CARING PLACES FOR DEMENTIA: EXAMINING THE CONTINUUM OF CARE IN RURAL AND SMALL TOWN ONTARIO

by

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Abstract

This dissertation contributes to the growing body of geographic, gerontological, health, and social science research on community support for persons with dementia and their partners in care with a particular focus on rural and small town settings. Focusing on rural and small town settings as well as the range of sites and services involved in caring for dementia is increasingly important. The bulk of care for dementia is taking place in home and community settings, raising questions about the quality and kind of support available, particularly in rural areas that generally have fewer formal health services and a higher proportion of older people than urban areas. Within the current literature on dementia care in the community, there is evidence of distinct challenges to service provision in rural settings, differences in service use, and unmet care needs. However, both academic researchers and policy makers have generally failed to consider the experiences of the voluntary sector, partners in care, and persons with dementia in rural and small-town settings.

To address this gap, I examine the continuum of care settings and the suitability of support for those living with dementia and their partners in care in rural and small-town Ontario. I ask: what services are available across the province of Ontario; how do those living with and caring for someone with dementia in rural Ontario experience places of care; and what are their specific needs and challenges over the course of the disease? To answer these questions, I conducted a survey of service-providers (N=20) in the province and carried out semi-structured interviews with persons with dementia and partners in care (N=73). The findings revealed regional variation in service availability and delivery as well as challenges related to service delivery in rural and small town settings. In fact, community support for persons with dementia in rural and small town setting is generally underdeveloped. I analyze the consequences of this underdevelopment for persons with dementia and their partners in care. I conclude with a set of suggestions for improving community care for persons with dementia and their partners in care.
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List of Abbreviations

AC Alzheimer’s Chapter
AS Alzheimer Society
CCAC Community Care Access Centre
CCHS Canadian Community Health Survey
GB Grey-Bruce
KFLA Kingston, Frontenac, Lennox, and Addington
NPO Non Profit Organization
SSMA Sault Ste Marie Algoma
Chapter 1

Caring About Dementia

I’ve had Ron in three different places: the VON over here in Lakefield, just a day care, he’d just go once a week and then I took him into activity haven—I don’t know how long that lasted—he didn’t like it there; then we got him into the VON in Peterborough…. But he got to the point where he said he wasn’t participating in the group and yet the people up in the group said they couldn’t understand why he didn’t want to go… I kind of miss my one Thursday to myself. (Herron, 2011)

Stories about living with and caring for dementia have become increasingly common in the media as well as in the lives of many Canadians (Taylor, 2015). The excerpt above is one of the stories that propelled this dissertation and the questions underlying its design. What were the different places like for Ron? What made him feel that he was no longer participating in the group? How did the group, the staff and/or volunteers, respond to him? What else could have been done to help his wife Tracey? Even in this single excerpt, it is evident that there are multiple and diverging dementia stories that raise questions about what kind of care and where care for dementia should take place. Such questions have garnered increasing public attention in the last decade as the population ages and the prevalence of dementia increases to over 35 million people world-wide (Prince et al., 2013).

Dementia is a complex syndrome that affects multiple cognitive domains including memory, language, and attention. Different types of dementia are associated with specific symptoms and changes to the brain. The most common form of dementia is Alzheimer’s disease, but other forms of dementia include vascular dementia, dementia with Lewy bodies, frontotemporal lobar degeneration (e.g., Pick’s disease), mixed dementia, and Parkinson’s disease dementia. There is no cure or single cause for dementia. Age is the primary risk factor with the risk of developing dementia doubling every five years after the age of 65. In Canada,
approximately 15 per cent of persons 65 years of age and older have mild cognitive impairment or some form of dementia and one third of persons 85 years of age and older have a form of dementia (Alzheimer Society, 2010). Although change and rate of change vary from one individual to another, dementias are characterized by persistent loss in ability to perform everyday activities. While persons with dementia may manage their own care to a certain extent, as the illness progresses they typically require a range of supports and sometimes constant care. Much of the care is unpaid and performed by family members. Indeed, a good deal of the experience of living with dementia takes place, for persons with dementia and their families, outside of hospitals and medical institutions in homes and various community contexts. Support for dementia requires a care continuum, or range of services, that draw on the resources of individuals, families, communities, and health and social care systems. Moreover, the social consequences and responsibilities of care for and about dementia are intrinsically geographical.

1.1 Why geographers should care about dementia

Social responses to dementia stretch across a range of spatial scales, from global advocacy groups (Bartlett, 2014), to regional service provision (Morgan et al., 2009), to dementia friendly community initiatives (Wiersma & Denton, 2013). The signs and symptoms of dementia also manifest themselves in particular spatial experiences. For instance, persons with dementia may withdraw from larger social gatherings, they may have difficulty navigating once familiar places, they may wander, they may need assistance with activities once performed in private spaces such as toileting and bathing, and they may eventually move into a long-term care facility. Over the course of the illness, persons with dementia and their family members experience changing relationships to their physical and social environments. While many people view these changes solely in terms of loss, others have argued for the need to recognize the agency
of persons with dementia in negotiating places of care (Bartlett & O’Connor, 2010). The stigma and vulnerability of dementia are also inherently geographical as they are rooted in the social and cultural practices of places. Geographers are well-positioned to contribute to social understandings (i.e., care about) and social responses to (i.e., care for) dementia.

Human geographers have a longstanding interest in the spatial organization and, more recently, the lived experiences of care and caregiving. To date, dementia, however, has been largely ignored by geographers (for a notable exception see Egdell et al., 2010). Over the last four decades, health and social geographers have examined issues of aging (Andrews et al., 2013) mental health (Parr & Davidson, 2010) and the rights and responsibilities of care and caregiving more broadly (Milligan & Power, 2010). In doing so, they have identified a complex web of spaces and places that are involved in care and caregiving, including institutions, homes, community settings (i.e., drop in centres, retail settings, post offices etc.), and the body itself as the site closest to care (Dyck et al., 2005; Parr, 2002). They have also identified how these spaces and places can be experienced quite differently by particular groups. For example, studies have examined the gendered implications of health and social policies and prevailing cultural norms surrounding care in the home (Dyck, 2003); the therapeutic qualities of a range of places (William, 2010; Wood et al., 2013); the role of emotion and affect in care and caregiving (Andrews et al., 2013; Davidson & Milligan, 2004), and the ethics of care in relation to who cares and where care takes place (Parr et al., 2004; Stacheli & Brown, 2003). Lawson (2007) goes so far as to argue that geographers across the decades have always been concerned with a responsibility to care for and about particular issues. Furthermore, she suggests that geography’s attention to the particular sites and relationships that produce a need for care is an asset in this regard. Both a longstanding interest in the spatial distribution of resources and more recent interest in emotion and relationality (see Chapter 2) provide a rich foundation for exploring
questions of what makes experiences and settings of dementia care ‘good’ In particular, geographers have much to contribute to the small body of social science literature on dementia care in rural and small town settings.

1.2 Dementia in rural and small town settings

Both in the Canadian and international contexts, rural communities and small towns pose particular challenges to delivering targeted services (Dal Bello-Haas et al., 2014a; Skinner & Rosenberg, 2006). Low population densities, small numbers of persons with particular health conditions, distance, weak or non-existent public transportation systems, weather conditions, and individuals’ degree of flexibility and mobility all affect provision of and access to services in rural settings (Panelli et al., 2006; Skinner et al., 2009). Persons with dementia and their partners in care face additional challenges including difficulties getting a diagnosis from a family practitioner, wait times to see a specialist, limited service options, lack of flexibility in services, and lack of educational resources (Dal Bello-Haas et al., 2014a). Studies suggest that people living in rural areas with dementia typically use fewer community-based services because of competing priorities (e.g., farm labour), not knowing how to access services, socio-cultural barriers, stigma, and privacy issues (Forbes, 2006; Morgan et al., 2002). Moreover, the range of formal supports required to meet different knowledge and care needs over the course of the illness are often underdeveloped in rural communities (Forbes et al., 2012; Wiersma & Denton, 2014).

In spite of these challenges, little attention has been given to the specific rural contexts in which people with dementia and partners in care actively negotiate the care they need (Innes et al., 2005). Furthermore, few studies have included the voices and
perspectives of persons with dementia to examine the suitability of services in rural settings (Blackstock et al, 2006; Forbes et al., 2012). If the unmet service needs and additional barriers associated with dementia care in rural settings are to be addressed, research must explore a range of services with reference to the experiences of persons with dementia and their partners in care.

1.3 Research goals and objectives

The overarching objectives of the research presented in this dissertation are: 1) To understand the relationship between living in rural places and experiences of dementia care; 2) More specifically, to understand how living in rural places affects service availability and service use from diagnosis with dementia to death; 3) To understand the relationships between specific sites of care, care needs, and experiences of care and caregiving; and 4) To contribute in a meaningful way to the lives of persons with dementia, their partners in care, and their communities by building on the current academic literature on rural dementia care and bringing together information about service organization and service experiences at the community level to inform local practice. To achieve these goals I have developed a set of specific research questions to be addressed in my dissertation:

R1: What services are available to persons with dementia and their partners in care across the province of Ontario?
R2: What services do people living with dementia in rural places need and use?
R3: How do persons living with dementia experience care services and sites of care in rural places?
R4: How can the lives of rural people with dementia and their partners in care be improved by taking into account their experiences over the course of dementia and at different sites of care?

