



**Lee Steuer (S320810)**

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## **Who Cares for Caregivers?**

**Exploring social health among family caregivers of people  
living with dementia**

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## **Abstract**

This thesis explores social health among caregivers of people living with dementia. Secondary analysis of qualitative interview data draws new information and perspectives from existing data. This analysis is a secondary analysis of anonymized semi-structured qualitative interviews from an individual living with dementia and their family caregiver. It focuses on the experience of the family caregivers versus the experience of the person living with dementia. Family caregivers of people living with dementia have increasing care responsibilities. The individual and social impacts of these care responsibilities prove difficult to manage for some. While there has been increasing focus on the concept of social health to maximize the quality of life of people living with dementia, this concept has not been as closely examined as a measure of the wellbeing of family caregivers. Understanding social health as a maximization of quality of life and individual experience despite external factors which limit optimal wellness, an understanding of how best to meet the individual support needs of caregivers of those living with dementia can be conceptualized. This thesis identifies general coping strategies and variables affecting social health of family caregivers while also emphasizing that individualized policies promoting family caregiver wellness and risk mitigation would be most effective in dementia management frameworks.

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## **Introduction:**

Aging management, specifically policies related to dementia management and caregiver support, is of interest to the author of this thesis. After attending a university research fair and hearing of ongoing projects, the author joined an existing study, the “Neighborhoods: our people, our places” project, a five year initiative jointly funded by the United Kingdom’s Economic and Social Research Council and the National Institute for Health Research (UK). It is a qualitative longitudinal and comparative study exploring the meaning and experience, specifically the “lived experience”, of neighborhood for people affected by dementia (Ward et al., 2017). This analysis uses a sub-sample of data collected at the Manchester field site.

In discussion with two of the Manchester researchers, and through the author’s own interaction with the provided data, a distinct analysis was conducted. This analysis is a secondary analysis of 15 qualitative interview transcripts provided by study researchers, framed in different theoretical concepts, exploring different research questions, and focused on the experience of the family caregiver versus the experience of the person living with dementia. It is an independent work distinct from the original study but allied to the larger discussion of managing dementia in communities.

In this analysis grounded theory informs an understanding of the experience of family caregivers of those living with dementia. Specifically, how the caregivers negotiate the challenge of providing care to someone living with dementia while still accounting for their own well-being. Additionally, the concept of social health is defined and discussed to understand caregiver wellbeing and possible risk management interventions.

A literature review was conducted examining the prevalence of dementia, the challenges of caring for someone dementia, whether caregivers are included in care management plans, discourse on caregiver respite, the stigma oftentimes attached to dementia, and the role of social capital in building social networks of support for caregivers.

The findings and discussion sections are combined with direct quotations from the caregiver illuminating the themes identified, drawing on principles of grounded theory and a foreground discussion of the data. The individual experiences of dementia caregiving narrate the

larger conversation of how best to care for those caring for others. To that end, policy recommendations are suggested based on the themes revealed and a conceptualization of social health. The structure of the thesis is as follows: an introduction to dementia and social health, a presentation of the research questions, a literature review pertinent to caregiver experience, an overview of applicable methodology and theory, a findings and discussion section including policy recommendations, suggestions for future research, and a conclusion.

## **Prevalence of Dementia**

Dementia is a range of diseases or conditions of the brain with essential symptoms being: impairment in short and long-term memory, impairment in abstract thinking, impaired judgment and other disturbances of higher cortical function, along with personality changes (Robillard, 2007, p. 293).

According to the World Health Organization (WHO), dementia is chronic and progressive in nature, and the deterioration in cognitive function, or the ability to process thought, is beyond normal aging processes. The WHO also emphasizes that impairment in cognitive function is commonly accompanied and/or preceded by deterioration in emotional control, motivation, or social behavior (WHO, 2019b). According to the World Health Organization's Dementia Fact Sheet, about 50 million people have dementia, with nearly 60% living in low- and middle-income countries. And every year, there are nearly 10 million new cases (WHO, 2019b). The total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050. Much of this increase is attributable to the rising numbers of people with dementia living in low- and middle-income countries. Currently, of the general population aged 60 and over, the rate of dementia at a given time is between 5-8% (WHO, 2019b).

The financial toll of dementia is also notable. The social and economic implications of direct medical and social care costs, and the costs of informal care, are relevant impacts of dementia. According to the WHO, in 2015, "the total global societal cost of dementia was estimated to be US\$ 818 billion, equivalent to 1.1% of global gross domestic product (GDP). The total cost as a proportion of GDP varied from 0.2% in low- and middle-income countries to 1.4% in high-income countries (WHO, 2019b)."

In the United Kingdom, where this study data was collected, 850 million people are living with dementia, with 24.6 million people knowing someone with dementia (UK, 2019). Additionally, 1 in 3 people born in the United Kingdom in 2019 are predicted to develop dementia, with 1 in 4 people over 65 already having dementia. Scaling out further, 1 out of 79 people in the entire population of the UK currently have dementia (UK, 2019).

What these macro-level WHO facts and UK figures do not comprehensively reflect are the spouses, extended family, friends, and communities that are deeply affected by dementia. For each person living with dementia, or each new diagnosis of dementia, the waves of impact on that individual person's social network are profound. Caregiving matters come into question, quality of life issues come into question – for the person living with dementia as well as the families, friends, and communities involved. For the purposes of this analysis, the experience of the family caregiver of someone living with dementia is highlighted in order to illuminate that experience further.

### **Caregiving for Someone Living with Dementia**

The symptoms of dementia and progression of dementia vary person to person. However, caregivers must often cope with someone experiencing memory loss; aggression; depression, anxiety or apathy; difficulty sleeping; delusions and hallucinations; repetitive behavior; walking and getting lost; and changes in judgement (WHO, 2019a, p. 165).

The experiencing of caregiving for someone living with dementia is both objective and subjective. The “objective burden” of dementia care reflects the dependency of the person with dementia and the level of behavioral disturbance (Brodaty & Donkin, 2009, p. 219). The “subjective burden/strain” of dementia care is the caregiver's appraisal of the situation, including their personal evaluation of the physical and emotional impact as well as their psychological state, and resources (Brodaty & Donkin, 2009, p. 219). Therefore, a caregiver's maintenance of personal wellbeing while caring for someone living with dementia has both objective and subjective components, an important concept when understanding how best to support them.

## **Inspiration for Focus:**

As stated, this work is a secondary analysis of a sub-sample of qualitative interview data collected in Manchester, England. The focus of the original study was on the “lived experience” of people living with dementia. However, the author was inspired to focus on the experience of the spousal caregiver of the person living with dementia. This shift solely to the caregiver specific focus was the result of a few factors.

Firstly, to comply with the European Union’s General Protection Data Protection Regulation (GDPR), the transcripts were anonymized prior to sharing. This created a situation in which the voice of the family caregiver was more strongly reflected than the person living with dementia. In the interviews, the person living with dementia spoke less, used less descriptive language, and was ultimately more difficult to access and understand since the author was not there in space and time. Additionally, in discussion with two researchers affiliated with the study, the author concluded that there were new angles to take on the data by showcasing the experience and perspective of the family caregiver. Finally, the author has experience as a paid caregiver for the elderly and/or disabled, and that experience created interest in the impact of caregiving on a caregiver.

## **Dementia Management from a Social Health Perspective**

The exploration of the concept of social health emerged from critique of the World Health Organization’s 1948 definition of health, “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Huber et al., 2011). Huber et al’s critique emphasizes the absoluteness of the term “complete” and how in the age of chronic disease and infirmity, this medicalized and absolute definition is inadequate and often unattainable (Huber et al., 2011).

Huber et al assert that the WHO’s definition, “minimizes the role of the human capacity to cope autonomously with life’s every changing physical, emotional, and social challenges and to function with fulfillment and a feeling of wellbeing with a chronic disease or disability” (Huber et al., 2011, p. 2). Huber et al suggest moving away from a static definition of health to a dynamic understanding based on “the resilience or capacity to cope and maintain and restore



one's integrity, equilibrium, and sense of wellbeing" (Huber et al., 2011, p. 2). Huber et al articulate a specific understanding of social health (Huber et al., 2011, p. 2):

Several dimensions of health can be identified in the social domain, including people's capacity to fulfill their potential and obligations, the ability to manage their life with some degree of independence despite a medical condition, and the ability to participate in social activities including work. Health in this domain can be regarded as a dynamic balance between opportunities and limitations, shifting through life and affected by external conditions such as social and environmental challenges.

The conceptualization that the author uses for social health is based on the explanation above. And below is a simplified working definition creating specific measures of social health, based on Huber et al's articulation:

**Social Health:**

- People's capacity to fulfill their potential and obligations
- The ability to manage their life with some degree of independence
- The ability to participate in social activities including work
- Balancing opportunities and limitations, as affected by external conditions such as social and environmental challenges

Social health is the maximization of well-being despite a unique set of sub-optimal variables and circumstances. And while the social health definition articulated by Huber et al pertains to the person directly experiencing the chronic illness or condition, the author is using this definition for family caregivers because, they too, are experiencing constraints to maximizing and optimizing their wellbeing directly as the result of caregiving for someone living with dementia.

## **Research Questions:**

1. How do family caregivers manage and negotiate the challenge of providing care to a spouse living with dementia?
2. What variables are observed to affect social health? In this context, how could social health among family caregivers of people living with dementia be increased?
3. How does secondary analysis of anonymized semi-structured qualitative interview data affect the analytical process of a neophyte researcher?

## **Aims and Objectives:**

1. Conduct a literature review of pertinent topics (dementia caregiver challenges, social health in dementia management, perceived stigma of dementia, existing literature about respite and caregiver support, current approaches to dementia case management which include input from and concern toward the family caregiver, social network development) and identify research gap(s)
2. Conduct a secondary qualitative analysis specific to the experience of the dementia caregiver
3. Position this analysis within policies supporting the social health of dementia caregivers
4. Reflect on the effectiveness of using anonymized semi-structured qualitative interview data for secondary data analysis

## **Literature Review:**

A literature review was conducted to understand the experience of caregiving for a family member living dementia. Additionally, an overview of the concept of social health and its representation in discussions on dementia was completed. The concepts of person-centered care, integrated care, caregiver support interventions, stigma, and understandings of respite and social capital are also illuminated for a multi-dimensional understanding of the experience of caregiving for a spouse living with dementia. Taken as a whole, these concepts provide a foundation from which to build an understanding of how family caregivers manage and negotiate the challenge of providing care to a loved one living with dementia, while still accounting and providing for their own wellbeing.

The literature is vast when it comes to the social impact and relational effects of dementia. However, there is a research gap when it comes to understanding the nuances of social health for family caregivers of those living with dementia. Oftentimes, caregivers are a tool in the toolbox of dementia management, not subjects of concern unto themselves. Additionally, an understanding and measure of social health is still an emerging concept in terms of quantifiable measures and policy applications (Vernooij-Dassen, Moniz-Cook, & Jeon, 2018).

## **The Responsibility and Importance of the Family Caregiver in Dementia Management**

The role of the informal and/or family caregiver is increasingly important in society. As dementia progresses a person becomes more dependent on others for assistance with daily living. Reductions in cognitive and physical function adversely affect quality of life for the person living with dementia and create considerable burdens of care for the caregiver. And this high need for care typically culminates in the need for the person living with dementia to move to residential care (Clemson et al., 2018).

Prior to residential placement, dementia care is typically provided by an informal or family caregiver (Brodaty & Donkin, 2009). And without these informal caregivers, individuals living with dementia would need institutional care more quickly. From a policy standpoint, a quick and extended placement in institutional care would quickly overwhelm national economies due to the costs and resources associated with providing dementia care (Brodaty & Donkin,

2009). Thus, according to the articles and literature reviewed, it is important to develop policies and interventions to support caregivers and people living with dementia in the period prior to residential placement. The hope would also be to even delay placement in residential facilities, so long as the caregiver is not overwhelmed by the burden of care.

### **Course of Dementia:**

The usual course of dementia is 3 to over 9 years, with dementia symptoms changing over time (Huang et al., 2015, p. 135). At the beginning of dementia, self-care deficits occur and increase over time with oftentimes distressing behavioral changes occurring in late dementia (Huang et al., 2015, p. 135). Thus, a person with dementia's needs and thus a caregivers' role will both change over time. Also, the emotional toll on the family caregiver as the person they know and love changes, can be pronounced.

Disease recognition and diagnosis of dementia depends on aspects such as: healthcare infrastructure, underlying socioeconomic conditions, cultural norms, modes of caring for the elderly, access to healthcare, age structure, and recognition of pathological changes in function (Launer, 2019, p. 26). Since the 1980s, there have been attempts to standardize dementia and Alzheimer's disease (a form of dementia) assessment and diagnosis. However, since dementia is a multisystem condition, its definition is still evolving in research and clinical settings (Launer, 2019, p. 26).

### **Perception of Dementia and Associated Stigma**

According to Gove et al, dementia is perceived in different ways by the public at large: as a predominantly biomedical condition, a natural part of aging, or as a mental disorder or 'insanity' (Gove, Small, Downs, & Vernooij-Dassen, 2017, p. 949). In recent years, attention to the rights, dignity and well-being of people living with dementia has increased; however, dementia is often still perceived as a stigma (Gove et al., 2017, p. 949). According to Gove et al, "Stigma is a complex social phenomenon involving a process whereby people sharing a socially salient group difference are identified and subsequently devalued and discriminated against, either overtly or covertly" (Gove et al., 2017, p. 949). Gove also notes that stigma can be a process where the person or group internalizes the perceived stigmatizing attitude of others

(Gove et al., 2017, p. 949). Ultimately, the consensus among researchers is the stigma of dementia should be challenged and that “we need to understand better the meanings associated with dementia which contribute toward it being perceived as a stigma and to the stigmatization of those with dementia, which in some cases extends to their family and friends” (Gove et al., 2017, p. 949).

In addition to the social and emotional impact of the perception of dementia as a stigma, the stigma of dementia has been linked to delays in timely diagnosis, thereby impacting health care access and treatment (Gove et al., 2017, p. 949). Thus, the fear of social exclusion associated with a stigmatizing diagnosis contributes to a fear of embarking on a diagnostic procedure for dementia (Vernooij-Dassen et al., 2018, p. 775).

