness and if/how both frameworks can be integrated.

Research Questions

The study design was guided by the following research questions:

1. Based on the lived experience of people with dementia and their carers, including barriers and supporting factors related to daily activities, what characteristics should a DFC encompass?
2. What, if any, are the differences between the perspectives of people with dementia and their care partners?

3. (How) do the identified characteristics of a DFC relate to the WHO's domains of age friendliness, and (how) can both frameworks be integrated?

Reflections on Paradigm and Methodological Approach

Paradigms as philosophical frameworks or heuristics in social research are traditionally distinguished by how their proponents understand the nature of “truth” and “reality” (ontology), how they assume humans hold, gain, and interact with their knowledge of the world (epistemology), and what they consider appropriate tools or methods to gain this knowledge (methodology) (e.g., Kaushik & Walsh, 2019).

Interviewing individuals with dementia and their carers lent a noteworthy explicitness to the ontological question of what constitutes truth or reality. The cognitive, behavioral, and psychological changes associated with dementia typically lead to changes in people's accounts of their worldview, which those *not* experiencing dementia tend to perceive as a frustrating divergence from their own “intact” reality – a discrepancy, or dissonance, that care partners commonly attempt to remedy with repeated corrections intended to guide the person with dementia back to a previously shared “actual” truth. While one might empathize with this “reality orientation” strategy as a means to reestablish common ground, it unarguably denies the existence of the “other” truth, hereby missing a pivotal opportunity to reconnect on new terrain. This new terrain, from my experience, is often found between the lines.

Since divergent realities within and among groups were expected, paradigms aimed at approximating one universal truth by minimizing “interpretive bias” were not

suited for this study as the participants' subjective experiences were what I was setting out to investigate. Departing from (post)positivism and other paradigms predominant in quantitative studies, phenomenological and similar approaches to qualitative research are explicitly focused on describing lived, subjective experiences and perspectives. However, many of these approaches seek to suspend the researcher's preexisting knowledge and beliefs as unwanted bias. This was not feasible for this research because I was not entering – or claiming to enter – the scene as a novice to the field, let alone a “blank slate” able to absorb new input without preconception. Like most, I have witnessed dementia in my own family and among the aging parents of close friends, but the majority of what I know about dementia was gained in the professional context of my previous career. After completing my graduate degree in psychology at a university in southern Germany, I had spent six years working as a neuropsychologist at an outpatient memory clinic that was part of the university's medical school. My daily work at the *Zentrum für Geriatrie und Gerontologie* consisted of administering and evaluating cognitive assessments; assisting with clinical trials and other intervention or prevention studies; designing and delivering educational presentations for informal carers, long-term care staff, general practitioners, medical students, and interested community members; and planning and facilitating support groups for family members of people diagnosed with dementia. Through those years at the *Zentrum*, I had developed a differentiated understanding of dementia as well as expertise in interviewing people showing symptoms of Alzheimer's disease and other forms of dementia as well as their

care partners. However, while my interactions with care partners had taken place in varied contexts (e.g., standardized clinical interviews vs. informal conversations in the support groups and during informal gatherings over coffee and cake), the communication with the individuals diagnosed with dementia had mostly occurred in the context of neuropsychological assessments, leaving little room for dialogues. This clinical experience was useful for the study as it allowed me to make an educated guess about my interviewees' cognitive status, which in turn helped me determine how to go about the interview; on the flip side of this coin, I was aware of the "clinical bias" the experience added to my interactions as my silent assessments were impossible to suppress throughout the interview.

Overall, my professional background was critical in planning and conducting this research. It enabled me to predict the "answerability" of the interview questions, allowed me to swiftly change wording and strategies during the conversations, provided the alertness and empathy needed to navigate through emotionally difficult moments, and assisted in "making sense" – in a highly interpretive way – of interviews with participants whose ability to comprehend the questions and to articulate a coherent response was no longer present. In summary, attempting to distance myself from my background for the sake of objectivity would not only have been impossible, but neglecting its value for the success of this study.

With these considerations, along with the large amount of data I planned to collect and analyze, I found my paradigmatic position most closely related to

pragmatism. Pragmatism provides a framework that puts human experience in socio-cultural contexts at the center of scientific inquiry and acknowledges that this inquiry cannot be detached from the researcher's beliefs and preconceived assumptions about the human experience in question (e.g., Morgan & Nica, 2020; Kaushik & Walsh, 2019). As Morgan (2014) explained, "pragmatism presents a radical departure from age-old philosophical arguments about the nature of reality and the possibility of truth" (p. 1049). Reality is understood as constantly changing, shaped through an ever-evolving circular interplay among preexisting knowledge and beliefs, actions, and experiences: We take actions based on our knowledge and beliefs about the possible outcomes of those actions. As we act and experience the outcomes, we reshape our beliefs; and as we experience predictable outcomes in a somewhat consistent fashion, we develop knowledge, or "warranted assertions" – a term coined by philosopher and educational reformer John Dewey in the 1940s (Kaushik & Walsh, 2019; Morgan, 2014).

Research in Dewey's terms can be understood as a special form of inquiry initiated by the discovery of a "problem" or "uncertainty," such as a gap or dissonance within what is currently known about a particular issue. Problems spurring an inquiry are formulated as research questions, and data collection and analysis are the actions taken to resolve them (Morgan & Nica, 2020). A pragmatist paradigm in the sense of Dewey acknowledges the researcher as a scientifically (and otherwise) trained human embedded in the social context of ever-changing experiences who approaches the inquiry based on a set of ever-changing beliefs deriving from those experiences

(Morgan, 2014; Morgan & Nica, 2020). As the scientific inquiry proceeds, the reshaped initial beliefs eventually transform into the knowledge necessary to close the gap that initiated the inquiry in the first place.

Inclusion Criteria

Individuals were eligible to participate in the study if they met the following inclusion criteria:

- 1. The person with dementia was living with (self-reported) dementia of any type, with mild or moderate symptoms (early or middle stage of the disease progression).**

Rationale: Since it was not feasible to obtain formal clinical data from or for the study participants, inclusion in the study had to rely on diagnostic self reports. The original plan had been to include only people in the early stage of dementia to ensure they had the cognitive capacity to fully understand the purpose and consequences of their participation. However, after consulting with collaborating clinical experts at Oregon Health and Science University (OHSU), I extended this inclusion criterion to also allow for participation of individuals with moderate dementia. The stage of dementia could have easily been assessed and formalized with a screening tool, such as the Mini Mental Status Examination (MMSE; Folstein et al., 1975). However, I decided against the use of such instruments because I did not want to forcibly embarrass, sadden, or otherwise burden the interviewees, especially since I had never met them before and had to quickly build rapport and establish trust, which I

am certain would not have been possible after confronting them with a clinical test. Instead, I used my own clinical judgment in combination with a carefully designed consent protocol to ensure that each individual sufficiently understood the purpose and procedures of the study, or was deemed “safe” to be interviewed without experiencing negative side effects.

- 2) Both the person with dementia and their informal (unpaid) care partner were willing and able to participate in one 60-minute, face-to-face interview each (written consent was required); this included that both were able to communicate in English.**

Rationale: I interviewed dyads to facilitate a direct comparison between the perspective of the person with dementia and that of their care partner. Only care partners were included who did not receive monetary compensation or other “contractual benefits” (e.g., free housing) in exchange for the provision of care for the person with dementia as this study explicitly focused on the perspective of informal supporters, such as close family members or close friends. Interviews took place in person because phone conversations without nonverbal cues would have been too difficult or exhausting for many participants. The lack of opportunity to observe the participants’ behavior in situ would also have led to less richness in the collected data. Due to their potentially limited cognitive ability to make informed decisions about their participation in research studies, people with dementia are considered a vulnerable population requiring additional protection. Although most of the

individuals I interviewed were in the early or moderately advanced stages of dementia and able to understand the purpose of the study, several individuals, after inclusion, turned out to be in the more advanced stages so that consent was provided by proxy, that is, via consent by their care partners.

- 3. The person with dementia and their carer were living in a community setting (i.e., in their own home or in a retirement community, but not in a long-term care setting) and within or at a reasonable distance from Portland.**

Rationale: Since this study was focused on the interviewees' everyday experiences in their communities and neighborhoods, individuals living in long-term care settings such as nursing homes or assisted living arrangements were not eligible to participate. As for the "reasonable" distance from Portland, the initial inclusion radius of approximately 20 miles from Portland State University was later expanded and decided upon on a case-by-case basis.

- 4. Both members of the dyad were either living together or seeing each other in person for a significant amount of time each week.**

Rationale: Frequent in-person contact between both members of the dyad was required for study inclusion to ensure that the interviewed care partners were not just peripherally involved with the people with dementia and therefore less affected by the changes that living with dementia brings about. The frequency and duration of personal contact was not specified in

terms of hours, but the screening questions served, for instance, to prevent long-distance care partners from being included.

Recruitment

The recruitment phase started after the study protocol had been approved by Portland State University's Institutional Review Board (see Appendix A). Participation in the study was not associated with any direct benefits; however, as a token of gratitude, each person received either a \$20 gift card for a local grocery store or a virtual \$20 Amazon gift card upon completion of the interview. For recruitment, I collaborated with several local partners. The majority of contacts were provided through the Layton Aging and Alzheimer's Disease Center (Layton Center) at OHSU: The Layton Center is a research and educational institution that also provides specialized clinical outpatient services at OHSU's Center for Health and Healing. These services include, among others, initial and follow-up diagnostic assessments of cognitive impairment. During clinical visits, Layton Center staff informed the patients about the study and, if they expressed interest, added their contact information to a list shared with me through a secure cloud-based network. The Layton Center further provided contact lists extracted from their clinical research database as well as contacts from a registry of community members (ACTNOW!) who had agreed to be contacted about dementia-related research projects. The individuals on this registry were not necessarily OHSU patients; rather, they had added themselves to the list in the context of community-based events or initiatives, such as the Alzheimer's Association's Trial Match program. After reviewing

these lists to determine which contacts might be a good fit for the study, I shared these contacts with a trained student assistant who cold-called them to gauge their interest in participation.

The study information was also shared through mailing lists and at Memory Cafe meetings organized through the Multnomah County Family Caregiver Support Program. Further, the Alzheimer's Association Oregon & Southwest Washington Chapter (Alzheimer's Association) supported my research by displaying the flyer at its office and by sharing the information via e-newsletters with facilitators of support groups for people with early-stage dementia and support groups for care partners. With the Alzheimer's Association's permission, I staffed a table at two Alzheimer's Walks, in Portland and Vancouver, WA, where I talked to Walk attendees, distributed fliers, and collected names of people expressing interest in the study. Another local organization, Oregon Care Partners, invited me to a well-attended Teepa Snow workshop in Salem where I did the same. Friends and acquaintances associated with the Village movement, dementia-focused programs run by Volunteers of America, and private support groups and Memory Cafes in the Portland metro area were also asked to spread the word. Lastly, some of the interviewees offered to advertise the study among other carers.

Once I received or collected contact information for an interested dyad, I reached out to them via phone for an initial conversation to confirm their interest, provide additional details as needed, and go through a set of screening questions to confirm eligibility. If at the end of the conversation we mutually agreed that the study

would be a good fit, we determined the interview location, a date and time, and which type of gift cards the participants wished to receive. As expected, in most cases I spoke with the care partners only; only a few care partners called the person with dementia to the phone to either talk to me directly or to let them hear the conversation via speakerphone. Having included individuals with moderate dementia, I chose not to insist on speaking with them to respect everyone's comfort zone; however, I made sure to ask each care partner to thoroughly discuss the study with the person with dementia prior to the appointment and to get back to me with any questions or concerns. Once an appointment was made, I sent a confirmation letter, including the flyer as well as the consent form, either via regular mail or via email. All letters and emails were addressed to both, the person with dementia and the care partner, and they encouraged the recipients to familiarize themselves with the consent form before the appointment.

Despite all these efforts, it took a surprisingly long time to achieve the goal of a sample size of 25 dyads. Many contacts from the lists I had received were not approached in the first place because it was clear from the list that they did not meet the inclusion criteria. Of those we cold-called, some had changed their mind about participating in studies since joining the list, passed away, separated from their care partners, become too busy with other activities, moved out of state, transitioned into a care home, progressed too much to participate, or, in two lucky instances, had received a different diagnosis and thereby "recovered" from dementia. I was contacted by one interested care partner who was not eligible because she provided care remotely from a

different state, and one identified dyad was excluded after the care partner asked me to conceal the topic of the study from their mother by using a consent form that did not mention the word “dementia.” Due to these recruitment difficulties, I eventually resorted to including participants living outside of the Portland metro area. All recruitment materials (flyer, study information shared via email, screening questions, and confirmation email/letter) are compiled in Appendix B. Appendix C shows a map with the final interview locations.

Sample

The final study sample consisted of 25 individuals living with dementia and their 25 informal care partners for a total of 50 interviews, structured for this analysis as 25 interview dyads. The interview setting was not “dyadic,” however, as all participants were interviewed individually. The stage of dementia varied across the participants. As expected, the most frequently reported diagnosis was Alzheimer’s disease. Other diagnoses included frontotemporal lobar degeneration, Lewy body disease, vascular dementia, and posterior cortical atrophy. The diagnoses reported by those living with dementia and their carers did not always match; in fact, several participants did not identify with having dementia at all or chose to emphasize other health issues (e.g., stroke). Most of the interviewees were White, with the exception of one Asian couple as well as one Asian, one Hispanic, and one multiracial interviewee, all three of whom were married to White partners and living with dementia. The age of the participants with dementia ranged from 54 to 94 (median = 77) and that of their care partners from 45 to

89 (median = 72). Of the 25 people with dementia I interviewed, 13 were men and 12 were women, and the group of care partners consisted of 10 men and 15 women. Of the 25 dyads, 22 were couples, one was a daughter-father dyad, one was a daughter-mother dyad, and one was a sister-sister dyad. All dyads lived together, except for the daughter and father where the father lived in an assisted living arrangement. This dyad had accidentally been included in the study, which I deemed acceptable because the assisted living home was located in the father's old neighborhood, blending in with the residential homes around it. The daughter lived within walking distance and sometimes had her father stay with her for several days. This setting had helped preserve his sense of familiarity with the location and was still shaping his activities the way it had previously. However, he was the only participant in the study who did not live with a family member. Two of the couples I interviewed lived independently in apartments in retirement communities, and the remaining 22 dyads owned their own homes, 19 of which were single-family homes; the remaining three were condos in larger buildings or multiplex settings. Two couples shared their homes with one or two other family members. Of the 17 dyads with combined household incomes who chose to share financial information, one had an annual income below \$20,000, three above \$50,000, six above \$75,000, four above \$100,000, one above \$150,000, and two above \$200,000.

Data Collection

Instruments

To prioritize participants' voices, I conducted semi-structured in-person interviews with each member of the 25 dyads. The interview guide was informed by the previously described Innovations in Dementia study on DFCs in the UK that included the day-to-day experiences of people with dementia (Innovations in Dementia, 2011; Local Government Association, 2012) and the WHO framework of age friendliness (WHO, 2007b).

Data collection started with the phone calls with individuals/dyads who had expressed interest in being interviewed. A sheet with screening questions served to confirm that the eligibility criteria were met. Consent (or assent) was obtained with a consent form signed by each participant on the day of the interview.

The interviews consisted of four sets of questions modeled after a survey used in the UK project (Local Government Association, 2012). The first three sets of questions aimed at collecting information about the participants' current, past, and potential future activities and everyday experiences, including barriers and supporting factors; the fourth set of questions asked more specifically about their thoughts on dementia-friendly communities. For each question, prompts related to age friendliness were used when interviewees had difficulties understanding or responding, but also to explore areas that had not been mentioned yet.

Q1: Please think about your daily activities – what sort of things do you usually do?

[Prompt: Think about the things you do at home/in your neighborhood/in the larger community.]

What helps you to do these things?

What makes it more difficult for you to do these things?

[Prompt: Think about the physical environment/social environment/available services.]

Q2: Are there things that you used to do, but have stopped doing? If so, why have you stopped doing them? *[If desired to resume:]*

What might help you to start doing them again?

[Prompts as above.]

Q3: Are there new things that you would like to be able to do in your community? If so, what? If you haven't started doing these things, what do you feel is stopping you? What might help you to start doing them?

[Prompts as above.]

Q4: Some cities and communities in this country have made a pledge to become more dementia friendly. What, in your opinion, does that mean? If you had a magic wand, what would you do to make your neighborhood, community, or city more dementia friendly?

[Prompt: Show overview of domains of age friendliness, on paper. Ask what resonates with the interviewee, and if they think anything is missing.]

The interview for care partners was identical with that for the participants with dementia, but, for each question, included an additional sub-question:

Q: How do you think *[person with dementia]* would answer this question?

The questions served as my interview guideline and were not shown to the interviewees. I took the liberty to flexibly rephrase questions and prompts as needed, for instance, in response to a participant experiencing difficulties understanding me or

staying on track. In some instances it seemed appropriate to exchange the term “more dementia friendly” with terms like “better places for you” or “better places for older people” to ensure the interviewee identified with the question. To preserve the natural flow of the conversation, the questions were not always asked in the same order, and if a participant provided answers to questions that had not been asked yet, these questions were frequently omitted. As a visual aid for the “domains of age friendliness” prompt for question 4, a diagram showing the domains was presented after the participants had been given the opportunity to answer the question freely, that is, without prompt.

In addition, a one-page questionnaire completed by the participants before or during the interview visit served to assess sociodemographic information including their age, gender, race/ethnicity, highest level of school completed, current/former occupation, annual household income, housing type (renter/owner), type of residence, number of children (if any), and whether they were sharing their home with others.

All interview materials and the consent form are compiled in Appendix D.

Implementation

I conducted the interviews over 16 months in 2018 and 2019. All participants were interviewed at their homes, except for one dyad who was interviewed at OHSU’s Hatfield Research Center during a clinical study visit. One person was interviewed in the courtyard of an assisted living home; all other interviews took place indoors. All dyads but one were interviewed in the same visit; in the one exceptional case, due to

scheduling issues on the part of the care partner, I interviewed the care partner seven months after interviewing the person with dementia.

All visits resembled the following pattern, with small variations depending on the spatial setup: After arriving at the participants' homes, the sessions started in everyone's presence with introductions, an overview of the study, and an explanation of the consent/assent process, which included a thorough review of the consent form with the opportunity to ask questions. All participants with dementia signed their own consent form, but some forms were co-signed by their care partners. After the forms were signed, one participant was asked to retreat to another part of the house and tasked with completing the sociodemographic data sheet while waiting; in many cases, the care partner ended up completing both sheets, one for themselves and one for the person with dementia. I chose to first interview the person with dementia unless either participant, or both, had a strong preference for starting with the care partner. After the first interviewee had settled in a comfortable position, I placed a digital recorder and a backup device (iPhone) between me and the participant, started the recording, and began with the interview. At the end of the first interview, the person who had left the room was called back in, and the first interviewee left. At the end of the second interview, after the recordings were stopped, both partners rejoined for a brief wrap-up conversation during which I either handed out the physical gift cards or collected the participants' email addresses to send the virtual gift cards to.

After each interview session, I documented my reflections about the interview in the form of memos. These memos included thoughts about my reactions to the participants' answers as well as any observations about the situation, the interviewees (including my informal assessment of their cognitive status), and myself that seemed noteworthy but would not appear in the transcription of the interview.

As planned, all participants were interviewed separately, that is, in absence of the other member of the dyad. Two care partners announced during the initial conversation that they needed to be around to serve as "interpreters" while I interviewed their partners, either because the person with dementia had difficulties speaking or because the care partner feared I would not be able to "make sense" of their narratives. Both agreed, however, to let me try without them first, which worked out well in both cases. One care partner interrupted my interview with her husband and attempted to sit in for one of the questions because she was eager to hear his response. With some careful guidance, she agreed to leave and rejoin the conversation after the official end of the interview.

The length of the interviews had been advertised as 60 minutes maximum, and while it was possible to stay within this limit, the actual interview duration ranged between 44 and 99 minutes for participants with dementia and between 49 and 159 minutes for the care partners. Part of the reason for the extended length within the care partner group was that they had to answer the additional questions regarding how they thought their spouse, father, sister, or mother, respectively, had responded. Another

reason was that participants in both groups seemed to welcome the opportunity to share experiences beyond what I was asking, including highly emotional and/or personal content. With each interviewee, I attempted to keep a balance between staying on track with the questions and allowing them to elaborate and digress, spontaneously or intentionally.

Among the participants with dementia, several were further than moderately advanced in the progression of their symptoms. Naturally, this led to changes in the way the questions were asked. During several interviews, it became apparent that the participants did not identify with having dementia, although some of them admitted to experiencing memory problems. To keep them engaged in the conversation, I adapted my language flexibly to match their interpretation of their situation.

Emotional reactions to the interview content were expected and not unfamiliar to me. Several participants in both groups started to cry as they were reflecting on their lives and experiences. Interviewees were given space to go through the emotions at their own pace and to resume the interview when they were ready. No interview had to be terminated prematurely due to emotional distress, fatigue, or any other negative side effect of being interviewed. In fact, several interviewees reported experiencing the conversation as pleasant, as illustrated in the conclusion of my interview with Max (PLWD²):

² In pursuit of a person-centered writing style, I chose not to abbreviate “person/people living with dementia” with “PLWD” or any other acronym in the main text of this document; however, I decided to use “PLWD” and “CP” (care partner) in the context of quotes for the sake of readability.

Max: We had a ball.

Ruth (CP): That's good!

Iris: Thank you for sharing, it was really informative, and I enjoyed listening to you.

Max: I enjoyed it too.

Data Protection and Confidentiality

Any materials containing sensitive data, such as recruitment lists, were shared only through secure cloud-based networks (e.g., Box). All screening sheets and demographic surveys were kept in a locked file cabinet at Portland State University and not viewed by anyone but myself. The original recordings were not shared outside of the CITI-trained “study team,” consisting of myself and the previously mentioned student assistant who helped with recruitment and some of the early transcriptions. I transcribed most recordings myself. Some recordings were transcribed by a professional subscription service. I edited these recordings with audio editing software before submitting them to the transcription service to remove any names, any parts of addresses, or any other protected information as defined by the Office for Civil Rights (2022). To further enhance the protection of the participants with dementia, most interviews transcribed externally were interviews with care partners.