1.4 Broad approach to the research

The conceptual underpinnings of the research are informed by social science research on dementia care in rural and small town settings, the geographies of care and caregiving literature, and the geographies of mental and emotional health literature. The mixed-method design of the project is influenced by these fields of research as well as philosophical debates within them (see Chapters 2 and 3). The first stage of the research involved a survey of the services provided in the province of Ontario by the Alzheimer Society (AS) and Community Care Access Centres (CCACs) to better understand the availability of services for persons living with dementia and their partners in care. The purpose of the survey was to examine service provision and rural service demands regionally and provincially. The survey collected information about the challenges and differences in providing services across urban–rural jurisdictions as well as information about the approximate percentage of service users from rural areas in each jurisdiction (see Appendix D). The information from the survey served as a platform for selecting case study sites to explore issues of availability and service use from an in-depth, qualitative perspective.

The second stage of the research consisted of a qualitative case study approach featuring a series of in-depth, semi-structured interviews with persons who identify as having early dementia and persons who identify as having formerly (within the last 1-5 years) been a partner in care for someone with dementia in three rural areas of Ontario.
The purpose of the case study approach was to examine qualitatively the experiences, needs, and challenges of caring for dementia across a range of rural settings and over the course of the illness. The interviews were designed to gather detailed reflections on the processes and contexts of service use and care needs for persons with dementia and their partners (see Appendix G and J). Since little is known about the service needs and service use of people living with dementia in rural and small town Ontario, the research is designed to explore the broader geography of service provision and availability as well as experiences of services and service needs across a range of rural settings (Keating & Eales, 2012). It is not my objective to compare the rural sites, rather I have chosen to use a collective case study approach to elucidate the diversity of, and relationships among, rural places that shape and are shaped by experiences of caring for dementia (Stake, 2005). I describe definitions of rural and care and caregiving in Chapter 2. The case study approach, data collection, and analysis are described in greater detail in Chapter 3.

1.5 Structure of the dissertation

The remainder of the dissertation is organized into 6 chapters. Chapter 2 discusses the empirical foundation for the research and theoretical approaches to dementia, rural places, and care and caregiving that inform the research. In particular, it describes how a relational approach can contribute to current research on dementia and rural settings of care. Chapter 3 describes the research design, linking the bodies of literature reviewed in the previous chapter to the methods, design, and analysis of the data collected. In Chapter 3, I also discuss the particular ethical challenges of doing research with persons with dementia and their partners in care. In the fourth chapter, I examine the variation in services available through the Alzheimer Societies across the province of Ontario. I discuss the challenges of providing services at the regional and provincial level. Chapter 5 examines the experiences of persons with dementia living in the three case study
sites. Chapter 6 analyzes the narratives of former partners in care, reflecting on their needs and challenges as well as those they observed and discussed with the person for whom they cared.

Finally, Chapter 7 highlights the key findings of the dissertation and its empirical and theoretical contributions. I reflect on the limitations of the dissertation and future directions for research that might improve the lives of persons with dementia, their partners in care, and their communities.
Chapter 2

Conceptualizing rural places of care and living with dementia

This dissertation contributes to the growing body of geographic and social science research on the experiences of persons living with and caring for dementia with a particular focus on rural and small town settings of care. The theoretical approach to the research stems from the recognition that rural and small town settings of care are diverse, changing, and interconnected to other rural and urban settings in the experiences of people living with and caring for persons with dementia. The conceptual foundations of the research derive from three broad bodies of research: research on rural aging and health services, research on the geographies of care and caregiving, and research on the geographies of mental and emotional health. Each body of literature comprises key debates that provide a framework for understanding the limitations as well as the potential of living with dementia in rural and small town settings.

In the chapter, I argue that rural settings of care and the experiences of persons living with dementia can be understood better, even enriched, through the use of a relational approach. I begin the chapter by reviewing the contributions of more ‘conventional’ approaches to researching rural aging, service provision, and service use, with particular attention to the relatively small body of social science research on dementia care in rural settings. Next, I discuss key debates about rurality and geographic conceptualizations of spaces, places, and settings of care. I turn to the literature on the

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1 In this chapter, I use the terms caregiving and caregiver as they are used in particular bodies of research and specific studies that are referenced herein. In talking about research participants in this study, I use the phrase “partner in care.” I address this choice later in the chapter.
geographies of mental and emotional health to elucidate the ways in which geographers have, and might continue to, interpret care with attention to the emotional lives of persons with mental health problems. In the final section, I explain how these intersecting threads of research inform my theoretical framework—a relational approach—and the methods and findings that form the remainder of the dissertation.

2.1 Rural aging and health services

Research on rural aging and health services provide an empirical foundation for this dissertation with evidence of the significance of rural population aging, rural health and health service disadvantages, and challenges and needs associated with dementia care in rural and small town settings. Much of this research has adopted a relatively conventional approach to defining rural communities, care, and health; that is, one that views aging and dementia as growing problems and seeks to examine particular service needs and challenges within bounded national, regional, and community contexts. As such, it provides a portrait of the limitations of dementia care in rural and small town settings as well as some new directions in the field on which this dissertation builds.

The rural focus of the dissertation is informed by research within geography and the social sciences, more broadly, about rural aging as a significant demographic and social phenomenon. Although urbanization has been a dominant population trend in the last half of the twentieth century, in both Canadian and international contexts the aging population is greater and growing at a faster rate in rural settings. Globally, 48 per cent of the population 65 years and older live in rural areas (Hennessy et al., 2014). In Canada, the percentage of the population 65 years and older in predominantly rural regions varies from an average of 15 per cent of the total population nationwide (Dandy & Bollman,
(Statistics Canada, 2011). The large representation and proportion of older people in rural communities is the outcome of multiple migration trends including the out-migration of younger people seeking employment opportunities elsewhere, the in-migration of retiring people to rural and small town Canada, and the large number of older people that are choosing to age in their homes and communities (Bryant & Joseph, 2001). Moreover, increasing life expectancies, migration trends, economic change, and advances in health technologies and treatments have contributed to the growing number of older people living (relatively) independently in rural communities.

While older people in rural settings continue to be a significant group in the aging population, both research and policy literatures typically reflect the needs of an urban aging population or the aging population, broadly defined. Such an approach lacks sensitivity to context as well as recognition of the contributions of older people in rural areas and elsewhere. In their review of the rural aging literature, Burholdt and Dobbs (2012) suggest that research in the field has tended to view aging as inherently problematic, focusing on declines in labour force participation, increasing dependency ratios, and service needs. They suggest that future research must, following critical social gerontology, acknowledge the contributions and positive aspects of aging in diverse rural settings. Research on the well-being of older rural adults and rural community development have moved in this direction, examining the contributions of older adults in terms of social support (Wiersma & Denton, 2014), informal care (Keating et al., 2011), and voluntarism (Skinner & Power, 2011; Winterton et al., 2014). Fast and de Jong Gierveld (2008) found that rural older adults in Canada belong to more community
organizations and spend more time volunteering and helping others than their urban counterparts (Fast & de Jong Gierveld, 2008). They interpret these finding with caution, suggesting that low levels of formal service infrastructure in rural communities can put older adults at risk of becoming compulsory volunteers. Other studies on rural health care restructuring corroborate these findings and call into question the capacity of informal caregivers and volunteers to meet the growing demands of the aging population in already underserviced rural communities (Cloutier-Fisher & Joseph, 2000; Skinner, 2008; Joseph & Skinner, 2012). Indeed, a critical contribution of rural aging research has been the recognition that older rural adults are simultaneously contributing to, and vulnerable within, their communities. The bulk of the literature, however, has focused on their vulnerability in terms of health.

Key studies have found that older people in rural settings typically experience poorer health at the aggregate level and have fewer resources with which to achieve their health potential than their urban counterparts (DesMeules & Pong, 2006; Kulig & Williams, 2012). In particular, research has shown that older rural people exhibit higher rates of diabetes (Patenaude et al., 2005), obesity (Self et al., 2005), mental distress (Karunanayake & Pahwa, 2009), and activity limitations (Fast & de Jong Gierveld, 2008). While few urban–rural differences have been found in the prevalence of dementia, the increasing number of older rural adults means that a greater proportion of the rural population is at risk of dementia (Innes et al. 2005). Meeting the needs of this growing, but relatively small and geographically dispersed, population poses particular challenges.
2.1.2 Dementia care

Following traditions in the broader health services literature, the majority of studies on rural dementia care have examined patterns in service provision and use from the perspective of formal/paid caregivers and informal/unpaid caregivers. Much of the Canadian research on dementia service provision is based out of Saskatchewan. The research focuses on the perspectives of formal service providers to assess the program and training needs particular to rural areas and make policy and practice recommendations (Morgan et al., 2011). Studies have evaluated different models of dementia care in rural settings including the development of memory clinics and the use of telehealth technology to assess patients at home (Morgan et al., 2009). At the other end of the care continuum, Morgan et al. (2003, 2004, 2005) examined the capacity of rural nursing homes to care for persons with dementia; these studies focused on work stress, training needs, and the supportiveness of the environment for residents, drawing on surveys and focus groups with nursing home staff. Although understanding the organization, training, and technologies used to care for persons with dementia and their families is essential, until relatively recently there has been a “global neglect of service users’ and [informal] carers’ experiences of dementia care provision in rural areas” (Innes et al., 2005: 354).

In the last decade, a handful of Canadian studies have sought to integrate the perspectives of formal and informal caregivers to better understand the relationships between service provision and use. Dal Bello-Haas and colleagues (2014a) compared formal and informal caregivers’ perceptions of the challenges and needs of providing support to persons with dementia in rural and remote Saskatchewan. In the study,
physicians were more likely than other care providers to believe that services were adequate. Informal caregivers indicated that they faced challenges getting a diagnosis, long wait times to see specialists, and a lack of community support services. The community service managers and providers in the study were most likely to report that services were inadequate and they suggested a need for improved services (i.e., respite, home care, day programs, long-term care, and more early stage support), better coordination of services, a means of addressing travel burden, and staff training and education. The findings of the study raise significant questions about the physicians’ position within the community support system and the limitations of their role in terms of assessing caregiver needs. They also point to the increasing demands being placed on the community sector. Consistent with other studies on dementia service use, the study confirms the continuing challenges related to accessing appropriate community support services in rural settings.