### **What does family caregiving look like?**

The concept of care providers and care managers is a helpful way to understand approaches to caregiving. Typically care providers handle the hands-on care, i.e. dressing, daily activities and finances. Care managers typically arrange for other people to provide the care to the person living with dementia. Spouses are typically care providers and adult children and other relatives tend to be care managers (Brodaty & Donkin, 2009, p. 218).

In this context, dementia is associated with long care hours filled with physically and emotionally demanding caregiving, and many studies have concluded that caregivers of those with dementia, especially spousal care providers, have higher levels of burden than other caregivers (Brodaty & Donkin, 2009, p. 218).

However, studies also show that maintaining social engagement next to the caregiver role enhances feelings of well-being, and may delay placement of the person living with dementia, that they are caregiving for, in institutional care (Dam, Boots, van Boxtel, Verhey, & de Vugt, 2018, p. 881).

### **Responsibilities of Family Caregivers**

Family caregivers of people living with dementia have time-consuming decision-making responsibilities, especially during the phase of exploring options once the loved one receives a

dementia diagnosis (Huang et al., 2015, p. 135). In this context, the caregiver's acceptance of the diagnosis is also important to decreasing the person living with dementia's anxiety and resistance to care, but few studies describe and compare caregiving experiences at different stages of dementia illness trajectory (Huang et al., 2015, p. 136). However, Huang et al conducted a study of caregiver responsibility in relation to disease trajectory and found that in mild dementia, transportation assistance was most present (Huang et al., 2015, p. 140). While in moderate and severe dementia, protection, housekeeping, and personal care interventions increased (Huang et al., 2015, p. 140).

Ultimately, studies show that the effects of caregiving are complex and varied, and that caring for a person with dementia is more emotionally taxing and stressful than caring for someone with a physical disability (Brodaty & Donkin, 2009, p. 219). Dementia caregiving is also associated with social isolation and loneliness, indicating that social support for caregivers is not always available (Dam et al., 2018, p. 881).

### **What motivates a family caregiver?**

Family caregivers can be motivated to care for a family member for a variety of reasons. Feelings of love and commitment, reciprocal bonding, spiritual fulfillment, sense of duty and/or guilt, societal pressure and expectations, or even access to the financial resources, or lack of financial resources, connected to the person living with dementia are notable motivations (Brodaty & Donkin, 2009). According to Brodaty and Donkin, caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent the role of caregiver and subsequently suffer from greater psychological distress than those reporting more "positive" motivations, like love or spiritual fulfillment for example (Brodaty & Donkin, 2009, p. 218).

### **Managing Dementia from a Social Health Standpoint**

In 2018 the journal *International Psychogeriatrics* devoted an entire edition to articles exploring the concept of social health in relation to dementia. Some of these articles, reviewed below, showcase the concept of social health as an emerging way to reflect on maximization of wellbeing despite limiting circumstances.

Vernooij–Dassen and Jeon argue that three decades of psychosocial research on dementia care reveal the power of social engagement, environmental support, as well as the remaining capabilities that exist for people living with dementia. They assert the concept of social health is an overarching lens through which health and well-being of people with dementia can be brought into focus. From their perspective, social health would be promoted by restorative care, reablement, tailored activities and environmental modifications, and person-centered care. Additionally, they make the point, that at its foundation, social health reflects endeavors to promote and or restore reciprocity, dignity and resilience (Vernooij-Dassen & Jeon, 2016, pp. 701-702).

They further explain that as Huber et al first articulated, social health involves a dynamic balance between opportunities and limitations, with external conditions such as social and environmental challenges playing a key role (Vernooij-Dassen & Jeon, 2016, p. 701). Vernooij-Dassen and Jeon, as Huber et al before, assert that the concept of social health addresses the gap within the World Health Organization’s definition of health, “a state of complete physical, mental, and social well-being” in that social health acknowledges adapting to limitations and while maximizing opportunities, allowing people to live as fully as possible despite chronic illness or less than optimal conditions of health and wellness (Vernooij-Dassen & Jeon, 2016, p. 701).

Ultimately, according to Vernooij-Dassen and Y.H. Jeon, social health is “still an underestimated opportunity in the medical community”, and they encourage looking beyond a biomedical model of health care delivery and policy making and ushering in social health as a new paradigm in dementia care (Vernooij-Dassen & Jeon, 2016, p. 702).

## Social Support to Improve Social Health

In a qualitative study, Dam et al found six themes related to supply and demand of social support in dementia care, for caregivers, and the categories within these show the balancing act of caregivers asking and receiving the support they need and want. Below is a table representation explaining the themes and categories presented in that analysis. (Dam et al., 2018, p. 884).

Themes	Categories
<b>Barriers to ask for support</b>	<ul style="list-style-type: none"> <li>• <b>Maintaining autonomy</b></li> <li>• <b>Preventing becoming a burden to others</b></li> <li>• <b>Protection and love toward the person living with dementia (PLwD)</b></li> <li>• <b>Incomprehension by the social environment</b></li> <li>• <b>Feelings of isolation/loneliness</b></li> <li>• <b>Practical factors (energy, time, and distance)</b></li> <li>• <b>Not experiencing an urgent need for help</b></li> </ul>
<b>Facilitating factors to ask for support</b>	<ul style="list-style-type: none"> <li>• <b>Awareness that need for support is a necessity</b></li> <li>• <b>Positive experience with support</b></li> <li>• <b>Social participation and connectedness</b></li> <li>• <b>Good quality relationships</b></li> </ul>



<b>Barriers to offer support</b>	<ul style="list-style-type: none"> <li>• <b>No insight into support needs and at which moment</b></li> <li>• <b>Rejection or confrontation with the spouse and the PwD</b></li> <li>• <b>Fear to stigmatize partner or PwD</b></li> <li>• <b>Practical factors (time and distance)</b></li> </ul>
<b>Facilitating factors to offer support</b>	<ul style="list-style-type: none"> <li>• <b>Support for better or for worse (positive focus)</b></li> <li>• <b>Good quality and cooperating relationships within the network</b></li> <li>• <b>Observed decline in health and mood</b></li> </ul>
<b>Mismatch between supply and demand</b>	<ul style="list-style-type: none"> <li>• <b>Cognitive bias regarding each other's intentions</b></li> <li>• <b>Unfulfilled expectations</b></li> </ul>
<b>Openness in communication to repair the imbalance</b>	<ul style="list-style-type: none"> <li>• <b>Early social network mobilization and involvement</b></li> <li>• <b>Openness in communication</b></li> <li>• <b>Early education and raising awareness by healthcare professionals</b></li> <li>• <b>Reciprocity/equality in relationships</b></li> </ul>

In Dam et al's study, interview data demonstrates that spousal caregivers experience social support needs such as respite care, emotional support and practical support (Dam et al., 2018, p. 883). The study also notes that the maintenance of a social network enabled caregivers

to have feelings of usefulness, worthiness and belongingness next to the caregiver role (Dam et al., 2018, p. 883).

Their study demonstrated a mismatch between the need and provision of social support, and highlighted the intention to ask for support or provide support not translating into a specific action (Dam et al., 2018, p. 887). Explaining this, a cognitive bias was observed among the caregivers and their social network. “They tended to think for others and might incorrect or unverified presumptions concerning each other’s needs and intentions, which prevented tangible support seeking and support provision” (Dam et al., 2018, p. 887). To address this mismatch, caregivers and social network members “emphasized that more openness in communication is required in both informal social networks and formal healthcare settings in an earlier phase of disease. As reported sharing needs and wishes and mapping support opportunities might increase involvement and awareness of support needs” (Dam et al., 2018, p. 888).

As discussed above, a focus on social health in the context of dementia management seeks to counterbalance the emphasis on biomedical, cognitive and functional status in dementia typically present in empirical studies (Vernooij-Dassen et al., 2018, p. 775). In the words of Vernooij-Dassen et al, “social health goes beyond the neuropathology of dementia, to understand how people, their social networks and wider society with its norms, interact with the condition” (Vernooij-Dassen et al., 2018, p. 775).

### **Knowing When a Caregiver Needs Additional Support**

According to Moniz-Cook et al, there are over a dozen Quality of Life (QOL) rating scales for people living with dementia and the conceptual basis for QOL measurement is ever increasing. And for family caregiver QOL, two conceptually distinct measures exist, health-related and disease-specific tools (Moniz-Cook et al., 2008). Notably, the COPE (Caregivers of Older People in Europe) Index, as identified by Whalen and Buchholz, measures caregiver subjective perceptions of positive and negative aspects of caregiving (Moniz-Cook et al., 2008, p. 21). It was developed as a first-stage assessment to identify caregivers who may need supportive interventions. Within the COPE index (Juntunen, Nikander, Törmäkangas, Tillman, & Salminen, 2017, p. 103):

A caregiver is seen as a partner and expert rather than a resource, and this holistic view of caregiving includes both perceived positive and negative aspects of caregiving in light of existing support. Highlighting positive aspects of caregiving can give experiences of empowerment for caregivers, and pointing out negative impacts can help targeting their supportive actions more accurately.

The COPE Index is a comprehensive 80 item questionnaire, but has been adapted by researchers such as Juntunen et al into briefer 15 question questionnaires measuring three subscales: Negative Impact (i.e. Do you find caregiving too demanding?), Positive Value (i.e. Do you find caregiving worthwhile?), and Quality of Support (i.e. Do you feel supported by your friends and your neighbors?) (Juntunen et al., 2017, p. 103).

In introducing a discussion on what can be done to help caregivers manage caregiving for a loved one living with dementia, a one-size-fits-all approach is not effective according to de Vugt and Verhey, they note that “Caregiver burden is a multi-component construct, influenced by the characteristics of both the person with dementia (e.g., behavioral problems) and the caregiver (e.g., perceived stress, psychological wellbeing, lack of knowledge, immature coping), as well as the social context (e.g., finances, social support, family help” (de Vugt & Verhey, 2013, p. 55).

As noted before by other researchers (Brodaty & Donkin, 2009), de Vugt and Verhey discuss objective and subjective burdens of caregiving. They note objective burden of caregiving as aspects such as time spent caregiving and the specific tasks that are performed while caregiving whereas subjective burden refers to the emotional reaction of caregiving, such as feeling exhausted or incompetent (de Vugt & Verhey, 2013, p. 55). Subjective burden is distinct from psychiatric symptoms, such as anxiety and depression (de Vugt & Verhey, 2013, p. 55). In conclusion, de Vugt and Verhey state “caregivers differ in their competence and skills” to manage the day to day manifestations of dementia (de Vugt & Verhey, 2013, p. 55).

### **How is Dementia responded to socially from a Local Case Management Perspective?**

Articles were reviewed which looked at how family members are incorporated into dementia management plans. One approach in the United Kingdom is Integrated Care, the

overall aim of which is a holistic view of care that incorporates health and social care needs of the patient living with dementia (Robertshaw & Cross, 2019, p. 1498).

A study was conducted in the United Kingdom to identify the views and experiences of Integrated Care from the perspective of caregivers and family members living with dementia, healthcare professionals, and researchers (Robertshaw & Cross, 2019, p. 1497) . The three themes which emerged from the data were: achieving person-centered holistic care, challenges of Integrated Care, and roles and diffusion of responsibility (Robertshaw & Cross, 2019, p. 1497). One of the takeaways of this study was (Robertshaw & Cross, 2019, p. 1499):

Participants recognized that the person with dementia's community and the people within it (including family, government and clubs in addition to health professionals) could play a strong role in influencing care planning. Under this view, Integrated Care is seen as broader than health and social care but also included the community to retain person-centered approach that dementia requires. This was seen as important in recognition that each person with dementia has unique needs as a result of symptom heterogeneity and different psycho-social support needs.

In the United Kingdom, when someone is diagnosed with dementia their informal caregiver is entitled to a free "carer's assessment" through the National Health System (NHS). This assessment gives advice about the experience of caregiving, puts people in touch with resources, and gives more information about what dementia might mean for the person they are caring for in terms of behavior, cognitive difficulties, and other experiences (NHS, 2019).

In the Netherlands, Geriant is an organization providing community-based services for people living with dementia. The organization "provides clients and their informal caregivers with care and support from the first presumption of dementia until the client moved to a care home or deceases" (Glimmerveen & Nies, 2015, p. 1). Throughout the trajectory of the dementia experience, a case manager supports the person living with dementia and the caregiver, coordinating care services and providing treatment or counseling as well (Glimmerveen & Nies, 2015). Also, throughout the trajectory of case management, the client's (person living with

dementia) informal caregiver is explicitly included as a target group of Geriant's activities. They are not seen as just a resource, but "approached as co-clients who might also need counselling, training and support. Geriant acknowledges that overburdening of informal caregivers, even in the initial stages of clients' care, is one of the main reasons for admission to a nursing home" (Glimmerveen & Nies, 2015, p. 4).

### **Person-Centered Care and Personalization in a Dementia Context:**

The concept of person-centered care emerged through the course of the literature review. According to Brooker, person-centered care encompasses four elements, VIPS (Brooker, 2004, p. 216):

1. Valuing people with dementia and those who care for them (V)
2. Treating people as individuals (I)
3. Looking at the world from the perspective of the person with dementia (P)
4. A positive social environment in which the person living with dementia can experience relative well-being (S)

The term person-centered care has its roots in the work of psychotherapist Carl Rogers and his emphasis on seeing the person receiving treatment as being the expert on themselves, and the therapist being a facilitator to their improved wellbeing (Brooker, 2004, p. 215). Person-centered care in relation to dementia has also been influenced by the work of Tom Kitwood who distinguished person-centered approaches from medical and behavioral management approaches (Brooker, 2004, p. 215).

Kitwood's view of person-centered care for people with dementia is that occurs in the context of relationships, and those relationships are based on the concept of personhood which he defined as, 'a standing or status that is bestowed on one human being by others in the context of relationship and social being. It implies recognition, respect and trust.' (Brooker, 2004, p. 218). Ultimately, a "person centered approach" to care was first used by Kitwood to distinguish methods of working with people living with dementia outside of a strictly biological or technical model (Brooker, 2004, p. 219).