Random pseudonyms for each interviewee were assigned and incorporated at the transcription stage to ensure a high level of confidentiality. To preserve the sense of authenticity of quotes and excerpts, I decided against using impersonal identifiers like numbers; instead, I chose real names common during the era in which the participants

were born using an official database of popular baby names by decade (Social Security Administration, n.d.). One dyad asked to, and did, choose their own pseudonyms.

Data Analysis

As outlined earlier, pragmatism as a research paradigm does not engage in the epistemological debate about the nature of truth and reality in dichotomous terms. From a pragmatist perspective, “reality is not static – it changes at every turn of events” (Kaushik & Walsh, 2019, p. 3). Researchers take up inquiries based on initial beliefs that, through further inquiry (action), are continuously revised and eventually shaped into what Morgan and Nica (2020) called “settled beliefs.” Based on this understanding, the authors introduced the method of “Iterative Thematic Inquiry” (ITI) for the analysis of qualitative research, which aligned very well with my own positioning and the overall design of this study.

Unlike other approaches to analyze qualitative data that put the creation, development, or “emergence” of themes at the end of the analytic process, ITI holds that qualitative inquiry starts with a set of preconceived themes on the part of the scientist. Like initial beliefs, the researcher builds on these preconceived themes through memo writing and data collection, continuously revising and eventually transforming them into final – or rather, temporarily satisfying – themes. Instead of using coding as a method to identify themes, codes are used toward the end of the theme refinement phase to evaluate the last iteration of tentative themes (Morgan & Nica, 2020). Another difference between ITI and other methods is that the production of

themes does not start with the analysis of the collected data; in fact, it starts long before any data are collected, as will be explained in more detail below.

Morgan and Nica (2020) described the iterative process of thematic inquiry in four phases: (1) assessing initial beliefs as themes, (2) building new beliefs through data collection, (3) listing tentative themes, and (4) evaluating themes through coding. The following paragraphs describe how the reflections and activities associated with each phase were applied to this study.

Assessing Initial Beliefs as Themes

This first phase of ITI is focused on the researcher's reflections on their preconceptions about the research questions: "ITI begins by making these potential influences as explicit as possible, so that the repeated, conscious re-examination of potential themes can avoid the trap of simply reproducing an analyst's own preferred answers to the research questions" (Morgan & Nica, 2020, p. 4). In the context of this study, the age- and dementia-friendly community frameworks, complemented by my professional experiences and familiarity with the existing literature on dementia-friendly communities, served as deductive sources for the preconceived themes I brought to the inquiry.

My reflections about the interplay among and integration of the different frameworks and experiences had preceded the planning of this dissertation by several years. For instance, I became involved in the Age-Friendly Portland and Multnomah County initiative in 2013 and, under its umbrella, chaired a "dementia-friendly

communities task team” in 2016-17. Given this background, I already had an iteratively refined set of themes at hand when the idea for this dissertation was born. The “problem” leading me to look further into the topic was my observation that a crucial piece missing from the literature and experiences was the perspective of those living with dementia.

According to Morgan and Nica (2020), the analytic reflexivity of this phase is documented by composing, in writing, the identified preliminary themes “using the same format as the ultimate Results section, and then to revise that starting point through encounters with data” (p. 4). The organization of the age-friendly framework in domains made this a straightforward task. I elaborated on the domains I expected to encounter in the interviews, then added what I anticipated participants would tell me about their challenges and supporting factors within each domain. Memo writing supported this process.

Building New Beliefs Through Contact With the Data

The second ITI phase involves the development and refinement of the preliminary themes through contact with the data. As Morgan and Nica (2020) pointed out, “working with the data is a learning process where analysis happens every time researchers hear or observe something that has an impact on their prior beliefs” (p. 5). In this sense, the analytic process commences with any instance that either reinforces, challenges, or expands the initial set of themes (Morgan & Nica, 2020). In this study, it was during the initial phone calls with potential participants that I started writing

memos about how some of these short conversations related to prior experiences, as exemplified in this reflection on an observation that reinforced my existing beliefs about frustrations common among care partners:

Today I talked to a care partner to confirm her and her husband's participation. Unprompted, she told me that I would have to talk to her first so she could let me know in advance which parts of his narrative I had to take with a grain of salt. Setting the stage like that appeared of immense importance to her. Even after just a few minutes of talking to her, I could tell that her ambition to get the interview on the calendar was fueled by despair about the loss of her partner and a "reality" they had once shared. When we got to making the appointment, I asked what time of the day they would prefer. She said, "Do you want him at his best or at his worst?" And that was by no means a rhetorical question – she was in all earnestness offering, perhaps even hoping, to present her partner's condition to me, at its worst. This is not uncommon and, from my experience, often reflects the care partners wish to have someone – anyone! – witness firsthand what they experience every day. Someone to somehow validate their loss and pain. I carefully explained that I was neither interested in assessing her husband's symptoms nor in determining what was objectively correct. "All I'm interested in are stories," I said, "and therefore I don't want him at his best or worst, but at his most comfortable."

Further encounters with the data leading to updates of my initial set of themes occurred while I conducted the interviews, transcribed the interviews, listened to the recordings transcribed by others, proof-read the transcripts, and read through the transcripts again for coding purposes.

During this phase, as I started conducting and transcribing interviews, I became increasingly concerned with yet another strong link between the pragmatist approach and my study aim to give voice to people with dementia who often are at the center of the discussion but not usually invited to be part of it. I found my study goals reassuringly reflected in the connection between social justice and Dewey's pragmatism as discussed

by Morgan (2014), where “individuals and social communities are able to define the issues that matter most to them and pursue those issues in the ways that are the most meaningful to them” (p. 1050). As Morgan further explained, “inquiry as the revision of beliefs places a central emphasis on the capacity for growth” (Morgan, 2014, p. 1050), which includes the recognition of the limitations of one’s prior knowledge. To maximize this capacity for growth, for instance, I contemplated how to best achieve an equitable treatment of my participants’ narratives. A memo written during the recruitment phase illustrates this deliberation:

As I ponder the best way to collect, prepare, and analyze my data, I find myself trapped by what I think is an unavoidable bias: The tendency to acknowledge the care partner’s version of the truth as closer to a reality matching my own observations and beliefs. My concern is grounded in my past exposures to mismatched stories between people with dementia and their family members. It came into my focus after two recruitment calls with care partners who announced that they were going to give me a “heads-up” prior to the interview about what incorrect information I might receive from their husbands. This makes me wonder: Who should I interview first so I’m not preoccupied with that person’s truth when it comes to engaging with the other? Whose data should I transcribe first, given the order chosen for the interview? And is this about getting a balanced view or more a question of equity, in which case – because of the aforementioned bias – I should always talk to the person with dementia first?

Explained through the pragmatist lens, I was expecting that my prior beliefs would be shaped by the first interviewee’s story, which in turn would influence the way in which I would conduct my inquiry with the second interviewee and how I would integrate their narratives to refine my set of themes. Following the pragmatist rule of thumb that a researcher’s decision should primarily be based on what is most conducive to answering the research questions, I decided that order mattered and should be

actively addressed. Since I expected for the care partners' version to be closer to my own understanding of the situation at hand, I came to the conclusion that interviewing the person with dementia first would be the more equitable approach, ensuring that the "voice" I was hoping to give to those living with dementia would not be drowned out by my own beliefs reinforced by prior exposure to the respective care partner's perspective. I followed the same order when transcribing and coding the interviews.

Listing Tentative Themes

At this third phase, theoretical saturation is reached when no additional observations are made that would yield the writing of additional memos, which typically marks the point at which no additional data needs to be collected. The set of preliminary (now tentative) themes refined in the second stages is turned into a codebook that serves the evaluation of themes in the final phase. Since it is not possible to know beforehand when theoretical saturation will be reached, I had proposed a recruitment goal to include 25 people with dementia and 25 care partners. Fewer interviews would likely have been sufficient to identify relevant themes if the participating people with dementia had been in similar stages of the disease progression. Since the interviewees ranged from "early stage/questionable dementia" to "advanced," however, additional themes and theme refinements continued to unfold, especially among the participants with dementia. In the same vein, I was also able to gain further methodological insights regarding necessary adaptations to my interview strategy and technique based on the interviewees' cognitive status. These

adaptations included, for example, the observation of behavioral patterns during the interactions. In summary, interviewing this number of people with dementia enabled me to include the dimension of symptom severity in the interpretation of the results.

Evaluating Themes Through Coding

The last phase of ITI serves the purpose of systematically evaluating the tentative themes via coding in which “the coding system is inductively generated from the earlier phases, and then deductively applied at this point” (Morgan & Nica, 2020, p. 6). Memos written during this phase typically address whether the codebook accounts for the data, and if not, how the themes and codebook were revised and how the mismatch might be explained. To code the data, I used the Atlas.ti software available through the university.

To illustrate this step, here is an example of a match between the data and one of the codes I had identified for a tentative theme:

Tentative Theme: Transportation & Travel

Code: Adequate, accessible options to get around or travel

Data: Interview quote from Mary (CP):

The one thing that I think that... community-wise, I wish there was more transportation. More public transportation. More easy public transportation. Because to get to the bus, you’ve gotta walk quite a ways to get to the bus. [...] And we haven’t conquered Uber yet. I don’t think there’s any taxis here in town.

Scientific Rigor and Quality Criteria

Evaluations of quantitative research are focused on internal and external validity as measures of scholarly rigor and research quality; however, these measures tend to be less applicable to qualitative studies and paradigms that reject the assumption of one objective reality. Instead, the rigor of qualitative research is commonly assessed in

terms of trustworthiness, established through thoughtful planning, ongoing reflexivity, and diligent documentation on part of the researcher: According to Lincoln and Guba (e.g., Schwandt et al., 2007), trustworthiness can be characterized by how well the researcher can (1) demonstrate that the results reflect what the study was supposed to shed light on (credibility), (2) lay out the research context in sufficient detail for others to determine whether the results might apply to other situations (transferability), (3) provide sufficient information for others to repeat the study (dependability), and (4) ensure that the reported results derive from the collected data rather than the researcher's biased beliefs and assumptions (confirmability). One way to increase credibility is to collect feedback from study participants ("member check") on whether their responses were reflected accurately in the study report. Although this would have been possible with most interviewed care partners, most of the participants with dementia would not have been able to recall the information they had provided. In addition, collecting their feedback would have required extensive preparation and a second visit at their homes. This level of follow-up was not feasible given the scope of this project. However, the detailed descriptions of the study design, procedures, and materials provided in this chapter aim to strengthen the transferability and dependability of this study. Furthermore, the ITI requirement for an early identification of my preliminary beliefs and assumptions as well as the continuous reflective memoing were particularly suited to detect and address potential biases in my interpretations of the data.

Chapter 3: Findings

This chapter is divided into three parts: Part 1 looks at differences in the responses of participants with dementia and their care partners, with a focus on areas of concerns specific for each group and the carers' thoughts about the perspective of the other member of the dyad. Part 2 is dedicated to the development of a DFC framework in relation to the WHO's domains of age friendliness and the question of whether the two frameworks are compatible. Part 3 addresses my experience conducting this study from a methodological point of view.

Part 1: Group Comparison

In the DFC literature, the expression "people affected by dementia" is often used to refer both to those living with Alzheimer's disease or a similar condition and those who support them. Living with dementia and being a carer means having to continuously adjust to cognitive, physical, emotional, and behavioral changes that are associated, in part, with different stages in the disease progression. Consequently, both groups should be at the core of a dementia-friendly initiative, which sets DFCs apart from AFCs where informal carers play only a peripheral role. While I expected to see a fair amount of overlap between the accounts of people with dementia and their care partners, I was interested in shedding light on some group-specific struggles and concerns as well as potential positive experiences.

Respite and Peace of Mind

Before collecting data, I started out with the experience-based assumption that care partners would have much to share about their role in the dyadic care relationship and that many interviewees might be wishing for more (or more appropriate) assistance and occasional breaks from their daily support tasks. Evidently, the reduction of stress and avoidance of negative health outcomes related to the *carer role* are needs specific to care partners. Whether these needs are met, of course, also affects the well-being of the person with dementia: Care partners who feel overwhelmed tend to experience greater distress from psychological and behavioral symptoms of dementia than their less overwhelmed counterparts (Reuben et al., 2022), and those who harbor a “desire to escape the caregiving role” tend to consider placing the person with dementia in professional long-term care settings more readily (Martin et al., 2022, p. 594). I named this preliminary theme “support and respite for informal carers.”

Collecting and reviewing the interview data supported my initial assumption that the need for support for informal carers was indeed an important theme commonly mentioned by care partners. Over the course of the data review, I changed the name of the theme to “respite and peace of mind” and added several aspects that later served to develop the codes that were then applied to the data to evaluate the theme. The final codes used for this theme included: “engaging in own activities,” “respite: taking a break,” “dementia-aware personal companions,” “peace of mind,” and “community-based support offers for informal carers” (see Table 4).

Table 4*Respite and Peace of Mind: Theme Modifications and Final Codes*

Preliminary Theme	Support and respite for informal carers	<ul style="list-style-type: none"> ● Carers can pursue activities of their own ● Carers can take a true break ● Affordable, dementia-aware personal companions are available ● Appropriate, accessible support offers for informal carers and family members are available
Final Theme	Respite and peace of mind	As above
Codebook		<ul style="list-style-type: none"> ● Engaging in own activities ● Respite: Taking a break ● Dementia-aware personal companions ● Peace of mind ● Community-based support offers for informal carers

Without any doubt, informal carers are essential for the well-being of those living with dementia. The degree to which the participants with dementia in this study needed support from others varied greatly with the stage of dementia; however, for those who needed assistance on a daily basis, this assistance was mostly or exclusively provided by the interviewed care partners, all of whom were the primary carers.

Dementia differs from most other “disabling” conditions in that much of the help needed relates to “instrumental activities of daily living,” or “IADLs.” IADLs are activities that involve planning, reasoning, and other cognitive processes, such as preparing meals, using transportation, doing errands, managing financial tasks, etc. The more basic “activities of daily living,” or “ADLs,” such as bathing, walking, or eating, tend to remain intact until the more advanced stages of dementia are reached. In many cases,

care partners gradually take on the majority of domestic tasks while also providing structure, guidance, supervision, transportation, emotional support, and companionship for those living with dementia who become progressively dependent on their carers. Max (PLWD) expressed this as follows: “I think we got the best marriage in the whole place. Pretty positive. [...] If it wasn’t for Ruth, I don’t know what I would do.”

Engaging in Own Activities. For many care partners, the carer role can become an all-consuming full-time job. While they are not living with dementia in a diagnostic sense, their daily lives are greatly affected by the demands that go along with the progressing condition. Most informal supporters, at some point, experience distress and grief and feel emotionally overwhelmed by the unexpected turn their life has taken. In addition, many care partners in this study reported that supporting their family member was a barrier to engaging in activities of their own, as described by three different care partners:

For instance, get the car fixed – how the hell am I supposed to get the car fixed when it takes 3 to 4 hours, and I don’t even know how long it’s going to take?! So I can’t leave her alone while I get the car fixed. I can’t go to a doctor’s office for me unless I have her sit in the waiting room. So I can’t do anything by myself. (Paul, CP)

There are a lot of times I wanna go grocery shopping or out to lunch or maybe to a concert down at PSU [Portland State University], PSU at lunch, or something. But it’s really interesting trying to juggle how to get help to feel a little freer... because it really is a burden, it really is a burden. (Dorothy, CP)

If I had somebody that could stay with him and just talk to him. Actually, I’m a master gardener, but the backyard and the front yard is just gone... because I can’t get out there. I can’t do it because I have to watch out for him constantly. (Bettina, CP)

Respite: Taking a Break. Respite is a term commonly used in the context of caring for a family member. However, the term carries the notion of taking a “breather,” which is desirable, but often far from realistic. If care partners find ways to free up some time away from their support tasks, that time is often filled with errands, housework, or other domestic responsibilities that, due to seeming more urgent, take priority over activities conducive to self-care, including replenishing one’s mental and physical energy by resting. Sally (CP) summarized: “It’s all about self-care. It’s so much taking care of yourself so that you can take care of someone else.” Several care partners reported being concerned about their own health, and two had recently needed surgery which had required creative solutions and external support to manage daily life. In both cases, being forced to have in-home assistance for themselves had spurred the idea of pursuing this option for their partners.

Dementia-Aware Personal Companions. For longer stretches of “alone time,” several care partners had hired a paid helper, either occasionally or on a regular basis, to watch over their spouses while they caught up on domestic duties or other activities. However, hiring paid help is not an option for everyone, the most obvious barrier being the associated expenses. Judy (CP), who had been on a leave of absence from work since her husband had received his diagnosis, stated, “I’m not gonna be able to go back to work because I would have to have someone watch him, and it would be more expensive to have that happen than what I make.”

Apart from the added cost of paid assistance, several factors were brought up in this context that participants described as challenging. For example, familiarity and continuity are essential for building trust in a sensitive care situation, but they cannot always be guaranteed. Brenda (PLWD) reported experiencing anxiety when she learned one day that her usual professional carer was unavailable and had to be substituted with another person. Dementia-specific knowledge and skills as well as being a good fit regarding personality traits were other factors mentioned as important characteristics of a paid carer. As Bettina (CP) reported:

Bettina: Then, if I could really count on somebody... I did one time have somebody here, and they were sitting in here and he was in the other room, and they didn't know what he was doing. And I said, "I can't have that."

Iris: Didn't know what he was doing because they were not...

Bettina: ... they were not aware.

Iris: ... following him around?

Bettina: Yeah. They were not aware that people with Alzheimer's... you better keep track. You've gotta be there.

Iris: You feel they were not experienced.

Bettina: Nuh-uh.

Iris: I see. They were just untrained?

Bettina: Yeah, they were not trained.

In a similar vein, Dorothy (CP), recounting her experiences with various paid and volunteer helpers, pointed out, "You can get these superb caregivers or you can get somebody like I had that needed more... I mean, I ended up taking care of *her!*" Furthermore, Ruth (CP) mentioned a lack of flexibility as a barrier to utilizing professional help more often: "I can hire, we have a service, and you have to use a

minimum of two hours. [...] I could do that. That is available. You have to plan ahead, however; you can't just say, 'I gotta go.'"

Many interviewees could call on other family members for additional support, although many were reluctant to do so on a regular basis due to concerns of burdening others. For instance, several of the participating couples had adult children living nearby who stepped in when the spousal care partners had to engage in other activities. Brenda (PLWD) shared,

We've got a great family of daughters and [...] three of them are really good about taking care. And when Paul has a meeting, one of them usually has plans to come and sit with me or pick me up and we'll go some place. [...] Even if they're mandated to take care of me – which they're not, of course, but they do a wonderful job at that.

In all cases in which informal and formal help had been used, the helpers' tasks did not comprise much more than simply being around, providing companionship, preparing simple snacks, or engaging in pleasant activities or light conversation. Brenda (PLWD) shared about the person her husband had hired to spend time with her on weekday mornings:

Brenda: She sits right where you are sitting all day and reads. 'Cause there's really very little that I need her for. I don't need her to help me bathe, I don't... so at this point...

Iris: ... she's just here, just in case?

Brenda: Yes. If I wanted to take a walk, we'd put our sweaters on and walk around the block. It's working out well.

Similarly, when asked what would help her do some of the things she was interested in doing, Bettina (CP) explained: "Somebody who would be a full-time

caregiver. Somebody who does exactly what I do, and that's basically listen and keep your eyes open." However, some carers also wished for someone other than themselves to accompany their family member to activities outside of the home.

Peace of Mind. As the above examples illustrate, people living with dementia, at least in the early to moderate stages, do not require much, if any, hands-on assistance. As previously pointed out, they can usually perform at a sufficient level with ADLs, albeit reminders, instructions, and/or supervision may be necessary. Significant difficulties usually arise in the context of IADLs that require the capacity to plan and make judgments. In addition, memory loss as well as spatial and/or temporal disorientation can lead to behavioral expressions of anxiety or frustration. Hence, care partners in this study were mostly concerned about being absent and unable to interfere in unexpected situations provoking distress or during moments of forgetfulness or poor judgment on the part of the person with dementia. Examples for such moments brought up by interviewees were ample and ranged from not flushing the toilet or misplacing groceries to accidentally misusing and damaging items or getting upset with small children over a board game. Paul (CP) elaborated:

I was uncomfortable with her being left alone. A couple of events occurred... well, she got really scared, really scared. I was gone, and she got really scared, and she ended up calling her daughter.

Trusting another person to be a substitute can be difficult, especially for carers who consider themselves the only person capable of understanding and adequately responding to the needs and habits of their family member. But not only people can be

helpful in alleviating stress. Sometimes, all it takes for a carer to allow themselves to step away for a moment is a well-designed built environment. Ruth (CP), for instance, did not want to leave her partner alone at home while doing errands, but felt comfortable having him wait for her in a rest area in front of the store:

Now, he's gone [shopping] with me the last couple of weeks. It kind of impedes me a little bit but that's ok. When it's nice I have him just sit outside; there are picnic tables, and he'll have something to drink. But I have him with me and I feel fine about that.

Community-Based Support Offers for Informal Carers. In addition to enabling care partners to free up some time to take a break or engage in necessary, pleasant, or otherwise meaningful activities, communities can support families affected by dementia by offering educational opportunities and ways to socialize, especially with peers going through similar experiences. Several care partners I interviewed were currently involved with formal or informal peer support groups, and others had been involved in the past or were considering joining one. Formal facilitated settings often involve elements of dementia-focused and/or self-care-focused psychoeducation, but the groups also serve a social purpose and often generate close and lasting friendships. Dorothy (CP) described her encounters with fellow carers whom she had met in the context of a painting activity offered by the local Alzheimer's Association but had stopped seeing after her husband discontinued the activity:

So we did socialize, and we did things together. But it always kind of was in the same context of the caregiving. And then we included our partners as often as we could. [...] So we did lots of connecting. I not ever put all that together and realize that for six, seven years I did have... you know, it wasn't just a support

group, it was a social group, too. And that's all gone in my life right now, so yeah, it's lonely without those things.