Other key studies in Canada and the United Kingdom have documented barriers to accessing community support services in rural areas (Forbes et al., 2006; Innes et al., 2005; Morgan et al., 2002). Using the Canadian Community Health Survey (CCHS), Forbes et al. (2006) examined the use of health services by urban and rural residence with and without dementia; they found that persons with dementia were more likely to report that their health needs were unmet than those without and those in rural areas were more likely to report being too busy, care not being available, feeling that the care would not be adequate, and not knowing how to access services as reasons for unmet care needs. Similarly, Morgan et al. (2002) identified eight barriers to service use drawing on focus groups and semi-structured interviews with formal and informal caregivers. They noted
that informal caregivers were reluctant to publicly acknowledge the presence of dementia because of the stigma associated with the illness and they felt that they should be self-reliant and responsible for their family member’s health and caregiving. They also identified lack of privacy as a barrier to accessing services in their communities and financial barriers associated with travel costs and respite services. Moreover, the range of formal supports required to meet different knowledge and care needs over the course of the illness is often underdeveloped in rural communities (Forbes et al., 2012; Wiersma & Denton, 2014).

Since the bulk of community-based support for persons with dementia is provided by family members, there has been considerable emphasis on their needs and experiences of burden in the broader social science literature on dementia. Studies have noted that behavioural and emotional challenges associated with the later stages of dementia as well as functional decline contribute to the burden and distress experienced by caregivers (Stewart et al., 2014). Gender and relationship to the person with dementia also have an impact on experiences of burden, with women and spouses experiencing higher levels of distress. Furthermore, Lilly and colleagues (2012) argue that aging at home strategies in Canada, which place increasing pressure on family caregivers to provide support without recognizing their own care needs, exacerbate caregiver burden and distress. Although the distress is often linked to admission into long-term care, there has been limited research on transitions into, and the characteristics of, different care settings in rural and small-town settings (i.e., day programs, long-term care, alternative residential care settings, or hospice). The space and place of care for dementia in rural and small town settings, remains relatively unexplored (a point to which I will return later in this chapter).
Although many of the studies above have outlined the limitations of rural service provision and barriers to service use from the perspectives of formal and informal caregivers, relatively few studies have focused on the experiences of persons living with dementia in rural and small town settings. The majority of studies have relied on family caregivers to provide proxy accounts of experiences of dementia suggesting that the accounts of persons with dementia are unreliable (Murphy et al., 2014). Countering this approach, a growing number of researchers have argued that it is not only desirable, but also absolutely necessary to include the perspectives of persons with dementia in research on their care to address issues of vulnerability and stigma, recognize the personhood and citizenship of persons with dementia, provide appropriate support, and understand dementia as a social experience (Bartlett & O’Connor, 2010; Blackstock et al., 2005; Cahill et al., 2012). Several recent studies on caring for dementia in rural Canada have involved persons with dementia in their design; Forbes et al., (2012) conducted interviews with five persons with dementia to evaluate their information needs and Dal Bello-Haas et al., (2014b) conducted patient surveys to examine exercise, diet, and other health behaviours. However, these studies paid little attention to the context of persons’ experiences. In this regard, the work of Blackstock et al. (2006) on the experiences of persons with dementia in rural Scotland provides a notable counter example. Blackstock and colleagues examined how people living with dementia in rural settings actively negotiate the support required to cope with and care for dementia, identifying positive aspects of rural communities and the agency of individuals. They linked the experiences of persons with dementia and their partners in care to a rural idyll, which casts rural places as healthy environments and rural people as resilient and self-sufficient. As such,
their work provides some consideration of the socio-cultural contexts and lived experiences of care in rural settings. A central limitation of the work of Blackstock and colleagues, and the social sciences literature on dementia care in the community, is the almost exclusive focus on home and formal sites of care (e.g., day programs and long-term care). The range of sites and services available and desirable to people living with dementia, including their partners in care, has not been fully explored or connected; although studies have identified the need for more information and assistance with decision-making and transitions in care (Forbes et al., 2012; Forbes & Hawranik, 2012; Forbes et al., 2008; Jansen et al., 2009). This dissertation seeks to address this gap using a relational approach to examine experiences and settings of care.

Given the continued identification of challenges related to navigating and negotiating care, it seems that conventional approaches fall short in identifying the relationships in and to place that support or present challenges to finding appropriate care. Indeed, such bounded models of care, rurality, and place have been challenged by geographers. In the sections that follow, I outline these debates and the ways that they inform the research.

2.1.1 Changing rural places and conceptions of rurality

The findings of studies on rural health, aging, and dementia rest on evolving debates about the way that rural should be defined and operationalized to answer specific research questions. Dandy and Bollman (2008), suggest that the definition of rural must derive from the requirements of the question being asked. This assertion marks an evolving range of rural typologies and definitions that have developed since the 1980s following conceptual engagement with the post-modern challenge and growing
acceptance of qualitative and ethnographic methods as well as evidence of changing conditions in rural places themselves (Chalmers & Joseph, 2006; Hennessy at al., 2014). For instance, in the 1990s Statistics Canada’s definition of rural was still based on economic activity in agriculture. Much of the research on rural Canada reflected a belief that rural places developed from early settlement, were characterized by isolation, and shared economic activities and cultural norms that centred on controlling the natural environment (Keating et al., 2011). With a declining proportion of the rural population involved in primary industries such as agriculture, increasing urbanization, and developments in technology and transport, more sophisticated definitions of rural were certainly required. To delineate rural from urban, most definitions have incorporated measures such as population size, density, and distance alongside socio-demographic and cultural characteristics, acknowledging that rural places and experiences within them are diverse (Williams & Kulig, 2012). For instance, Bryant and Joseph (2001) developed a three-part typology: urban countryside, rural hinterland, and remote hinterland, which describe rural differentiation in terms of proximity to urban centres as well as in relation to economic and social change. Similarly, Statistics Canada’s (2003) Metropolitan Influenced Zone (MIZ) uses commuter flow (i.e., percentage of persons living in a rural area but working in census metropolitan area) as a proxy measure to differentiate the social and economic influence of urban centres. This typology departs from traditional, static definitions of rural such as activity in agriculture and urban versus non-urban, allowing for a more nuanced view of rural as a continuum in relation to broader regional flows. It is not, however, designed to capture the social experience of living in a rural place.
Since the early 1990s, there has been a growing interest in the socially constructed nature of rurality and individual experience as the bases of definitions of rural (Cloke 2000). Recognition of local experiences and the variety of experiences within specific localities has led geographers to agree that a static all-encompassing definition of rural is “neither desirable nor feasible” (Halfacree, 1993, 34). Instead, Murdoch (2003) suggests that rural is a collection of cultural constructs, not a set of bordered spaces. Although these debates have extended the literature on rural places by encouraging a more holistic, interdisciplinary and experiential approach to understanding rural, they raise questions about why, whether, and how diverse rural places really matter in terms of health and care (Kulig & Williams, 2012). What then is distinctive about a rural place? Rural places hold in common empirical conditions such as distance and low population densities (Cloke, 1977), socio-cultural attributes such as relative homogeneity (Pahl, 1966), and social representations such as idyllic country lifestyles (Cloke & Little, 1997), but perhaps most importantly, they hold in common specific challenges associated with change and unevenness, which are fundamental to understanding the contexts of health and care for older people. Indeed, older people’s experiences of health and social care in rural communities take place against the backdrop of changing rural lifeways, work, and landscapes, which are influenced by processes within and outside of rural communities (Hennessy et al., 2014). Recognizing the changing nature of rural communities, populations, and cultures is essential to understanding the experiences of persons living with dementia in, and across, different rural settings. As such this dissertation involves the study of several different types of rural communities and settings within, or connected to, them (See Chapter 3).
2.2 Space, place, and care in Geography

Rural settings are positioned within, and provide a context for, a broader and more complex geography of care that stretches from the global to the local (Milligan & Wiles, 2010). Within human geography, the spatial extensiveness of care has been explored with increasing attention to health and well-being, recognition of the value of qualitative approaches, and the use of a broad range of critical theories. A complete review of these developments is beyond the scope of this dissertation; in the section that follows, I focus on the changing geographic conceptualizations of space, place, and care.²

In particular, I outline how these developments have contributed to more relational approaches to understanding settings and experiences as well as how they might better inform the study of rural dementia care in the social sciences more broadly.

Care has often been categorized by the settings (e.g., rural or urban) and scales (e.g., community, home, body etc.) in which it takes place (Bowlby, 2012). Traditionally, in health geography, settings of care were defined in terms of space. Their specific location and boundaries were identified so that it was possible to measure and compare distance and spatial patterns such as how resources and services are distributed and how people might ideally move to access health services (Cummins et al., 2007). This conceptualization of space largely originated from the positivist tradition in the 1950s and 1960s, which sought to examine health and healthcare objectively. While such spatial patterning remains an important part of examining healthcare access and patterns of aging

² For the purposes of this dissertation, I use the term space to refer to the physical environment in which people move and experience care. This includes particular settings such as an individual’s house, the arrangements of objects within such settings, and other sites within the community or region. Such spaces may also be referred to as places when they are imbued with particular meanings. I use the term place, when I am referring to people’s feeling and perceptions within particular spaces.
in geography and the social sciences, this approach has long been critiqued for its inability to account for the competing demands, power relations, identities, and meanings that influence human behaviour across space. Responding to these critiques, health geographers have developed more comprehensive approaches to examining the complex relationships among space, place, and care.