In the United Kingdom, another concept increasingly relevant to dementia management is person-centered care and its evolution toward personalization, a government policy to extend

individuals' choice and control over their social care and ways to meet health care needs (Manthorpe & Samsi, 2016, p. 1733). This evolution of person-centered care has its origins in critical perspectives on practice and social responses to people living with dementia (Manthorpe & Samsi, 2016, p. 1733). Reflecting about person-centered care and movements toward personalization, Manthorpe & Samsi caution (Manthorpe & Samsi, 2016, p. 1739):

Care is needed in using them (personhood, person-centered care and planning, and later ideas of personalization) and presuming that definitions are necessarily shared or that they can be conventionally measured as processes or outcomes. The fundamental values behind them may need to be highlighted and critical perspectives should not be muted just because they seem to be implicitly positive.

### **Caregiver Resources**

The World Health Organization has a 273-page downloadable i-tutorial for caregivers. Specifically the document aims to be aims “to prevent and/or decrease mental and physical health problems associated with caregiving and to improve the quality of life of those caring for people with dementia” (WHO, 2019c). The downloadable resource outlines dementia, its effects, and what caregivers can anticipate while caring for someone with dementia. It also provides interactive exercises for the caregivers to work through to develop better management strategies for their specific caregiving situation.

### **Reflections on the Concept of Caregiver Respite:**

In her article, “We Build Vacations into Everyday Life: Rethinking Carers’ Restorative Experiences Through the Lens of Place”, Silverman reflects on the concept of respite. She notes that respite is traditionally seen as giving families a break, a service given to them to prevent burnout and allow them to continue in their caregiving role, thus allowing the vulnerable family member to remain in the community and out of institutional care for as long as possible (Silverman, 2018, p. 1). Silverman also notes the importance of Chappell et al’s work in which carers identified respite as multifaceted, made up of both internal states and external activities

achievable within or without the presence of the care recipient, and as something which can be attained through social connections as well as mental or physical activities (Silverman, 2018, p. 2).

By definition and concept, respite means a pause, a temporary cessation, or an interval of rest (Chappell, Reid, & Dow, 2001, p. 202). In practice and in research, “respite is described as a service or a group of services that provide periods of relief or rest for caregivers away from care receivers” (Chappell et al., 2001, p. 202). The services are provided with the goal of strengthening informal caregivers in their efforts to care for elderly or disabled persons in the community (Chappell et al., 2001, p. 202).

According to Chappell et al, caregiver respite has been conceptualized as a service rather than an outcome (Chappell et al., 2001). In her research, she focused on the significance of allowing the meaning of respite to be determined by the caregiver. By collecting and reviewing nearly three hundred interviews of caregivers, six themes emerged related to caregiver respite: Stolen Moments, Relief, Physical/Mental Stimulus, Connections, Minimizing its Importance, and Angst-Free Care Receivers. Her study recommended that *policymakers and service providers redefine respite as an outcome rather than a service*. 60% of the caregivers interviewed in her study redefined a “break” in ways that policy makers, professionals, and researchers would not (Chappell et al., 2001). For the sake of context and relevance about the importance of defining and understanding respite from the caregiver perspective, informal caregiving of seniors has been well-documented as the first resort of care and predominant source of care, 75-80% of all personal care in industrialized countries, regardless of whether the country provides universal healthcare (Chappell et al., 2001, p. 202).

### **How Caregivers Experience Respite**

In the research of Chappell et al six meanings of respite emerged: stolen moments; connections; relief; mental or physical stimulus; angst-free care receiver; and minimizing importance (Chappell et al., 2001).

*Stolen moments* are brief periods of time away from caregiving but do not take place outside of their daily routine. It includes activities such as running errands to taking the dog for a walk, taking a bath, and having a haircut etc. An activity qualifies as a stolen moment when it is

a) something that has to be done (like grocery shopping) b) is something that may be enjoyable for the caregiver but it part of a regular routine such as watching the news or reading before bed c) it is associated with caregiving but provides a change of pace or scenery and, therefore is something of a break even though it is still part of their caregiving daily routine (Chappell et al., 2001, p. 207).

*Connections* refers to social involvement and making connections with other people either in social interactions or as part of support groups. Individuals were placed in this category “only if they perceive such contacts as providing a break in and of themselves (Chappell et al., 2001, p. 207).” Chappell et al emphasize in this category that the connection with other people, regardless of the activity, is what mattered to these individuals.

*Relief* is a separation from caregiving, essentially a more traditional definition of respite, and distinct from *stolen moments* in that “the caregiver specifies that an activity is a complete physical and mental break from the caregiving, an opportunity to distance not only the body but also the mind from the care receiver” (Chappell et al., 2001, p. 208). Breaks such as these entail a vacation or an activity of extended duration during which the caregiver is out of touch with the care receiver. In this category the caregiver attains freedom from concern through disengagement of the mind, whereas in the next category engagement of the mind is the respite for the caregiver (Chappell et al., 2001, p. 208).

The category of *mental or physical stimulus* refers to challenges not associated with caregiving which engage the mind or the body in an all-encompassing manner (Chappell et al., 2001, p. 208). Activities such as hiking, tinkering with electronics, or having seasonal or part-time work as an accountant, for example, were representative of this category. Chappell et al specify that “the activity qualifies only if it provides an all-encompassing absorption, not if the activity is burdensome” (Chappell et al., 2001, p. 208).

Respite through the form of an *angst-free care receiver* is when the caregiver experiences respite due to the care receiver being relatively happy/comfortable/angst-free. In this example, “it is not the person from which they need a break, but their condition” (Chappell et al., 2001, p. 208). According to Chappell et al, there is also a category of caregivers who claim they do not need a break, instead they *minimize the importance* of respite. In this description “some caregivers insist that a break is simply not an issue in their case, in effect, minimizing the



importance of having a break from their caregiving situation” (Chappell et al., 2001, p. 209). Chappell go on to those that this category “refers almost exclusively, but not entirely, to spouses caring for spouses, who frequently cite wedding vows when explaining their position – to love and to cherish, in sickness and in health” (Chappell et al., 2001, p. 209).

Chappell et al further broke down these themes between internal respite and external respite, citing percentages according to the breakdown among the group. The table below is adapted from one in Chappell et al’s article (Chappell et al., 2001, p. 209). Their sample is of caregivers of seniors in Victoria, British Columbia (Canada).

Type of Respite	Theme	Percent of Categories indicating Theme	Total percentage by Type
Internal Respite	Stolen Moments	48.1	
Internal Respite	Minimize Importance	12.0	61.3
Internal Respite	Angst-free care receiver	1.2	
External Respite	Relief	18.3	
External Respite	Mental/physical boost	11.2	38.6
External Respite	Connections	9.1	

Most caregivers, according to the study by Chappell et al, identify with experiences of *internal respite*, with the highest percentage finding comfort breaks in *stolen moments* throughout their daily routine.

While respite can be an individual experience, as members of communities, the social bonds and support networks available caregivers are influenced by social and community dynamics. The concept of social capital is a way to understand the network of support available, or not available, to family caregivers.

## **Building Social Capital in Communities:**

Social capital, can be defined as, “the goodwill that is engendered by the fabric of social relations and that can be mobilized to facilitate action” (Adler, 2002, p. 17). The concept of social capital reflects something we all know from our life and experience, that social connection of one kind, such as friendship, can be used for other purposes, including moral and material support or work and non-work advice (Adler, 2002, p. 17).

There are many working definitions of social capital. The definitions vary based on whether the focus is on the substance, the sources or the effects of social capital as well as whether its dependent on the relations an actor maintains with other actors, the structure of relations among actors within a collectivity or both (Adler, 2002, p. 19). For the purposes of this analysis, the structure of social relations within the context of social health and wellbeing is relevant.

Social capital’s sources lie in the social structure within which the individual is located. Thus, social capital is the resource available to actors as a function of their placement and location within the structure of their social network (Adler, 2002, p. 18). Conceptually, there are three dimensions of social structure to focus on: market relations (products and services are exchanged for money or bartered), hierarchical relations (obedience to authority is exchanged for material and spiritual security), and social relations (favor and gifts are exchanged) (Adler, 2002, p. 18). The third dimension, social relations, is what underlies social capital and is the dimension relevant to this analysis.

Social capital can be described as consisting of seven domains, listed below, and within each of those seven domains, there are opportunities for policy development. This list is adapted from Table 5 in the relevant article (Forrest & Kearns, 2001, p. 2140):

*Empowerment:* empowerment is when people feel they have a voice (which is listened to); are involved in situations and circumstances which affect the; and when they themselves can act to initiate change in their own lives and circumstances.

- What this looks like as policy: Anything that provides support to community groups; giving locals a voice; helping provide solutions to problems; and giving local people a direct in policy processes

*Participation:* people taking part in social and community activities; local events occurring which are well-attended.

- What this looks like as policy: establishing/supporting local activities and local organizations; publicizing local events.

*Associational activity and common purpose:* people cooperating with one another through the formation of informal and formal groups to further their interests.

- What this looks like as policy: developing and supporting networks between organizations and groups in the area.

*Supporting networks and reciprocity:* That individuals and organizations cooperate to support one another for either mutual or one-sided gain; an expectation that help would be given to or received from others when needed.

- What this looks like as policy: creating, developing and/or supporting an ethos of cooperation between individuals and organizations which develop ideas of community support; good neighbor award schemes.

*Collective norms and values:* That people share common values and norms of behavior

- What this looks like as policy: developing and promulgating an ethos which residents recognize and accept; securing harmonious social relations; promoting community interests.

*Trust:* That people feel they can trust other people in their community as well as local organizations responsible for governing or serving their area.

- What this looks like as policy: Encouraging trust in residents in their relationships with each other; delivering on policy promises; bringing conflicting groups together and working toward reconciliation.

*Safety:* People feel secure in their neighborhood and are not restricted in their use of public spaces as a result of fear of safety or well-being.

- What this looks like as policy: Encouraging a sense of safety in residents; involving them in local crime prevention; providing visible evidence of security measures and actions.

*Belonging:* People feel connected to other co-residents of their community, feel connected to their home area, and have a sense of belonging to the place and its people.

- What this looks like as a local policy: Creating, developing and supporting a sense of belonging in residents; boosting the identify of a place by neighborhood design; street furnishings and naming of streets and public spaces in the community.

Social capital is notable for what one does with it, or can attain by it (Forrest & Kearns, 2001, p. 2141). The question then arises of how social cohesion and social capital can be operationalized in local urban policy and research (Forrest & Kearns, 2001). According to Forrest and Kearns, one argument is that social cohesion at the societal level may be derived from the forms and quality of social interaction at the local level (Forrest & Kearns, 2001, p. 2137). So in this sense, social cohesion is viewed as a bottom-up process founded upon local social capital versus top-down overall society level social capital trends trickling down to local communities (Forrest & Kearns, 2001, p. 2137).

From a policy perspective, breaking down social capital into manageable elements which can transfer from “abstraction to implementation” (Forrest & Kearns, 2001, p. 2139) in terms of identifying the phenomena to be influenced and creating an intervention, would be helpful to policy makers. Adler in his article references that social capital needs maintenance, social bonds need to be periodically renewed and reconfirmed or they lose efficacy (Adler, 2002, p. 22). Therefore, if a person living with dementia and their caregiver are not out in the community, or being visited by the community, it is difficult for those individuals to stay connected.

### **Social Capital and Health**

Murayama et al conducted a review of prospective multilevel studies of the association between social capital and health and noted the intervention strategies which enhance social

capital. Their working definition(s) of social capital are presented in the following table (Murayama, Fujiwara, & Kawachi, 2012, p. 180):

<b>Social Capital</b>		
<b>Cognitive Social Capital</b> (people’s perceptions of the level of interpersonal trust, sharing, and reciprocity)		<b>Structural Social Capital</b> (density of social networks, or patterns of civic engagement)
<b>Bonding Social Capital</b> (relationships within homogeneous groups (i.e., strong ties that connect family members, neighbors, and close friends and colleagues)		<b>Bridging Social Capital</b> (links between individuals/groups in different structural positions of power (i.e., weak ties that link different ethnic and occupational backgrounds); can refer to links above and below)

Murayama et al discuss mechanisms by which social capital exerts an effect on an individual’s health. Attributing to Kawachi and Berkman, they identify the following four pathways: diffusion of knowledge on health promotion, maintenance of healthy behavioral norms through informal social control, promotion of access to local services and amenities, and psychological processes that provide affective support and mutual respect (Murayama et al., 2012, p. 181). Murayama et al emphasize establishing a causal relationship between social capital and health in order to develop intervention strategies. However, they caution against reverse causality, such as good health determining social capital rather the reverse (Murayama et al., 2012).

Accounting for impediments to causal inference, Murayama et al divided their analysis into measures of workplace and community social capital and looked at the following as measures of health: mortality, hospitalization, self-rated health, health-related behavior, and depression (Murayama et al., 2012). Their review indicated that both area/workplace social capital and individual social capital appear to have positive effects on health outcomes, but that due to the limited number of studies, the robustness of the evidence is questionable. Additionally they noted that, “social capital does not always generate a beneficial effect on health outcomes: the effect of social capital may provide a benefit for one population while disadvantaging another” (Murayama et al., 2012, p. 184).

### **Summary of Literature Review:**

Theories and approaches to dementia management, caregiver support and social relations as explained through social capital, are relevant to the experience of family caregivers of people living with dementia. These elements form a from which to increase the social health of family caregivers.

## **Research Design**

### **Data Origin**

The data analyzed is from the, “Neighborhoods: our people, our places” project, a five year initiative jointly funded by the United Kingdom’s Economic and Social Research Council and the National Institute for Health Research (UK). It is a qualitative longitudinal and comparative study exploring the meaning and experience of neighborhood for people affected by dementia. The study aims to understand how the onset and progression of dementia is managed in the context of a focused neighborhood environment (Ward et al., 2017). Individuals living with dementia and their primary caregiver were interviewed. The study began in 2014 and ended in spring of 2019. Specifically, the goal of the study was understanding “lived experience” in communities and how the onset and progression of dementia is managed in this context (Ward et al., 2017). Ultimately, the research is meant to inform the design and piloting of neighborhood-based interventions for dementia management. The study has three field sites: Manchester, Central Scotland and Linkoping, Sweden. This paper solely focuses on the Manchester field site.

An underlying theme of the study was creating a clearer understanding of the capabilities, capacities, and competencies of people living with dementia, as well as the contribution of social engagement and environmental support to social health. In the study, concepts of social health and citizenship were drawn upon to contextualize the data and make a case for recognizing and understanding the strengths and agency of people with dementia (Ward et al., 2017). The author was inspired by this focus when choosing how to structure this analysis. However, the experience of the family caregiver was highlighted, not the experience of the person living with dementia.