Preserving Self and Identity

For people living with dementia, I anticipated that the WHO's AFC domain "respect and social inclusion" would be a particularly important topic because it plays a more fundamental role for them than for their carers as people with dementia struggle on a more self-threatening level with the fear of embarrassment and being stigmatized in social situations. Of course, care partners can be directly affected by their partners' exclusion or withdrawal from social interactions, especially if this exclusion or withdrawal prevents them from continuing jointly pursued activities or if they experience stigma by association. This theme will be more thoroughly discussed in Part 2 of this chapter.

Over the course of the data collection phase, I came to reflect on repetitive behavioral and narrative patterns I observed in some interviewees, especially those in the more advanced stages of the disease progression. Although often unable to follow the interview questions, many participants were still highly communicative in that they told me stories instead. These – often repetitive – stories could be related to memorable events, childhood experiences, personal values, relationships, or previous professions and pastime activities. Even though this was not expressed verbally, it seemed apparent that these narrative accounts served as a vehicle to convey and reaffirm a part of the person's identity. As people with dementia start losing memories about themselves, others, and the world around them, their sense of self and identity is

increasingly threatened. Typically, the first memories lost are those of the more recent past, while memories of the distant past (known as “remote memory”) and memories of emotionally meaningful times, events, and relationships have a tendency to remain surprisingly intact. Rehearsing these remaining historic facets of one’s life, skills, values, motivations, and preferences can protect and re-create a person’s sense of self in an otherwise confusing state. I preliminarily called this implicit theme “preserving self and identity in the face of loss.” I later eliminated the second part about loss to practice a more positive use of language. Over the course of the data review, I identified three codes that I was able to confirm as aspects of this theme: “storytelling,” “past interests and activities,” and “values and personality traits” (see Table 5).

Table 5

Preserving Self and Identity: Theme Modifications and Final Codes

Preliminary Theme = Final Theme	Preserving self and identity	Identity is strengthened through: <ul style="list-style-type: none"> • Reference to life stories & life-course perspective • Acknowledgement of past interests and activities • Reaffirmation of values & personality traits
Codebook		<ul style="list-style-type: none"> • Storytelling • Past interests & activities • Values & personality traits

Storytelling. Many participants recounted stories of the past which often included a life-course perspective that explained, for example, the origins of a lifelong passion or the reasons for someone to turn out one way or another. Ed (PLWD) was able to stay on track with the interview for only short moments before reliably defaulting to

a rotating set of stories about his childhood that were narrated with similar wording and always referred to the dichotomous personalities of his parents, describing his father as a strict, Catholic “black-and-white” thinker and his mother as a “gem” or “saint.” Ed shared that he had often opposed his father openly, making him “turn red like a beet” and “going berserk.” The father, in turn, angrily used to call him his “mother’s boy,” which is a meaningful detail regarding Ed’s self concept as he described his mother as a wise and kind woman with subtle ways to teach her kids how to see and interact with the world in differentiated ways. Having been an educator and lifelong advocate for fairness and inclusion himself, Ed’s childhood stories likely served the purpose of drawing a picture of himself and his values by proxy through his mother.

Max (PLWD), who also had difficulties staying engaged with the interview questions, shared a story from his recent past. The story was delivered in a way that made it obvious that he was not telling it for the first time, and he visibly enjoyed developing the story to culminate in his own final remark, portraying himself playfully as a “witty guy,” despite the unpleasant experience of hurting himself in the process:

Max: [Excited] Can we move off of this for just a couple of minutes?

Iris: Of course.

Max: Ok. I’ll tell you about a little story. It was a Sunday and we were going to church. And Ruth said, “We got a new car and you’re not driving it.” And I said, “I’m glad we got a new car, and I don’t care if I don’t drive it” [laughs]. So she took off to find a parking place. I, on the other hand, got out of the car and was walking into the church. [...] I got all three... four steps, and all of a sudden I tripped and I fell, and I landed – smash! – on whatever it was. We have a lady, uhm, what do you call the person in charge in a church? I forgot. Ok, as long as you got the idea. She saw me fall and she rushed over to me, and I was still laying on the ground.

And other people were coming in the church, ok, I had... various people asking if they can help me. "Do you need to go to some place? Is your wife here?" All sorts of things. I raised my head and I saw the minister and I said, "I fell for you!" And the place busted, and everyone went wild.

Past Interests and Activities. Johannes (PLWD), who had a remarkable ability to react swiftly to social cues with a humorous remark, did not have much input regarding the interview questions but did not get tired of telling me about his professional background as a salesman, which he strongly identified with and which he used both literally and metaphorically:

I was in sales all my life, from 14 'til I retired, and even in retirement I'm in sales. I'm selling, I'm selling, I'm selling. So... listen to my answers really carefully because they are sales answers all the time. That's just who I am.

Throughout my visit, Johannes vehemently rejected any mention of dementia and declared that he did not have any problems apart from "getting older." However, at some point he remarked, possibly alluding to the facade he was keeping up, "I'm selling the best Johannes you ever met! You know what I mean?"

Relating to one's former occupation was common among both interviewees with dementia and carers. Like in Johannes' case, those with dementia often identified with their past professional life in current terms, as this comment from Ruth (CP) exemplifies: "He doesn't have any hobbies; except he would say that computers are his hobby because that's what he's done for so long." She also reported that her husband had been talking about making some money on the side doing his former job, although he was no longer capable of doing that work.

As for past activities, Joseph (PLWD) declared that he “used to be a hunter” and repeatedly mentioned this past activity as well as being “proud to be a VFW member” due to his military involvement during World War II. Another participant, Richard (PLWD), shared elaborate stories about riding his bike, which, according to his wife Sally (CP), he had loved in the past but not done in years. Although it seemed obvious that riding his bike was part of Richard’s idea of himself, Sally was struggling to find ways to react to what she saw as an unacceptable deviation from the objective truth:

“Sometimes I feel it is just lying.” She recounted a conversation at the cardiologist’s office where Richard had told the physician that he was riding his bike up to three times a week: “I said, ‘No, that’s not true.’ So, I think he thinks he does. I know he wants to. I know he writes notes to himself all over the place. It says, ‘ride the bike.’” Sally also reported that her husband had not read in a long time, despite constantly wishing for new books. The reason for Richard’s book hoarding became apparent during my interview with him: He had several non-fiction books on different topics piled up next to his armchair that he referred to while we were talking, and each of the books seemed to relate in a unique way to his personal history and interests. In other words, even though he was not reading those books, he used them as a tool to remember and share facets of his identity that he considered meaningful.

Values and Personality Traits. References to personal values and personality traits were also used as markers of continuity in the interviews. Apart from the salesman story, Johannes had two other themes he alternately resorted to: “helping

others” and “doing the right thing,” both of which he wove like a thread through his self- and identity-preserving narrative about his life.

“What Would ... Say?”

In addition to sharing their own perspectives, the participating care partners were asked to provide input, for each question, on how they thought the person with dementia would respond (“How do you think [...] would answer this question?”). This additional question was not meant to “quiz” the carers to test the quality of the dyadic communication or relationship. Rather, I had included it as an explorative element to see if it would yield any further information useful for the development of a conceptual DFC framework.

In reality, I was unable to apply this additional query in a consistent manner and often had to skip it because many interviews, especially with the care partners, exceeded the announced length significantly even without these added reflections. The responses I was able to collect were not scrutinized for a one-to-one matchup with the responses of the other member of the dyad. Due to the open-ended nature of the interviews, there were no “incorrect” responses on the part of the carers: Some interviews with the participants with dementia touched on a wide variety of topics; others somewhat arbitrarily focused on one particular idea in reaction to something I had said or something the interviewee was randomly reminded of as we were talking. In these cases, it would have been impossible to determine if what the care partner assumed to be particularly important for the person with dementia was accurate or not,

as it might have been mentioned had the conversation gone on longer or taken a different turn. In addition, several interviewees with advanced dementia were unable to fully understand the questions or formulate a clear answer, which would have left me with nothing to compare the care partners' assumptions with. As a result, instead of focusing on matches or mismatches as such, I looked for patterns in the content of the responses.

One special kind of "mismatch," for example, was brought up by several carers who made a point of letting me know that they no longer knew what the person with dementia was thinking about or wishing for. Not surprisingly, these were mostly spouses of partners in more advanced stages of dementia where communication about topics meaningful for either partner had become difficult or impossible. An exchange with Dorothy (CP) illustrates her frustration with this lack of communication:

Iris: So the questions that I asked you about the things that you're currently doing, used to do, might wanna do in the future – if you imagine him answering these questions...

Dorothy: That would be interesting!

Iris: ... is there anything that you think he might want to do that he's currently not doing? Or something that he might be missing?

Dorothy: If he tells you any of those, I would sure love to know!

As for "matches," some carers demonstrated great insight into their partners' interests and preferences. George (CP), for example, shared that his wife liked hiking and enjoyed "just being out there, being in that moment. And seeing those environments is just a real pleasure – the flowers, the colors, and just all that's out there

in nature. She's always loved that; she still does." Showing that he was right on point, his wife described her experience in a very similar way. Besides preferred activities, many carers, like Bettina and Ruth (CPs), were well aware of topics and stories commonly recited by their partners:

Bettina: Did he tell you about his color schemes?

Iris: His color schemes?

Bettina: Mm-hm.

Iris: No.

Bettina: Oh, my goodness! It's a wonder he didn't look at you and see whether you were appropriately dressed for this day.

Ruth: He probably told you that he tripped and fell flat on his face.

Iris: Yeah, he told me that.

Ruth: I'm sure he did. It comes entertaining how he thinks of clever comments in a difficult situation [laughs].

While this last quote shows that some interviewees were able to see a purpose behind often-told stories (here: the "entertainment effect"), others grappled with aspects of their partners' repetitive narrative that did not match their sense of truth or reality. As discussed earlier, several carers were quick to point out that what the person with dementia declared to be their current activities were long-abandoned interests pursued at an earlier time in life. The incompatibility of a partner's story with one's own perception of the world can be an utterly devastating and estranging experience, and it can be difficult for those close to a person with dementia to let go of the urge to correct or "repair" the other person's "altered" worldview. Sally (CP) described her own ongoing learning journey as follows:

One thing I developed on my own is the idea that I will listen to him tell a story and determine whether the accuracy of it matters. And if it doesn't matter to anybody that he's telling, I won't change it. If it's something that I determine matters, I will subtly try to correct it.

Shifting one's attention from the actual content of what is being shared to the function it serves in the greater scheme of things (therefore "mattering" in its own right), as discussed in the previous section on identity preservation, may be a helpful exercise for carers uncomfortable supporting "lies." This exercise in accepting another person's reality is commonly known as "validation," a communication method introduced by Naomi Feil in the 1960s that is still encouraged today by organizations such as the Validation Training Institute (<https://vvalidation.org>).

Part 2: Developing a Dementia-Friendly Communities Framework

As outlined in Chapter 2, the analytic process of developing a DFC framework began with the documentation of my initial beliefs in the form of preliminary themes, based on prior experiences and theoretical concepts I had been exposed to or as part of the preparation for this dissertation. Namely, the WHO's eight domains of age friendliness as depicted in Chapter 2, Table 3 (WHO, 2007a,b), enriched with proposed DFC features adapted from the WHO (2007a) and DFA (n.d.), formed the foundation for the iterative theme refinement process (see Tables 6-13) .

As I conducted, transcribed, and reviewed each interview, I reflected on the responses to all four interview questions (barriers and supporting factors reported for past, present, and possible future daily-life activities; ideas regarding DFCs) to determine whether they were aligning with any of the WHO domains used as

preliminary themes, and if so, whether the responses were reflective of the pre-formulated dementia-friendly features. I documented matches as well as any additional topics mentioned in interview-specific memos and decided whether these new topics should be added to the framework as additional themes or features, integrated with the existing ones, or omitted as irrelevant to the research questions. Other memos typical for this phase of the analytic process were concerned with gaining clarity over the conceptualization of the different themes, complicated by their unavoidable overlap:

I'm struggling with the distinction between "participation in meaningful activities" and "respect, inclusion, and spirit of support." In my understanding, they are closely related as the latter feeds into the former. For example, the overlap feels "messy" when it comes to groups, such as faith-based communities. Groups are not activities; they offer or facilitate them. And groups do and are much more than that: They represent a space, perhaps even a home-like entity, something people "belong" to. One can identify through activities, but one cannot belong to them. I hence decided that community groups fit more genuinely under "respect, inclusion, and spirit of support."

After modifying and finalizing the tentative list of themes and features based on data collection and review, I transformed the features, or aspects, of the individual themes into codes. These codes were applied to the data to provide evidence for the tentative framework's validity. During this phase, the interview-specific memos proved helpful in identifying the interviews which had inspired the addition or revision of themes and features.

Since this dissertation was focused not only on people living with dementia but also their care partners, and because the well-being of people with dementia and their carers is inseparably intertwined, the development of the DFC framework was based on

data from both groups. The identification and refinement of themes did not specifically address which theme was mentioned by whom, or who brought it up more frequently.

Public Outdoor and Indoor Spaces

AFC framework: The characteristics of the publicly accessible built environment, including outdoor spaces, play an essential role in the WHO AFC framework. According to the 2007 WHO study, these characteristics include the accessibility, cleanliness, aesthetic appeal, noise level, and safety of outdoor spaces or public buildings.

Accessible and safe green spaces, such as parks, were also identified as features of an age-friendly environment, as were places to rest and adequate public restrooms (WHO, 2007b). Turner and Cannon (2018) summarize: “The accessibility of parks, streets and public buildings significantly impacts the mobility, independence and quality of life of older people” (p. 10).

Initial beliefs: My initial beliefs were grounded in the supposition that most people navigate built community environments – outdoors or indoors – on a daily basis. I further assumed that most appreciate and use parks in one way or another, especially in the Pacific Northwest, where residents of all ages tend to harbor a special liking for being outdoors, “rain or shine.” Consequently, I adopted this domain as a preliminary theme with an emphasis on accessibility, safety, appeal, adequate facilities/amenities, and general ease of navigation and wayfinding.

Summary of modifications: My modifications to this preliminary theme included the rephrasing and regrouping of dementia-friendly features to increase clarity.

Throughout the interviews, when introducing the AFC domains, I noticed that participants often had difficulties understanding what exactly was meant by “outdoor spaces and buildings.” I found that describing the domain as “public outdoor and indoor spaces” was more helpful and consequently decided to rename the theme. I further included the “safe streets” feature as a general safety characteristic of public spaces and added “diversity and intergenerational interactions” and “opportunities to connect with nature” as separate features to underscore their special importance and to allow for the inclusion of nature spaces outside of the urban environment as some of the interviewees enjoyed hiking in the wilderness. As Table 6 shows, “safe, appealing, and easy-to-navigate public spaces,” “diversity and intergenerational interactions,” “connecting with nature,” and “adequate facilities/amenities” were used as final codes.

Table 6

Public Outdoor and Indoor Spaces: Theme Modifications and Final Codes

Preliminary Theme	Outdoor spaces and buildings	<ul style="list-style-type: none"> • Outdoor spaces and buildings are accessible, safe, appealing, and easy to navigate • Outdoor spaces and buildings feature adequate facilities/amenities • Streets are safe and easy to use
Final Theme	Public outdoor and indoor spaces	<ul style="list-style-type: none"> • Public outdoor and indoor spaces are accessible, safe, appealing, and easy to navigate • Public spaces support diversity and intergenerational interactions • Opportunities to connect with nature are available and accessible • Public outdoor and indoor spaces feature adequate facilities/amenities
Codebook		<ul style="list-style-type: none"> • Safe, appealing, and easy-to-navigate public spaces • Diversity and intergenerational interactions • Connecting with nature • Adequate facilities/amenities

Safe, Appealing, and Easy-to-Navigate Public Spaces. Having safely accessible public spaces of personal interest in close proximity was equally appreciated by interviewees with dementia and their care partners. For example, the following quotes show two descriptions of the same outdoor space shared by a participating couple:

We are really fortunate here, you know. Five blocks down, there's a school with a huge park around it, and tennis courts. I think that people in government have heard and make sure that there's a balance in the neighborhoods of things for all people, instead of like it was when I was growing up. (Ed, PLWD)

One of the things I have discovered is that I can get him outside a little bit. He doesn't walk much anymore, and his physical stuff is starting to show the signs. But there's a school with a wonderful park and playground that's just three blocks over here, three short blocks. And then there's a big space, so we can go over there. He really shuffles, so I can't really get any kind of walking or exercise or health benefit walking with him. But if we go over there together, at a snail's pace, then I can kind of keep my eye on him. And he'll either sit down and watch the kids or shuffle around. So that's one way to get some exercise and still be with him. (Dorothy, CP)

Another aspect of public spaces that seems obvious but is not often emphasized is their visual or emotional appeal. When asked what he liked about his neighborhood, Joseph (PLWD), while standing in his small side yard, gestured toward the center of the complex and responded, "The people are friendly. You know, they take care of everything. The outside... anything outside of the building, they take care of it. [...] They take good care of everything, just like a park here." Along the same lines, Andrew (PLWD) mentally interacted with the features of his surroundings through a large window from his living room:

The house across the street, it's got a variety of vegetation. A giant, what the hell is that? It's an evergreen and just a little bit to this way, there are... yeah, this neighborhood has got a lot of green in it.

While the ease of navigation of a public space or building can be considered an aspect of accessibility, spelling it out as an explicit feature of a DFC seemed necessary because people with dementia easily get lost or confused because of memory gaps and difficulties orienting themselves spatially. George (CP) described the increasing difficulties his wife had finding her way around the neighborhood:

I have to be very careful where Becca goes on her own because she now tends to get lost... not lost, but disoriented. She finds her way, she's not like abandoned somewhere, but it becomes problematic when she heads to an appointment, and then suddenly I get a call, and she can't find that office.

Diversity and Intergenerational Interactions. Ed's (PLWD) above-cited statement about the government creating a "balance" by implementing "things for all people" adds an important neighborhood design aspect to this domain. Inclusion, diversity, and intergenerational interaction were topics Ed had, directly or indirectly, reflected on extensively during the interview. Like several other study participants, he was a former teacher and, consistent with his lifelong passion to educate and encourage young people, enjoyed the opportunity to meaningfully interact with children playing in the nearby schoolyard:

I go over to the playground, and I'll see some kids who aren't being called into play and some things. And I'll go and get them involved. And what's interesting is how thankful they are. Especially the girls. [...] I'll say, "What do you wanna be doing?" And they'll say anything from playing with dolls to getting into one of the games that the boys are playing. And my thing will be, "Well, I've been watching them, and there's no doubt that you're as good as a number of those boys out there. Why don't you just come over, and I'll get you in the game?" "Oh, do you think they'll accept me?" "Yeah, I know for sure they're gonna accept you!"

In contrast, a barrier to intergenerational interactions was elaborated on by David (PLWD) who had been an athletic coach for children for several decades. After verbally socializing with a young child at a public pool during a family vacation, his wife and daughter had advised him to refrain from interacting with children he did not know, which had added to David's increasing insecurity regarding the potential inappropriateness of his social behavior as a result of his cognitive changes. Relating the current experience to his former occupation as a coach, he recounted:

But the kids knew me, and if the kids had a family problem or emotionally, you know, needed a hug, I gave a hug. You know. They're cold, I'd give them a hug. I don't care [sniffles]. You know, I gave them a hug. But now it will be hard. But I will be more sensitive in a pool aquatic social interaction to catch the ball, throw it back to the kid. But that'd be it.

Connecting With Nature. While green spaces, such as parks, are encompassed in the outdoor spaces described above, it seemed important to mention the opportunity to connect with nature as a separate feature within this theme. Several study participants commented on the healing qualities of nature that enabled them to forget about their worries for a while. Max (PLWD), reflecting on his difficult childhood, shared:

Max: Oh, when I was young, I used to live outside in the woods. Creeks, fishing, hunting, I was very active in that, that was my own self-help.

Iris: Like therapy, right?

Max: Yes, yes, yes! Interesting things that happen.

Becca (PLWD), an avid hiker, expressed her love for the great outdoors in a similarly powerful way:

I mean, you love it – it's good for the soul. [...] It's hard to wipe a smile off your face the whole time; it's really great. [...] When you're, on a sunny day, in the

wilderness, you can't be mad, you can't be upset, you can't be a grump [laughs]. That's the way I feel. There's no way! It's just too beautiful, oh gosh!

Adequate Facilities/Amenities. Regarding amenities and facilities, the importance of accessible public restrooms was a common topic, mostly as a perceived barrier. Paul (CP), who had enjoyed walking and going to state parks with his wife prior to the progression of her symptoms, noted, "Her intestines are irregular, and she is reluctant to leave the house." Judy (CP), whose husband frequently needed to use the bathroom, was using a phone app to locate the nearest public facilities, which illustrated that in addition to making restrooms available, people also need to know where to find them... quickly. Moreover, Judy pointed out that restrooms in parks were typically closed during the winter months, which was not reflected on the app and a barrier to visiting parks during the facilities' seasonal closures.

Benches to rest on were another supportive feature of outdoor spaces that some interviewees considered worth mentioning. Ruth (CP), for instance, explained:

I love to go hiking. Not strenuous up and down stuff, but I love to be in the woods. He's gone several times; his legs just don't hold out. Even going outside and walking down [the street], he doesn't go very far, and he needs to sit down. So I get him on a bench there, and I go further and come back and pick him up.

Transportation and Travel

AFC framework: Transportation is an area of great importance in the AFC framework. Turner and Cannon (2018) summarized the domain as follows: "Accessible and affordable transportation supports older people to get out and about and stay active and connected, including to community and health services" (p. 10), which

illustrates the interconnection of the different domains. The original WHO study identified a multitude of transportation-related aspects as crucial for an age-friendly community. For public transportation, these aspects included: availability, affordability, reliability, frequency, coverage, the design of vehicles and transport stops, safety, comfort, and courtesy toward older passengers. Further, specialized transportation for older people, including taxis or private as well as community-sponsored options, were mentioned as helpful, along with adequate information about these options. For older drivers, the WHO guide emphasizes the importance of driving conditions (including signage and traffic signals), courtesy toward older drivers, and adequate parking (WHO, 2007b).