In health research more broadly, it is now generally accepted that illness, health, and well-being are influenced by the broader environments of communities in which people live, rather than being the domain of medicine alone. The acceptance of this social model of health has been associated with a so-called spatial turn or growing interest in space and place (Andrews et al., 2013). In geography, this turn has also been theoretically driven by calls for the sub-discipline to engage with cultural and humanistic approaches to health and well-being (Kearns, 1993) as well as poststructuralist and cultural theories about the body (Dorn & Laws, 1994; Parr 2002). As such, spaces are no longer conceptualized as neutral containers; there has been an increasing interest in people’s relationships to and within space. For instance, earlier studies by Joseph and Hallman (1998) explored the ways in which gender and distance between employed caregivers and their aging relatives influenced the frequency and duration of their caring. In doing so, they explored not only the difference space makes in terms of human behaviour, but also how space can amplify differences such as the gendered expectations that women provide care. Other key studies have explored the multi-dimensionality of space itself using the term “social space” to refer to the assemblage of settings that people regularly visit and move among, including their homes, their friends’ homes, post offices, retail and community settings, drop-in centres, and even virtual spaces (Conradson, 2003; Milligan
et al., 2004; Parr, 2008; Wiles et al., 2012). Importantly, the concept of social space marks a departure from conventional views of space in the study of care, which have tended to view sites and settings of care in isolation from one another. Instead, this approach to space views mundane social settings as interconnected in individuals’ lives, movements, and experiences of care and uncaring. As studies have explored the movement of people using the concept of social space, they have also contributed to geography’s longstanding interest in emplacement by examining how experiences in particular spaces, over time, produce attachment to place.

The concept of place is often used to refer to the operational, constructed, and experiential aspects of a space (Kearns & Moon, 2002), but the two concepts of space and place are mutually constituted (Andrews et al., 2013). As Wiles (2005) explains, place is a process that occurs in relation to space; it is negotiated over time and in relation to other people and places; and it is simultaneously material, symbolic, and social. Studies examining places of care have looked at the contested meanings of home for women caring for children and older people (Dyck et al., 2005; Wiles, 2003; Yantzi & Rosenberg, 2008). They have observed the ways in which the scheduling of care activities and the placing of care devices changes the home for both care recipients and caregivers. They have also explored the meaning of aging in place for older people, looking beyond the home at the places with which older people continually negotiate meaning, identity, and attachment (Wiles et al., 2012). Wiles and colleagues argued that place attachment is not merely influenced by history and family relations in the home; feelings about home are also influenced by the physical and social supports in the surrounding neighbourhood. To some extent, each of these studies have employed a
relational framework to the study of care and caregiving by examining linkages between care and caregiving and changing spaces and places of care at multiple scales. This approach is also evident in studies of healthcare restructuring.

In many advanced capitalist countries, changes to health and social care policies in the last three decades have shifted care from institutional settings to community and home-based settings (Milligan & Power, 2010). As these shifts have taken place, health geographers have studied the consequences of health care restructuring for particular groups, including care recipients, informal caregivers, health professionals, the voluntary sector, and communities. In the last two decades, a body of geographical research has emerged to focus specifically on the implications of such shifts for the voluntary sector (Milligan, 2007; Skinner & Power, 2011). The voluntary sector—nonprofit organizations, their staff, community groups and volunteers—have been given an increasing share of the responsibility of providing health and social care programs such as meals on wheels, transportation, friendly visiting, and respite (Yantzi & Skinner, 2009). Although many of the nonprofit organizations delivering these services existed outside of the formal health care system for decades, through government contracts they have been increasingly co-opted to provide services once performed in institutional settings (Skinner & Power, 2011; Skinner, 2008). The results of these changes have played out in different ways in different places, but scholars have noted that smaller, often rural, organizations have struggled to compete for scarce resources while experiencing constraints on their flexibility and dynamism (Skinner, 2008). There is some evidence of resistance toward governments downloading responsibilities to nonprofits (i.e., nonprofit organizations withdrawing from providing services directly funded by the government in favour of their
own autonomy); however, not all organizations have the capacity to resist in such a manner (Joseph et al., 2013). By emphasizing the role of the voluntary sector as a mediator, responding to long (e.g., demographic) and short (e.g., political) cycles of change spanning multiple scales, this work has contributed to the development of more relational approaches in the geographies of care literature.

In several commentaries on the development of the geographies of care literature, Milligan and colleagues (2007; 2010) have suggested that care in geography is often interpreted within a relational framework. Much of this work has focused on the changing “landscapes of care” coined by Milligan and Wiles (2010) as a metaphor and framework to describe “the complex spatialities that care and care relationships entail” building on earlier geographical work around deinstitutionalization (e.g., landscapes of despair) and cultural geographies longstanding interest in landscapes (p. 736). Importantly, this approach draws together the macrolevel governance and policy around care with the microlevel interpersonal experiences of care. The landscape, then, is one with multiple layers of social, cultural, and political influence that shape and is shaped by care.

Similarly, research on social reproduction provides another relational framework for examining the gendered generational expectations of care work across spaces with specific attention to time (Bowlby, 2012; Bowlby et al., 2010). Bowlby and colleagues (2012) use the terms “carescape” and “caringscapes” to examine the interplay between changing formal structures of care and changes in care relationships. They explain that care trajectories are influenced by many lifecourse decisions and relationships (e.g., parent-child relations over time), past experiences and memories, anticipations of the future, social expectations, and the wider socio-economic and political environments.
Importantly, they identify multiple time scales (e.g., the rhythm of everyday life, stages over the lifecourse, linear expectations related to work) as overlapping in the lived experiences of care and caregiving. In geography, both landscape metaphors have been used to direct analyses of the dynamic, multi-scaled, socio-political nature of care and caregiving, contributing to more relational understanding of care itself.

2.2.1 Defining care and care relationships

As geographers have examined the importance of space, place, and scale in the organization and re-organization of care and caregiving, they have critiqued particular conceptualizations of care. Drawing on feminist and critical theories of care, geographers have defined care as physical and emotional labour (Conradson, 2003), a practice, politics, and moral appeal (Atkinson et al., 2011), and a social relation (Brown, 2003; Lawson, 2007). In defining care, many feminist scholars have drawn attention to the epistemological power of emotion (Dyck, 2005; Lawson, 2007; Milligan, 2005). Lawson (2007) argued that emotion often shapes how we know what is caring and what is uncaring or unjust. Indeed, conceptions of ‘good care’ often include assumptions about the way it should be performed affectively and the way an individual receiving care should feel. As Milligan (2005) explains, caring often involves embodied emotional experiences (e.g., guilt and grief) as well as affective dimensions such as the expression of love. I will elaborate further on the utility of emotion in understanding experiences of care in the next section. Here, I emphasize that emotion is often cited as a definitive characteristic of care and caregiving, a way of knowing care, and a means of exploring the ethics of care (Hankivsky, 2004; Tronto, 1993).
Many scholars have pointed out that relationships of care are not necessarily
emotion or action, care is always already a social relation. It structures relations between
carers and dependents that help mutually constitute subject positions of gender, class,
ableism and race inter alia” (p. 835). Furthermore, many disability scholars suggest that
the terminology of care is problematic because it reinforces notions of dependency rather
than independence (Oliver, 1998). Recently, there has been considerable debate about
moving away from care towards a study of support and assistance, but Milligan and
Wiles (2010) argue that the problems of care “Arise as a consequence of how we think
about care itself” (p.737). They argue that care is not a unidirectional dyad in which one
person gives and the other person receives; it involves a complex network of actors,
unidirectional flows, reciprocity, coproduction, and connection. Following this
characterization Atkinson et al., (2011) suggest that care should be thought of as
relational and flowing through nodes. Moreover, debates about the nature of care—what
it is and where it takes place—draw attention to the need to view care as it flows across
sites and from multiple perspectives.

As a relationship, care involves understanding the perspectives of those caring
and the cared for. Few studies on formal and informal dementia care ever explicitly
define what is meant by the term care, although they often report on a range of supports,
services, and caregiving tasks. Furthermore, the term ‘caregiver’ is frequently used
without reference to debates about the appropriateness of the title. Dupuis et al. (2012)
suggest that dementia research ought to move toward defining and practicing care as a
partnership. As such, they use the term “partner in care.” In this chapter, I have used the
term caregiver; however, in the introduction and subsequent chapter I use the term partners in care. I acknowledge that this term is contested. Indeed, not all those in relationships of care would characterize it as a partnership. As such, I also provide other identifiers in the findings chapters such as spouse or daughter, which may hold greater significance to individuals than the term partner in care. Arguably, the language of partnership presents more opportunities to recognize the interrelated needs and contributions of persons with dementia and those supporting them. In a partnership, persons with dementia are not seen as passive recipients of care while those supporting them are not necessarily and always in a position of power. I seek to examine the diversity and complexity of these relationships, rather than treat them as static subjectivities. While the literature on the geographies of care and caregiving has extended conceptualizations of space, place, and care in relational terms, the literature on mental and emotional health provides additional direction with regards to understanding the dynamic emotional lives of persons experiencing mental ill-health in place. In the section that follows, I highlight the ways in which this literature can augment relational approaches to care with its particular emphasis on emotion and empowerment beyond the service delivery environment.

2.3 Geographies of mental and emotional health

While the geographies of mental and emotional health refers to a small sub-field of work influencing the geographies of caregiving literature, it deserves specific attention because of its critical and ontological contributions to mental health research more broadly (Boyd & Parr, 2008). Using conceptions of space, place, and scale, studies of mental health in geography have long critiqued the spatial strategies of caring for mental
‘patients’. Much of the early work on mental health in geography explored the long-lasting implications of the asylum model of care for those regarded as mentally ill (Dear & Wolch, 1987; Philo, 1997). Drawing on the work of Goffman and Foucault, geographers illustrated the ways in which the treatment of persons with mental health problems, particularly social and spatial segregation, created and reinforced a prevailing geography of difference both inside and outside of asylums (Parr, 2008; Philo, 1997).