### **Methodology of Original Study**

The Manchester data corpus is comprised of information from 40 walking interviews, 32 home tours, and 52 social network maps. 56 people were study participants, 29 people living with dementia and 27 nominated care-partners. Semi-structured interviews were conducted to obtain this information. The goal was to allow the respondents to discuss their social network and their neighborhoods in their own words and without a strict framework of questions.

The Neighborhoods: Our People, Our Places study sought to explore the “locally situated, lived experience of people with dementia and their care partners” and “understanding how those affected by dementia experience their local neighborhoods and exploring the ways in which local places might better support people living with dementia and their care-partner” (Campbell et al., 2019, p. 3). This was in response to research that shows the “shrinking world” of dementia may result in “an increase in the importance placed on local social and spatial connections to provide day-to-day practical support, including neighborhood spaces” (Campbell et al., 2019, p. 3).

Participants were recruited mainly through third-sector support groups in the United Kingdom, and ethics approval was obtained through local governance systems in each locality, including the NHS Health and Social Care panel (Campbell et al., 2019).

The first technique used to gather interview data was a walking tour in which the interviewer walked with the person living with dementia, and sometimes the caregiver, and observed them navigate with their physical neighborhood and community and explain their routines and observations.

In the social network mapping data collection method used in this study, the family caregiver was first asked to “map” their social network, showing interviewers who they saw on a regular basis, explain the relationships they have with other people, and who supports them and the person living with dementia and in what way (Campbell et al., 2019, p. 3). This social network mapping was first a written activity in which the caregiver spatially mapped out their social network. The physical mapping was then used as an elicitation for the oral interview (Campbell et al., 2019, p. 3). Written transcripts of the oral interviews were used by the author of this analysis.

The author of this analysis had access to 15 interviews in total. The interviews received were selected by researchers from the initial study. The author did not have the opportunity to review all the interviews before deciding which ones to analyze nor see the written social network maps. However, halfway through the initial analysis of 9 interviews, the author noted intentions to focus on the experience of the family caregiver, and additional interviews were selected and anonymized by the original researchers which highlighted the voice and experience of the spousal caregiver. The specific ages and races and backgrounds of the participants were unknown; however, it was understood they were aging couples in the Greater Manchester area in which one spouse served as the caregiver to the other spouse currently living with dementia.

### **What is a Neighborhood in the context of the original study?**

In the United Kingdom, the term “neighborhood” appears in conversations related to public policy, town planning, urban regeneration, social science, and efforts of social and health care commissioning (Keady et al., 2012, p. 155). A definition of “neighborhood” is also referenced by Keady et al, attributed to Tim Blackman, as ‘walkable zone of experience’ and ‘smallest significant socio-spatial scale of societies of which they are part’ and ‘a local bounded space that holds within it various attributes that are both physical and social’ (Keady et al., 2012, p. 155). However, policy makers typically define a “neighborhood” by purely geographical boundaries as opposed to any sort of concept of micro-culture (Keady et al., 2012, p. 155).



## **Inspiration from Original Study**

In the original study, the role of place and what defines a neighborhood was a foundational concept. The author was similarly inspired to focus on an aspect of this concept, but more specifically how people feel a sense of connectedness and support from the daily interactions of their everyday life, and how that is facilitated or not facilitated. The geographic and/or spatial aspects were not as central to the analysis and understanding. Thus, the focus on general social health of family caregivers evolved.

## **Sub-Sample of Data Used for this Thesis**

For this analysis, 15 interviews were used, 9 social network mapping interviews and 6 walking tours from the Manchester field site. As stated, the study informants were individuals living with dementia and their primary family caregiver, a spouse in all the examples used for this analysis. These interviews were copied down by a transcription service, anonymized by a study researcher, and then placed in a digital shared folder. The interviews used for this analysis were conducted in 2015 and 2016.

## **Undertaking Secondary Analysis:**

Secondary analysis is analysis involving the re-use of data collected during previous research studies (Heaton, 2008). Secondary analysis is distinct from meta-analysis and systematic reviews of qualitative data because those approaches typically involve reviewing published findings of previous studies, whereas secondary analysis is a revisiting and re-working of the data (Heaton, 2008, pp. 34-35). There is growing acceptance of secondary analysis as a recognized methodology in analyzing qualitative data, for instance the UK National Centre for Research Methods cites it as a standalone research method in social science (Bishop & Kuula-Luumi, 2017). In fact, The United Kingdom's Economic and Social Research Council (ESRC) requires research grant applicants to demonstrate that relevant data is not already available from the UK Data Archive (Bryman, 2016, p. 309).

Advantages of using secondary data include: saving the cost and time of collecting new data; the opportunity for longitudinal, cross-cultural, or sub-group analysis; and access to high-quality and well sampled data sets (Bryman, 2016, p. 310). Additionally, reanalysis of existing

data may offer new interpretations and also gives more time for data analysis, since data collection is often time and labor intensive (Bryman, 2016, p. 311).

Limitations of secondary data include a lack of familiarity with the data; complexity of the data creating data management issues; no control over data quality; and absence of key variables (Bryman, 2016, p. 313). The period of familiarization can be substantial with data you do not collect yourself, and the sheer volume of data can be problematic with the management of the information at hand (Bryman, 2016, p. 313).

### **Purpose of Secondary Analysis:**

There two principle purposes of secondary analysis, the first of which is investigating new or additional research questions, and the second of which is verifying the findings of previous research (Heaton, 2008, p. 35). However, there is some controversy with using secondary analysis for verification of qualitative research findings due to epistemological foundations of qualitative research and different traditions of qualitative research (Heaton, 2008, p. 35). It could be argued, that in a secondary analysis of data using a grounded theory approach, an ability to direct and guide the data collection as theory emerges may not be a possible. However, since the transcripts used are from a much bigger study, the author was able to seek data that would help focus theories and analysis, i.e. instead of focusing on responses of people living with dementia, the author sought transcripts where the voice of the caregiver was more prominently heard and reflected.

Formal data sharing where datasets are deposited in public or institutional archives and then re-purposed in secondary research, is one approach to secondary data. In this process, the data is likely to be vetted for archiving purposes and having met ethical and legal requirements for being shared with other researchers (Heaton, 2008, p. 35).

Informal data sharing is a second way to facilitate secondary analysis, examples of this might be a primary researcher handing over data to another researcher who then uses that data in a separate secondary analysis, of which the primary researcher has no part. A primary researcher might also share data with others and then the primary research in conjunction with the new researchers would participate in a secondary analysis. An underlying factor though in informal data sharing is that the primary and secondary researchers have different relationships to the

data, and therefore might have different contexts and approaches in reviewing the data (Heaton, 2008, p. 35). My secondary analysis is reflective of this approach.

And a third approach to secondary analysis is re-use of self-collected data to investigate new or additional questions/approaches to the primary research or to verify previous findings (Heaton, 2008).

As stated, this analysis fits most squarely in an informal data sharing aspect of secondary analysis. The author worked under one of the primary researchers of the original study, however, the research questions and analysis were developed from the author's own interests and from discussions with the original researchers about how less attention was focused on caregivers within their original study. Additionally, a review of the existing literature showed the concept of social health as timely and emergent, especially in relation to the role and experience of family caregivers.

### **Reflexivity and Secondary Analysis**

In an article reflecting on her process of working with secondary data, Libby Bishop details her interactions working with secondary data and the importance observing the interaction with the data. Bishop noted "while all qualitative data is constructed within a context, reusing data adds dimensions to that recontextualization process, both across time and across two sets of research questions" (Bishop, 2007, p. 11). She also notes "the greater sense of finiteness of the data" and that "the experience of being able to probe in later interviews for themes that emerge early was constrained by not having data specific to my purpose and not being present at interviews" (Bishop, 2007, p. 11). The author experienced this same data predicament interacting with the data, however, was able to share the shift in focus to caregiver experience with the original researchers and obtain additional transcripts which further highlighted those perspectives. The author maintained a reflexivity journal, emulating the approach of Bishop, to understand the nuances of interacting with secondary data.

## **Grounded Theory:**

Grounded theory could generally be defined as theory derived from data, systematically gathered and analyzed through the research process (Bryman, 2016, p. 381). In this method, two central features are that it is concerned with the development of theory out of data and that the approach is iterative, or recursive, meaning that the data collection and analysis proceed alongside each other, referring and forth on a continual basis (Bryman, 2016, p. 381).

Alan Bryman refers to tools of grounded theory as being theoretical sampling, coding, theoretical saturation, and constant comparison (Bryman, 2016). A definition of theoretical sampling, as referenced by Bryman and attributed to Glaser and Strauss, is the process of data collection for generating theory through which the analyst jointly collects, codes and analyzes data and decides what data to collect next in order to develop a theory as it emerges (Bryman, 2016, p. 411). As the author analyzed the transcripts first assigned, the importance of the role of family caregivers of those living with dementia emerged. The unique experience and needs for social support for dementia caregiving also revealed itself. Consequently, the author asked for additional transcripts with in-depth responses from the caregiver in order to have a greater sample from which to code categories and refine an analysis specific to caregiver experience.

The next step in the process Bryman references is coding, or classifying the data into component parts and giving those categories names with the understanding that these categories seem to be of potential theoretical significance or seem to be notable within the social world(s) being studied. (Bryman, 2016, p. 573). Ultimately, coding is an important first step in the generation of theory (Bryman, 2016, p. 573). The author employed this technique while reviewing the data as well.

It's important to note that another perspective on theoretical sampling connecting to the concept of coding, as mentioned by Bryman and attributed to Charmaz, is that theoretical sampling is concerned with the refinement of the theoretical categories that emerge in the course of analyzing data that has been collected, rather than boosting the sample size (Bryman, 2016, p. 411). Thus, while the author's initial analysis led to seeking data further illuminating caregiver perspectives, this refinement approach was also used in that after created coding categories, the author went back through the transcripts and coding and realized that some of my categories were somewhat redundant and/or tangential to the main concept illustrated by the observation.

For instance, the author made notes and then subsequently categories about daily or weekly exercise classes as well as daily walks to buy the paper. However, upon further review, that category was refined to represent routines facilitating community interaction versus just the errand or activity itself.

Continuing with Bryman's tools for grounded theory, theoretical saturation occurs when you have pulled all you can and need from the data. And another tool, constant comparison, ensures a close connection between data and the concepts/categories you are pulling from the data (Bryman, 2016, p. 573). In this context, the author reviewed transcripts, asked for additional transcripts, and then refined the analysis to reach the analytical categories most representative of the data until no further data was needed to illuminate the concepts.

In a grounded theory method, there is an "everything-is-data" characteristic, meaning that everything observed in the data and everything you bring to the process of looking at the data (your past life experience, education, etc.) is also in a sense, data (Bryant & Charmaz, 2007, p. 115). It is important to note that since the author did not gather this data, the interaction with the data is in a secondary data context. However, grounded theory still applies in the author's relationship and interaction with the data. And it gives a unique interaction and interpretation of the data.

In grounded theory, the cyclical process of moving between empirical data and emerging analysis makes the collected data progressively more focused and the analysis successfully more theoretical (Bryant & Charmaz, 2007, p. 1). The theoretical concepts in grounded theory result from the going back and forth between the data and categorization of the data. However, there are critical discussions of grounded theory which call into the question the transparency of how a concept emerges to a theory (Bryant & Charmaz, 2007, p. 25). In this analysis, especially given it is secondary data which the author did not have a role in collecting, a reflexivity journal was kept documenting the process of interacting with the data.

In keeping with the need to document the experience of interacting with the data, some grounded theorists assert that categories emerge automatically when researchers study, compare and iteratively focus the data, whereas others researchers say that emergence does not occur independently of interpretation, and therefore cast doubt on the concept of emergence (Bryant & Charmaz, 2007). To avoid this potential validity pitfall, the reflexivity journal was important.

## **Reflections on Limitations of this Analysis**

During this analysis, I maintained a reflexivity journal to document the challenges and/or advantages experienced working with anonymized qualitative interviews and secondary data. For one, since the data was anonymized, I was saved the step of receiving clearance from the Norwegian Centre for Research Data (NSD) since the information did not reveal personally identifiable information.

However, the inability to actively engage with the informants by asking follow-up questions, clarification of a response, elaboration on a response, or pursue another tangent of questioning entirely, left me feeling at times disengaged and distanced from the conversation. This was especially true during the walking tours. I was not there in time and space walking with the individuals, so the descriptions and dialogue read a bit stilted, sterile and downright confusing at times.

It is also important to note that I was unable to select the transcripts used nor listen to the original audio transcripts of the interviews. All background information and transcripts were provided by the study researchers. Therefore, I did not know what I did not know in terms of context or other details.

Additionally, since I am from the United States and the data was collected in communities around the greater Manchester, England area, some of the vocabulary and turns of phrase/idiomatic expressions used by the informants were foreign to me. Therefore, I relied on online search engines to query the meanings of certain words or phrases and/or asked friends I have who grew up in northern England for clarification. Some examples were subtle, including “mobility cards” which I discerned to mean a card used to access public transit. Another example is “district nurse” which I took to mean a nurse serving a given geographic area on behalf of public health services, something we would refer to in a different manner in the USA, especially since our health care system is different.

An example of foreign vocabulary was “ginnel” or a narrow passageway or alley between terraced houses. Also, “living on the Wirral” was explained to me as a specific peninsula in Northwest England. References to a “chippy” and a “Chinese chippy” were also confusing to me. I came to understand it’s cheap and easy food café. While these points of confusion were not

serious, if I had not had Internet access and personal resources, it would have been difficult for me to follow the subtleties and nuances of an already anonymized transcript conversation.

I visited Manchester on a couple occasions and met with the researchers, saw photos from some of the walking tours, watched videos showing their approaches to social network mapping and walking interviews, and met some of the study participants at an end of study conference. These interactions during my visits to Manchester left me feeling more connected to the community and the people involved in the study. I also attended an end of study conference in Manchester in April of 2019 during which I was able to meet and interact with the researchers and some study participants.