Initial beliefs: Living with dementia usually means that, at some point, the person experiencing cognitive symptoms will have to give up driving. Memory-related symptoms can lead to drivers getting lost, confused, and anxious; however, what makes conducting a motorized vehicle a potentially fatal activity for those behind the wheel and other traffic participants is the drivers' diminishing ability to react promptly and adequately in unexpected situations requiring quick judgment. Difficulties with spatial orientation, which is a cardinal symptom of Alzheimer's disease and related pathologies affecting the posterior cortex, can lead to further confusion and dangerous miscalculations, for example, of distances. Based on prior experiences, I knew that turning in one's driver's license can be an emotionally difficult decision because it means losing a part of one's independence. People with dementia who are no longer

able to drive and unable to use public transportation usually rely heavily on family members, friends, or volunteer services to take them where they need to go, or otherwise they have to give up the activities they can no longer reach. I consequently expected that transportation would be an important theme in my interviews, with a focus on the availability and accessibility of public transportation, the importance of friendly and understanding drivers, the availability of specialized alternative options and assistance, and accessible and adequate information on how to get around.

Summary of modifications: During the data collection and review process, I refined the theme by rephrasing and regrouping the preliminary dementia-friendly features and renaming the theme to include “travel” because several participants mentioned the intricacies of air travel, mostly in the context of visiting relatives or friends. The final codes included: “adequate, accessible options to get around or travel” (with accessibility encompassing affordability), “dementia-aware, helpful personnel,” “ample, accessible parking,” and “useful and accessible transportation-related information” (see Table 7).

Table 7

Transportation and Travel: Theme Modifications and Final Codes

<p>Preliminary Theme</p>	<p>Transportation</p>	<ul style="list-style-type: none"> • Transportation is available, accessible, and affordable • Alternative, specialized options exist • Drivers are trained, dementia aware, and friendly • Special supportive assistance along the way is offered • Ample, accessible parking is available • Transportation-related information is available and accessible
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Final Theme	Transportation and travel	<ul style="list-style-type: none"> • Adequate and accessible options to get around are available • Drivers/staff are trained, dementia aware, and able to provide special supportive assistance along the way • Ample, accessible parking is available • Useful and accessible transportation-related information is available
Codebook		<ul style="list-style-type: none"> • Adequate, accessible options to get around or travel • Dementia-aware, helpful personnel • Ample, accessible parking • Useful and accessible transportation-related information

Adequate, Accessible Options to Get Around or Travel. While some of the interviewees with dementia were still driving, many had given up their license as a result of their cognitive changes and/or other health-related reasons. For some, like Lynn (PLWD), the loss of mobility had occurred very suddenly:

And my grandkids, I don't know what I would do without them. I mean, they're just the... I see them, I get to see them... you know, we do stuff with them. It's hard for me though, because it's not like I can just jump in a car and go. I miss that. I miss it so much. And, just one day, you know, boom!

Patricia (PLWD), who – like Lynn – lived in a suburban area and was reluctant to burden her husband with transportation requests, reported:

I always have been very active. Not so much anymore. I can't drive and I can't get any place on my own. And even living here... it's a nice city, but walking to anything is at least a mile for me. So, I don't do much of that. I do some walking, but I don't go as far as I would like.

As anticipated, most interviewees who were no longer driving now relied on family members or friends to take them where they had to be. Connie (CP), for instance, had arranged for her sister to be picked up regularly by different, rotating fellow church

members and taken to a nearby nursing home, where she spent the afternoons with her mother until Connie gave her a ride home on her way back from work.

It should be noted that providing transportation is not always possible for spousal carers, who may be dealing with health problems or age-related changes of their own that pose a barrier to driving. Some participants who resided in centrally located urban neighborhoods, like Ruth (CP) and Dorothy (CP), had successfully used the bus, streetcar, or the light rail (“MAX”) as alternative ways to get around with their partners:

Ruth: We went to a choral concert last week. And we took public transportation. We take the bus and the MAX, as long as I am with him. He would never have figured it out by himself.

Iris: Yeah, it’s hard.

Ruth: But it worked out fine.

Dorothy: Yeah, actually, when we moved in here in the 1970s [...] we didn’t want to have a whole bunch of cars, we wanted to be public transit people. [...]

Iris: Uh-hm, it’s a great system.

Dorothy: Yeah, oh yeah! When I’m walking a little more – and I can do it now with the walker – it’s, for me, probably a 20-minute walk now. But all the MAXes and two other bus lines besides [the one line] that pretty much goes wherever I need.

As for more specialized transportation services, cities often provide special transportation options for older adults and people with disabilities. While these options might generally be more suitable for people with dementia than public trains and buses, they have their limitations regarding coverage, schedule, and organization. Lynn, for example, had once tried to use an on-demand bus service for older adults and people

with disabilities to get home from an appointment. Unfortunately, the driver who was supposed to pick her up at the public bus stop never arrived, leaving Lynn stranded and scared until she was eventually collected by a friend:

It's weird to feel... be there, and you see all these people going in and in... in and out [of the public buses], you know, and you've been sitting in that chair for like, you know, a few hours. I felt... I just... it was just weird. I felt like I was really lost at that point. It was like, "Why can't I get home?" I can't walk. Because it's like... you saw it, we're off the highway.

Dementia-Aware, Helpful Personnel. Public transportation is a wonderful option for those able to use it, either alone or accompanied by others. As Ruth (CP) remarked: "Transportation is a problem if you are alone, but then how many people let their person with dementia go out alone?" While this rhetorical question may be justified for carers of people with moderate- or advanced-stage dementia, people in the early stage may well be able to get around on their own if provided some guidance and/or hands-on assistance. Lynn (PLWD), even after her unpleasant experience with a local on-demand transportation service, was generally interested in taking a commuter bus that was provided for free by a local company, but she was reluctant to try it out:

Lynn: I don't know how to use the bus. I thought I would try to take the bus because it's free.

Iris: Oh, nice!

Lynn: And I thought, "Well, I maybe I should try it." But then, what if I miss it? Then where do I go? [...] I'm afraid I won't get off the right place. And then that's when I get nervous. I was trying to find somebody who would go on the bus with me and try it, because it's free. But I think I would want somebody with me, at least the first time.

In the context of air travel, Brenda (PLWD) told me about a stressful situation involving staff being unresponsive to her condition that had impacted her and her partner's confidence in being able to visit their out-of-state family again:

Paul and I had such a negative [...] experience a couple of years ago. And I'm like, "Well, this is it." And we haven't really gone traveling much since then. It was just kind of a big mess of a plane [...] flight, and we ended up like, "I don't think we can do this anymore." And I don't expect to be able to impact those people necessarily, but I think a lot of them did learn what it can be like. And they would have been, as a result, hopefully, been more supportive. [...] It involved... there was an air flight problem, there was a delay, and one little thing after another piled up, and I was like, [whispers] "Help!"

An even more disturbing travel experience that an empathic flight attendant was able to prevent from turning into a disaster was shared by Marsha (CP):

By the time we got to Spain, we had been traveling for 20 hours. And we took a night flight the last leg, and on the plane he started to say that he was ready to get off. And he was like, 'We're not on the plane; I can see the Broadway Bridge right there.' It was dark, and it freaked me out. He climbed over me, and he headed to the back, and I thought, "Oh, for sure he is going to try to open the door!" And the stewardess was there, and I said, "My husband has dementia and he wants to get off the plane." And so he was like, "She's making me stay on." And luckily, this dear, dear person comes and says [chokes up and starts crying] "Do you want to sit with me?" And so then [continues crying]... I slept a little bit, and then she sat with me for the rest of the flight. So we knew that traveling overseas was going to be done.

Ample, Accessible Parking. For those still driving, parking can be a barrier to making a trip, especially if the person with dementia has difficulties walking because dropping them off at a building may not be a feasible option. Max' (PLWD) fall at the church steps demonstrated this: "Yeah, oh, parking anytime at the church is difficult,"

Ruth (CP) explained. “We have a parking lot, and we own a parking lot across the street, but we have far more people than that.”

Useful, Accessible Transportation-Related Information. Whether existing public or private transportation options are used depends, in part, on how well they are advertised. Lynn (PLWD), for instance, might be more open to using the bus if she had a clearer idea of the schedule and the route showing the different stops.

Housing and Living Environment

AFC framework: As Turner and Cannon (2018) summed up, “the availability of appropriate and affordable housing for different life stages is key to staying safe, healthy and in control as we age” (p. 10). In the WHO’s international AFC study, the participants mentioned the following aspects as crucial: the availability of different affordable housing options; the presence of essential utilities (e.g., electricity, heating, clean water); structurally sound buildings and adequate design (e.g., elevators, railings, age-friendly bathrooms and kitchens); options for modifications and adaptations; the ability to maintain one’s home; access and proximity to services; continued connectedness with family and the community; and adequate, secure living environments (WHO, 2007b).

Initial beliefs: The question of adequate accommodation is important for older adults in general, but especially for people with dementia and their carers since dementia affects a person’s ability to live independently more profoundly than many other health conditions. As many carers I conversed with over the years confirmed,

dementia care at home is a demanding task which may, at some point, no longer be possible. Carers and people with dementia alike often struggle with the decision to leave their familiar environment to move into an assisted living home or similar arrangement, alone or as a couple. Apart from the emotional impact of this decision, high-quality long-term care options may not be affordable. Based on these initial beliefs, I expected to encounter “housing” as a theme, with a focus on affordable options for people at different stages of dementia as well as models for aging in place or alternative housing.

Summary of modifications: Modifications made to this theme over the course of the data collection and review process included the merging and rephrasing of dementia-friendly features and the addition of the “living environment” to the theme’s name, including characteristics conducive to remaining active. As depicted in Table 8, the final codes for the theme were: “adequate and accessible housing options” (with accessibility encompassing affordability), “aging in place,” and “features of the immediate living environment.”

Table 8

Housing and Living Environment: Theme Modifications and Final Codes

<p>Preliminary Theme</p>	<p>Housing</p>	<ul style="list-style-type: none"> • Housing options accommodate different stages of dementia • Affordable options for aging in place exist • Alternative housing models are available
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Final Theme	Housing and living environment	<ul style="list-style-type: none"> • Adequate and accessible housing options exist • Aging in place is supported • The living environment is appealing and accommodates interests and meaningful activities
Codebook		<ul style="list-style-type: none"> • Adequate and accessible housing options • Aging in place • Features of the immediate living environment

Adequate and Accessible Housing Options. “Adequate” housing can refer to many things, including the size of the living space in relation to the residents’ space requirements as well as their ability to keep up with maintenance tasks such as cleaning. In a dementia-friendly context, however, it first and foremost refers to housing options that can accommodate people at different stages of dementia. In the earlier stages, for example, aging-in-place supports can help keep people in their homes for as long as possible. An alternative option several interviewed couples had chosen was to relocate to be near their adult children or other supportive family. Yet another option participants had utilized was to move to a retirement community that offered convenient services and in-house support options, as previous quotes have illustrated.

Several care partners shared their thoughts about the future, most of which included the anticipated necessity of moving to a “facility” at some point. Becca (PLWD) touchingly added the perspective of a person with dementia on this difficult decision: “I think the fear that everyone with dementia has is that somebody is going to put them away some place. [...] I don’t want to go to that place alone [chokes up].”

Other care partners commented on the lack of intermediate options for accommodation for people with advanced dementia or additional health problems.

Laura (CP), whose father had gone through a severe mental health crisis after his initial diagnosis, criticized: “So he had to go to a locked facility. That’s my biggest regret – that he was there and not at home. Because there’s nothing in the middle.”

As for accessibility and affordability, Laura (CP) also had insightful input about the cost of high-quality long-term care:

I had to think a lot, you know, about how much money he has, how long he has to be in a place like this, and whether it’d be better for him to be in a place that’s nicer for as long as he can while he is still really aware of his surroundings and can still interact with people in a meaningful way. And we chose to err on that side, to spend more money initially and then, as his condition changes, he may not be in a facility like this... he may be somewhere different over time.

The most elaborate response I received regarding housing and the lack of “in-between” options was from Dorothy (CP), who had put a lot of thought into non-traditional housing models over the years:

And then I think in terms of living in buildings, I think there could be options for people with dementia and Alzheimer’s. Somewhere between living in your own home and going to a memory care unit. I think we’re really missing the boat when we have no other option except trying to live at home with as much in-home care as you can and then the eight thousand, ten thousand dollar a month walk-in institution that’s really not a very... for all the money you pay, that’s not a life I want for him [voice breaking.] My dream – and of course we’ve lived in community now for so long, I think human beings need community in way more places than we allow it. It’s such a narcissistic nuclear family culture. We don’t have the clans and the tribes that people in other places and spaces and times have. But if we could create... I always looked at these little u-shaped apartment buildings that are mostly condo-ized now and thought, “Oh gosh, if could just buy one of those things with a couple of other buyers and then create multi-generational...” – you know, half a dozen units for oldies, and half a dozen units for young people, and turn one into a dining room kitchen for big groups and

have a unit or two so that when you have to hire a nurse to be there for old people as they start to fall apart. I've been dreaming and scheming on that, but I haven't been able to make it happen. [...] I just think we need some more creative kinds of buildings, spaces for living. They're building all these condos all over, and then, of course, they need all the lower income housing. I want some developers to start thinking creatively about these other needs that are on the schedule, that are on the docket; the numbers are there. And why isn't somebody building a place that's kind of dementia friendly, and a couple of nurse units, and, you know, the Village concept but in real concrete space for living. So it's real, talk about magic wands, but that's been kind of a dream of mine forever. And I think I'm getting too old to create it. I'm sad about that. But all my energy is going to take care of him.

Aging in Place. Housing is not just about having an agreeable place to live; it is also about where that place is located in the context of a person's geographic and social history. Homes and places carry meaning and memories, and they connect people with others through geographic proximity, thereby fostering a sense of belonging. Bettina (CP) expressed her feelings as follows:

Bettina: So, the thing about it is the kids want us out of this house. I just love this house; it was a friend's of ours. And they think it's just too much work, too much da-da-da-da-da, too much to do with the yard work and all kinds of stuff.

Iris: What would they like for you to do?

Bettina: Move into a facility.

Iris: Oh, with him?

Bettina: Mm-hm. I can't. I'm not ready to give up my home. We've been here 14 years, and I just love this house.

Having to leave one's familiar surroundings can be difficult for anyone, but for people with dementia, it may be what sets the seal on losing another important part of their identity. Andrew (PLWD), whose answers to most of my questions were somewhat cryptic and persevering, verbally and behaviorally exhibited a strong sense of place and

relationship with his surroundings throughout the interview. "I don't seek nor do I draw strength from the composition of human beings in the community," he declared in response to the question whether he felt supported by his neighborhood or community. Despite this disinterest in contact with neighbors, he attentively observed and commented on everything he saw happening outside and got up in the middle of a sentence to leave the house and fetch the mail, which upon returning he immediately started sorting. He also pointed to several large trees and informed me about their shared history, "I planted that, I planted that. I planted that." When asked about his "magic wand" wish, he responded in a way that demonstrated that even in the more advanced stages of dementia, place as a personal point of reference is recognized and continues to be meaningful:

And this is very oversimplified, but the two categories of wishes that I am quite satisfied with is where I live. And I am not here to tear this place apart. I am here to save it. And I mean the house, street, the neighborhood, the northern part of Oregon. And I declare myself quite satisfied with that.

Features of the Immediate Living Environment. Another feature related to housing communicated during (and sometimes after) the interviews concerned the characteristics of the immediate living environment. Living environments can be appealing and accommodate interests and meaningful activities. Keith (PLWD), the only participant who was no longer living at home, was very fond of the spacious patio adjacent to his room that had enabled him to nurture his lifelong passion for gardening by growing flowers and vegetables in containers. "I'm lucky because that's the only patio in the whole place," he told me. "So I was lucky that the kids found that because I

don't know that there'd be any other places around that would have that type of opportunity." Likewise, Joseph (PLWD) ended the interview by drawing my attention to the flowers in his yard: "Yeah, I want to look at those [goes outside]. They were much prettier. The other day we got a big rain, but before that it was beautiful." Tree-loving Andrew (PLWD) phrased his appreciation of his immediate surroundings in his own unique way:

And I'm sitting here on a fucking couch looking out through a multi-pane window and seeing all these trees in great relief. There is an evergreen within, with a distance there is two of them. I planted that bugger, and I forgot the name. They're all evergreens.

Participation in Meaningful Activities

AFC framework: The WHO described the "Social Participation" domain in the AFC framework as encompassing social support and opportunities for "participation in leisure, social, cultural and spiritual activities in the community, as well as with the family" (WHO, 2007b, p. 38). Turner and Cannon (2018) added the importance of "allowing older people to continue to learn, stay active and build and maintain relationships throughout life" (p. 10). The participants in the WHO study identified the accessibility, affordability, and variety of opportunities offered as important features of an age-friendly community. Further, it was discussed that older people needed to be (made) aware of activities and events, that special encouragement might be necessary to include those at risk for social isolation, and that intergenerational and multicultural activities were more desirable than activities offered just for older people (WHO,

2007b). It is worth mentioning that the “social participation” domain is the only domain in the WHO’s AFC guide that includes an entire paragraph focused on informal carers:

Caregivers, many of whom are older people themselves, are particularly vulnerable to feeling isolated because their world is so centred on the person for whom they care. Participants suggest more programmes and options whereby older people with disabilities can socialize outside the home without requiring the presence of their caregiver. Provision of day programmes and respite options are suggested as ways of helping older caregivers and their charges to continue to connect with society. (WHO, 2007b, p. 41)

Initial beliefs: As for my preliminary beliefs about the application of this theme to a DFC, I suspected that accessibility, affordability, and variety in opportunities would be mentioned as important by study participants. I further expected that “appropriateness” of the activities offered would be brought up in the context of different stages of the disease progression going along with different demands and that the interviewees would consider well-trained facilitators and the availability of programs designed especially for people with dementia as helpful. I did not include the aspect of social support in my conceptualization of this theme because it was not sufficiently explained in the WHO guide, and it fit better with my understanding of another WHO domain, “respect and social inclusion.”

Summary of modifications: While conducting the first interviews, I encountered discrepancies between the WHO description of the domain and my idea of the theme in relation to my activity-related interview questions. For example, I struggled with the theme’s name after realizing that not all leisure, cultural, or even spiritual activities were necessarily social. For instance, several participants enjoyed reading, walking, or

riding their bikes. In response to this insight, I changed the name of the theme from “social participation” to “participation in meaningful activities.” From a DFC perspective, it could be argued that activities like reading books or listening to music, if performed in a solitary setting, do not involve the community. However, this argument fails to recognize that communities can, and do, provide relevant resources making these activities possible in the first place. One care partner, for instance, regularly received reading materials and audio books through a “bookmobile” that conveniently delivered them to the retirement home as an age-friendly service provided by the public library. Another modification I made was changing the description of the first dementia-friendly feature from activities *being available* (i.e., offered) to people *having access* to activities to account for the fact that participating in activities is not limited to activities offered but also includes activities people are already doing that communities can help them maintain. The final set of codes included: “meaningful and adequate activities,” “dementia-specific activities,” and “trained, dementia-aware staff/facilitators/providers” (see Table 9).

Table 9

Participation in Meaningful Activities: Theme Modifications and Final Codes

Preliminary Theme	Social participation	<ul style="list-style-type: none"> • A variety of activities appropriate for people at different stages of dementia are available, accessible, and affordable • Special offers for people with dementia exist • Activity leaders are trained and dementia aware
Final Theme	Participation in meaningful activities	<ul style="list-style-type: none"> • People at all stages of dementia have access to a variety of meaningful and adequate activities • Special offers for people with dementia exist • Staff/facilitators/providers are trained and dementia aware

Codebook		<ul style="list-style-type: none"> • Meaningful and adequate activities • Dementia-specific activities • Trained, dementia-aware staff/facilitators /providers
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Meaningful and Adequate Activities. “There is no reason why people with dementia [...] can’t be included in whatever,” Ruth (CP) remarked in reflecting on DFC features. “Well, knowing the limitations, but they still could participate.” Remaining active, however, is not a trivial wish for those affected by dementia. For instance, activities performed with others can naturally decrease in older age with the loss of connections due to life transitions (e.g., adult children moving out, retirement, friends or family members passing away). In addition, cognitive and behavioral changes associated with dementia can make it difficult to remain engaged, either because the person with dementia is feeling overwhelmed and/or embarrassed or because the activity partners do not feel comfortable maintaining the relationship. Judy (CP), after observing that several old friends had withdrawn from interacting with her husband David, had come up with sophisticated schedules to arrange for family members and friends to spend time with him so he would not feel like she was “babysitting” him. She justified these efforts as follows:

It’s just that your world becomes so much smaller. You know, you become more isolated, so you have to really be aware of that and generate things to do, you know, for him. Because otherwise I think it gets really small.

In support of Judy’s efforts, family members, friends, and neighbors had been including her husband in yard work and other tasks to keep him connected. Judy (CP)

shared: "I think it feels good to him to be productive and to be giving in some capacity. [...] He's got a very kind heart, and he still has that. That's kind of what brings him joy."

However, due to changes in his ability to make appropriate judgments, David (PLWD) no longer spent time alone with the grandchildren, which was a family agreement he was struggling to accept:

Now you've got all those visions of things that you're gonna do with your grandchildren [...] when you retire. Why, I can't do that unless my daughter comes or my wife is there. Well, that's huge. My eyes get a little watery. And I don't mind sharing, but that's huge. That's an acceptance that's huge. Because you work hard, you raise your kids, you talk about the grandkids. You were a grandchild once.

Another barrier mentioned was the accessibility of activities. As outlined earlier, many people with dementia I interviewed were no longer able to drive or to use public transportation. Although most of them were supported by family members or friends who made themselves available to pick them up either to spend time together or to take them where they needed or wanted to be, asking for rides was a barrier for some as they did not want to inconvenience others. Sally (CP) shared her idea of solving this dilemma: "What I would like to have, if I could have my way, was some service that came and took him to an activity that he would enjoy."