Empirically, Dear (1977) identified the emergence of new “asylums without walls” in portions of inner cities in North America where former asylum patients remained isolated, poor, and without appropriate care. These sobering stories offer a view of the choices, criticisms, and reactions surrounding care for people living with mental illnesses in community settings. Certainly, this work provided much of the impetus for a shift toward more social approaches to care.

Focusing on community care specifically, studies have identified the continued complexity and stigma associated with mental health care as well as the social and environmental conditions needed to support mental health, recovery, and well-being in communities (Curtis, 2007; Curtis, et al., 2009; O’Campo, 2009; Tucker, 2010). As in research on dementia care and the geographies of care, qualitative methods including case studies, interviews, and ethnographies have become common means for eliciting the perspectives of persons with mental illness. Parr (2008) argues, however, that the increasing attention to the lived experiences of persons with mental illness does not go far enough when focusing on empowerment in service use alone. She advocates that more attention must be paid to embodied experiences of community participation, social inclusion and exclusion, and new spaces of care. Moving away from landscapes of
despair, she suggests that we adopt a “hopeful ontology,” critical of the limitations of certain spaces/structures of care, but also optimistic that these spaces “might in the future be infused by respect for, and a valuing of, embodied difference” (p. 29). As such she frames the limitations of community living and care as the product of differencing. To explore the potential of community living, she focuses on the experience of persons with serious mental health problems in a range of social spaces, including rural communities, urban gardening projects, the arts, and online self-help groups.

Parr’s work is particularly instructive for this dissertation because of her attention to the cultures of rural places, the emotional and embodied experiences of persons with mental illness, and their changing subjectivities over time and across space. She explains how the rural landscape, and the service landscape more broadly, can contribute to this precarious subjectivity, as the lack of formal service infrastructure in rural areas can mean that a visit from a worker is all the more noticeable. Such visibility and watchfulness have implications for the status and movements of persons with mental illness in and out of the community. They may stay in the home for some time after returning from the hospital, feeling afraid of what other community members know and might say. In the long term, they may choose to relocate in urban areas where they may have more anonymity. The broader dementia care literature would benefit from such attention to the changing landscape, interactions, movements, and subjectivities of persons with dementia.

Parr’s work demonstrates the value of emotional and embodied experience as evidence of the limitations and potential of care in a community for persons with mental illness. Embodied encounters (e.g., others crossing the street, entering a store, avoiding
eye contact etc.) shape the experiences and routines of persons with mental illness as well as their sense of belonging and care. Although it is often assumed that rural communities are more supportive, Parr provides a more nuanced view of the social proximity of rural living. She notes that many of the participants in her case study experienced and appreciated the care and concern of neighbours, but at times certain expressions of care also made them feel awkward or as though they are being monitored by their community. Thus, stigma and exclusion are not necessarily acts of ignorance; they are embedded within particular cultures, places, and practices of caring.

Within the geographies of mental and emotional health literature, there has been limited attention to the embodied and emotional experiences of persons with dementia. Certainly, research on dementia could be enriched by attention to how persons living with dementia in rural communities feel in and about their communities and particular settings of care at particular times.

2.4 A relational approach to experiences of dementia in rural Ontario

The above bodies of literature provide a framework for understanding experiences of dementia in rural Ontario as processes involving changing temporal, spatial, and emotional relationships. As such, I have chosen to develop a relational approach to researching these experiences. In reviewing the literature, I have established some of the limitations of conventional approaches to aging and dementia, space and place, and care and caregiving. I conclude the chapter by outlining what a relational approach looks like (see Table 2.1).
Table 2.1: Distinguishing relational approaches to dementia, rurality, and care

<table>
<thead>
<tr>
<th></th>
<th>Conventional</th>
<th>Relational</th>
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<tbody>
<tr>
<td>Dementia</td>
<td>• Aging/dementia as growing problems</td>
<td>• Older people positioned within networks of giving and receiving over time and across space</td>
</tr>
<tr>
<td></td>
<td>• Defined by needs and demands for services</td>
<td>• Negotiating meaning in relation to other people and place</td>
</tr>
<tr>
<td>Rural Places</td>
<td>• Rural places as static and bounded</td>
<td>• Rural places as nodes in networks that are multi-scaled</td>
</tr>
<tr>
<td></td>
<td>• Separated by distance</td>
<td>• Rural places as separated/connected by social and cultural attributes</td>
</tr>
<tr>
<td></td>
<td>• Characteristics fixed in time</td>
<td>• Changing over time in relation to social, demographic, economic, and political shifts</td>
</tr>
<tr>
<td>Care</td>
<td>• Settings of care as neutral</td>
<td>• Settings of care imbued with cultural meaning, social power relations, and emotions</td>
</tr>
<tr>
<td></td>
<td>• Settings of care as bounded; studied on a single site basis (e.g., rural nursing home)</td>
<td>• Settings of care as interconnected (i.e. influenced by feelings and practices in other settings)</td>
</tr>
<tr>
<td></td>
<td>• Services described in terms of use and barriers to use fixed in time</td>
<td>• Services negotiated through differing pathways in time and place</td>
</tr>
<tr>
<td></td>
<td>• Care understood as a need and a unidirectional activity from caregiver to receiver</td>
<td>• Care understood as a relationship with specific attention to the changing roles, responsibilities, and social and emotional lives of those involved</td>
</tr>
<tr>
<td></td>
<td>• Care understood from the perspective of formal and informal caregivers</td>
<td>• Care understood from the perspective of multiple actors in a complex network</td>
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the interconnectedness of people’s experiences and the places in which they occur over time and across spatial scales. As such, a rural community, social and cultural life within it, its meaning, and its significance, emerge in connection to other rural and non-rural locales. People living with dementia in rural places move around and outside their immediate community over the course of a day, weeks, and their lives. For instance, as a person with dementia experiences changing language capacities, their encounters in social space are likely to change. As they experience stigma or become less mobile, their sense of freedom and autonomy and their overall relationship to people and places changes. Over their lifecourse their attachment to a home or community may change, so too may their relationships with family members and friends. As family structures change it is also particularly important that the multiple spaces, homes, community centres, and institutions be viewed within a relational context of webs and nodes rather than focusing on the idea of a singular home as the best place of care. Time and history can have a significant effect on relationships, commitment, and practices of care (i.e., an adult child and their aging parent). It can affect ones sense of routine and ability to cope with change. Such time-space relationships are implicated in the marginalization and taken-for-grantedness of certain types of care and the groups of people that provide it. For instance, practices and patterns in formal service use are connected to practices and power relations at home and at broader regional and provincial scales of governance. Indeed, relational frameworks have emphasized the significance of power relationships and political decisions on the changing nature of people-place interactions.

The relational approach in this dissertation is grounded in a theoretical and analytical framework that seeks to integrate experiences of care and caregiving across a
range of overlapping scales, rural contexts, and emotional nodes as well as over the course of the illness. In doing so, I contribute to the growing interest in transitions and trajectories of care in the rural aging/dementia literature as well as the longstanding interest in rural health disadvantages and challenges to service delivery. The dissertation also contributes to the geographical literature on care and caregiving and mental and emotional health, which has largely ignored the experiences of persons with dementia. It responds to recent calls to think relationally in geography, gerontology, and social science research more broadly (Andrews et al., 2013; Cummins et al., 2007; Skinner et al., 2014). As such, it seeks to develop a more comprehensive view of the potential and limitations of care in the community for persons living with dementia.

The conceptual framework for the dissertation is informed by debates about the diversity of rural places, theoretical discussions about the potential of aging well and the ethics of care and caregiving within these settings, and the empirical contributions of research on rural health service availability and utilization. The first two objectives of my research draw on the longstanding interest within health geography in patterns of rural service availability and use by examining the relationship between living in rural places and the availability as well as experiences of dementia care in these settings, specifically (objective 1, 2). The spatial and temporal (i.e., from diagnosis to death) scope of these objectives extend the literature on rural dementia care in Canada, and internationally, by contributing to discussions about the organization, provision, and transitions involved in caring for dementia. The third objective of the research builds on this broad platform with a detailed analysis of rural dementia care and caregiving experiences in three rural communities (objective 3). In doing so, I aim to contribute to discussions within the
geographies of care and social sciences literature about the specific socio-cultural
influences on perceptions of health services, and experiences of care and caregiving. The
final research objective (objective 4) draws together the empirical and conceptual focus
of the research methodologically and operationally by articulating the need for a
community-based methods and outcomes. In the next chapter, I discuss the methods and
design that I have developed to link these theoretical conceptions to research practice.
Chapter 3

Knowing about dementia: Methods and research design

“…you almost have to live through it to know.”

As the previous chapters have suggested, living with and caring for dementia involves multiple stories and multiple ways of knowing. The excerpt above comes from the end of an interview with a former partner in care, a 65 year-old retired nurse who cared for her husband and mother, both with dementia. She commented that as a nurse she used to tell families that she knew how they felt, but having “lived through” caring for dementia, she felt “stupid” now for suggesting that she could know how others were feeling without having gone through their experience. Her reflection elucidates the impact and depth of lived experience while drawing out the limitations of more expert knowledge, even if it is sympathetic. It resonates with the work of feminist scholars regarding the value of qualitative research as a means of giving voice to the taken-for-granted components and every day lived realities of caring (Moss, 2002; Williams & Crooks, 2008). Moreover, it offers a poignant starting point for a thoughtful discussion of methodology and research design.