It is also important to note that I have worked as a caregiver in the past, not for members of my own family, but as paid support staff for the elderly and disabled. I have done anything from 3 hour shifts where I simply sit and talk to someone over coffee, all the way to exhausting 12 hour shifts involving bed baths, bathroom and hygiene assistance, physical transfers, and the interpersonal drain of one-on-one contact with someone who is cognitively impaired. And I will also note, some of the clients I worked for were still cognitively intact yet highly demanding and micro-managing in their expectations of paid help, and that is a demanding, draining and at times frustrating experience as well. Thus, my personal experience as a caregiver likely led to the responses of the family caregivers resonating on a deeper level.

### **Reason for Data Anonymization**

The data reviewed was anonymized since it was worked with remotely and accessed through an electronic shared folder, and that sharing of data needed to be compliant with the General Data Protection Regulation (GDPR). And while the anonymization enabled me to access the information remotely, names of specific geographic locations, people and other places were removed, thus adding to a feeling of separation from some of the topics discussed. The anonymization process also contributed to my focus on caregiver responses. Caregiver comments were more detailed, focused and easier to glean themes from than the responses of the people living with dementia. The context of how and why something was said was easier to discern.

**Ethics:**

Ethical clearance was received under the existing approval obtained by the researchers who conducted the original Neighborhoods: Our People, Our Places study. A document was signed by the author pledging to adhere to existing policies and considerations. It was explained that when reviewing and working with the study data, nothing should be shared with third parties. Additionally, since the transcripts received had been anonymized, the Norwegian Centre for Research Data (NSD) advised that additional ethical clearance was unnecessary since personally identifiable information was not provided.

**Analytical Process**

The anonymized transcripts (data) took the form of Microsoft Word documents uploaded to a digital shared folder. The author's approach to working with the interviews was to make notes when the caregiver made a comment about their unique experience of caring for someone living with dementia – whether it be an activity, a routine, a person, a relationship, or a feeling resulting from a particular event or outing, etc. After making these notes, categories were created within each transcript, and a grounded theory, iterative way of interacting with the data occurred.

Various reviews of the data (transcripts) and the categories further refined the categories and established themes illuminating the caregiver experience. From this process, themes identified as being foundational to the experience of caring for someone living with dementia were explored. An understanding of social health was also kept in reference as coding and themes were identified.

As the author began reviewing the data, a journal was kept noting the process of interacting with secondary data. What emerged from this reflexive activity were the barriers to a confident assessment of the experience of the person living with the dementia, therefore a shift occurred in which the perspective highlighted was the experience of the family caregiver. Additionally, the author asked the study researchers for additional transcripts which further reflected the voice of the family caregiver. And additional transcripts were received and reviewed until the author felt the themes were effectively illuminated and theoretical saturation was achieved.



In order to maintain a sense of connection to the individuals and emphasize their unique experiences, the author created a pseudonym key associating each transcript and couple interviewed with corresponding names. Some couples were interviewed for both a social network mapping exercise and walking interview. However, different response types were gathered based on the elicitation technique. Additionally, any and all information provided by the original researchers was also included in the transcript key document. This key/document is included in the appendix.

## **Findings and Discussion:**

Caring for a spouse living with dementia redefines the daily life, responsibilities, and emotional experience of the caregiving spouse. Based on the observations of this analysis, the role in the marriage, the ins and outs of household management, and the role in the community as individuals and as a couple are all irrevocably altered. One respondent, Kathy, noted the daily toll of no longer having her husband, Kirk, as an equal partner in household maintenance and projects, and the need for her to oversee the entirety of their finances when in the past that had been his domain. Kathy noted in this context, "Of late I have noticed that I do get - I can't do this, I need someone to come in and take over and just do it for me." She felt utterly overwhelmed by her new role.

So much of the caregiver experience is in relation to and in reaction to the person living with dementia (the physical safety of the person; protecting the dignity of the person as well as the privacy/dignity of the family unit; keeping someone living with dementia calm and helping quell any worry or fear that arises) it can at times prevent the family caregivers from a full expression of their individual self and wishes. While the secondary aspect of this analysis distanced the author from the experience of the person living with dementia, it allowed the experience of the family caregiver to shine through.

The findings and discussion are presented together under the categories of each of the three research questions.

**Question 1: How do family caregivers manage and negotiate the challenge of providing care to a loved one living with dementia?**

Eight main themes were identified fitting under two core concepts within the context of social health: *Coping Strategies* and *Negotiating Challenges*.

*Coping Strategies* were actions or reactions that the caregiver used to improve the situation for themselves and/or the person living with dementia. *Negotiating Challenges* are the obstacles to overcome in order to maximize a caregiver’s social health. These two concepts occur in a feedback loop and emerged from a Grounded Theory based recursive interaction with the data, viewed through the lens of social health.

This table presents the themes as well as the subcategories noted within each theme. Examples of *Coping Strategies* and *Negotiating Challenges* are noted in the discussion following each theme heading. PLWD is an acronym for “person living with dementia”

	<b>Theme</b>	<b>Subcategories</b>
<b>Theme 1</b>	<b>Manifestations of Worry and Fear</b>	<ul style="list-style-type: none"> <li>• <i>Coping Through Risk Mitigation</i></li> <li>• <i>Impact of Caring on the Mental Health of Caregivers</i></li> <li>• <i>Worry and Fear of Care Receiver Controlling Activity of Caregiver</i></li> </ul>
<b>Theme 2</b>	<b>Support Through Routine Activity and Meeting</b>	<ul style="list-style-type: none"> <li>• <i>Relationship Nurturing</i></li> <li>• <i>Involvement in Dementia Support Groups</i></li> <li>• <i>Ritual of activity building community for caregiver and PLWD, dignity promoting activities</i></li> </ul>

<b>Theme 3</b>	<b>Positive Effect of Other Relationships on Caregiver</b>	<ul style="list-style-type: none"> <li>• <i>Support from Animals</i></li> <li>• <i>Support from friends with errands and hospital visits</i></li> <li>• <i>Role of children in facilitating social interaction</i></li> </ul>
<b>Theme 4</b>	<b>Sensitivity and Understanding from the Community</b>	<ul style="list-style-type: none"> <li>• <i>Dignity promoting interventions</i></li> <li>• <i>Openness and rejection of stigma</i></li> <li>• <i>Maintenance of privacy</i></li> </ul>
<b>Theme 5</b>	<b>Impact of Dementia Caregiving on Other Caregiving</b>	<ul style="list-style-type: none"> <li>• <i>Self-care for those aging alongside caregiving</i></li> <li>• <i>Care for aging parents</i></li> </ul>
<b>Theme 6</b>	<b>Accessibility of Social Support</b>	<ul style="list-style-type: none"> <li>• <i>Complications of family provided support</i></li> <li>• <i>Additional household responsibilities and need for outside assistance</i></li> <li>• <i>Fear of being perceived as an imposition holding back from asking for help</i></li> <li>• <i>Defining respite</i></li> </ul>
<b>Theme 7</b>	<b>Influences of Physical Landscape and Temporality</b>	<ul style="list-style-type: none"> <li>• <i>Nostalgia for past creating distance from present feeling of connection</i></li> <li>• <i>Recent relocation affecting community bonds</i></li> </ul>

<b>Theme 8</b>	<b>Changing Roles</b>	<ul style="list-style-type: none"> <li>• <i>Role in relationship (marriage)</i></li> <li>• <i>Role in community</i></li> </ul>

**Theme 1: Manifestations of Worry and Fear**

Both the caregiver and the care receiver (PLWD) sometimes experience worry and fear as a result of living with dementia. Plans are put in place (*Coping Strategies*) in the event the PLWD gets lost (ensuring they have a pre-programmed phone when out in the world, an ID card with their address). Actions are also taken so that the PLWD doesn't cause damage to property (using the microwave instead of a gas oven).

The mental health of some respondents was also an issue whereas for others the PLWD's need for support on public outings was a barrier to the caregiver having a break (*Negotiating Challenges*). In these cases, family members and/or medical professionals provided interventions in the form of mental health treatment or efforts to accustom the PLWD to other family members so that the spouse could have a break if desired (*Coping Strategies*).

**Coping Through Risk Mitigation**

Both the person living with dementia (PLWD) and their caregiver took steps to minimize the vulnerability of the PLWD to getting lost, injuring themselves or property, or experiencing any other negative outcome as a result of the cognitive impact of dementia.

A repeated observation of the data was the implementation of protocols for avoiding getting lost, or if someone does get lost, methods for reaching the caregiver. Examples of this were that the PLWD would always bring their identification card which notes their physical address, bringing money for a taxi, or taking a phone with pre-set phone numbers to call family members or friends if they get disoriented (*Coping Strategy*).

Paul mentions taking his ID out and about and a "ticket" with his address when he leaves the house. However, Larry who is also living with dementia notes, "Everytime I open my phone it's... I have to relearn how to do... I'm okay phoning home but trying to find a number I'm not familiar with it takes a long time to scroll through and find it." So, while the phone is a tool for mitigating risk, the cognitive impairment and confusion associated with dementia interferes at times as well with the full use of these efforts and tools.

A concern of harm or neglect coming to the person living with dementia was reported throughout the data. On the heels of a bad fall, Kathy who cares for her husband Kirk notes, "he's (now) carrying a laminated card now that my daughter made for him, which has our home telephone number on and my mobile number." The hope being that if he falls or is injured again while on his own, someone would be able to find the card and contact family members more quickly.

Further, Kathy also notes "I've got a carer's emergency card if anything should happen when I was out by myself, they have... they're aware that someone would need help" – Kathy does this so that if she has an accident or other issue, this card would alert people to the fact that Kirk has dementia and might be alone and in need of intervention in her absence.

### **Impact of Caring on the Mental Health of Caregivers**

Most respondents note impacts on their self-described mental well-being (stress, worry, frustration), but they do not allude to specific diagnoses nor interactions with mental health professionals as a result of caring with dementia, except in one case. Mary who is the spousal caregiver, says she has been put on medication for since her husband Matt has been diagnosed with dementia. Specifically:

And he was really, really bad at the time, and I wasn't feeling well. And my daughter-in-law said, she thought I ought to go on something. She said, you're getting to the end of your tether, aren't you. And I said, well I feel like it...So, that's when I mentioned it to the doctor, so that's when she gave me these tablets. She said, they're not for depression, they're for anxiety.

In another example, caregiver Nancy seems to semi-joke about her horse, "I call him Prozac because he is better..." but she later explains more, "I don't know what I'll do when I can't do that (visit horse), because I'm not very good at being in and I'm not a natural carer." She also speaks of anticipating not being able to cope with the intimate hygiene assistance her husband Nick will eventually need, "when it comes to the intimate personal care there is no way I'll be able to do that - I don't know what I'm going to do then."

Nancy's discussion of a specific aspect of caregiving, helping someone use the bathroom and attend to their personal hygiene, becoming overwhelming is an example objective responsibilities of caregiving (helping someone with toileting and hygiene) creating a negative subjective experience of caregiving (for her individually, having to help her husband use the bathroom and clean him up is too much for her) (de Vugt & Verhey, 2013). Helping her husband with his intimate hygiene is perceived to be too great a burden for Mary, whereas other respondents did not note this specific additional responsibility as being overwhelming. (*Negotiating Challenges*)

### **Worry and Fear of Care Receiver Controlling Activity of Caregiver**

Many of these couples have been married for 40+ years according to their own comments. The marital and personal bond is strong between the couples, and the PLWD is often scared and uncertain due to the progression of their disease and in some transcripts will only attend certain activities when accompanied by the spouse.

Rachel who is living with dementia, doesn't want to attend dementia group activities unless her husband and caregiver, Rick, can also attend. When asked about what dementia support activities he or Rachel might be able or willing to attend, "It's available but Rachel doesn't want to attend unless I can go with her," He continues, "And of course I've got the work commitments. I can only like go once a week really."

## **Theme 2: Support Through Routine Activity and Meeting**

Routine activity and meetings were a source of support and social connection for the caregiver and care receiver (*Coping Strategies*). Some caregivers found comfort and support in routine social outings with friends or family. Others found community and belonging in attending dementia support groups. Additionally, when discussing the concept of stigma and stigma associate with dementia, those attending the dementia support groups seemed empowered by that gathering to reject any associated stigma. The rejection of stigma took the form of publicly sharing a dementia diagnosis on social media (the person with dementia being the one to initially share), or the caregiver sharing the coworkers, neighbors and friends that this is something their family is now dealing with in a matter of fact way. However, some individuals still saw dementia as a private matter, possibly in the way they would see any other medical issue or illness and were more selective with who and how they shared the diagnosis. The sense of privacy did not come from an articulated sense of embarrassment about dementia but from a desire to maintain a general sense of privacy. However, as Gove et al discussed, the stigma of dementia, “may be accompanied by a private process whereby the stigmatized person or group internalizes the perceived stigmatizing attitudes of others” (Gove et al., 2017, p. 949). (*Negotiating Challenges*)

### **Relationship Nurturing**

Rick the husband and caregiver of Rachel has weekly visits with a work colleague who lost his wife a few years ago, and they go have beers at the pub. “I just invited him around here once a week. I mean he comes round every Thursday. We go down the pub. We have a couple of beers and then we come back and I cook our tea and he normally falls out of our house about 11pm... it’s probably been 3 years now (that they have this routine).” This ritual of activity and the shared experience of dealing with a declining wife seems to be a source of comfort for them both. Similar to the themes which emerged in the work of Chappell et al, it is the connection with the other individual, not so much the outing to the pub itself that brings Rick comfort (Chappell et al., 2001).

Mary, a caregiver, is involved with a woman’s club which just celebrated its 60th anniversary. She speaks to the club being non-denominational and a good place for connecting with other women and having a sense of community regardless of your background. Specifically,

“it’s the kind of club that anybody, you can go in and everybody talk to you, it’s not cliquish at all. Everybody sits in their own groups, don’t get me wrong. But if you went in on your own, you could say, do you mind if I sit here, and they’d say, oh no, and they’d talk to you.” Her continued participation in the group brings her a sense of community and connection to other women.

*(Coping Strategy)*

Additionally, caregiver Kathy mentions yoga classes and hairdresser appointments as routines she has that get her out in the community seeing people and building friendships. This type of activity is reminiscent of Chappell’s et al’s *stolen moments*, or brief periods of time away from caregiving but outings still part of their daily routine. This type of respite was the most common caregiver defined restorative break noted by their research (Chappell et al., 2001).