As discussed earlier, care partners often struggled to find time for activities beyond their support tasks and daily duties. If the person with dementia had reached a more advanced stage, the carers' inability to leave them alone often created insurmountable barriers to engaging in social or other activities. Both for people with dementia without transportation and carers without time to spare, it was perceived as

helpful to be offered opportunities to engage in activities without having to travel. Ruth (CP), who had recently moved into an independent living setting with her husband Max, emphasized this as follows:

Iris: So, I hear that one thing that makes things easier for you is that, if [the activities] are in-house, he can be around?

Ruth: Yes, yes! He's around. And I always tell him where I am going to be. You know, one meeting I go to is usually in the same room. And he knows that he can come and get me if he needs me.

Max (PLWD) echoed Ruth's excitement about the accessibility of in-house services and activities:

Max: Yeah, we belong to a... like a club where we go work out three times a week, sometimes four, and I enjoy doing that. And of course you meet people, and you laugh together.

Iris: Is it in the building here?

Max: Yep.

Iris: It's all in one place. Is there anything that you do in the city sometimes?

Max: [Whispers] No, we stay *right here!*

In addition to difficulties engaging in social interactions, previously enjoyed solo activities often become more difficult as the cognitive symptoms experienced by the people with dementia become more severe. Becca (PLWD) explained how her own expectations regarding her performance had been part of the struggle:

It's interesting, because I read all the time, that sometimes I forget what I read. But I decided that I wasn't [going to] let that bother me, that it was important to be in the moment. For as long as I was in the moment and enjoying things, it didn't matter – it doesn't matter if I can remember it.

Adaptations can help people with cognitive difficulties remain engaged in a preferred activity, or simplified versions of it. To stay with the example of reading, Brenda (PLWD) noted that her reading speed and habits had changed due to her cognitive changes, but that her daughter had been able to “get books that are large print and easy to read. And so the book hasn’t changed except it looks kinda clunky, but it’s something for me to feel more comfortable about.”

Another barrier to staying active frequently mentioned by care partners was that the person with dementia was getting tired easily. “She has a very low level of energy, so she can only do one thing a day,” Paul told me about his wife. “She’ll be out of gas like a balloon.” The experience of sudden or general fatigue was also a reason for carers to change previous habits to accommodate for the additional time needed for the person with dementia to get ready to leave the house. “Even just the day hiking is more challenging because of the Alzheimer’s,” George (CP) explained, “and the amount of time it takes to organize for a simple trip has exponentially increased.”

Dementia-Specific Activities. In addition to enabling people to continue what they were already doing, social, leisure, and cultural activities especially designed for people with dementia can be helpful in creating a safe space to participate without embarrassment. Becca (PLWD) had observed a lack of “dedicated” offers for people with dementia when it came to participating in “normal” activities such as bike riding or knitting. She further wondered how she could learn about other people with dementia who shared a similar professional background to exchange thoughts with. Activities

offered by the local Alzheimer's Association or other local organizations, including a painting program, an opportunity to attend interactive sessions at a local art museum, and a music experience involving symphony musicians were mentioned by some participants who had participated and liked them. On the flip side of the coin, several interviewees in the early stage reported having attended a "dementia group" where they felt out of place and emotionally affected by the more advanced stages of the other participants.

Trained, Dementia-Aware Staff, Facilitators, and Providers. It goes without saying that facilitators of programs open to attendees with dementia should be trained and dementia aware. This may be easy to realize for dementia-specific offerings; however, it also applies to any place where activities are performed, such as restaurants, libraries, stores, etc. Theresa (CP), for instance, reported that her husband had been banned from his gym after making comments to staff members that they had perceived as inappropriate despite his never having approached other gym users. Brenda (PLWD) reflected on her own and other people's abilities to resume past activities, such as singing in a choir, stating:

And I think that sometimes depends on the expertise of the people who direct those services, and they say, "Oh sure, come!" And nobody pays any attention and doesn't give you a book or there is something you can't read, and I can understand why... that people do drop out of things.

Respect, Inclusion, and Spirit of Support

AFC framework: The domain of respect and social inclusion in the AFC framework is concerned with "creating places where older people are respected,

recognised and included in the community and family life” (Turner & Cannon, 2018, p. 10). According to the WHO study, AFCs provide respectful and inclusive services (including options for economically disadvantaged people), public education campaigns to change negative public images of old age and aging, opportunities for intergenerational and family interactions, and the inclusion of older adults in community development activities (WHO, 2007b).

Initial beliefs: As discussed in Chapter 1, stigma and negative attitudes toward dementia and people who live with it are, unfortunately, a common experience. I adopted the domain as a preliminary theme for the DFC framework and included the provision of safe, inclusive, and supportive environments, community efforts to raise awareness and reduce stigma, and the inclusion of people with dementia (especially in discussions about dementia) as preliminary features.

Summary of modifications: As expected, aspects of respect and social inclusion were mentioned frequently in the study, especially by those living with dementia. While collecting and interacting with the data, I decided to include “spirit of support” – a term used by DFA (n.d.) – in the name of the theme to emphasize both the need for additional assistance on the part of the people with dementia and the need for others to not only be willing, but proactively offering to provide it. I further observed that many participants were affiliated with long-standing “communities within communities,” such as faith-based groups, which were described as inclusive and particularly suited to foster a culture of care and support. This observation led me to add the aspect of “cohesion”

as a feature of dementia-friendly environments. As final codes, I used “safe, inclusive, cohesive, and supportive environments,” “awareness and stigma reduction,” and “all voices are included” (see Table 10).

Table 10

Respect, Inclusion, and Spirit of Support: Theme Modifications and Final Codes

Preliminary Theme	Respect and social inclusion	<ul style="list-style-type: none"> • Communities provide safe and inclusive environments with a “spirit of support” • The community engages in efforts to raise awareness and reduce stigma • The voice of people with dementia is recognized and heard
Final Theme	Respect, inclusion, and spirit of support	<ul style="list-style-type: none"> • Communities provide socially cohesive environments where people of all abilities feel safe, respected, included, and supported • The community engages in efforts to raise awareness and reduce stigma • The voice of people with dementia is recognized and heard
Codebook		<ul style="list-style-type: none"> • Safe, inclusive, cohesive, and supportive environments • Awareness and stigma reduction • All voices are included

Safe, Inclusive, Cohesive, and Supportive Environments. Fostering awareness and respect is an essential aspect of both AFCs and DFCs, but they can only gain traction and be fruitfully implemented if community members are open to learning and caring about each other. As is known from the literature on dementia-related stigma, negative attitudes and lack of knowledge about dementia are more common among those who have little contact with people who are affected by it. The more socially connected community members are as neighbors or colleagues or through faith- or interest-based groups, the higher the chances that they will befriend a person with dementia and/or a

member of their family and hence develop a genuine stake in understanding their situation and perspective.

Many comments from interviewees pointed toward the importance of social cohesion within communities and confirmed the need for the above-mentioned spirit of support. Paul (CP), for example, was actively involved as a volunteer with his neighborhood association and emphasized that DFCs, and communities in general, should “promote neighborliness” – a feature he was missing after moving away from his hometown to be closer to family:

That town was small, and I knew everyone. And that is not here. Not... zero. If this town [...], or this neighborhood [...], is any indicator of what it's like in urban America... I lived in what I call a true neighborhood community – and this is dysfunctional. I mean totally, totally. Because I believe that human connection is the essence of the human experience. And that ain't what I am experiencing. [...] Everyone here is more concerned about privacy and not knowing people. Give you an example: The guy who lived next door [...] didn't even say hi to me. And they lived there for three years before they moved out to the other house. One day, I was down on my hands and knees, right down by that shrub down there at the end of my driveway, clipping the edge of the grass of the sidewalk. And he was mowing his grass, and he came within like five feet of me with his lawnmower. And I looked up and tried to get eye contact with him to say hi. And he wouldn't, or he didn't. He just cut his grass. To me that exemplifies urban-ness. Guy is five feet from me, lives next door to me for three years and doesn't say hi. And I'm just not used to that. I came from the opposite extreme where I knew everyone on my block, I had their kids in school – it's just connections, connections. So I knew when people got sick, I knew when people lost their jobs, I knew when people had achievements. And you don't know that in the city. I realized now that the city exists for anonymity. They say for freedom, but it's anonymity, more importantly than freedom, I believe. But that is just my bias from my life experience of 40 years. And my prejudice is that I think human connectedness and the satisfaction of psychological needs is so much more important than stuff, toys, making money. But that's just my wisdom that I've gathered after 70-some years.

In age- and dementia-friendly initiatives, communities are often understood as geographically determined entities – much like neighborhoods, but on a larger scale. Other types of communities are formed around a shared belief, mission, or interest. Being part of a cohesive community can foster a sense of belonging and culture of support, as Brenda (PLWD) aptly described when reflecting about communities in general:

It was just a sense of being willing to make a commitment to support... not necessarily financially, but to support someone that needs assistance and to really be there. [...] You just sometimes forget that it's really simple to be helping someone... and sometimes it isn't. And that's where you really do need to have all kinds of people who are connected together doing this thing.

Many participants in this study were part of faith-based groups that served multiple functions. For many, going to church was an opportunity for social interactions and the formation of lasting relationships. As Joseph (PLWD) shared, "I'm involved in church. I have a lot of friends there, enjoy... with them." In several cases, fellow church members were providing hands-on support to keep the person with dementia involved in community life, such as taking turns giving them a ride to relevant activities. Because of the long-standing connections they foster between people who often reside in close geographic proximity, church communities were also described as familiar environments in which people with dementia felt safe and included. Ruth (CP) reflected on her introverted husband's reluctance to get connected with others at their retirement home: "He's not been really great at talking to people, picking up on cues, and asking questions." She then added:

He thinks that he impedes my being able to get out and do things. “Why am I living? I hate the fact that this has happened to me,” and this kind of talk, which takes a little help to talk him out of those feelings, the depression. So, getting out with people is good. People at church are friendly with him, of course. No problem there.

Another community-based group that was mentioned repeatedly was the local branch of the national Village movement. Graham et al. (2017) summarized:

Villages are a relatively new, consumer-directed model that brings together older adults in a neighborhood or community who have a mutual interest in aging in place. These membership organizations provide social and civic engagement opportunities, volunteer provided support services, and referral to vetted community providers to achieve their primary goals of promoting independence and preventing undesired relocations. (p. 335)

One dyad had been involved loosely with one of the local Villages, and several others had recently learned about the movement and considered joining. Brenda (PLWD), even though she was neither able to provide volunteer services nor eligible to become a Village member due to her cognitive condition, had participated with her husband in monthly social gatherings at local restaurants and perceived these encounters as a friendly and welcoming:

I can really say I have just encountered really wonderful people in the community. There is an organization [...] they are very wonderful in making an effort to include that we are getting invitations and the right to be involved if we want to. [...] The group is always clearly very open to and positive about my being there and participating if I can. [...] It's really helpful, I think, to get you more involved. But at the same time, it's sometimes really hard to get involved because you don't feel as well as you were used to feeling, and things like that can get in the way.

Awareness and Stigma Reduction. For a community or neighborhood to provide a truly inclusive and supportive environment for people of all ages and abilities, in

addition to increasing social cohesion, it is important to foster awareness, understanding, and respect. For Becca (PLWD), this applied to her existing friendships, too:

I do think that there is not enough awareness of what it means to lose your memory. That you can be with people who don't shun you. I do wonder from time to time, "Are they not calling me because it's hard to be with me because I repeat myself?" You know, that kind of thing. And I can't even answer that question for myself. I think people get scared about something that they can't really know how it feels, they can't really know how to fix it; they don't wanna hurt anybody's feelings. There just isn't enough awareness that this happens.

David (PLWD) was tormented by great concerns about losing his sense of social boundaries, partly because his wife had asked him repeatedly to refrain from inconveniencing neighbors and other people with extended conversations. When prompted to reflect on the meaning of DFCs, he accordingly responded:

I think that we – Alzheimer's – have to let go of our self-control. So my insightfulness would be as at, we have to be cognitive of the boundaries that need to get put on us. So my advice to you is, or my question for you is: How do we put boundaries on the public that don't insult the dementia, but serve them so that they know when to cut me off? I don't mind you telling me that you're really busy, and, "I'd like to talk more and I call you," or, "I'm really busy and I've enjoyed this, but I need to go." Something neutral in a friendly way that lets me know.

Even more poignantly, David shared his growing fear of strangers perceiving his genuine friendliness toward children as inappropriate. "With a child," the former elementary school teacher explained, "I can get down to their level quickly, in a safe, humorous, silly way. I can do that. I think I'm a natural for that." However, the previously mentioned situation where he had socialized with an unknown child at a

public pool had led to conversations with his wife and consequent pondering. He concluded, “It’s very difficult for me who is a helping, gentle, kind adult. [...] I can’t give what naturally just was easy to just... to give naturally.”

All Voices are Included. It should go without saying that people living with dementia can and should play a critical role in educational efforts to increase awareness and understanding, yet the lack of awareness and understanding might just be the barrier preventing their involvement. While the stigma around dementia might suggest that people living with it are no longer able to express their fears and hopes, the opposite appears to be the case. For instance, when asked for her “magic wand” wish, Becca (PLWD) responded: “Compassion and understanding. Accepting you as you are as opposed to what you used to be or what ‘normal’ people are like.”

Several interviewees who were living with dementia explicitly voiced a desire to share their experiences with others as advocates for themselves and other people living with Alzheimer’s or a related condition. It may not be surprising that those most interested in informing others had a professional background in education, advocacy, or communication. Brenda (PLWD), who admitted that she was not sure what her diagnosis meant, described her condition as a “disability” instead. This was likely due to her previously working in disability services, which might also have been the reason for the strong sense of advocacy she demonstrated throughout the interview:

I guess one thing that could be helpful would be, I guess, being willing... I could be willing to share my experiences and my feelings and things like that that could be helpful to people with disabilities. [...] If you don’t [communicate], I mean... a few people will learn, but if you can learn how to share it without being a

grouch... but I never feel that way, I think it's just maybe that I have a sense of knowing that it will occur. We just have to keep working, to let people know.

Participants with dementia as well as carers also expressed interest in spreading the word about DFCs and my project, and the diagram showing the WHO's age-friendly domains I used as a prompt enjoyed an unexpected popularity as several interviewees asked if they could keep it. Elaine (PLWD), for example, found it "suitable for framing" while others, like David (PLWD), were excited to use it as a dementia-friendly assessment tool:

You're gonna give me that? [...] Because now I will go around, being an educator, with a little bit more insightful eye [...] and if there's something that, "Oh, it would have been better if..." and I will try and jot it down or put it on where it says "notes."

Civic Engagement and Employment

AFC framework: Turner and Cannon (2018) summarized the WHO's "civic engagement and employment" domain as "ensuring opportunities to continue to contribute to their communities through paid work or volunteering and to be engaged in the political process" (p. 10). Age-friendly aspects related to this domain that were identified in the WHO study included the availability of options for employment, entrepreneurship, volunteering, and civic engagement for older adults; the provision of training (e.g., to use new technologies); accessibility (including transportation); the appreciation of older adults' contributions; and adequate compensation (WHO, 2007b).

Initial beliefs: Since the usual age of onset of dementia is past the age when older adults typically retire, the question of *continued* employment may not be as

relevant for people with dementia as it is for older adults in general. However, times are changing, with many older adults continuing to work past retirement age, and early-onset forms of dementia are not uncommon. Volunteering often plays a large role in older people’s lives, and civic engagement of those living with dementia is a cornerstone of DFC initiatives. Hence, I included the WHO domain as a preliminary theme with an emphasis on volunteer opportunities, continued involvement at work, and the involvement of people with dementia in political decision making.

Summary of modifications: The main modification to this theme was to add carer support as an important feature related to employment. In a dementia-friendly work environment, care partners should be able, for example, to flexibly take time off, if needed, to engage in activities related to caring for their family member that could not be pursued within the boundaries of their regular work schedule. “Dementia-friendly work environments,” “dementia-friendly volunteer opportunities,” and “opportunities for political engagement” were the final codes used to evaluate the final theme and features (see Table 11).

Table 11

Civic Engagement and Employment: Theme Modifications and Final Codes

<p>Preliminary Theme</p>	<p>Civic engagement and employment</p>	<ul style="list-style-type: none"> • Employers and work environments offer opportunities for continued involvement • A variety of meaningful dementia-friendly volunteer options exist • People with dementia are involved in political decisions (e.g., about DFCs)
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Final Theme	Civic engagement and employment	<ul style="list-style-type: none"> • Employers and work environments support carers and offer opportunities for continued involvement for people with dementia • A variety of meaningful dementia-friendly volunteer opportunities exist • People with dementia are involved in political decisions (e.g., about DFCs)
Codebook		<ul style="list-style-type: none"> • Dementia-friendly work environments • Dementia-friendly volunteer opportunities • Opportunities for political engagement

Dementia-Friendly Work Environments. A few interviewees in this study had early-onset dementia and were still working when they received the initial diagnosis and their physician’s advice to retire. Elaine (PLWD) had experienced difficulties at her job prior to her diagnosis and felt relief over not having to deal with work-related stress anymore:

I do remember when I was starting to screw up on things, and if it wasn’t for my colleague who cleaned up my mess [...] I’m sure I would have been fired or something. I mean, [...] it was getting bad. I sort of do miss that, but I don’t love the pressure. I’m so glad to not have the pressure of it all, of expectations that affect so many other people.

Leaving one’s job because of a dementia diagnosis can happen unexpectedly and abruptly, for both the person with dementia and their care partner. David (PLWD), for instance, was told by his physician to discontinue working after learning about the concerning results of his clinical tests. He consequently retired early but struggled with the sudden loss of his employment although he acknowledged having become a “liability” due to his cognitive changes. Similarly, David’s wife Judy (CP) decided to take

an extended leave of absence from her job to be around for her husband. She shared, “I think just adjusting to that piece in itself is a big thing. I’ve never not worked.”

As for work environments supportive of care partners, Marsha (CP), whose husband – like Elaine and David – had been diagnosed with early-onset dementia, was able to adjust her work hours to attend a carer support group:

So my work schedule is changing that I could go to a once-a-month group that is for all stages right here [...]. So I’ll be able to start doing that because they changed my work schedule to reduce the time.

Dementia-Friendly Volunteer Opportunities. Many of the study participants were volunteering in some way or another, even though many talked about the barriers that living with dementia created for continued involvement. For the care partners, of course, the previously discussed time constraints and the inability to step away from their support tasks were the main reasons to postpone or discontinue their volunteer engagement.

For the interviewees with dementia, transportation was mentioned as both a supporting factor and a barrier. Elaine (PLWD), as mentioned before, was spending her afternoons with her mother in a long-term care setting where she had become friends with residents and staff and been encouraged to read to the residents:

One of the people who manages that [place] wants me to read, read to the seniors. Because they were gathering around in their wheelchairs when I was sitting in this one corner. And that’s one thing I’ll be doing. Mom read to us our whole life! They’re all like honing in.

Elaine clearly enjoyed this volunteer task but would not have been able to take it on if it had not been for the volunteer transportation her sister had arranged for her through their church group. Patricia (PLWD), who had volunteered as an usher at a theater for decades, had abandoned this activity after giving up her driving license.

I really enjoyed that. I ushered at the [...] big theaters downtown, you know, the live theaters. And I really enjoyed that, and I can't really do that because I can't drive. [...] Well, I could get there, but my husband would have to drive me into [the city] and then come and get me. And that would really be a burden on him so I just stopped doing it. You know, I don't want to make him... he would do it if I asked him to, but it's too much trouble to have him drive into [the city], come back home and wait for me, and go back down there in three or four hours, that's ridiculous. So, I'm just not doing it anymore.

Apart from logistical barriers, several interviewees with dementia talked about concerns related to their ability to perform at a sufficient level. Becca (PLWD) shared:

I was invited to join a board. And what I realized after I left that meeting... and this friend of mine who invited me wanted me to be on the board... and she was very upset when we left this meeting because I might have repeated myself a couple of times. But I thought, "I can't do boards anymore." Because there's too much memory stuff involved in it.

In a more fortunate instance, David (PLWD), after retiring from his beloved teaching and coaching job, had been able to find some fulfillment in a similar occupation where he could apply his long-standing experience and knowledge as a volunteer supervised by his wife or others. His example shows how volunteering can become a suitable replacement for a professional activity a person with dementia can no longer maintain, but that additional supports may need to be in place to make it a safe and enjoyable experience.

Opportunities for Political Engagement. While political involvement was not explicitly mentioned, this DFC feature ties in with the “all voices are included” feature discussed as an aspect of “respect, inclusion, and spirit of support.” People living with dementia and their carers can and should be granted opportunities to advocate for themselves and others, especially when it comes to designing DFCs, and the willingness of all interviewees to participate in this study to share their stories and perspectives should suffice as testimony for their ability and openness to participate in the greater DFC discussion.

Communication and Information

AFC framework: According to the WHO, in an AFC, different types of general news media or specialized information outlets help older adults stay in touch with what is happening in their communities. This domain of age friendliness is “supporting older people to stay connected with events and people and have ready access to relevant information in a variety of forms” (Turner & Cannon, 2018, p. 11). Features of age-friendly communication and information that were mentioned in the WHO study included the availability and targeted dissemination of information; the availability of printed, electronic, automated, and personal oral communication; and the use of plain language and clear instructions (WHO, 2007b).

Initial beliefs: Staying informed and connected is important for all community members; however, I knew from participants in carer support groups that I facilitated in the past that people with dementia and their care partners are often overwhelmed by

the demands of their daily lives and lack the capacity to proactively seek out information. I adopted the domain as a preliminary theme with features relating to the availability and accessibility of information and to dementia-friendly aspects of its delivery.

Summary of modifications: “Communication and information” was the only WHO domain I did not modify. The final codes were “accessible information about services, activities, and other relevant topics” and “dementia-friendly dissemination of information” (see Table 12).

Table 12

Communication and Information: Theme Modifications and Final Codes

Preliminary Theme = Final Theme	Communication & information	<ul style="list-style-type: none"> • Information about community services and activities is available and accessible • Proactive outreach strategies exist for people with dementia and their families • The design of materials is age and dementia friendly
Codebook		<ul style="list-style-type: none"> • Accessible information about services, activities, and other relevant topics • Dementia-friendly dissemination of information

Accessible Information About Services, Activities, and Other Relevant Topics.