This chapter introduces the careful steps that were taken to examine the range of care experiences and settings in rural Ontario. The first section situates the research approach in relation to the conceptual framework and other philosophical positions that guided the research. In the subsequent section, I reiterate the primary objectives of the first phase of the study, explaining the research instruments and procedures that were used to explore larger scale trends in service availability and provision. Next, I explain how and what communities were selected as case study sites for the second phase of the
research followed by a description of the communities, community partners, and participant recruitment strategies. I discuss the ethical concerns and limitations associated with the study design and the processes used to address them. I conclude with an explanation of how this information was analyzed while also providing an outline of the presentation of findings in Chapters 4, 5, and 6.

3.1 Conceptual and methodological inter-linkages

The research design and methods for this project are informed by community-based and feminist approaches to research and operationalized through a mixed method design. The specific research instruments chosen for the study reflect, in the first stage, research traditions in health geography and the study of service provision, while the focus on service user experiences in the second stage of the research reflect the interests of feminist and health geographers in experiential and situated knowledge, power relations, and social change. The research draws on several methodologies to explore experiences and settings of care at multiple levels.

A combination of quantitative and qualitative methods was employed in the study. Typically, quantitative methods are associated with an objective positivist tradition that seeks to identify observable and generalizable truths while qualitative methods are associated with numerous approaches to research that recognize reality as subjective and constructed (Kitchin & Tate, 2000). Mixed-methods are characterized by the integration of quantitative and qualitative methods with the aim of developing a rich contextual understanding of multi-level perspectives and an appreciation of socio-cultural influences (Cresswell et al., 2011). In this particular study, I am analyzing a series of related and constructed layers of care that includes the broader provincial landscape of service
provision as well as community responses and individual experiences. A mixed method design is well-suited to exploring the relationships between contexts and experiences of care. Quantitative perspectives are useful in this project for identifying the amount of services and service variation as well as patterns in use. Qualitative perspectives, on the other hand, provide detail and depth about the contexts of care and emphasize the voice of participants. Typically a mixed-method design is not a stand-alone approach; rather mixed-method research is framed by numerous philosophical and theoretical positions (Cresswell et al., 2011).

Community-based “orientations,” as coined by Minkler (2005), provide a point of departure for this project as do feminist methodologies (Moss, 2002, 2005). Both community-based and feminist methodologies stress the importance of research relationships as a part of the process of rigorous and sensitive research. As Cornwall and Jewkes (1995) explain, community-based approaches emphasize how, by, and for whom research is conceptualized and conducted. Underlying these points are assumptions about who can know and how things are known, for which feminist scholarship on care and emotion provide a framework (see Chapter 2). As such, this research evolved through particular processes and dialogues that aim to ground the research at the community level in ways that might realize more relevant research contributions for persons living with dementia and their families (see objective 4). Like most studies that involve a degree of community engagement, there are limits to the extent of participation in this project (Balazs & Morello-Frosch, 2013). I will address these challenges in the limitations section. First, I outline each stage of the research, explaining how the methods are informed by feminist and CBPR approaches. Table 3.1 displays how both approaches are
linked to the bodies of literature reviewed in Chapter 2 and the overall research objectives.
Table 3.1: Conceptual and methodological inter-linkages

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<tr>
<th>Conceptual Framework</th>
<th>Methodological Approach</th>
<th>Research Objectives</th>
<th>Specific Research Questions</th>
<th>Methods, data and scale of analysis</th>
</tr>
</thead>
</table>
| Rural health services organization, accessibility, and utilization | Spatial contextualization of service organization and provision (community-based participatory approach) | 1) To understand the relationship between living in rural places and experiences of dementia care; 2) To understand how living in rural places affects service availability and service use from diagnosis with ADRD to death; | R1: What services are available to persons with dementia and their caregivers across the province of Ontario? R2: What services do people living with dementia in rural places need and use? | Phase 1:  
- Analysis of survey  
- Macro/meso-scale: Provincial/ regional focus |
| Experiences of care settings, sites, and services | Gathering and analysis of experiences of care in rural settings (feminist/community-based participatory approach) | 3) To understand the relationships between specific sites of care, care needs and experiences of care and caregiving; and 4) To contribute in a meaningful way to the lives of persons living with dementia, their caregivers, and their communities by building on the current literature on rural dementia care and bringing together information about service organization and service | R3: How do persons living with dementia experience care services and sites of care in rural places? R4: How can the lives of rural people with dementia and their caregivers be improved by taking into account their experiences over the course of dementia and at different sites of care? | Phase 2:  
- Coding and analysis of transcripts from interviews with persons living with early dementia and former caregivers in three rural case study sites  
- Micro-scale, local |
3.2 Surveying the landscape of care

The primary objective of the first phase of the study was to examine the availability of services for persons living with dementia and their partners in care in the province of Ontario. To do so, I conducted a survey of service providers at Alzheimer Societies (AS) and Community Care Access Centres (CCACs) across Ontario. Surveys are a frequently used technique in mixed-method design since a single survey questionnaire can combine both quantitative and qualitative data sources through standardized, structured questions, as is the case in this study (see Appendix D). Although there are limitations to the depth of data that a survey can collect, they are ideally suited to examining broader social, economic, and spatial trends efficiently and extensively (McGuirk & O’Neil, 2010). In this case, the survey offered a structured approach for collecting information from service providers that were geographically dispersed across the province, which was later combined with more intensive forms of qualitative research.

CCACs and AS chapters were selected as the target sample for the survey because of their prominent role in facilitating health and social services for persons with dementia and their support networks. CCACs coordinate the envelope of long-term care services available across the province of Ontario including the management of access and eligibility to home care services and institutional facilities such as nursing homes and continuing care facilities, as well as a range of community-based services designed to support people in their homes and communities such as respite, palliative, chronic, and rehabilitative care and support for activities of daily living (e.g., bathing, eating, and dressing) (MHLTC, 2012). There are 14 regional CCACs operating with some having several branch offices across the province.
The AS, on the other hand, is the only dementia-specific service provider in the province. The Alzheimer Society of Ontario (ASO) represents and advocates for the health and social needs of persons with dementia and their families. At the regional level, 34 AS chapters across the province provide care for people living with dementia in the form of education and information sessions, support groups, private and family counselling, respite care, and art and music programs (AS, 2011). Unlike CCACs, the AS does not provide medical service; however, chapters may be involved in the diagnosis of those suspected of having a dementia. They also play a role in helping persons with dementia and their families navigate the formal health care system. As such, they offer a particularly valuable point of departure for exploring not only service provision, but also the service needs of the population with, or caring for dementia, as a whole.
Figure 3.1 Location of Alzheimer Chapters, CCAC, and case study partner offices
Over the last three years, I have volunteered with the AS chapter of Kingston, Frontenac, and Lennox and Addington (KFLA). Initially, I helped facilitate social events for persons with dementia and their partners in care and later I joined the Board of Directors. In doing so, I was able to establish rapport and trust with a specific AS chapter, which has been essential to maintaining an ongoing dialogue throughout the research process. My encounters with persons with dementia and their partners in care in the early stages of research development sensitized me to the ordinariness of living with dementia, on the one hand, and the challenges associated with more advanced stages on the other hand. My involvement on the board gave me the opportunity to bring the stories of persons with dementia, partners in care, and other Societies to the discussion table in ways that might influence the shape of the organization. My experiences and observations as a volunteer for the Society are not used as research (i.e., ethnography), but they provided an important starting point for the development of the survey and subsequent research processes, practices, and relationships.

With ethics approval from the General Research Ethics Board (see Appendix A), the survey of CCACs and AS was carried out over the course of 6 months from December 2012 to May 2013. I reviewed the objectives, questions, wording, and format of the survey with the KFLA AS. Presenting a draft letter of information, consent form, and questionnaire to the Executive Director and other staff, I asked if they would like to alter, add, or remove questions, what kind of information they thought might be most useful for their chapter to know, and whether the wording reflected the terms used within the broader organization. This process helped to confirm the appropriateness of the priorities and instruments of the research (Sandoval et al., 2012). Once the survey was
finalized, it was administered by email and each AS and CCAC chose person(s) of responsibility they identified to be the most appropriate to complete the survey. In most instances, multiple persons collaborated to answer the questions. The respondents held a range of positions (e.g., executive director, program manager, support counsellor, and education coordinator). From the survey, I gathered objective measures of service provision and the subjective perspectives of numerous service providers in each region.

The first part of the survey was designed to capture descriptive information about the catchment area of the CCAC/AS, the relevant sub-populations of interest including the number of staff, volunteers, number of programs provided, total number of persons served, and the percentage of rural persons served. The second part of the survey consisted of open-ended questions about the challenges of providing services across each region, and any additional challenges the service providers faced in delivering services to rural persons. Providers were also asked to compare service use patterns between urban and rural persons served.

In total, 4 completed questionnaires were returned from CCACs and 20 completed questionnaires were returned from the AS chapters. Although there were few questionnaires returned from the CCACs, the responses confirmed the predominant role of the AS in providing support specifically targeted towards dementia and from diagnosis to death. In the subsequent findings chapters, I focus primarily on the AS chapters (Chapter 4); however, the 4 CCAC surveys provide information about the eastern, western, and northern parts of the province in the second phase of the research. Overall, the sample of regional providers represent a range of urban, suburban, and rural populations each with distinct physical terrain, work and recreational activities, municipal
infrastructure, and ethno-cultural communities. Information gathered in this phase served as a platform for selecting case study sites to explore availability and service use from an in-depth, qualitative perspective.