### **Involvement in Dementia Specific Support Groups and Activities**

This category should have the caveat that many of the informants of the larger study were found and sampled due to their involvement with Age UK and other dementia support groups, known as third sector organizations, around the greater Manchester area. However, participation in these groups and activities was cited as a positive and supportive experience, especially by the caregivers, and therefore worth including. *(Coping Strategy)* The importance of dementia support groups for social support might be an accident of recruitment, but it’s one of the strongest themes throughout this analysis.

Larry a spousal caregiver mentions a dementia trainer and facilitator who was a "fabulous presenter but also he does organize trips out and things like that..." Larry talks about the value of talking to another man "he's just an all-around nice bloke really", Larry further explained that he felt out of place in some caregiver support groups because it was mainly women in attendance, so he appreciates the opportunity to speak to another man. By his own description, as a man, Larry may face additional barriers feeling comfortable accessing social support *(Negotiating Challenges)*.

A “dementia swim” occurs every Friday is mentioned which brings enjoyment to Barb, the person living with dementia. She feels that, "they treat you with respect." This activity brings comfort to both the caregiver and the person living with dementia. Bob highlights that that Barb feels comfortable and respected at the outing. Possibly an allusion to internal or external



perceptions of the stigma of dementia, or ways they have been treated differently due to her diagnosis or changing behaviors (Gove et al., 2017)

In reference to dementia support groups, Carrie the spousal caregivers says, “you learn a lot from other people and you listen to other people” and “everyone is different.” Carrie also notes that her husband Chris, who living with dementia, gets in a bad mood if he misses dementia group. From her observation, even if not explicitly articulated by him, her husband enjoys the ritual of the activity and finds a sense community with the other people living with dementia in much the same way Carrie does with the other caregivers. (*Coping Strategy*)

Carrie and Chris also reference a different dementia club they used to be able to stay at for free, but that it’s since closed – the conversation arose after running into another acquaintance dealing with a family member with dementia – and the other person referencing management problems of workers within care organization in general. The loss of this access seems to be a negative for them all. (*Negotiating Challenges*)

Annie the spousal caregiver mentions that the dementia group she attends is standing room only – “publicized and out to, sort of, remove the stigma of dementia – I mean it’s like standing room only sometimes, you know, so it’s well up in the twenties now.” To her, the fact the event is well-attended, and everyone is open about living with dementia and having a loved one with dementia, is a positive and comforting experience. Additionally, Annie mentions that dementia group volunteers call every couple months to do a wellness check on the household.

Rick the caregiver says about Rachel his wife who is living with dementia attending her dementia group, "it's the highlight of the week actually. She loves going. It's a really good little group of people. It really really friendly and everybody supports each other brilliantly. It's a really really good group." He continues "I'm fully supported as well cos (*sic*) all the carers are there." And, he also explains that once every couple months the caregivers and people living with dementia go in separate rooms and "carers would go into another room and have a chat and just discuss any problems that they have...it's just good to see how other people cope as well." Rick the caregiver says that the dementia group participants eventually exchanged numbers after meeting together so many times. The ritual of activity brought everyone together more and more over time. (*Coping Strategy*)

Mary the caregiver says that Matt her husband, who is living with dementia, doesn't like the name of the café group being noted as "dementia café" – likely a reference to perceived or experienced stigma on his part (Gove et al., 2017) but Mary says it's a worthwhile thing for her, meeting other caregivers.

However, not all the caregiver are fully invested in the dementia specific support groups, Kathy a spousal caregiver said, "No, I wouldn't confide in them (the dementia group staff), I talk to them, the support they give is practical." Kathy knows of other dementia group opportunities but doesn't feel the need to go or has schedule conflicts but acknowledges there "might be a time when I really do need it." Kathy was an exception in that she was more guarded about disclosing information to the dementia support staff or seeking more dementia-based activities for social support. (*Negotiating Challenges*)

### **Theme 3: Positive Effect of other Relationships on the Caregiver**

The intention of the original interview guide was to map the social network of the respondents; therefore, it makes sense relationships would be mentioned throughout the interview transcripts. However, some interesting themes emerged such as the role animals took for some respondents as well as the objective importance of relationships for a caregiver to have health care needs met (to attend doctor appointments and schedule surgeries for instance). Additionally, a respondent's children were often a gateway to other forms of relationship building and support even if the children themselves were not included in the interaction. For example, the church secretary who checks on the parents because the son is the minister of the church where the church secretary works.

Caregiver Nancy references her horse, "I call him Prozac because he is better..." In much the way that dogs and cats provide comfort and support to individuals, Nancy's relationship with her horse, both the outings with it and her interactions with it, are meaningful to her. Nancy also gets emotional when discussing how her friends support her, like by taking her to hospital appointments because her husband Nick is unable due to his dementia, she's known these friends over 20 years.

## **Role of Children in Facilitating Social Interaction and Social support**

The children of caregivers play important roles in accessing social support and interaction. Caregiver Barb notes that their daughter is “sort of integral in us seeing people.” Annie, the caregiver to Alan, mentions she relies on her oldest daughter for emotional support more than anyone. As referenced prior, the secretary of the church where Matt and Mary’s son is the minister has his church secretary call his parents while he and his wife are away. In all these examples, the children of the couple provide a connection to support, either directly through the familial relationship or through connections made with the greater community.

## **Theme 4: Sensitivity and Understanding from the Community**

When the community, whether it be neighbors, friends, or acquaintances, reacted patiently and kindly to the person living with dementia, the caregiver was comforted and felt more secure being out in the world with the PLWD. They would still go out to dinner as a couple with friends because another friend would accompany the PLWD to the restroom, ensuring they didn’t become disoriented or confused when returning to the table. This was both a practical concern but avoiding any type of embarrassment or feeling of shame, for both the caregiver and PLWD, was also a factor.

As alluded to before, the concept of stigma of dementia emerged repeatedly. Overall, the data showed that people felt more relief and understanding when the community understood why the PLWD stumbled over words, became confused etc. However, again, some respondents preferred to keep details of dementia to just their close friends and family, whether this was simply a matter of privacy preference or conversely an internalized experience of the stigma of dementia (Gove et al., 2017) is unknown.

Larry, the husband of Liz who is living with the dementia, discusses his involvement in a band and that one of his bandmates cares for his wife living with rheumatoid arthritis. The men connect both through the music and the shared experience of caregiving for their wives. This example is similar to the prior category of *relationship nurturing*, but in this case the respondent notes how that sensitivity and understanding from his bandmate, and how it affects his involvement with the band, is the primary takeaway.

## **Dignity Promoting Intervention**

A male friend will take the Paul, who is living with dementia, to the toilet when out and about, offering his wife Pam some support and peace of mind, preventing embarrassment for both her and her husband should he have an issue in the toilet or when returning and trying to find a restaurant table, etc. This dignity supporting intervention comforts them both. (*Coping Mechanism*)

### **Openness and Rejection of Stigma**

Larry mentions his wife Liz is living with dementia and "she took the decision very early on to tell people (at a running club they attend) and I think it's something you recommend to anybody." He also mentions a situation, for example, that if people see the wife struggling to put on her coat they will step in because they know what is going on with her. Liz, the spouse living with dementia, shared that she posted the third anniversary of her dementia diagnosis on social media and received supportive feedback. Both Larry and Liz spoke to their openness about living with dementia and how it helps them manage the experience. (*Coping Mechanism*)

Nancy the caregiver notes, "we don't make any secret of it (dementia) because otherwise it just becomes impossible, it's easier if people know, much easier" she continues that people react sympathetically to her, "because most people know somebody in a similar situation - it's horrendously common."

In response to whether she is comfortable telling people about her husband's dementia, Mary says, "I think it's important, for people to understand why people don't always remember things, isn't it.?" And she continues, "if they know something is wrong, they understand."

Carrie the caregiver mentions another couple she's friends with, also with a husband with dementia. They "compare notes and help each other because they go to different groups to the ones we go to."

However, on the other side of the stigma category/understanding from the community categories, Kathy mentions how her husband Kirk, who is living with dementia, sometimes interacts with impatient people and people assuming he is incapable of participating in general conversations since he has dementia, and this is something that upsets her. This reaction from the an individual or community is a classic example as explained by Gove et al of why, "we need to understand better the meanings associated with dementia which contribute toward it being

perceived as a stigma and to the stigmatization of those with dementia, which in some cases extends to their family and friends” (Gove et al., 2017, p. 949). (*Negotiating Challenges*)

Rick and Rachel’s neighbor always initiates conversation with Rachel when he sees her outside getting the paper, a small but meaningful gesture to Rick based on his description of action. The neighbor knows Rachel has dementia. Additionally, Rick mentions that his work gave him flexibility to work from home once a week when they were informed of his wife Rachel’s dementia diagnosis. These gestures from his neighbor and his work support Rick and are examples of cognitive and bonding social capital (Murayama et al., 2012).

On the other side of the stigma spectrum, Rick and Rachel note in relation to visiting a pub for drinks, "I mean they are not aware of the situation (dementia) because I mean that's something private." So, while Rick and Rachel are comfortable with the neighbors knowing about her dementia and sharing that information with his place of work for the sake of flexible work hours, they are not comfortable telling other layers of acquaintanceship out in the community about her dementia diagnosis. This could potentially hold them back from interacting with the community as fully especially as Rachel’s dementia progressed. (*Negotiating Challenges*)

### **Theme 5: Impact of Dementia caregiving on Other Caregiving**

Many of the respondents noted that caring for their spouse with dementia took away time from their ability to attend their own medical appointments, schedule minor surgeries etc. and in at least one case, their ability to care for aging parents. One of the respondents, a woman living with dementia, noted her concern for her husband as a caregiver. She had worked in social services prior to her diagnosis and saw the toll of caregiving on caregivers.

Social capital, as explained by Murayama et al and Forrest and Kearns, also played in a role in these situations. Oftentimes it was neighbors or friends who took the caregiver to medical or hospital appointments or who stayed at home with the PLWD so that the caregiver could attend to their own health needs. These networks of support were created through bonding and structural social capital (Murayama et al., 2012).

## **Self-Care - Aging alongside caregiving**

Barb who is living with dementia reflects on her concern for her husband Bob's health as her caregiver. Barb had a background in nursing before being diagnosed with early-onset dementia, and still remembers the toll she saw on the family caregivers of people living with dementia. Additionally, caregivers noted difficulties in scheduling medical appointments and even minor surgeries since care plans would need to be established for their spouse living with dementia.

### **Care for aging parents:**

Nancy says that her mother in law, "one of the first things she asked me when my parents moved down here was, who would my priority be - my husband or my parents?" Earlier in the transcript Nancy referenced that early onset dementia runs in her husband Nick's family, his father also developed it. To free up time to go help her aging parents, Nancy mentions how she taught Nick to use the microwave so he could feed himself when she must attend to her mother's needs.

## **Theme 6: Accessibility of Social Support**

Social support takes many forms in this theme and brings out difficult family dynamics for some respondents. In just about all the interviews, extended family members are part of the existing network of social support. However, accessing social support from these individuals proves difficult at times. As discussed, the supply and demand of social support was at times mismatched, and some experienced difficulties comfortably communicating expectations and needs to members of their family (Dam et al., 2018). These dynamics left many caregivers feeling like they could not fully rely on their family members to help. This is an example of cognitive social capital, or the lack of it. Per Murayama et al's working definition, cognitive social capital is a person's perception of the level of interpersonal trust, sharing and reciprocity available to them (Murayama et al., 2012).

In other examples, the caregiver did not want to feel like an imposition to family or friends and sought support from third sector or paid assistance when knowledge and financial resources were available to access these other outlets. Additionally, respite took different forms for different people (tea with a daughter, spending time with a horse, reading a book,

participating in dementia support groups), but in most cases respite was the ability to go run errands or take care of personal business while the PLWD was supervised by someone else. This matched Chappell's findings about respite and the highest reported experience of respite being *stolen moments*, or brief periods of time away from caregiving but outings still part of their daily routine (Chappell et al., 2001).

### **Complications of Family Provided Support**

Caregiver Nancy says her daughter is "very, very supportive, but I don't want to take advantage of them though" (daughter and boyfriend of daughter) also in relation to daughter "I'm careful about what I say to her because it's hard for her." To protect her daughter, she withholds information that might upset her.

Pam the caregiver says her family offers to help, but they don't concretely offer to "stop in with grandad while you have half a day out." The implication that assistance is generally offered by extended family, but Pam does not specifically follow up on because she does not perceive it as a concrete opportunity, just a passing comment made from courtesy. Dam et al allude to this mismatch between social support need and provision, as well as perception of the availability of assistance, and the need for more open communication between those seeking and offering caregiver support (Dam et al., 2018).

Bob and Barb say they can "pop in on" their daughter anytime, but need to pre-arrange with their son, he would turn away an unplanned visit. This speaks to the different relationships and boundaries parents have with one child over another, as well as the need to navigate those relationships and boundaries or else face being cut-off. These are concepts that were explored in the work of Dam et al (Dam et al., 2018).

### **Additional household responsibilities and need for outside assistance**

Caregiver Kathy noted, "Of late I have noticed that I do get - I can't do this, I need someone to come in and take over and just do it for me." And she mentioned this in the context of household chores and financial matters, specifically those that had once been shared with her husband Kirk or were once his role entirely.

Additionally, Kathy mentions that her brother in law watches her husband on a weekly basis so she can have an outing, however, she feels uncomfortable that the brother in law may feel anchored or trapped by the weekly obligation, thus she's started exploring adult daycare options for her spouse so as to not feel like she's continually imposing on her brother-in-law.

### **Fear of Being an Imposition**

A hesitancy of caregivers to feel that they are imposing on anyone, even their own children or family members, is a repeated observation. Thus, the options of neutral third parties (like non-profit or government programs) or paid options for care are consistently explored when they are known as an option in the community. Rachel who is living with dementia says that their kids call but "they've got their own network of family. They've got their own children."

Mary the caregiver says of their children "we don't see them so often because they're busy", and she further mentions that one of her children has a Down Syndrome daughter, so they are busy taking care of her. Mary says the grandchildren live far away and granddaughter with Downs, "couldn't help, other than to give you a big hug."

Barb says that people have their own families and responsibilities, "you can get out of the rut and see people, but you tend to drop back into it." In a sense, speaking to how easy it is to feel isolated. Barb also references the small but supportive circle of friends she and her husband Bob have. A point about quality over quantity in friendships – "it's unique and it's enough" "we don't need many more people" these people "are very special in so much that they all know, they're all aware what's going on."