Similar to transportation and respect, communication and information is a theme inseparably interrelated with all other themes: Activities, services, transportation and housing options, opportunities for civic engagement, awareness trainings, etc. can be available and thoughtfully designed, but they need to be adequately advertised to be found and used. Several study participants reported that they were unaware of

available services or activities because they had not actively looked for them (yet). “I’m not sure what’s out there,” Becca (PLWD) told me. “And I’m not sure if need it yet.” After voicing a wish for more community-based activities for her husband, Ruth (CP) admitted that these activities might exist at local community or senior centers without her knowing about them: “I wouldn’t be surprised. I don’t know for a fact if they have something like that.”

Another aspect of communication and information in the context of a DFC is its role in informing families affected by dementia about the underlying disease as well as resources available to live with it. Many care partners were gathering their knowledge about dementia at educational events, through the Internet, or from the peer support groups for carers they were physically or virtually attending. Ironically, for people who have dementia, these opportunities for education and peer exchange are much harder to come by, as Lorraine (PLWD) pointed out: “I’m trying to find if there was anything for people who had a support group for the people who had a cognitive impairment, and there is nothing like that.” Along the same lines, Brenda (PLWD) was relying on her previous profession in disability services to construct her understanding of what she was experiencing:

I don’t even know, really, what dementia means. It’s used totally a lot and but it’s sorta like, what does that really entail? [...] But what did help me was that I worked in the field. [...] All of a sudden it’s like, “Oh, I think this seems familiar to me, what is it?” But that was because of my orientation and interest. I’m sure it’s difficult for people who have never had anything, don’t know anything about it.

Dementia-Friendly Dissemination of Information. The previous examples illustrate that getting information to those who need it most must take a more proactive approach, including special dementia-friendly outreach strategies. What makes the endeavor of knowledge distribution even more complicated is the fact that dementia as a syndrome is a moving target. What is important to know at one stage might be either insufficient or overwhelming for people at different stages. In a conversation with Peter (CP), we talked about possible in-home visits to provide stage-appropriate information about dementia and available community resources, which Peter thought would be very helpful.

Dementia-friendly dissemination does not only refer to delivery strategies and the content of the information but also to the design of the information shared, verbally or in writing. This includes using language appropriate for different levels of cognitive functioning as well as font size considerations to account for age-related changes. As David (PLWD) stated, “The first thing with old age is going to be vision. And vision is going to be the font – the font of public access to things.”

Community-Based Support and Health Services

AFC framework: No one will argue with Turner and Cannon (2018) that “having access to health and support services that are affordable, of good quality and appropriate is vital for older people to maintain health and independence in the community” (p. 11). Health and support services are essential for the well-being of older adults and help them remain as active as possible for as long as possible, thereby

facilitating aging in place. Participants in the WHO study identified the accessibility of health services as an area of concern, which included not only geographical barriers, but also economic barriers, insufficient advertisement of available services, and perceived negative attitudes toward older patients among health care professionals, aggravated by poor communication and an atmosphere of disrespect. Making available a wider range of health services and equipment, putting a stronger focus on health promotion, providing more in-home care services, and offering better solutions for those no longer able to live in their home were brought up as suggestions. The study participants further wished for better and more carefully coordinated community-based services of various types, for more volunteers available to fill service gaps, and for more appropriate emergency preparedness plans (WHO, 2007b).

Initial beliefs: As the previous paragraph illustrates, most services mentioned in the WHO study in the context of this domain were closely related to health care services. Dementia being a clinical syndrome, appropriate health care can be considered one of the most obvious components of a DFC framework. Community-based support services, however, are equally important as they can provide much-needed assistance on a regular basis. I hence included this domain in the preliminary theme structure of the DFC framework. In accordance with the AFC framework, I supposed that from the perspective of those affected by dementia, a variety of adequate and accessible community support and health services should be available, that the providers of these services should be trained and dementia aware, and that people with dementia should

be included in community-based emergency preparedness planning. To avoid overlap with “participation in meaningful activities,” community support services associated with this theme do not include community offerings of “leisure, social and cultural activities.” This distinction, of course, is not always straightforward, as seen in the example of support groups that are both health focused and social.

Summary of modifications: For further clarification, I changed the name of the theme from “community support” to “community-based support” to avoid the misconception that the services only referred to government-sponsored support. I further rephrased the emergency preparedness feature to emphasize that emergency preparedness planning should include dementia-specific elements. As shown in Table 13, the final codes for this theme were “adequate and accessible support and health services,” “trained, dementia-aware providers,” and “dementia-aware emergency preparedness.”

Table 13:

Community-Based Support and Health Services: Theme Modifications and Final Codes

Preliminary Theme	Community support and health services	<ul style="list-style-type: none"> • A variety of adequate and accessible community support and health services are available • Service and health care providers are trained and dementia aware • People with dementia are included in emergency preparedness planning
Final Theme	Community-based support and health services	<ul style="list-style-type: none"> • A variety of adequate and accessible community support and health services are available • Service and health care providers are trained and dementia aware • Emergency preparedness planning includes dementia-specific elements

Codebook		<ul style="list-style-type: none"> • Adequate and accessible support and health services • Trained, dementia-aware providers • Dementia-aware emergency preparedness
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Adequate and Accessible Support and Health Services. Community-based support services in the DFC framework are understood broadly as any assistive service promoting the well-being of people with dementia and their carers and can be provided by paid professionals or volunteers. Dementia-specific examples already mentioned in previous sections include support groups, special transportation services, paid or volunteer helpers or companions, and educational events related to living with dementia. Another important support service a community can provide is legal or financial advice as several interviewees admitted feeling insufficiently prepared although one care partner reported having made the fortunate decision to purchase long-term care insurance at the right time.

At this point, it seems appropriate to revisit the importance of care partners and other supportive family members. Without doubt, they play a crucial role in DFCs and the daily lives of people with dementia, yet they are not explicitly integrated in the AFC framework (for instance, even in the “community support and health services” domain, they are only briefly mentioned in the context of respite care and carer training). This omission is due partly to “caregiving” being less pronounced in AFC’s more general context of older adulthood; in addition, individual-level support is not usually captured in community-level approaches. However, no functional DFC framework can exist

without including family carers. Instead of outlining the individual assistance provided *by* informal carers without providing a plan to support the supporters, a DFC framework must take an active approach to recognizing their immense importance by shifting the focus to community-level support *for* family carers. Shifting the emphasis aligns with the ecological model of DFCs that this dissertation is based on, fostering an understanding of dementia as a societal rather than private concern. This by no means is to downplay the tremendous value of what care partners do, achieve, and struggle with every day; in contrast, recognizing the necessity to come up with new family support concepts underscores that both people with dementia and their carers are and remain at the heart of any DFC initiative.

In relation to community-based support and health services, the special limitations of both people with dementia and carers in accessing these services must be addressed. For carers, ways must be found to grant them the time and peace of mind to utilize support services, unless the services include the provision of adequate companionship for the person with dementia. For people with dementia, the question of transportation must be resolved, unless the services are offered within walking distance. And even then it is possible that a service turns out to be inaccessible for people like Brenda (PLWD) with very limited energy levels. “I have pretty good mobility and so [getting what I need] depends on sometimes what time of day it is,” she shared. “It depends on how long I have to wait to wade through the system to get what I want.”

In terms of the adequacy of services, again, a variety of offers appropriate for different stages in the disease progression will be helpful, as shown in the previously mentioned scarcity of support groups for people with dementia in the early stages, especially in more remote locations.

As for health services, many participants talked about health care professionals who were involved in the original diagnosis or follow-up care. Many experiences were positive, and physicians were described as “very, very helpful,” “exceptionally good,” or “a miracle person.” A few carers, however, had had unpleasant experiences with providers being inadequately prepared for visits or being perceived as insensitive or insufficiently qualified that in at least one case had led the family to switch to a different clinic.

Trained, Dementia-Aware Providers. According to current surveys, physicians do not always do a good job tending to their patients in a dementia-friendly way, which can range from incorrect assumptions about the disease to non-existent bedside manners. Sally (CP) provided a somewhat tragic example for a missed opportunity to be properly informed about the nature of dementia:

I’d learned so much in that [virtual support group]. I really wish I had been given that at the beginning because for seven years, I have thought it was memory. And one time quite a few years ago, probably four years ago now, he said to me, “What can I do to make this easier for you?” And I said, “I know you can’t remember things, but you can still reason. You can still figure stuff out.” And now I know that that all goes. And so, that would’ve just been easier for me to realize. And it would’ve been an easy thing for the neurologist to say, but it was always just done in terms of memory. And maybe it’s because they know, and so they don’t think to tell the patient or the caregiver that it’s every aspect of the brain.

Dementia-Aware Emergency Preparedness. Emergency preparedness planning on neighborhood level is an important community activity that people with dementia and carers should be involved in to ensure appropriate inclusion of dementia-specific considerations. While emergency preparedness in this sense was not explicitly mentioned during the interviews, it is evident from the carers' reluctance to leave people with dementia unattended that unexpected situations can have disastrous effects on their emotional and, in the worst case, physical well-being. George (CP), for instance, had grown wary of extended hiking adventures out of fear that something might happen to him leaving his wife helpless in the wilderness. Becca (PLWD) had become increasingly fearful of driving long distances because she did not trust herself to be able to manage a car emergency:

If something happened to the car when I'm driving, and he's somewhere else, that would make it difficult. And since things like my memory are not improving, I just need to be more careful about being in situations that, if something happened, might be difficult to gather the right people or organizations or whatever together to do it.

Technology

Technology is not a domain of age friendliness in the WHO framework. In the AFC guide, technology *training* is briefly mentioned in the context of employment and volunteering, and information technology is discussed as an ambivalent aspect of communication and information, with some older adults embracing it and others accusing it of exacerbating feelings of social exclusion (WHO, 2007b).

During the interviews, it quickly became apparent that technology played a significant role in the lives of the interviewed carers and people living with dementia, and while it overlaps with some of the other domains, I chose to include it as a separate theme. In addition to serving as a tool to communicate and stay informed, technology was used by participants for other purposes as well, such as entertainment and everyday-life support.

Several aspects of technology can be relevant for users living with dementia and their carers: Devices and applications can be specifically designed for people with physical or cognitive limitations; existing technology can be utilized as aids for specific purposes; and technology can be evaluated in terms of its user friendliness with older adults and people with dementia in mind. I had initially titled the theme “assistive technology,” which is a term describing “technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible” (University of Washington, 2022). However, as most accounts of technology use in this study referred to mainstream devices and applications, this term seemed inappropriate. Further, since the main research question was focused on exploring whether aspects of DFCs could be integrated with an age-friendly framework, phrasing the theme in a more general way seemed more fitting. The final codes used were “accessible, relevant, and enabling technology,” “age- and dementia-friendly devices and applications,” and “technology training” (see Table 14).

Table 14:

Technology: Final Theme and Codes

Final Theme	Technology	<ul style="list-style-type: none">• Technology is accessible, relevant, and enabling• Devices and applications are age and dementia friendly• Adequate training opportunities exist
Codebook		<ul style="list-style-type: none">• Accessible, relevant, and enabling technology• Age- and dementia-friendly devices and applications• Technology training

Accessible, Relevant, and Enabling Technology. Supportive technology as a daily assistant can be as simple as a phone, as shown in the example of 92-year-old Joseph (PLWD) who was closely connected to his extended family:

- Joseph: I keep in contact with a lot of nephews and nieces and great-nephews and -nieces, and I like to keep in contact with them.
- Iris: And how do you do that?
- Joseph: Mostly by telephone.
- Iris: And with your brothers?
- Joseph: Yes. We talk to him at least every two weeks, I talk to each of them. [...]
- Iris: Uh-huh, catch up and see what's going on?
- Joseph: Mm-hm, mm-hm. With their kids and so on.
- Iris: That's a lot of phone calls [laughs].
- Joseph: Yes. Actually, my wife keeps in contact with her part of them, too, and we all talk to each.

In addition to facilitating communication, technology can also serve as a memory aid, support leisure activities, and help with spatial orientation on a daily basis. David (PLWD), who was still engaging in solo activities, had learned to text with his wife to keep her informed about his whereabouts and plans. He also used the Internet to

download music because he thought going to live concerts was too expensive, and he relied heavily on his cell phone to keep track of his numerous activities, appointments, and duties:

David: So dementia for me is memory and judgment. For memory, my phone has saved me. But you have to have the mindset, or the opportunity, to know how to use a cordless touch-tone phone.

Iris: Sure. But you do.

David: But I do, and I'm getting to learn to use it better. I am forgetful; that's part of my Alzheimer's. So everything that I have to remember goes onto the phone. Or notes. But I just put it on the calendar.

Other examples for technology facilitating everyday-life tasks in this study were the previously mentioned phone app Judy (CP) used to map out public bathrooms and the setup of specific hardware at grocery stores to assist customers like Lorraine (PLWD), who did not feel comfortable asking employees for help finding items:

Lorraine: Another thing that not enough places have that I wish they did... where they have – it's not even a kiosk, it's either just a phone you can pick up and ask where a certain thing is or what aisle, or a directory. That's really nice because then you don't even have to ask anyone. You can just go type in what you're looking for and it'll show you not only what aisle it's in but, like a map... and show you, "Okay, here you are and it's over here." That would be really nice.

Iris: I just discovered the [grocery store] app. [...] It will recognize by your location what store you're at, and then you can search for whatever item you're looking for, and it gives you the aisle.

Lorraine: I'm gonna have to get that. [...] I bet lots of places have that, and I didn't even know. That's a great idea. Yeah. Why would you need a kiosk? You can just use your phone. [...] That's great. See? I learned something from you today; very useful.

Technology not only supports orientation and daily chores, but can also serve to overcome social isolation and increase a person's quality of life through interactive

entertainment. While watching television and listening to DVDs were frequently mentioned as current activities by carers and people with dementia alike, two participants demonstrated in a genuine way the added potential of newer technology: Rosa (PLWD), who was the oldest participant in the study (94) and in an advanced stage of dementia, sat in the living room by a small table on which she operated an iPad playing videos that she was watching attentively while also engaging in a friendly chat with me. After I had placed my iPhone on the same table to record the interview, Rosa repeatedly expressed interest in the phone. Eventually, she inquisitively tapped the red “stop” button which prematurely ended the recording. Richard (PLWD), enthroned in an armchair in the realm of his upstairs room, interrupted our conversation several times to pose a question to his “Alexa” device which reliably and comprehensively responded. At the end of the interview, Richard asked me for my favorite song and, when I hesitated, instructed Alexa to play a piece by Frank Sinatra as a cordial farewell in lieu of his seeing me out.

As discussed earlier, a common barrier for care partners to partake in activities or utilize services is their reluctance or inability to leave the person with dementia unsupervised. In addition, some carers were dealing with their own health conditions, fatigue, or time constraints due to work responsibilities that further limited their ability to participate in anything that was not already on their to-do list or easily accessible. As recent advances in telehealth show, technology can bridge this geographic gap by delivering services virtually, directly to people’s homes. Ruth (CP), for instance, had

been considering joining a web-based support group that was offered as part of a clinical study:

I know there are support groups through the community, through the Alzheimer's Association, and I probably should. But then I have to go out, and this I can do at home and not worry about Max.

Bettina (CP), referring to the same study, demonstrated the need for better technological equipment as an enabling factor:

That just didn't work out too well because everybody had to be on a computer that we all could be seen and see others, and my computer just was not going to do it. So, I said... I couldn't really be a participant, so I backed out of it.

It is important to note that all interviews in the present study took place before the COVID-19 pandemic, an event which has doubtlessly spurred the development, use, and acceptance of technology on a much larger scale than anyone involved in the project at the time, including myself, could have ever imagined.

Age- and Dementia-Friendly Devices and Applications. To be useful, devices and applications need to be designed in a user-friendly way. While age-friendly technology is still understudied but not a new topic, dementia-friendly technology has just recently gained traction and is still heavily focused on aiding care partners or people with dementia in advanced stages of the disease.

David's (PLWD) extensive reflections about his phone as an indispensable tool to keep him organized led to a somewhat unusual insight about factors that might be barriers to using electronic devices:

I want you to get the phone company to work on our self-confidence and just call this a cell phone. Not a “smart” phone. How are we gonna get smarter than a phone if they call it a smart phone? Just call it what it is: It’s a cell phone, a highly useful cell phone. [...] It’s mentally challenging for an Alzheimer to get confident with a phone because it’s smarter than we are. And getting to know how to use it is quite confidence-building and -saving.

Technology Training. Technology was occasionally mentioned as a barrier. In contrast to the above examples highlighting technology and electronic devices as helpful tools, some interviewees were opposed to using them even though they were aware that this meant “missing out” in some way. Paul (CP) recounted that his reluctance to use email had been one reason to retire from his teaching job. In expressing his disappointment over the scarcity of phone calls from his wife’s son, Paul indirectly revealed a possible need for training and intergenerational agreements about feasible modalities to communicate and connect:

He’s into technology and all of that kind of stuff. He’s Facebooking and that, but we can’t Facebook. We don’t know how, we can’t figure the damn thing out. But he doesn’t ever call her, and he’s got unlimited long distance.

Part 3: Interviewing People With Dementia and Their Carers

Both people with dementia and carers are very special groups to interview, and it seemed appropriate to devote the last part of this chapter to reflections on some surprising or otherwise noteworthy experiences and observations during the interviews.

Creating Connection

I had never met any of the study participants before entering their homes, and I felt touched and honored by the trust they showed in responding in elaborate ways to

questions that could, and often did, trigger strong emotions. One care partner, whom I had perceived as rather reserved during the first part of our interview, ended up sharing very intimate details about her relationship with her husband. Many tears were shed without shame, but there were smiles and laughter, too, especially with those in further advanced stages of dementia. In fact, humor was not only an icebreaker, but, once established, also served as a reorienting constant woven through the conversations. Observing the ease with which interviewees with otherwise apparent cognitive difficulties responded to my tone of voice when making a teasing remark clearly spoke to the preservation of nonverbal social skills used to create connection in human interactions. Another obvious way to quickly build rapport was emphasizing shared interests, life mottos, autobiographical aspects, and so on. In summary, I am fairly certain that most participants experienced the interview as a friendly, non-threatening, or even pleasant conversation, and much of that was due to aspects of the conversations that were not included in the script.

Deviations From the Interview Structure

The data collection method I chose for this study was semi-structured interviews in the form of a prepared catalog of open-ended questions. Not far into the data collection phase, however, I had to abandon the idea of consistently adhering to the original order of questions. In some cases, I detached myself entirely from attempting to stick to the original guideline. Instead, I followed the interviewees' train of thought, occasionally intercepting with additional questions, some of which led back to the

original question while others did not. Methodically speaking, several of my semi-structured interviews turned into rather *unstructured* exchanges, allowing for a high degree of spontaneity and flexibility. The reasons for this adaptation were manifold, including several participants with dementia not being able to fully comprehend the questions or to stay on track with their responses, or care partners digressing in order to address topics more relevant to them than the interview's original focus. In their own right, all answers proved to be valuable and usable for the purpose of this study.

Spontaneous Rephrasing

Another deviation from the original interview guideline was that I took the liberty to rephrase questions in response to the interviewees' responses or reactions. The most prominent example of this adaptation was the use of the term "dementia." Although all participants had read and claimed to understand the focus and purpose of the study, it became apparent during the interviews that several people with dementia, even if officially diagnosed, did not identify with the condition. Some participants denied having any difficulties at all, others explained them with their age, the "lack of practice," or unrelated medical conditions. Even though I probed some, I did not push anyone into admitting to experiencing cognitive symptoms they denied having because I did not want to threaten their self-protecting coping system. In most cases, I did not use the "D word" until I felt it was safe to do so. To ensure the interviewees could relate to my questions, I listened carefully to their narrative and equally carefully adjusted my wording to match their reported experiences and interpretations. For instance, when an

interviewee rationalized any difficulties they admitted to experiencing as being a result of their age, I refrained from talking about DFCs, but asked how communities could become more accommodating “for an older person like yourself.”

Rephrasing proved helpful in other scenarios as well. Some interviewees showed signs of perseveration by providing the same answer or theme – often embedded in a life story – over and over again. Rephrasing the question occasionally helped to break the repetitive loop. As mentioned before, Johannes (PLWD) responded with a well-rehearsed story of having been a salesman his entire life whenever I asked for past, current, or potential future activities. Only when I added “for fun” to this question did he think of a different response; apparently, the more generally phrased questions had triggered his “default” response while the more specific addition enabled him to reorient his narrative.

Visual Materials

Using a graphic as a prompt was extremely helpful in many ways. Apart from the participants’ unexpected excitement over the simple handout, the visual display of the AFC domains also assisted greatly in refocusing, if only briefly, those with difficulties keeping on track or those who had gotten caught in repetitive content loops. This observation can serve as additional evidence for the importance of designing informational materials in an appealing, dementia-friendly way.

Carer Dynamics

This dissertation paper has provided ample evidence that informal carers are irreplaceable in all they do to support their family members with dementia on a daily basis. Being irreplaceable “experts” of their specific dyadic care situation also means that many care partners have difficulties taking a break from feeling responsible, which is another common barrier to utilizing support services or engaging in self-care activities. In this study, some care partners had difficulties accepting that their expert input, for once, was not needed during the interviews with their family members: As mentioned before, several carers felt obligated to “warn” me about possible incorrect responses. Assuring that I was more interested in stories than in the “objective truth” was usually sufficient to put them at ease. Similarly, the care partners who had told me they would have to be present for my interviews with their partners to make sure I understood them due to language impairment also accepted my request to let me give it a try first and get back to them should I need assistance. Carers sometimes tried to listen in out of interest in their partners’ responses, but only one interrupted the interview and was understanding when I politely asked her to leave and come back later. The only unpleasant situation I encountered was when a person with dementia walked into the interview with her husband and rightfully accused us of talking about her; her care partner quickly waved this off with a lie and sent her back upstairs, which I experienced as inadequate and patronizing. Having had a “script” for specific situations like this might have helped me interject with a more respectful response.