3.3 A qualitative case study approach

The objectives of the second phase of the study were to build on the understandings of service availability and service use in the first phase of the research and examine the relationships among specific sites of care, care needs, and experiences of care and caregiving (Objectives 2 and 3). A qualitative case study approach was used to examine a range of care experiences and settings. Consistent with community-based and feminist research approaches case studies focus on in-depth, site specific experiences through multiple forms of data collection (i.e., field notes, observations, and interviews). Within the social sciences, case studies have become increasingly popular as a means of exploring complex phenomena and processes, in detail, through a single unit or multiple units of study (Baxter, 2010). Multiple sites were chosen in order to develop a better understanding of the geographic variation identified in the first phase of the research as well as the ways in which the variation shapes and is shaped by local experiences.

The selection of three case study sites builds on rural typologies discussed in Chapter 2 and is empirically grounded by the information gathered from the survey (Bryant & Joseph, 2001). The case studies represent different areas of the province (i.e., east, west, north) and include a more remote rural resource-based area in the north (Sault Ste. Marie & Algoma District), a rural agricultural region in the south west (Grey-Bruce), and an urban countryside in the south east (Frontenac, Lennox, & Addington). Drawing on information collected about the perceived proportion of rural service users, I
categorized the jurisdictions of AS chapters from most rural (greater than or equal to 75% but less than 100%) to least rural (less than 5%). Importantly, the AS chapters in each case study are located in small to mid-sized cities and are all, to some extent, urban-influenced. A moderately urban-influenced area outside of a mid-sized city close to the study institution was selected as the first case study to build upon my partnership with the KFLA AS and the Hotel Dieu Memory Clinic. A second rural site was selected in south western Ontario, the area of the province with the greatest number of chapters that identified as having a client population, which was at least 50 per cent rural. Finally, a third case study site was chosen in a more northern location with a smaller proportion of rural service users in and around a mid-sized city (5-30 per cent). Relatively few of the northern chapters responded to the survey, and most of those who responded were located in mid-sized urban centres that serviced significantly larger areas than southern chapters with a small number of rural service users. The selection of the third case study site was limited by the ability and willingness of chapters in more northern areas to participate in the first phase of the study. This may be indicative of greater challenges not only in providing services in these areas, but also the challenges of sustaining voluntary sector services in these communities in general.

Taken together, this collective case study enabled a more comprehensive analysis of the spatial, social, and cultural conditions that shape experiences of care, both good and bad (Baxter, 2010). The strength of looking at multiple sites is that it enables comparison within and across settings; thus, it is more sensitive to the range of contextual factors that might influence experiences (Creswell, 2007). It was not my intention to

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3 In Ontario, northern is considered to be areas north of Parry Sound, or almost 90% of the landmass of Ontario (Bollman, Beshiri, & Mitura, 2006).
establish which rural area is the best place to live with dementia. Such an approach would, arguably, reinforce a false binary between context (i.e., place) and composition (i.e., people) (Cummins, et al., 2007). Instead, following a relational approach, I am interested in the characteristics of rural places, people’s relationships to and within them, and their experiences of dementia and settings of care.

3.3.1 Community profiles

The three case study sites have their own distinctive histories and geographies that have shaped the culture and resources of each region. The south eastern Ontario case study encompasses a broad area centrally located between Ottawa and Toronto extending from the community of Marmora on the west to Brockville in the east along Highway 401. While these communities fall outside the official boundaries of Kingston, Frontenac, and Lennox and Addington, the three AS chapters in the south east have a memorandum of understanding to work together serving sometimes overlapping populations, with Kingston as the largest and most central service hub. Thus, participants in this case study are those that draw on services from the memory clinic or AS in these communities, but live in the surrounding rural areas. The rural population in this case study live in the most urban-influenced area, characterized as an urban hinterland with a strong agricultural history. The northern half of the case study area forms part of the Canadian Shield and its rugged terrain serves as an attractive resource for tourism. The southern half is mostly rural, with many small towns (e.g., Gananoque) and villages and a few urban settlements including Kingston (pop. 159,561), Brockville (pop. 21,870), and Belleville (49,454) and suburban communities. The proportion of persons 65 years of age and older is higher than the provincial average in Kingston and higher still in the surrounding rural...
countryside (see Table 3.2). Frontenac County, in particular, has higher levels of education and income than the other rural case study areas and 70 per cent of the projected growth of the population is anticipated to occur within the southern part of the county because of its proximity to Kingston. However, Lennox and Addington and the agricultural areas around Kingston share more attributes with the south western Ontario case study site.

The south western case study, Grey-Bruce, is the most rural area in the project. The two counties run lengthwise along the shores of Georgian Bay and Lake Huron approximately 150 kilometers north west of the city of Toronto. The largest settlement, Owen Sound, boasts a population of 20,700 people; however, the city is the regional service centre for the two counties (pop. 158,670). Given its geographic location along Lake Huron and at the tip of the Niagara Escarpment, it is a seasonal tourism destination as well as a popular retirement area (Carrack, 2013). The area has the oldest population of the three case study sites with over 20 per cent of the population over the age of 65 in both counties as compared to the provincial average of 14.6 per cent. The median age of the population and the percentage of oldest old are also higher than the provincial average. The population is predominantly of European origin and English speaking, but also includes two First Nations Reserves and a significant Mennonite community. Typical of rural agricultural communities, the population has slightly lower educational attainment and levels of income than the provincial average. As a predominantly rural area with a lower population density, public transportation systems are relatively underdeveloped across the counties and lake-effect snow often poses severe constraints to travel across the area in the winter. These socio-demographic, cultural, and
environmental attributes are typical of the agricultural communities in the south western region of Ontario in which the counties are located.

The third case study site, Algoma District, is geographically the largest of the three case studies sites being approximately 50,000 sq. km, but only has approximately 115,870 people. The population is sparse, outside the largest census agglomeration of Sault Ste. Marie (pop. 79, 800) and a number of small towns including Elliot Lake (pop. 11,165), Bruce Mines (pop. 545), Spanish (pop. 696), Thessalon (pop. 1,279), and Blind River (pop. 3,549). The low population density and declining population overall has resulted in a general lack of municipal infrastructure outside of Sault Ste. Marie including public transit, but also other resources associated with improved health and well-being such as municipal parks, and arenas (Barnett, 2011). Given its more remote nature and fewer amenities, the area is generally not as marketable as a retirement destination as the other two case studies sites, with the unique exception of Elliot Lake. Moreover, the socioeconomic characteristics of the population are tied to the boom and bust cycles of particular resources industries. The area has a history of forestry and mining and steel-making are significant industries in Sault Ste. Marie. As such, the unemployment rate is higher in the region. In addition, the population has lower educational attainment than the rest of the province. The median age of the population as well as the population 65 years of age or more is greater than the provincial average. Although the majority of the population is English-speaking and of European origin, there is also a significant aboriginal population (11.4 per cent) as well as a large francophone population (22.9 per cent), which necessitates more overt cultural considerations when providing services.
Overall, these characteristics are representative of many of the northern rural resource-based communities in the province.

The communities in the three case study areas share broader migration and socio-demographic trends as well as specific health disadvantages cited in the rural aging and health service literature. Consistent with the literature on rurality, there is no singular way of defining the communities, especially given the size of each of the case studies areas. There are a range of different types of rural settings in each area. Broadly speaking, the case studies represent agricultural, recreational, and resource-based communities. The differences between the case study sites and communities within them characterize a number of distinct rural settings with their own social, cultural, and economic patterns. The distinct community contexts provide a foundation for specific research based partnerships and recruitment strategies.
Table 3.2: Statistical profile of case study areas in comparison to Ontario

<table>
<thead>
<tr>
<th>Variable</th>
<th>Ontario</th>
<th>Frontenac, Lennox &amp; Addington</th>
<th>Grey &amp; Bruce County</th>
<th>Sault Ste. Marie &amp; Algoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>12,851,821</td>
<td>159,561</td>
<td>149,738</td>
<td>41,834</td>
</tr>
<tr>
<td>Median Age</td>
<td>40.4</td>
<td>41.4</td>
<td>41.6</td>
<td>45.4</td>
</tr>
<tr>
<td>% population 65+</td>
<td>14.6</td>
<td>16.3</td>
<td>16.6</td>
<td>18.1</td>
</tr>
<tr>
<td>% population 85+</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Population density per km²</td>
<td>1,260.2</td>
<td>82.3</td>
<td>39.5</td>
<td>14.7</td>
</tr>
<tr>
<td>Post-secondary degree</td>
<td>54.6</td>
<td>57.6</td>
<td>57.5</td>
<td>49.1</td>
</tr>
<tr>
<td>Highschool diploma or equivalent</td>
<td>26.8</td>
<td>15.5</td>
<td>26.7</td>
<td>28.1</td>
</tr>
<tr>
<td>Average income of individuals</td>
<td>42,264.0</td>
<td>41,118</td>
<td>40,983</td>
<td>36,125</td>
</tr>
<tr>
<td>Median income of individuals</td>
<td>30,526</td>
<td>32,415</td>
<td>31,814</td>
<td>30,163</td>
</tr>
</tbody>
</table>
3.4 Case study design

The second phase of the research was integrated with the first through the processes involved in the case study selection and the continued development of community-based partnerships with AS chapters. AS chapters, in the selected case study sites were approached to participate in the second phase of the project between July 2013 and February 2014. The objectives of the study, letters of information, and interview guides were presented to Executive Directors and staff members to evaluate their appropriateness and usefulness for each AS chapter. The chapters made no changes to the instruments or study design. They expressed enthusiasm about the opportunity to be involved in research focused on rural settings and settings outside of major urban centres (e.g., Toronto). The value-added component of the research for these AS chapters was the specific focus on their communities.

The qualitative case study approach featured a series of in-depth, semi-structured interviews with persons who self-identified as having early dementia and persons who identified as having formerly (within the last 1-5 years) been a partner in care for someone with dementia in the three case study areas. The interviews were designed (see Appendices G and J) to gather detailed reflections on the processes and contexts of service use and care needs for persons with dementia and their partners in care.