Caregiver Annie mentions that they don't see their son as often because he tends to play football and golf on the weekend. However, their daughter is a mobile hairdresser and stops by around lunchtime often.

Caregiver Kathy also mentions she must make an appointment to chat with their daughter because she has three children and a job. And she mentions their standing tea appointment to spend time together is something she hopes can continue despite the job pressures of her daughter. Kathy mentions many other people in her life dealing with illness and decline, so she does not feel alone in that. "I'm beginning to sound like a prophet of doom really, but it's everybody." She also mentions she uses texting to stay in touch with her daughter and



granddaughters and 12-year-old grandson. And that her grandson will only text her, “sometimes, when he wants something.”

### **Examples of Respite** (*Coping Strategies*)

Throughout the data caregivers described their ways of coping while caring for someone living with dementia. Caregiver Carrie uses the time her husband is in dementia group activities to go shopping (her husband Chris gets stressed out by the noise etc. that goes with shopping).

Caregiver Annie says in reference to dementia, “we live with it, but not for it” and that she has friends who take her husband Alan to go do sporting activities and she has time to get out or even just read a book.

Caregiver Kathy mentions that her brother-in-law comes and stays with her husband Kirk, who is living with dementia, so she can have an outing. However, as described before, she feels hesitant to make the brother-in-law feel obligated to be on the hook for that every week, so as said before, she’s exploring senior day-care settings.

### **Theme 7: Influences of Physical Landscape and Temporality**

Some of the respondents have lived in their communities for decades whereas other individuals have recently moved in downsizing effort or wishing to relocate closer to family. Those with deeper roots in the community often felt deeper connection to, and support from, neighbors. However, the character of the community had changed in some instances, and the respondents noted how things were not as “good” as they had been. For instance, their longtime neighbors and friends had either passed away or moved away or that the neighborhood had declined and was not “what is was” (references to people littering more, neighbors less respectful of public spaces, children misbehaving in public etc.). Barb and Bob say, “the decline in this area started when that housing association started putting in all the troublesome families from all over the city. They put them into all them houses there it was one family, then another family, then another family.” This is an example of both structural and cognitive social capital being lacking for the respondents in these spaces. (Murayama et al., 2012).

This influence of physical landscape and temporality reference back to the role of place in the original Neighborhoods: Our People, Our Places study (from which this sub-sample of

data was supplied) in that the original study sought to explore the locally situation lived experience of people with dementia and their care partners (Campbell et al., 2019). Structural physical capital or the density of social networks or patterns of civic engagement is also reflected in this theme (Murayama et al., 2012). Additionally, bonding social capital, or the relationships within homogenous groups (strong ties that connect family members and neighbors) is also reflected (Murayama et al., 2012).

Bob and Barb reference the changing physical landscape of the community (new construction and roads) making their previous routes less accessible. Bob and Barb have been in the same house for 45 years. Nostalgically, they reference the shops that have come and gone including the rugby club where they first met. There is nostalgia in these reflections but also a sense that things are not as they used to be and that they are occupying a space that is no longer the home and community they once knew.

Paul and Pam reference that two major roads now make travel to a graveyard difficult. Their daughter is buried there and the routine of going to visit her grave is an important ritual, especially for Paul who is living with dementia. Urban development and changes to the local road and transit infrastructure have disrupted the routine and ritual of the couple.

Caregiver Kathy notes that she and Kirk left their community of 38 years in order to downsize, and while they have been living in their new home a handful of years now, she says she doesn't feel as connected to her neighbors in terms of turning to them for support or directly asking for help.

Chris, who is living with dementia, references living in the same house for about 40 years, and says his younger next-door neighbors are sources of assistance. Mary, a caregiver, says she has known her neighbors for 50 years and that they go shopping for her.

Caregiver Nancy says, "once my husband got his diagnosis I thought it better to move sooner rather than later, so he could cope with the move basically and would learn the new layout." She intentionally downsized once her husband was diagnosed with dementia.

*(Negotiating Challenges)*

## **Theme 8: Changing Roles**

In all interviews reviewed, the caregiver is the spouse of the care receiver. For many, especially the women, they assume responsibilities once the domain of their husband. Examples of these new responsibilities were driving, financial management of the household, and household maintenance. Looping back to the theme of accessing social support, many of these women felt overwhelmed by the new responsibilities and were experiencing or anticipated experiencing the need for additional outside assistance.

The caregiver role also took them away from activities in the community that they enjoyed. One woman was involved in non-profit work prior to her husband's dementia diagnosis but was unable to continue due to her care obligations. This inability to maintain her obligations and roles negatively impacts her social health, as defined by Huber et al (Huber et al., 2011).

One of the male caregivers noted that he is primarily his wife's husband, and that the caregiver role comes second to that. That respondent was not overwhelmed by his new role in the same way other respondents were. However, he did not seem to find the same support in the female-heavy dementia support groups he occasionally attended.

### **Changing Role in Marriage:**

Annie cites her husband as primary relationship in her life and that she's had to take over driving because that is how they can go see their daughters.

As mentioned before, caregiver Kathy says "of late I have notice that I do get – I can't do this, I need someone to come in and take over and just do it for me" – quote in reference to having to take over all the household tasks and maintenance and finances, things her husband Kirk dealt with more throughout their marriage prior to his dementia. She also mentions that would tackle projects together, and he's no longer able to be her partner in that.

In Transcript 6, the caregiver Bob notes, "so I'm a carer, but really I'm her husband first" in reference to his wife Barb who is living with dementia.

## **Changing Role in Community**

Prior to her husband Kirk's dementia diagnosis, caregiver Kathy notes she had been very involved with Save the Children but that stopped five years ago when her husband's dementia started.

Caregiver Nancy notes, "I don't know what I'll do when I can't do that (visit her horse), because I'm not very good at being in and I'm not a natural carer." Nancy likes to be outside riding her horse and fears that her husband's dementia will hold her back from expressing this part of herself.

## **Considering the Findings in the Context of Existing Literature**

The findings of this analysis are only reflective of fifteen interviews; however, the presented categories reflect themes and theories found in the literature review. Thus, while the sample size is small the results are in keeping with prior research. Additionally, while the secondary aspect of this data oftentimes prevented the author from connecting to the direct perspective of the person living with dementia, the experience of the family caregiver was accessible, and the author feels the analysis accurately reflects their experience as family caregivers.

These findings demonstrate what Dam et al (Dam et al., 2018) illuminated in their article, that there is an imbalance between needed/desired social support and received social support. Specifically, the lack of translation from an offer of support to an action of support (in this analysis, mainly from the children of the spousal caregiver and person living with dementia) is notable (Dam et al., 2018). As Dam et al also highlighted, better communication about needs and anticipated needs would be value added for the family caregiver and those wishing to support that person in the community (Dam et al., 2018).

The stigma of dementia is illuminated throughout the literature review, and while most of the respondents in this data speak about stigma, they also emphasize their rejection of it. Through the community of dementia support groups and activities, an openness about what the individual and couple is dealing with is shared. However, there were still a couple respondents who defined a sense of privacy being a motivation for not sharing the dementia diagnosis.

In the realm of social capital, both observable/structural and subjective connection, per Murayama et al (Murayama et al., 2012) is reflected in the themes of this analysis. The impact of physical location, and the movement of people from and to a location affects a sense of connectedness, and the social support that can grow from that. The proximity of neighbors in general relates specifically to Murayama et al's commentary on observable social capital. For example physical proximity enabling neighbors to be sources of practical support (running errands for the PLWD and the caregiver, collecting mail, feeling close enough to reach out to if something came up) (Murayama et al., 2012).

Themes of the accessibility of relationships, and the network and quality of those relationships, also deeply influenced the experience of the spousal caregiver. Based on the seven domains of social capital as articulated by Forrest and Kearns: empowerment, participation, associational activity and common purpose, supporting networks and reciprocity, collective norms and values, trust, safety, and belonging (Forrest & Kearns, 2001), the dementia support groups are a mechanism through which to build social capital in the community. Specifically relating to the concept of stigma, the author hypothesizes that the acceptance of dementia and the openness about dementia is a direct result of being in community with so many other individuals experiencing the impact of dementia.

## **Question 2: How can social health among family caregivers of people living with dementia be increased? In this context, what variables are observed to affect social health?**

Going back to a simplified definition of *social health* (Huber et al., 2011):

- People's capacity to fulfill their potential and obligations
- The ability to manage their life with some degree of independence
- The ability to participate in social activities including work
- Balancing opportunities and limitations, as affected by external conditions such as social and environmental challenges

An understanding and incorporation of the needs of an individual family caregiver, when a diagnosis of dementia is made for a loved one, would be an intervention accounting for the social health of the family caregiver as well as the person living with dementia. In case management protocols which are implemented upon the diagnosis of dementia, such as seen in the Geriant model of integrated care in the Netherlands (Glimmerveen & Nies, 2015), the protection and provision of wellbeing supporting activities among family caregivers is promoted and protected as well as the person living with dementia.

As reflected in the themes presented, a family caregiver also experiences a lifechanging shift when their loved one is diagnosed with dementia. Dementia in this context creates objective and subjective care burdens for the family caregiver and exposes vulnerabilities in their social network and access to social support. If these factors are understood and accounted for early on in dementia caregiving, it's possible that the caregiver would experience increased social health and the care receiver may have delayed placement in residential care (Glimmerveen & Nies, 2015).

A caregiver assessment tailored to questions about social health, similar to the COPE Index mentioned in the literature review (Juntunen et al., 2017) would be a way for social health of family caregivers to be recognized, protected and promoted. Examples of questions, structured around the tenets of social health, could be:

- **People's capacity to fulfill their potential and obligations**
  1. What social and professional activities do you plan to (or hope to) attend in the months and years ahead?
  2. Is there a hobby you enjoy and fear may be affected by time spent caregiving?
  
- **The ability to manage their life with some degree of independence**
  1. What household responsibilities have typically been handled by your spouse? (Bill pay, driving, errand running, household maintenance, for example) Do you feel you will be able to take these responsibilities over? Or will you appreciate outside guidance or mentorship?

- **The ability to participate in social activities including work**
  1. Which activities (professional, familial, and personal) do you fear might be impacted by your caregiving obligations?
  2. If you have a job, would you feel comfortable sharing your spouse's dementia diagnosis with your manager so that flexible work options may be constructed?
  
- **Balancing opportunities and limitations, as affected by external conditions such as social and environmental challenges**
  1. If you only had two hours in the day to spend anyhow you pleased... where would you go? What would you do?
  2. Who do you feel you could rely on if an emergency or other difficult situation occurred?
  3. Are you aware of support groups related to dementia caregiving? Would you be interested in finding more information about them?
  4. How is your own health? Do you have sources of support in your own medical and health journey?

**Hypothesized variables illuminated by these questions/analyses would be:**

- access to respite (however defined by the caregiver)
- Inclusion in a dementia management plan (aligned with the values of person-centered care and integrated care which incorporate the family caregiver of the person living with dementia)
- effectiveness of existing social support networks in providing social and material support
- whether the caregiver is active in the workforce, and if so whether the employer offers flexibility with hours and telework
- the gender of the caregiver could also be a factor seeing that the men in this analysis seemed less inclined to share their emotional burdens or attend support groups where mainly women were just in attendance. Additionally, many of the women who took on new roles in the household (maintenance, finances) were not as comfortable/experienced dealing with these matters and thus needed more help navigating those matters than the male caregivers.

Based on these variables and their contribution to social health, policy interventions could be developed to improve social capital mechanisms in the community. Specifically, the seven domains articulated by Forrest and Kearns would be applicable. These are: empowerment; participation; associational activity and common purpose; supporting networks and reciprocity; collective norms and values; trust; safety; and belonging (Forrest & Kearns, 2001).

As previously stated, the dementia support groups are a mechanism through which to build social capital in the community. In localities where dementia support groups are not present nor readily accessible, an examination of the seven domains of social capital would be helpful in developing an outreach plan and facilitating program development. Additionally, family and community education seminars could be developed to improve understandings of social network/social capital building while also empowering caregivers to improve their communication skills for expressing their needs and wants of support and respite.

From the articles reviewed for this analysis, sometimes social health and the well-being of family caregivers is eclipsed by the discussion of dementia itself. The acute needs of the person living with dementia and the cost constraints faced by governments and health care systems in managing dementia contribute to this marginalization of caregivers. As a result, family caregivers can sometimes be viewed as a tool in the management of dementia, not a policy priority unto themselves. However, Integrated Care models in the Netherlands (Glimmerveen & Nies, 2015), United Kingdom (Robertshaw & Cross, 2019) and other countries show how to absorb informal caregivers into dementia management and treatment plans, enhancing both the social health of the person living with dementia and the caregiver. Ultimately, the social health and quality of life of the family caregiver should be just as important as maximizing the social health of the person living with dementia. In the quest to prevent the marginalization and stigmatization of people living with the dementia, the well-being of the family caregiver should not be overlooked. There are resources and movements in this direction.

Outreach efforts to empower informal caregivers, or the governments and institutions serving them, to better understand dementia and its symptoms and behavioral manifestations, and offer coping tools, exist. For instance, The WHO's iSupport tutorial for dementia caregivers provides general guidance for caregiver coping. One of the modules, "Caring for Me" offers



topics related to what could be construed as an individual's social health enhancement. Lesson 1: Reducing stress in everyday life Lesson 2: Making time for pleasant activities and Lesson 3: Thinking differently (WHO, 2019a). However, the caregiver would have to be self-directed in accessing and adhering to these guidelines. A study on the utilization and effectiveness of the WHO's i-tutorial for improving a caregiver's general self-reported wellbeing and/or objective social health would be interesting.

While a tutorial of this nature is helpful for basic understanding, it is not a direct intervention nor something which addresses the nuances of a person's social network and the resources available to them. However, in a world of limited programs and policies (and resources) to address needs of basic survival let alone optimal wellness, it's better than nothing. Ultimately, in an ideal situation, social health in the dementia context would consist of local case management addressing family care dynamics, caregiver support, caregiver engagement, and social capital building in communities AND the direct health and social needs of the person living with dementia. A paradigm shift in dementia care from a biomedical model to social model (Vernooij-Dassen & Jeon, 2016) can and should also encompass the family caregiver, and this inclusion would be valuable from the time a person is diagnosed with dementia, not just when their care needs become overwhelming for the informal caregiver.