Off-the-Record Conversations

In several instances, interviewees shared important information after the end of the official interview. Interestingly, most of these additional conversations took place while moving around. When asked about current activities, Joseph (PLWD) had had some difficulties thinking of something other than going to church and occasionally meeting friends. However, after the interview he stood up and indicated that he wanted to show me something – much to the surprise of his wife who had doubted that I would “get much out of him.” He stepped outside the apartment onto a small fenced side yard and commented on their potted flowers and a tomato plant. Upon inquiry, he reported still doing some gardening. A conversation about the tomato plant then got him talking about going to the farmers’ market every week with his wife to get vegetables they enjoyed. A book on the patio table further inspired him to report that he liked to read, and that his wife played the piano while he enjoyed listening. This example shows the importance of visual cues for recalling memories and how a more active involvement with one’s environment than sitting at the living room table, such as walking interviews or photovoice projects, might lead to more and better data.

Symbols and Metaphors

As described in Part 1, interviewees with dementia often used stories and repetitive language patterns to convey aspects of their history they considered meaningful. Some of these patterns were highly symbolic or metaphorical, which was an

interesting observation, particularly for participants whose narrative could easily have been interpreted as “inapprehensible” or “off topic.”

Johannes the Salesman (PLWD), for example, as he regarded me sitting across from him with my notepad and recorder, suddenly started laughing and determined that I – obviously – was in sales as well! We had already bonded over sharing a zodiac sign at that point, but the additional connection likely contributed to his willingness to talk to me despite his categorical denial of having any “problems.” As already established, the salesman story seemed to be a way to express his identity, and the emphasis on his lifelong engagement – from the time when he was selling ice because refrigerators did not exist yet until the current moment – may have brought with it the comfort of continuity and pride of long-standing expertise and skill. “I was good,” he asserted. I wondered what being a salesman meant for him and asked if he liked sharing information and meeting new people, which he eagerly confirmed. In hindsight, not having asked him directly what he liked about being a salesman seemed like a missed opportunity.

Another interesting example was my interview with Andrew (PLWD), which, in my imaginary scrapbook, I titled “The Window to the World.” Not unlike Joseph, the visual cues Andrew spotted through the beautifully stained glass of the giant window separating his living room from the street, served to pleasantly remind him of his history with his neighborhood:

At this point [...], there is nothing that I find repulsive. I look out the window and I am so impacted by what I see. There is nothing in that window that I don't like. I like my window. Everything is red, it's brown, it's green, it's blue. It's near, it's far.

Dennis (PLWD), who was not unwilling, but very reluctant to speak of himself as having dementia, preferred to use the much safer metaphor of "boxes" instead. He spoke of the boxes as either containing "demons" or himself, and as being located near his feet or somewhere else below him, indicating his mastership *over* the boxed-up (or boxed-out) threats he found unsettling:

Dennis: I'm in the box, I'm in the box, and it's down in my basement right now. And it's down there. I can go pick it up now.

Iris: And what would happen if you would go and pick it up?

Dennis: What would happen? Well, I'm the owner.

Iris: You are the owner.

Dennis: So there you go. No one can take me out of that.

Iris: So you have control over your box.

Dennis: I have control over that box. And I have sisters, and you have to watch out. If any of you do something with my sisters, you are going to be knowing it. Because my one sister is a very good athlete and some things too, so yeah.

Iris: So you have protection.

Dennis: I do. I'm thankful for it. And there's other times when I don't want to do it. I get tired of it. That's just reality. You can't do it all the time.

Iris: Do you feel like your sisters have been supportive?

Dennis: Oh, yes, yes.

Iris: After you have put your box there?

Dennis: Yep!

Iris: They have been there for you.

Prior Experience – Blessing or Curse?

While, overall, I am certain that I would not have been able to conduct this study without my previous experiences in the field, I observed myself falling into two patterns related to my former profession. One of these patterns was that I could not help but pay attention to clinical symptoms I observed during the interviews. Since I had decided against using a cognitive screening test, I had initially come up with an elaborated system to retrospectively assign a cognitive “guess score” to determine the participants’ state of dementia, which I thought would be a valuable piece of additional information. I later abandoned this system, reminding myself that I was no longer a clinical psychologist, and just documented a very general status impression.

Similarly, I caught myself at different occasions sharing information and advice with both carers and participants with dementia who asked for it, mostly as part of informal conversations after the end of the official interview. This was, in part, an automated reaction relating back to when I had facilitated carer support groups and counseled family members of patients at the clinic I worked at. In retrospect, having encountered some participants’ dire need for basic information, I regretted not having prepared a handout with local resources I could have left with them for future reference.

Own Reactions

When asked about my research while I was in the thick of collecting and analyzing data, I often responded jokingly that I was feeling inspired not only to draft a

dissertation, but also a novel, along with an illustrated collection of rich stories told by and about everyone who had so generously invited me to have a tiny glimpse into their world, and perhaps a reflective essay on how the study had subtly been influencing significant events in my personal life and vice versa. This motivational overflow was springing from the personal involvement the research had demanded on various levels, proving the pragmatist point that “all our attempts to understand and act in the world are inherently contextual, emotional, and social” (Morgan, 2014, p. 1050). A field note reflected on a recurring emotional state:

Once again, today’s interview visit left me with a strangely incongruent mix of emotions. I’m suddenly reminded of the home visits I did with patients for a study a long time ago, only that I was doing cognitive assessments then. The act of stepping into someone’s home bears so much vulnerability on both ends, but more so on the part of those being visited. Apart from the physical act of entering their space, it’s like I’m forcing them to open the metaphorical door to their greatest fears and hopes and sorrows... On a relational level, I’m often witnessing the rich and loving sweetness between caring spouses while, between others, the unspoken tragedy of irreversible estrangement creates a tangible, heart-wrenching void. I’m feeling deeply humbled. Sad and disturbed. Inspired and grateful. Enlightened and forlorn. All of it, at once.

In summary, this study was a powerful experience from the beginning, and the participants’ accounts continue to inspire my thoughts and actions. While my findings, sadly, will not reach everyone who participated in this research, their valuable and valued contributions are here to last.

Chapter 4: Summary and Recommendations

Summary

This dissertation research was conducted to add to the growing scientific literature on the topic of DFCs and was centered around the questions of what, from the perspective of those living with Alzheimer's disease and related conditions and their care partners, such communities should entail and how the resulting DFC framework could be integrated with the WHO AFC framework. The following summarizes the answers to the initial research questions:

Research Question 1:

Based on the lived experience of people with dementia and their carers, including barriers and supporting factors related to daily activities, what characteristics should a DFC encompass?

The analysis of the interview data resulted in nine final themes, or domains, of dementia friendliness, aspects of which were discussed either as barriers or facilitating factors to the pursuit of preferred or necessary activities. Each domain was described by a set of dementia-friendly features some of which are specific to dementia while others have a broader focus.

DFC framework:

(1) Public outdoor and indoor spaces

- Public outdoor and indoor spaces are accessible, safe, appealing, and easy to navigate
- Public spaces support diversity and intergenerational interactions
- Opportunities to connect with nature are available and accessible
- Public outdoor and indoor spaces feature adequate facilities/amenities

(2) Transportation and travel

- Adequate and accessible options to get around are available
- Drivers/staff are trained, dementia aware, and able to provide special supportive assistance along the way
- Ample, accessible parking is available
- Useful and accessible transportation-related information is available

(3) Housing and living environment

- Adequate and accessible housing options exist
- Aging in place is supported
- The living environment is appealing and accommodates interests and meaningful activities

(4) Participation in meaningful activities

- People at all stages of dementia have access to a variety of meaningful and adequate activities
- Special offers for people with dementia exist
- Staff/facilitators/providers are trained and dementia aware

(5) Respect, inclusion, and spirit of support

- Communities provide socially cohesive environments where people of all abilities feel safe, respected, included, and supported
- The community engages in efforts to raise awareness and reduce stigma
- The voice of people with dementia is recognized and heard

(6) Civic engagement and employment

- Employers and work environments support carers and offer opportunities for continued involvement for people with dementia
- A variety of meaningful dementia-friendly volunteer opportunities exist
- People with dementia are involved in political decisions (e.g., about DFSc)

(7) Communication and information

- Information about community services and activities is available and accessible
- Proactive outreach strategies exist for people with dementia and their families
- The design of materials is age and dementia friendly

(8) Community-based support and health services

- A variety of adequate and accessible community support and health services are available
- Service and health care providers are trained and dementia aware
- Emergency preparedness planning includes dementia-specific elements

(9) Technology

- Technology is accessible, relevant, and enabling
- Devices and applications are age and dementia friendly
- Adequate training opportunities exist

Research Question 2

What, if any, are the differences between the perspectives of people with dementia and their care partners?

The data analysis revealed that “respite and peace of mind” was a theme primarily addressed by care partners in relation to the physical and emotional strain they experienced as a result of supporting the person with dementia.

Among participants living with dementia, especially at more advanced stages, the preservation of their sense of self and identity seemed to be of great importance. Stories and autobiographical content, often presented in repetitive ways, appeared to serve the purpose of delivering explicit or implicit self- and identity-strengthening cues. Other participants with dementia strongly related to topics of respect, awareness, and inclusion, and some expressed the desire to educate others about their lived experience to increase “compassion and understanding.”

The interpretation of the answers to the additional questions care partners were asked about the answers of the person with dementia proved to be difficult in a comparative sense. The questions also often had to be omitted due to time constraints. However, the responses collected illustrated two communicational aspects carers were struggling with: Some were frustrated about their lack of access to their partners’ inner

world of thoughts and wishes while others had difficulties accepting their partners' stories because they perceived them as distorted facts or lies.

Research Question 3

(How) do the identified characteristics of a DFC relate to the WHO's domains of age friendliness, and (how) can both frameworks be integrated?

The first eight domains of dementia friendliness are identical with the WHO's domains of age friendliness. The ninth DFC domain, technology, does not exist in the WHO framework, but there is no apparent reason why it should not be included, especially in the wake of the COVID-19 pandemic which led to an increase in the prevalence of remote communication technology in the lives of older adults.

Given the congruence of the AFC and the DFC domains, dementia-friendly features can be easily integrated into the efforts of existing AFC initiatives. Some domains were renamed in the course of the analysis, but the new names are equally applicable to age friendliness and may, in fact, add clarity to some domains that previously were difficult to distinguish from others.

Even though "respite and support" for carers and "preservation of self and identity" for those living with dementia are not included in the DFC framework as domains, they are important aspects that need to be integrated in the planning, implementation, and evaluation of DFC efforts for each domain. It is reasonable to assume that many older adults with or without dementia will resonate with both, so including these aspects is not expected to interfere with the mission of an AFC initiative.

Recommendations for Dementia-Friendly Communities Initiatives

The recommendations listed below highlight some central ideas discussed or developed in this study. Most of these ideas are included in the DFC framework outlined above, but some apply to more than one domain. Phrasing them outside of the domain model can be useful for DFC initiatives that are not currently collaborating with an AFC initiative. Evidently, communities can still use the DFC domain model to get off the ground; however, some might prefer to start working with the sector model promoted by the DFA network, some might use a combination of both, and others might choose an entirely different approach.

Join the DFA Network

Regardless of which approach a community chooses to initiate their dementia-friendly efforts, it is advisable to get familiar with the work of the DFA network. Even without joining the network, communities can benefit from a wealth of resources and support provided by DFA.

Train Companions and Dementia Friends

This study has shown that families affected by dementia can benefit from a friendly companion available to spend time with the person with dementia, be it for socializing, feeling safer at home, being taken to an activity, getting around on the bus, or going on a walk without getting lost. In a DFC, interested volunteers and professional providers alike will be trained to become such companions. A related concept is that of “dementia friends” where community members receive training to support a person

with dementia in whatever useful way they feel comfortable. “Dementia friends ambassadors/champions” are people with additional training who serve as community advocates and train others (e.g., <https://www.dementiafriends.org.uk>).

Intergenerational programs can be another opportunity to support people with dementia and their families while at the same time increasing dementia awareness and understanding in the younger generation.

Offer Cross-Sectoral Dementia Awareness Training

In a DFC, service providers, activity leaders, business owners, airport personnel, bus drivers, volunteer coordinators, property managers, church leaders, health care providers, employers, and many others participate in ongoing dementia awareness trainings and workshops to understand their own role in creating more dementia-friendly services and environments. This role could include being available to provide short-time companionship for people with dementia if needed, for instance at busy stores and airports.

Provide Opportunities to Share Stories

For those living with dementia who are interested in educating others, a DFC will provide opportunities to share their lived experience and to connect with those less familiar with dementia. Opportunities can include intergenerational encounters, public presentations, partnerships with “dementia friends,” and involvement in the design and delivery of training content. People in more advanced stages of dementia have stories to tell, too. These stories can serve to preserve meaningful aspects of one’s self and

identity and, in a DFC, should be recognized and supported in this important function without judgment. Opportunities can include activities focused on the playful rehearsal of personally meaningful autobiographic or symbolic content and on co-creating new stories with others. The creative engagement model *TimeSlips* is an example for such a scenario (<https://www.timeslips.org>).

Amplify the Impact of Existing Community Groups and Networks

Faith-based groups, aging-in-place Villages, and other “communities within communities” are established entities consisting of individuals who already know each other and often live in close proximity, which is conducive to mutual trust, social cohesion, and a genuine interest in each others’ well-being. Increasing dementia awareness within these communities can multiply the low-threshold support members are already providing to each other, opening up additional opportunities for respite, companionship, and social inclusion. Moreover, interest- and faith-based groups can serve as hubs for the distribution of information about community activities and other important news and can flexibly deliver this information directly to those less likely to actively seek it out, in their preferred way of communication (e.g., over the phone).

Focus on Interests Instead of Illness

While services and activities specifically designed for people with dementia are important and useful, a variety of dementia-friendly (but not necessarily dementia-*focused*) activities based on preferences and interests rather than illness should also be

offered, and their potential for intergenerational bonding over shared passions should be explored.

Design for Proximity

Getting around can be of great concern, not only for people with dementia. Clearly, transportation options need to be improved, but part of the solution could be to put more emphasis on walkability and the proximity of services and activities, including mobile or virtual options brought to people's homes. Having to spend less time with transportation is also helpful for carers who need to be around the person with dementia at all times.

Enrich the Built Environment

Public outdoor and indoor spaces can be designed in ways that benefit people of all ages and abilities and inspire intergenerational interactions that many people with dementia enjoy. Good signage and lighting are essential, and improving the visual and emotional appeal of a neighborhood by adding stationary art and distinctive landmarks can create a sense of place and familiarity which in turn can support wayfinding for those who easily get disoriented.

Accommodate "the Urge"

The availability and accessibility of adequate public restrooms and facilities with running water is unarguably essential not only for older adults and people with dementia. However, people with dementia in the more advanced stages may need to be accompanied by their care partners, which may render a gender-separated facility setup

inaccessible even if oversized stalls exist. Public restrooms are usually discussed in the context of outdoor spaces and public buildings. While crucially important there, the implications of frequent or irregular bladder or bowel movement should be discussed in other areas as well. For instance, providing restrooms near parking lots and major transit stops can make people feel more comfortable about getting around by car or public transportation. In addition, reliable information about bus and train schedules, as well as the locations and features of the facilities, will also have to be made available.

Fill in the In-Between Gap

People living with dementia are not a homogenous group, yet it appears that the common understanding of dementia does not reflect a differentiated picture but rather lumps people with dementia into one category. Against this background, it is not surprising that people with dementia are reluctant to share their diagnosis with others out of fear that they might immediately get “labeled.” It is also not surprising that there is a lack of “in-between” options, be it in the context of housing, transportation, services, or activities. For instance, for those in the earlier stages of dementia looking for an exchange with peers, participation in activities for people with advanced dementia is neither useful nor appropriate.

Offer Support Groups

Carer support groups are valuable and often the only opportunity for carers to connect with peers and to receive important information. Support groups and classes for carers can be dementia specific and address different aspects of the condition and

what it means to live with it (e.g. *Savvy Caregiver*[®], a program created by the University of Minnesota, <https://savvycaregiver.com>). They can also be more generally focused on self care for care partners of people with varying conditions (e.g., *Powerful Tools for Caregivers*, a curriculum developed in Oregon and administered through Iowa State University, <https://www.powerfultoolsforcaregivers.org>). However, many care partners will be unable to participate in groups if no companion is around for the person with dementia. One solution could be to offer parallel groups for people with dementia and care partners, or to offer groups virtually. As for people with dementia, groups offered are usually tailored to those in advanced stages and centered around an activity (e.g., painting or singing). Education- and conversation-focused groups for people in the early stages of dementia rarely exist, especially outside of urban environments.

Draw on the Healing Power of Nature

The positive health effects of nature have long been known, and it does not take a hiking trip to reap the benefits of outdoor spaces. Dementia-friendly walking groups can connect people with others, as well as with their neighborhoods, while enjoying the physical exercise and being outdoors. For those who do venture into the wilderness, dementia-friendly hiking groups could be established to foster social connections and support while accommodating fatigue-adjusted schedules and walking speeds and providing the peace of mind to each participant that someone else will be around to help in case of an emergency. For those confined to apartments, container gardens,

houseplants, or even just a window facing a pleasant scenery can make all the difference.

Utilize and Develop Dementia-Friendly Technology

For some of the concerns shared in this study, technology can be part of the solution, especially for those in the earlier stages of dementia. For instance, bus and train schedules are available in real time via mobile phone apps and can help with trip planning. Phones with GPS can be used to find, record, and share routes and, if needed, assist in locating a person if they become lost. In a DFC, hands-on public or in-home technology training could be offered for those already open to entering new terrain. Those on the fence could benefit from thoughtfully conceptualized demonstrations of purposes, limitations, and possible risks of using applications, platforms, and devices. Reluctance to use technology exists for many reasons, but it is reasonable to assume that explaining the “why” in a personally relevant manner can ignite a “low-tech” person’s interest in engaging more readily with the “how.” Further, intergenerational conversations could be facilitated addressing long-distance ways to connect (e.g., phone calls versus video calls or social media), with the goal to better understand each other’s needs and preferences and to help family members come to feasible and mutually acceptable agreements.

Chapter 5: Conclusion

With population aging and rapid increases in the number of people living with dementia worldwide, a global response is needed, but existing initiatives have been slow to gain a foothold on both a local and an international scale. Current directions of addressing dementia mark a departure from the prevailing understanding of the syndrome as a clinical problem to be dealt with in private to understanding it as a societal responsibility to be included as a priority in the agenda of community development and engagement activities. The integration of the well-being of those affected by Alzheimer's disease and related conditions and their care partners into the considerations of community planners and collaborators across various sectors needs to follow a person-centered and human rights-based philosophy that thus far has been lacking.

With the WHO's global action plan nearing the end of its implementation phase, it is high time to get active at all possible levels – from international agreements to local policies and awareness campaigns designed for the general public. To ensure the effectiveness of these activities, scientific research is necessary to further an evidence-based understanding of what is needed and how what is needed can be successfully addressed. To use the words of John Keady and his colleagues, whose work has greatly inspired this study: “There can be no research without the person living with dementia and thereby their perspectives, participation and knowledge are instrumental to turning any key of understanding” (Keady et al., 2018, p. 3).

Scientific Contributions

This study represents the intersection of various disciplines, including community development, gerontology, urban studies and planning, and public health. As such, this dissertation adds to the scientific literature within each respective field and also sheds light on interdisciplinary relations and opportunities for collaboration. This is particularly notable due to dementia's traditional association with the medical sciences.

Further, this research adds valuable insights to the knowledge base related to the use of social research methods with people living with dementia. This includes the balancing act between ethical considerations (e.g., ability to consent) and empowerment (e.g., giving people with dementia a voice).

In fulfillment of the study's aims, the results provide a theoretical framework of DFCs that can serve as an evidence-based guideline for both age- and dementia-friendly initiatives, campaigns, and policies and spur further scientific inquiry to dive deeper into the different domains identified as essential for the day-to-day activities and well-being of people affected by dementia and their carers.

Limitations

The main limitation of this research is that the study sample was homogenous, with most participants being White, affluent, and living in urban environments, which limits the applicability of the results to more diverse populations: Except for five interviewees, all participants identified as White/Caucasian. However, ethnic and cultural groups differ greatly regarding prevalent attitudes toward dementia,

interpretations of the disease, the tendency to conceal the condition from others, and perspectives on informal and formal care. Given these differences, it is probable that a more diverse group of participants would have responded to the interview questions very differently.

Similarly, less affluent participants would be expected to have different responses, for instance, regarding the affordability of services, appropriate housing, transportation, etc.

Most of the study participants resided in the greater Portland area in Oregon, which has been known for a comparatively progressive public transportation system. As interviews with participants in areas outside of the city's boundaries showed, issues of mobility abound in other parts of the state, pointing to geographic differences in daily-life experiences and perspectives. These differences, of course, are not limited to transportation. Rural areas, which were not represented in the study sample, may require adaptations to the DFC framework to include more basic aspects of the necessary infrastructure to plan and implement a dementia-friendly initiative, such as ensuring that stakeholders are available to champion the project.

Future Research

Implications for future research are manifold as evidence-based guidelines are needed to ensure the effectiveness of dementia-friendly activities within each domain of the DFC framework. As for priority, given the crucial role dementia awareness plays within each domain, exploring ways to increase this awareness and to create

community- and population-level momentum would be a consequential next step. Another area of focus could be the domain of technology, which, due to its not being included in the WHO framework of age friendliness, has not been sufficiently explored as an age-friendly, let alone dementia-friendly, community feature. Due to the contributions of technology to addressing social isolation during the pandemic, putting efforts into research and further development of technologies will likely add to its increased popularity among older adults, including those affected by dementia.

Since the data for this study were collected before the COVID-19 virus changed the world, it would be worthwhile inquiring how the pandemic has affected not only the use and acceptance of technology, but the daily lives of people living with dementia and their care partners and how barriers and supporting factors within the DFC domains might have shifted since 2020.

Further, the integration of the perspective of care partners in community-based age- or dementia-friendly initiatives has to date not received enough academic attention. Existing study areas include evidence-based interventions to reduce stress and perceived “caregiver burden,” but the interventions this line of research is usually focused on (e.g., training, support groups, and therapeutic approaches) are based on a clinical and individual- rather than community-based model of dementia care.

For each of these research areas, it will be important to take into account geographic and socioeconomic as well as cultural and ethnic differences. Close collaboration with local organizations representing diverse populations is necessary to

better understand how and where to recruit, for example, interviewees of color; however, such efforts must also include the review of study materials and techniques for cultural relevance and appropriateness. For instance, due to the stigma associated with dementia being greater among ethnic minority groups, it may be necessary to not just translate existing tools but to rethink the use of dementia-related expressions entirely.

Apart from research that can help flesh out and advance dementia-friendly community domains and features, studies are needed to evaluate dementia-friendly initiatives as a whole to ensure their effectiveness and continuous improvement. In particular, a natural succession of this dissertation research would be to evaluate the usefulness of the conceptual DFC framework developed in this study for the integration of age- and dementia-friendly initiatives.

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Appendices

Appendix A:

Portland State University Institutional Review Board Approval



Post Office Box 751 503-725-2227 tel
Portland, Oregon 97207-0751 503-725-8170 fax
Research Integrity (Research & Strategic Partnerships)
IRB (Human Subjects Research Review Committee)
hsrrc@pdx.edu

Date: September 12, 2017

To: Paula Carder / Iris Wernher, Institute on Aging
[SPA Awards]

A handwritten signature in black ink, appearing to read 'Lindsey Wilkinson', written over a light blue horizontal line.

From: Lindsey Wilkinson, IRB Chair

Re: IRB approval for your protocol # 174328, entitled: "Defining "Dementia-Friendly Communities" From the Perspective of Those Affected." [Oregon Tax Checkoff for Alzheimer's Research Fund, PIAF/grant # 170414]

Approval-Expiration: September 12, 2017 – September 11, 2018

Notice of IRB Review and Approval - Initial Review Expedited Review Categories 6, 7; as per Title 45 CFR Part 46

In accordance with your request, the PSU Institutional Review Board (Human Subjects Research Review Committee) has reviewed and approved the project referenced above for compliance with PSU policies and DHHS regulations covering the protection of human subjects. The IRB is satisfied that your provisions for protecting the rights and welfare of all subjects participating in the research are adequate. Please note the following requirements:

Approval: You are approved to conduct this research study only during the period of approval cited above, and the research must be conducted according to the plans and protocol submitted (approved copy enclosed).

Consent: You must use IRB-approved consent materials with study participants.

Changes to Protocol: Any changes in the proposed study, whether to procedures, survey instruments, consent forms or cover letters, must be outlined and submitted to the IRB immediately. The proposed changes cannot be implemented before they have been reviewed and approved by the IRB.

Continuing Review: This approval will expire on 09/11/2018. It is the investigator's responsibility to ensure that a *Continuing Review Report* is submitted to the IRB two months before the expiration date, and that approval of the study is kept current. The *Continuing Review Report* is available on the Research Integrity website.

Adverse Reactions and/or Unanticipated Problems: If any adverse reactions or unanticipated problems occur as a result of this study, you are required to notify the Research Integrity within 5 days of the event. If the issue is serious, approval may be withdrawn pending an investigation by the IRB.

Completion of Study: Please notify the IRB as soon as your research has been completed. Study records, including protocols and signed consent forms for each participant, must be kept by the investigator in a secure location for three years following completion of the study (or per any requirements specified by the project's funding agency).

If you have questions or concerns, please contact the Research Integrity office in Research & Strategic Partnerships at hsrrc@pdx.edu or (503) 725-2227.

Post Office Box 751 503-725-2227 tel
Portland, Oregon 97207-0751 503-725-8170 fax

Research Integrity (Research & Strategic Partnerships)
IRB (Human Subjects Research Review Committee)
hsrrc@pdx.edu

Date: January 22, 2018

To: Paula Carder / Iris Wernher, Institute on Aging
[SPA Awards]



From: Lindsey Wilkinson, IRB Chair

Re: IRB review and approval of your amended protocol # 174328, entitled: "Defining "Dementia-Friendly Communities" from the Perspective of those Affected." [Oregon Tax Checkoff for Alzheimers, PIAF# 170414]

Approval-Expiration: January 22, 2018 – September 11, 2018

Notice of IRB Review and Approval - Amendment
Expedited Review Categories 6, 7; as per Title 45 CFR Part 46

The amendment submitted on **09/25/2017** for the project identified above has been reviewed and approved by the PSU Institutional Review Board (Human Subjects Research Review Committee) and the Research Integrity office using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform Research Integrity within 5 days of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the approved informed consent document(s) (enclosed);
6. You will give each research subject a copy of the informed consent document;
7. **If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on 09/11/2018.**

Portland State University and the Research Integrity appreciate your efforts to conduct research in compliance with PSU Policy and the Federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation with the IRB process. If you have any questions regarding your protocol or the review process, please contact the Research Integrity office in Research & Strategic Partnerships at hsrrc@pdx.edu or call (503) 725-2227.

Approved: Amended application/protocol version 01/09/2018, including inclusion of people with moderate dementia, changes in safety measures, and inclusion of data collection shared with OHSU for storage for future research;
Recruitment Flyer version 01/09/2018;
Participant Consent version 01/09/2018;
General Screening Questions version 01/09/2018;
Demographic Information version 01/09/2018;
Interview Questions for Participants with Dementia version 01/09/2018;
Interview Questions for Care Partners of Participants with Dementia version 01/09/2018.

**Human Research Protection Program
Notice of Amendment Approval**

August 22, 2019

Dear Investigator,

The PSU Human Research Protection Program (HRPP) reviewed the amendment to the following submission:

Investigator(s)	Paula Carder / Iris Wernher
HRPP #	174328
Title	Defining "Dementia-Friendly Communities" From the Perspective of Those Affected
Funding Agency / Kualii #	Oregon Tax Checkoff for Alzheimer's / 170414
Determination Date	08/22/2019
Expiration Date	09/11/2019
Review Category(ies)	6, 7
Approved Changes	→ Use of a known professional transcription service (GMR) by providing de-identified files.

The IRB determined this study continues to satisfy the required provisions for protecting the rights and welfare of subjects participating in research. This amendment approval is given with the following ongoing Human Research Protection Program (HRPP) conditions:

1. The research must be conducted according to the approved protocol and amendment(s) (HRPP Forms enclosed).
2. Research Integrity must be immediately informed (within 5 days) of any injuries or adverse events.
3. Approval from the IRB must be requested and obtained prior to initiating any proposed changes in the research.
4. Research Integrity must be notified when the research is complete; Research Integrity will request annual updates on the study status or require continuing review submissions (if applicable). HRPP-related materials must be kept for at least three years following study completion.

The PSU IRB (FWA00000091; IRB00000903) and Research Integrity comply with 45 CFR Part 46, 21 CFR Parts 50 and 56, and other federal and Oregon laws and regulations, as applicable. If there are any questions, please contact Research Integrity at psuirb@pdx.edu or call 503-725-5484.

Sincerely,



Jack Barbera, IRB Chair



Participants Sought for Research Study: What is a Dementia-Friendly Community?

Who is conducting this research?

This study is led by Iris Wernher, who is a doctoral student from Portland State University's Institute on Aging. The research is funded, in part, through the Oregon Tax Checkoff for Alzheimer's Research Fund.

What is the study about?

Many American cities and communities are making plans to become more "dementia friendly," but little is known to date about the perspective of those who are living with the disease. This study will help to develop a better understanding how Portland can become a more inclusive place to live for people of all ages and abilities.

Flyer:

Who can participate?

We are looking for study participants who are living with **mild or moderate dementia** and who live with, or are in close contact with, an **informal care partner** (e.g., a family member) who is also able and willing to participate in this study.

What does participation entail?

Participants will take part in a one-time, in-person interview (maximal duration: 1 hour) at a Portland-area location convenient for both participant and interviewer.

Participants with dementia and their care partners will be interviewed separately. All interviews will be conducted in English. The topics will focus on your daily activities and experiences in your community and on what your community could do, in your opinion, to become more inclusive and dementia friendly.

Will participants receive payment?

You will not be paid to participate, but each interviewee will receive a \$20 gift card as a token of appreciation for your time and willingness to share your thoughts with us.

Who to contact with questions?

If you and your care partner would like to participate or have any questions about this study, please contact Iris Wernher at 971-XXX-XXXX or XXX@pdx.edu.

Appendix B:

Recruitment Materials

Information distributed via email by community partners:

Hello!

My name is Iris Wernher. I'm a doctoral student at Portland State University. For my dissertation and in collaboration with OHSU's Layton Center, I am conducting a study about the definition of a "dementia-friendly community."

For this study, I am looking for individuals living with dementia, and their care partners, who are willing to participate in a short interview. You should still live at your home, that is, not in assisted living or memory care. I would like to ask you about your daily experiences in your community or neighborhood and about your thoughts on what a "dementia-friendly community" should be like.

If possible, I would like to talk with you and your care partner separately. Each conversation will take about 1 hour. I am happy to visit you at your home or another location that is convenient for you. As a token of my appreciation for your time, both you and your care partner will receive a \$20 gift card.

Attached is a flyer with some more information.

If you are interested in participating, or if you have any questions, please email me (XXX@pdx.edu) or call me at 971-XXX-XXXX.

I'm looking forward to talking to you!

Iris

Confirmation sent to participants via email or regular mail before the interview:

Dear [name of person with dementia] and [name of care partner],

Thank you for your interest in participating in my study about dementia-friendly communities! I'm sending you a **flyer** as an overview of what we will be doing. I'm also attaching two copies of a **short demographic questionnaire** – one for each of you to complete – and two copies of our **consent form** – one for each of you to sign.

I will collect these forms when we meet for our interview on **[date and time]**. I'm sending them in advance so you have some time to read and talk about them beforehand. We will also go over the consent form together when we meet in person. Please don't hesitate to let me know if you have any questions.

I'm looking forward to meeting you,

Iris Wernher
XXX@pdx.edu
971-XXX-XXXX (cell)

Participant name: _____

General screening questions for all participants:

Person with dementia

Relation to participating care partner: _____

Living together? Yes No

Frequency of contact during a typical week: ___ days/week for approx. ____ hours total

Onset of dementia (first time symptoms were noticed): _____

Formal diagnosis? Yes; type of dementia (if known): _____ No

Care partner paid for caregiving? Yes No

Willing/able to participate (Portland area, fluent in English)? Yes No

Care partner

Name: _____

Relation to person with dementia: _____

Living together? Yes No

Frequency of contact during a typical week: ___ days/week for approx. ____ hours total

Onset of dementia (first time symptoms were noticed): _____

Formal diagnosis? Yes; type of dementia (if known): _____ No

Care partner paid for caregiving? Yes No

Willing/able to participate (Portland area, fluent in English)? Yes No

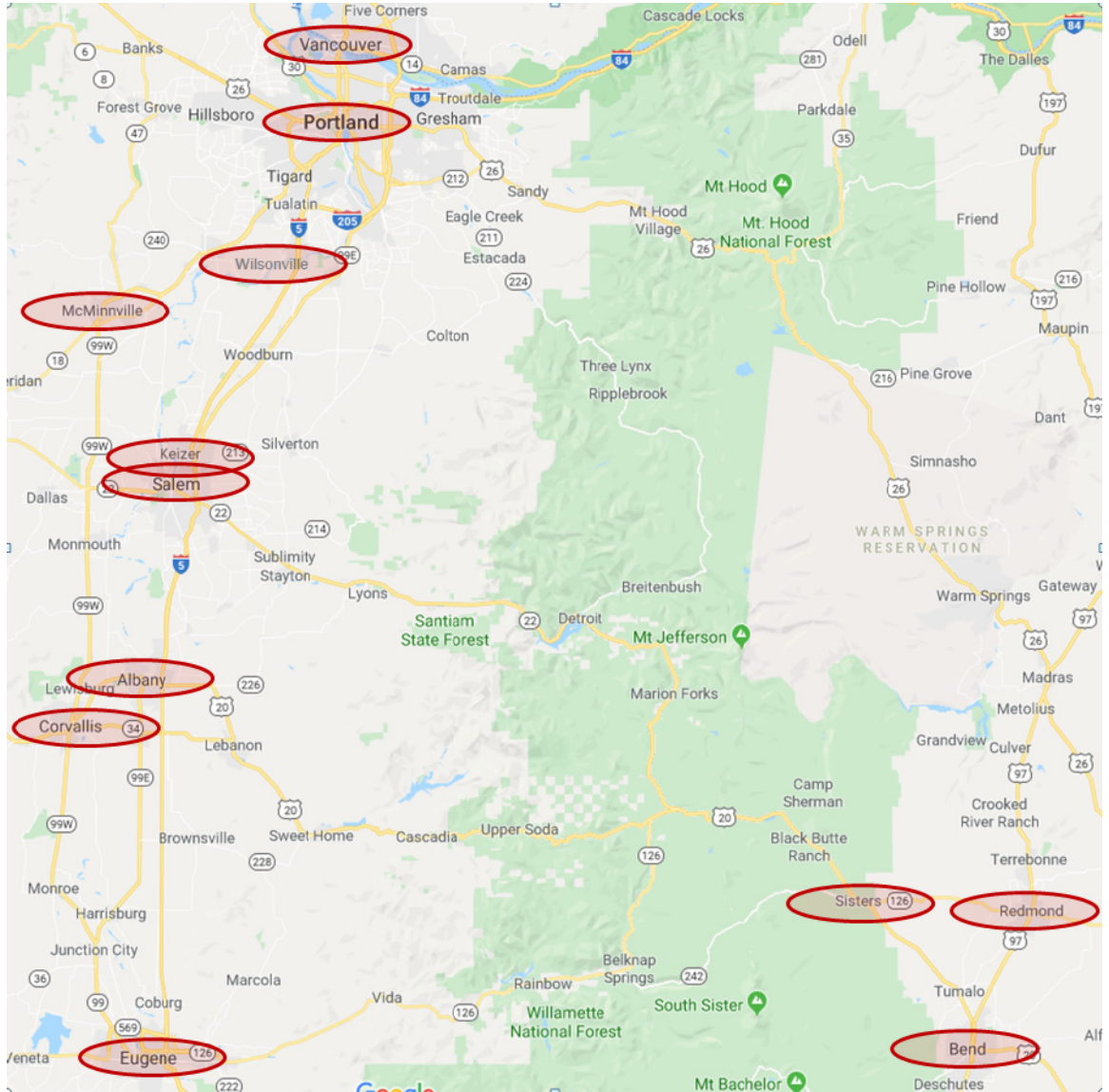
Preferred interview location: Own home / PSU / OHSU / Other: _____

Address: _____

Interview date and time: _____

Appendix C:

Interview Locations



Appendix D:

Interview Materials and Consent Form

Demographic participant information

Participant name: _____

DOB: _____ Gender: _____

Race: _____ Hispanic ethnicity? Yes No

Highest level of school completed:

- | | |
|---|---|
| <input type="checkbox"/> Less than high school degree | <input type="checkbox"/> Associate degree |
| <input type="checkbox"/> High school degree or equivalent (e.g., GED) | <input type="checkbox"/> Bachelor degree |
| <input type="checkbox"/> Some college, but no degree | <input type="checkbox"/> Graduate degree |

Currently working? Yes, number of hours/week: _____ No

Type of current/former work: _____

Yearly household income:

- | | | |
|---|--|---|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$75,000 - 99,999 | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> \$20,000 - 34,000 | <input type="checkbox"/> \$100,000 - 149,999 | |
| <input type="checkbox"/> \$35,000 - 49,999 | <input type="checkbox"/> \$150,000 - 199,999 | |
| <input type="checkbox"/> \$50,000 - 74,999 | <input type="checkbox"/> \$200,000 or more | |

Housing tenure: Owner Renter Other: _____

Type of residence:

- Single-family home
- Condo/apartment
- Cohousing
- Other: _____

Location of residence:

- City/urban
- Suburban
- Rural
- Other: _____

Other people in household:

- No, living alone
- Family members, number: _____
- Non-family room-/housemates, number: _____

Number of children, if any: _____ Number of children living nearby: _____

Consent to Participate in Research

**Defining Dementia-Friendly Communities
from the Perspective of Those Affected**

Introduction

My name is Iris Wernher, and I'm a doctoral student at the Institute on Aging at Portland State University. Supported by my academic advisor, Dr. Paula Carder, I am conducting a research study on the topic "Dementia-Friendly Communities."

We are inviting you and your care partner (e.g., family member or close friend) to take part in this study because you are, or your care partner is, living with dementia. The goal of this research is to understand the everyday experiences of people living with dementia and their care partners in their communities.

This form will explain some details of the research study. It will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this study.

What will happen if you agree to participate?

You will take part in a one-time, in-person interview at a time and location that are convenient for you. You and your care partner will be interviewed separately. I will speak with you about the things you like to do in your community and what makes your daily activities easier or more difficult. I will ask you what your community could do to become more "dementia friendly." The interviews will be audio-recorded for the purpose of transcription and should last no longer than one hour.

Risks/side effects of your participation

The protection of your privacy is very important to us. We will make sure that the interview takes place in a private room and quiet setting.

Since we will be talking about a sensitive topic (living with dementia), you may experience stress or emotional discomfort during the interview. You are free to skip any question you don't want to answer, and you can take a break whenever you need one. If, for any reason, you wish to end the interview, you can do that at any time.

Your decision to take part in this study is completely voluntary. You have the right to choose not to participate or to end your participation at any point without any negative consequences.

Benefits of your participation

While there is no direct benefit to participating in this study, your answers will help us to better understand the daily opportunities as well as challenges experienced by people living with dementia and their care partners. You will inform new ideas and recommendations for how Portland and other communities can become better places to live for people of all ages and abilities.

At the end of the study, we will send you a summary of the study results and keep you informed about events at which the study will be presented.

Confidentiality

We will be careful to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data. We will, however, make sure that all study material – including this form, audio recordings, and any notes – are kept in a secure place at all times. Only we, the research team, will have access to your personal information for research purposes.

The information we collect from you may be shared with approved researchers at the Oregon Health and Science University (OHSU) and stored in a data bank to conduct future research. Your name and other protected information will not appear in any published report, nor will we or the OHSU researchers use your answers in any way that could reveal your identity.

Exception: Because it is any researchers' legal obligation to report child abuse, child neglect, elder abuse, harm to self or others, or any life-threatening situation to the appropriate authorities, your confidentiality cannot be maintained in these cases.

Compensation

You will not be paid for taking part in this study. However, you will receive a \$20 gift card after the interview as a token of our thanks for your time and willingness to talk with us.

Questions

If you have any questions, concerns, or complaints about the research study, feel free to contact me (Iris Wernher) by phone (971-XXX-XXXX) or email (XXX@pdx.edu) at any time.

You can also contact the Office of Research Integrity (ORI) of Portland State University about your rights as a research participant. The telephone number is 503-725-2227.

CONSENT

By signing this form, you indicate that:

- You have **read** (or listened to) **and understood the information** provided on this form.
- You have had the opportunity to ask questions, and **all questions have been answered** to your satisfaction.
- You are **willing to participate** in this study, which means that you **agree to be interviewed** for one hour (maximum).
- You understand and agree that **your care partner** will also be interviewed. The participating care partner's name is: _____
- You give permission for the interview to be **audio-recorded**.
- You are aware that the **interview might cause some discomfort** for you.
- You understand that your **participation is voluntary** and that you can change your mind and **stop at any time**.

A copy of this consent form will be provided to you.

Participant's name, printed

Date

Participant's signature

Signature of care partner, in case the participant is unable to legally consent, but does agree to participate

INTERVIEWER SIGNATURE

This research study has been explained to the participant and all of his/her questions have been answered. The participant understands the information described in this consent form and freely consents to participate.

Interviewer signature (Iris Wernher)

Date

Interview questions for participants with dementia:

Q1: Please think about your daily activities – what sort of things do you usually do on a normal day?

[Prompts: “Think about the things you do at home/in your neighborhood/in the larger community.” Provide examples as needed.]

What helps you to do these things?

What makes it more difficult for you to do these things?

[Prompts: “Think about the physical environment/social environment/available services.” Provide examples as needed: Transportation, social support, etc.]

Q2: Are there things that you used to do, but have stopped doing? If so, why have you stopped doing them? [Clarify if interviewee would still like to be doing these things. If so:] What might help you to start doing them again?

[Prompts like above.]

Q3: Are there new things that you would like to be able to do in your community? If so, what? If you haven’t started doing these things, what do you feel is stopping you? What might help you to start doing them?

[Prompts like above.]

Q4: Some cities and communities in this country have made a pledge to become more dementia friendly. What, in your opinion, does that mean?

If you had a magic wand, what would you do to make your neighborhood, community, or city more dementia friendly?

[Prompt: Overview of domains of age friendliness, on paper. Ask what resonates with the interviewee, and if there’s anything they would want to add.]

Interview questions for care partners of participants with dementia:

Q1: Please think about your daily activities – what sort of things do you usually do on a normal day?

[Prompts: “Think about the things you do at home/in your neighborhood/in the larger community.” Provide examples as needed.]

What helps you to do these things?

What makes it more difficult for you to do these things?

[Prompts: “Think about the physical environment/social environment/available services.” Provide examples as needed: Transportation, social support, etc.]

How do you think *[person with dementia]* would answer this question?

Q2: Are there things that you used to do, but have stopped doing? If so, why have you stopped doing them? [Clarify if interviewee would still like to be doing these things. If so:] What might help you to start doing them again?

[Prompts like above.]

How do you think *[person with dementia]* would answer this question?

Q3: Are there new things that you would like to be able to do in your community? If so, what? If you haven’t started doing these things, what do you feel is stopping you? What might help you to start doing them?

[Prompts like above.]

How do you think *[person with dementia]* would answer this question?

Q4: Some cities and communities in this country have made a pledge to become more dementia friendly. What, in your opinion, does that mean?

If you had a magic wand, what would you do to make your neighborhood, community, or city more dementia friendly?

[Prompt: Overview of domains of age friendliness, on paper. Ask what resonates with the interviewee, and if there’s anything they would want to add.]

How do you think *[person with dementia]* would answer this question?

Domain of age friendliness shown at the interviews (downloaded from <https://www.cityofsanrafael.org/creating-an-age-friendly-and-livable-community>):