There are common themes and experiences among family caregivers, however, their individual experience is just that – individual. Caregivers should be empowered to make individual decisions and determinations as to what they need to thrive despite a challenging set of circumstances. However, the application of a policy promoting individual experiences versus cookie-cutter application for cost-savings and broad application, could be a challenge. Evidence-based assessments of the efficacy of individual interventions would be important but also possibly difficult to operationalize. As cautioned during the literature review, “care is needed in using them (personhood, person-centered care and planning, and later ideas of personalization) and presuming that definitions are necessarily shared or that they can be conventionally measured as processes or outcomes” (Manthorpe & Samsi, 2016, p. 1739). Manthorpe & Samsi continue, “the fundamental values behind them may need to be highlighted and critical perspectives should not be muted just because they seem to be implicitly positive” (Manthorpe & Samsi, 2016, p. 1739). However, the development and use of a social health specific

questionnaire, similar in design to the COPE Index, could be a helpful tool in developing and measuring the effectiveness of social health interventions.

Additionally, policies supporting social capital building would also help family caregivers. Social capital is sometimes a subjective experience, but structural social capital could be improved by the development of dementia specific support groups and gatherings in local communities.

### **Question 3: How does secondary analysis of anonymized semi-structured qualitative interview data affect the analytical process of a neophyte researcher?**

This difference in the clarity and context of responses between the caregiver and the person living with dementia influenced the course of the analysis. Since the data used was anonymized secondary qualitative interviews, the author had a one-dimensional view of the respondents. The author did not have the opportunity to meet the specific respondents, hear audio conversations of the transcript nor ask follow-up questions to the respondents since they were anonymous. All that was known was what was provided by the original researchers: the anonymized transcripts themselves; some details regarding age, sex, and socio-economic status; and location of the respondents. All other personal details were anonymized and/or unknown.

In the transcripts, the accounts and reflections of the caregivers were rich in depth and description, and it was easier to glean observations. Understandably, given their dementia diagnosis and the accompanying cognitive changes, the responses from the Person Living with Dementia (PLWD) were shorter, often with the caregiver jumping in to help the PLWD with a word choice or expression.

Interacting with anonymized transcripts was frustrating at times for the author. As Bishop notes in her article discussing reflexivity in secondary analysis, “whether the researcher did the interview or not, questions arise when facing a transcript: how was it transcribed, by whom, with what kind of notation, using what conventions? What was deemed significant enough to record?”

The room? Clothing? Gestures? Pauses? Whether reading transcripts of one's own interviews or others, these questions have to be addressed during analysis" (Bishop, 2007, p. 10).

The transcripts used by the author for this analysis did not detail what the informants were wearing nor a description of the room where they occurred. It was simply a verbatim transcription of what was recorded during the recorded oral interview. In reviewing Bishop's account of reflexivity and reviewing the author's own reflexivity journal for this analysis, the author does believe something was lost in terms of representing the caregivers. For instance, what if a caregiver appeared disheveled and/or tired during the interview? Does this reflect emotional upset or distress? If the author had been there in person, questions could have been sensitively asked regarding the feelings and emotional state of the caregiver at that point in time.

Despite this distance from the respondents and the data itself, the author believed the transcripts did expose aspects of caregiver experience - their fears, anxieties, frustrations but also contentment, sense of connection to the care receiver, and feelings of support from their family and community. It also revealed what was working for them in terms of family and community support, and on the opposite end of the spectrum, exposed gaps in how these caregivers accessed and experienced support.

The Findings reached reflect current literature and theory, however, the author believes some details and context were lost in the anonymization process. Additionally, from the author's perspective, if the intention was to validly and reliably represent the experience of the person living with dementia, from their individual description, it would have been difficult to achieve that representation. A study examining the lived experience of dementia through the eyes of someone with dementia, **NOT** predominantly from the perspective of the family caregiver, felt out of reach based on this way of interacting with the data and the respondents from which it was derived. Therefore, the focus sifted solely to the family caregiver.

It is also worth noting that the general, open-ended nature of these interviews (the interview guide issued for the original study is included in the appendix), while rich in content and potential angles of analysis, made for a broad conversation not easily classified or categorized into specific response types and categories, such as with a survey. This approach contributed to the author's use of grounded theory versus other theoretical approaches. The

author repeatedly returned to the data, working with it backward and forward, until eventually reaching the themes/categories noted.

### **Impact of Data Anonymization**

The question of data privacy is a factor in the reuse of qualitative interview data. For the purposes of this analysis, all data sets used were anonymized prior to access by the author. It was explained by the primary researchers that the General Data Protection Regulation (GDPR) necessitated this scrubbing of the transcripts prior to electronic access. According to an explanation provided by the European Union 's GDPR guidance website (EU, 2019).

General Data Protection Regulation (GDPR) is the toughest privacy and security law in the world. Though it was drafted and passed by the European Union (EU), it imposes obligations onto organizations anywhere, so long as they target or collect data related to people in the EU. The regulation was put into effect on May 25, 2018. The GDPR will levy harsh fines against those who violate its privacy and security standards, with penalties reaching into the tens of millions of euros.

With the GDPR, Europe is signaling its firm stance on data privacy and security at a time when more people are entrusting their personal data with cloud services and breaches are a daily occurrence. The regulation itself is large, far-reaching, and fairly light on specifics, making GDPR compliance a daunting prospect, particularly for small and medium-sized enterprises (SMEs).

If the author had been able to hear the transcripts in their original form it's possible different aspects of caregiver experience could have been communicated. For instance, if someone's voice quivered with emotion on an audio recording, it would be a notable observation that whatever they were speaking about was of emotional importance. Additionally, hearing the dynamic between the caregiver and care receiver could have led to additional observations about the bond between the individuals, and how they experienced and received support from each other. Ultimately, an anonymized written transcript with multiple speakers can be a flat, and at times

confusing, document which is hard to keep a person's attention for very long. Hearing an audio conversation of the individuals speaking while reading through a written transcript would have enhanced the analytical experience.

Moving forward, countries and entities bound by provisions of the GDPR may face further barriers to sharing raw data electronically for the purposes of social research. And while governments, such as the United Kingdom, hope to save money (Heaton, 2008) and resources by recycling archival data (Bryman, 2016), there is something lost in revisiting semi-structured qualitative interview data.

## **Suggestions for Future Research**

Each of the individual themes of this analysis could be explored in more detail as standalone concepts. As the literature review reflected, many of these themes and dynamics have been studied or are continually studied by social science researchers. This analysis was a grounded theory analysis based on existing data, meant to illuminate aspects of caregiver experience, it was not instigated to investigate a specific hypothesis.

In identifying a research gap relating to the social health of family caregivers of people living with dementia, the creation of a measurement to gauge and monitor a caregiver's social health would be helpful for program coordinators, casework managers, and policymakers. Studies commissioned using a quantifiable measure of social health could create better predictors and outcomes of social health interventions for family caregivers. Adaptations of existing measures of Quality of Life (QOL) and the COPE Index would be one approach. A study on the utilization and effectiveness of the WHO's i-tutorial on caregiving for people living with dementia would also be value added.

An interesting theme that arose in the author's observation, relating to changing roles in marriage, is that of consent and decision making – financial, medical, and even sexual. If a person's primary relationship to the person for whom they're caregiving is that of spouse, what happens when the care receiver is no longer "legally" able to consent to due to cognitive impairment? How does this fit within a person-centered, integrated care, possibly rights-based approach to dementia management? And how does social health enter this equation – for both the person living with dementia and the spousal caregiver?

The concepts of social exclusion/inclusion and rights-based approaches to dementia care were mentioned in some of the articles reviewed for the literature review. An examination of social exclusion/inclusion of family caregiver and the influence of rights-based approaches to dementia, in the context of caregiver experience, would also be an interesting literature review processes and/or topic of further study.

## **Conclusion**

The main conclusion of this analysis is that dementia caregiving is a multi-dimensional experience and an improved measure and monitoring of social health among family caregivers would enhance dementia management in communities. The individual caregiver's existing social network, communication of their wants and needs, access and inclusion in dementia case management, and willingness to participate (or even have access) to dementia support groups, all seem to be factors in improving social health.

Additionally, the most effective intervention for an individual caregiver may not be a universally implementable policy. While broad-stroke policy interventions would be more feasible, they would likely not be as effective as individualized approaches. As Chappell et al's analysis about caregiver experiences of respite showed, respite can take many forms (Chappell et al., 2001).

As the analytical themes showed, the symptoms and characteristics of dementia vary person to person as well as the objective and subjective burden of dementia on caregivers. Some caregivers find comfort and rest in their daily routines and interactions while other individuals need more outside intervention and social support to not feel overwhelmed. The dynamic between caregiver and care receiver is unique. Therefore, a policy framework which provides uniquely tailored intervention options for caregivers, and people living with dementia, would be most helpful.

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**UNIVERSITY OF  
STIRLING**



## **Neighbourhoods: Our people, Our places**

### **Topic Guide – Social Mapping Exercise**

**Aim:** The aim of the social networking exercise will be to understand the ways in which members of the network support the participants and family. It will enable us to understand how participants conceptualise their social networks and how the network members are connected to each other.

The exercise will be undertaken with a carer and participants will be encouraged to discuss their networks with regard to who is important to them and from whom they receive support. They will also be asked to ‘draw’ their network in order to show visually how and where people within that network connect and overlap. This exercise will help to situate the network within the neighbourhood setting so that the social network can be understood within the physical space of the neighbourhood and how this changes over time. The network map will also allow us to understand how the neighbourhood is part of, or nested within, a wider set of relationships.

Begin the session by briefly explaining again the research that is being undertaken and the subjects that the interviewer wants to explore. Discuss how the social mapping exercise will be carried out and the use of video and audio equipment. Go through the information sheet again and ensure that consent has been given for the interview and the use of any audio/visual equipment.

The following topics will be used as guides for the exercise. The researchers will use a semi-structured, responsive technique during the activity.

**TOPIC – Understanding relationships in the participant’s lives** – Who they know, where they live, how they are connected and how regularly they see them.

(1) Initial questions can be asked in order to record the personal details of the interviewee and his/her household. Demographic make-up of household. Number of years in residence there.

Ask the participant to ‘draw’, in any way they would like, a diagram of the people that are involved in their life. Start the process by asking the participant to talk about the people they know: Who are they; How do you know them; Where do they live?

Prompt them if necessary that the list/diagram can include friends, family, support services, neighbours and other local people who they may have contact with.

### **Understanding the social network map**

Ask the participant to explain who the people are, are they friends / family / other carers / acquaintances? Ask questions about how long they have known the person.

Other prompts and questions:

What about other people with dementia?

Are all these people those who you are still in touch with? Are there people you have lost touch with? (Sensitively probe for influence of diagnosis, or caring work, if appropriate)

Do all these people know each other?

Is there anyone on here you have not thought of yet?

What about people like neighbours / health and social care professionals / support group leaders/facilitators / friends of friends etc.?

Are some of these people closer than others?

Are some of these ties more about obligation than because you ‘like’ them?

Are you in regular contact with all these people?

How do you keep in touch with all these people?

Do you meet up and see all these people?

How do you get to see others?

Do you meet up with people as often as you would like?

What stops you from meeting up with others?

Has contact changed over the time that you have known each other?

**Questions about temporality:** To understand who is currently in the person's life and who is no longer around. Are there relationships that have ended and if so why?

Ask the participant who is not on this map? Whom have you left off because you have lost contact? Is there anyone that you are not in contact with at the moment? And who have you decided not to be in contact with?

**Questions about wellbeing:** This will help to understand if the person has a good support network and how it helps, or if there are any problems in getting enough support. Also where the support is mostly from.

Who do you turn to for help with the job of caring? (prompts: formal and informal support; those individuals and organisations already mentioned or others?)

What is it about these people on your network that makes you feel able to care? (prompts—probe for feel good about self, happy, contented, in-control, not sick, well, managing life for you and those you feel responsible for [love])?

What would you like to change (prompts what could make caring easier, what would you like more control over, support with etc.)

### **At end of the activity**

Can I ask you some questions about having to do this task:

What did you think about it? [Prompt: was it enjoyable, demanding, impossible, easy, and childish]

Did being recorded make any difference?

Have you been surprised by anything that came up?

Take photograph of social map to give to participant. Ask if participant wants an image of him/herself etc.

Ask for permission to take the social map away. Offer to make a copy for the participant.

	<b>Transcript Document Name</b>	<b>Provided respondent details (from original researchers)</b>	<b>Pseudonyms</b>
1	MP1Fcar_andP1Mdem_SN	Older couple, working class, living 40+ years in location	Paul and Pam
2	MP1MdemW sc anonymised transcript	Older couple, working class, living 40+ years in location	Paul and Pam
3	MP6Fdem_W_sc	Young onset, middle class, live in more suburban/countryside part of greater Manchester, not originally from the area	Larry and Liz
4	MP6Mcar_N-sc	Young onset, middle class, live in more suburban/countryside part of greater Manchester, not originally from the area	Larry and Liz
5	MP9Fdem and MP9Mcar W sc	Young onset of dementia, working class, PLWD grew up in area where they still live	Bob and Barb
6	MP9Mcar_N_ac	Young onset of dementia, working class, PLWD grew up in area where they still live	Bob and Bar
7	MP14Fcar_N_sc anonymized	Working class, lived in same area more than 40 years	Chris and Carrie
8	MP14Mdem_W_sc anonymized	Working class, lived in same area more than 40 years	Chris and Carrie
9	MP20Fcar_N_sc anonymized	Middle class, moved fairly recently back to area originally from. Moved to be closer to daughter	Alan and Annie
10	MP20Mdem anonymized	Middle class moved fairly recently back to area originally from.	Alan and Annie

		Moved to be closer to daughter	
11	MP15Fcar_N_sc anonymized	No details provided	Kirk and Kathy
12	MP15Mdem_walk anon	No details provided	Kirk and Kathy
13	MP12Mcar_N_sc anonymized (MP18 actual transcript name)	No details provided	Rick and Rachel
14	MP29FDem_N_sc	No details provided	Nick and Nancy
15	Anonymised MP22Fcar N SC	No details provided	Matt and Mary

Key for acronyms (provided by research involved with anonymization):

- M for Manchester fieldsite
- P for participant
- Number is the participant number
- F/M is sex
- “dem” for person living with dementia
- “car” for family caregiver