The interview guides were piloted with three volunteers, two persons with dementia and one former partner in care, in south eastern Ontario. Minor alterations were made to the language used in the research instruments after the pilot interviews, but the instruments and design of the study did not change. The word “caregiver” was replaced with “partner in care” and the phrase “loved one” was removed from the letter of
information after one of the pilot study participants suggested that partner in care was his preferred title and that some people do not feel as though they love the person for whom they are caring. This process helped to further sensitize me and the research instruments to the tensions in care relationships before recruiting more research participants.

3.4.1 Recruitment of interview participants

With the support and advice of the Executive Directors, recruitment notices were posted in the Alzheimer offices and their newsletters. They were also sent out to clients on their electronic mailing list. I attended support groups, with prior consent from the participants, where I explained the study and gave out letters of information to those who were interested. Perspective participants were asked for their contact information so that I could follow up with them to arrange an interview. Additionally, I made contact with memory clinics servicing the three case study areas. I did not, however, have access to any of the patient’s medical information. At the memory clinics, I spoke with persons with dementia and their partners in care away from their health care provider explaining that I was an independent researcher and their decision to participate would have no effect on their care.

Notably, no former partners in care responded to notices or emails through the KFLA AC and the majority of persons with dementia in the KFLA case study were recruited through a memory clinic. The limited uptake through this AC may reflect lower levels of service use in the rural areas surrounding the chapter, lower levels of activity upon the part of the AC, and/or lower levels of email use in the area. The Sault Ste. Marie Algoma AC also offered to phone their clients and previous clients on my behalf to inform them about the study. Using a telephone script (see Appendix K) approved by the
General Research Ethics Board of Queen’s University, the Alzheimer Society staff introduced the study and asked if persons interested in participating would be willing to have their name and contact information forwarded to the researcher.

A total of 73 semi-structured interviews were conducted. The sample size was based on principles of saturation, a state in which no new themes emerge, as well as time-cost constraints. Participants were given the option of coming to an AC office or participating in an interview at their home. The majority of interviews took place in the home. The interviews ranged in length from approximately 45 to 90 minutes. All interviews were digitally recorded with the consent of the interviewee(s) and transcribed verbatim to ensure the trustworthiness of the accounts. At the end of the interviews, participants were asked if they would like to review a transcript from the interview as part of a process of “participant checking” to ensure the accuracy and meaning of the interview record (Dunn, 2010). In total, 12 participants asked to see their transcripts; however, only two of the transcripts were returned.

3.4.2 Characteristics of participants

The 73 interviews included the perspectives of 46 persons with dementia, 43 current partners in care, and 27 former partners in care. Tables 3.3 and 3.4 provide profiles of the participants. The persons with dementia in the study ranged in age from 56 to 93 years old (26 identified as male and 20 identified as female). On average, they had a diagnosis of some form of dementia for about three years. Many had only recently, in the last year, been given a diagnosis while a few had been living with a diagnosis of dementia for as many as 10 years. Their partner in care was typically a spouse although daughters, sisters, and occasionally sons took on this role. The majority (i.e., 22) of
former partners in care were spouses to a person with dementia, four were daughters, and one was a son. They ranged in age from 46 to 89 years old. The majority were women (21 women and 6 men participated). To some extent, this reflects the longer life expectancy of women and gendered social norms and expectations that women take on a greater proportion of the caring role within marriage, not only for children, but also for the family unit as a whole. In addition, it may reflect a gendered pattern in those who make use of, and continue to volunteer with, community support services such as those at the Alzheimer Society, given that this was the primary source of recruitment for these individuals.
Table 3.3 Summary characteristics of persons with dementia by site

<table>
<thead>
<tr>
<th>Site</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
<th>Sex n (%)</th>
<th>Care Partner Relationship n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
<td>Age Range</td>
<td>Male (%)</td>
<td>Female (%)</td>
<td>Spouse</td>
<td>Spouse/ Son</td>
<td>Spouse/ Daughter</td>
<td>Spouse/ Children</td>
<td>Other</td>
<td>None</td>
<td>&lt;4 Years since Diagnosis Range</td>
<td>&gt;5 Years since Diagnosis Range</td>
<td></td>
</tr>
<tr>
<td>Kingston</td>
<td>60-88</td>
<td>10 (50)</td>
<td>10 (50)</td>
<td>18 (90)</td>
<td>1 (5)</td>
<td>1 (5)</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owen Sound</td>
<td>56-89</td>
<td>8 (67)</td>
<td>4 (33)</td>
<td>10 (83)</td>
<td>1 (8)</td>
<td></td>
<td>11 (92)</td>
<td>1 (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sault Ste. Marie</td>
<td>64-90</td>
<td>8 (57)</td>
<td>6 (43)</td>
<td>9 (64)</td>
<td>1 (7)</td>
<td>1 (7)</td>
<td>13 (93)</td>
<td>1 (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3.4 Summary characteristics of partners in care

<table>
<thead>
<tr>
<th>Site</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
<th>Sex n (%)</th>
<th>Relation to persons with dementia n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
<td>Age Range</td>
<td>Male (%)</td>
<td>Female (%)</td>
<td>Spouse</td>
<td>Son</td>
<td>Daughter</td>
<td>&lt;4 years of care</td>
<td>&gt;5 years of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owen Sound</td>
<td>50-89</td>
<td>2 (25)</td>
<td>6 (75)</td>
<td>5 (63)</td>
<td>1 (13)</td>
<td>2 (25)</td>
<td>6 (75)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.5 Ethical concerns and limitations

Understanding the continuum of care and care experiences for persons living with dementia, might best involve a longitudinal study; however, due to time and financial constraints, a longitudinal study was not possible. The perspectives of former partners in care contributed substantially, instead, to understandings of the time and space sensitivity of dementia care within the case study areas. Former partners in care are well-positioned to comment on transitions and changes over the entire course of the illness. Although some researchers suggest that there is a recall bias in asking participants to reflect on their needs and challenges, studies have found that retrospective interviews have a high degree of consistency and credibility (Morse, 2011). In particular, former partners in care may be more willing to express negative issues when there is no longer any potential fear that they might lose services for being critical of them. I argue that former partner’s memories are, if not precise, certainly poignant with regards to how they and the person for whom they cared felt. As such, they contribute to a deeper and richer understanding of the geographies of dementia care. In addition, they recognize those who have and continue to care for and about dementia in their daily lives through their voluntarism and advocacy.

Given the bereavement processes associated with care for and death of a person with dementia, there are some ethical considerations about recruiting and interviewing former partners that need to be discussed. First, partners who had lost their spouse within the last year were not actively recruited for the study. Although this one year period is somewhat arbitrary, as processes of bereavement will differ between individuals, this criterion was established to minimize the potential of emotional harm. It appeared that the
majority of former partners enjoyed telling their stories, but most became tearful during the interview as they reflected on difficult decisions, bad experiences, and their sense of loss. While tears are not necessarily an expression of emotional harm, the interviews required careful negotiation of any such risks and explicit, but sensitive, questioning of the participants to safeguard their emotional and physical well-being. For instance, I reminded participants that they could stop the interview or move on to the next question and I offered them information about counselling and bereavement, when they expressed particular difficulty with grieving. In addition to these standard protocols, I drew on feminist methodologies to respond to the highly emotional and potentially traumatic nature of the research with sensitivity to context, the consequences of my choices as a researcher, and my role in responding to participant needs (Herron & Skinner, 2013; Pain, 2014). As such, my response to emotion was not a neutral response that simply involved reminding participants of their rights. I aimed to foster a sense of care and minimize harm to participants by confirming, for instance, that they were not being “too emotional” and that many other people I had talked with had shared similar sentiments.

While experiences of illness and care are personal in nature and often highly emotional, studies involving partners in care tend not to discuss potential ethical challenges. Indeed, this population is assumed to be in a position of power more so than a position of vulnerability; however, partners in care often experience constraint, grief, and aggression (See Chapter 6) in the later stages of dementia. Replaying these experiences may be a source of trauma. Pain’s (2014) work offers some guidance in striking a balance between the risks of reinitiating trauma and the desire to voice fear, anger, and feelings of injustice. In her research on intimate partner violence, she advocates that researchers
should enable participants to be heard to the extent that they choose, be reflexive about power dynamics in the research, safeguard the well-being of the researched and the researcher, and engage with politically active research that extends the project beyond knowledge production to influence social change. While I am not suggesting that intimate partner violence and aggression in dementia are one in the same, researchers need to think more carefully about how they respond to experiences of violence in research on dementia. Participants should feel enabled and safe to talk about aggression, if they choose. Hearing these stories is essential to prevent and respond appropriately to aggression.

There were several ethical challenges involved with interviewing persons with dementia as well; however, studies have demonstrated that issues surrounding respondent bias, self-reporting, and informed consent can be overcome using similar protocols to other research on complex social phenomena (Bond & Corner, 2001; Leung et al., 2011). In this study, participants were required to provide informed consent before participating. No test (e.g., mini-mental health exam) was administered to assess the cognitive functioning of participants with early dementia. I practiced ongoing consent by observing the participant's body language, repeating the purpose of the research when necessary, answering participant questions as they arose, and asking participants if they wished to stop if they appeared at all agitated. At the end of each section of the interview guide, participants were asked if they wished to continue. They were also given the option of completing the interview over two or three visits; however, only one participant completed two interviews. Persons with dementia were given the option of having a partner present for the interview to provide support. All but two of the participants
completed the interview with a partner. These two participants were both female and lived alone. If a partner was present, they followed the same informed consent procedures. Additionally, in setting up the interview, I confirmed that both parties were comfortable participating together in the study.

Following research on the ethical complexity of partner interviews, I sought to clarify upfront the potential risks and imbalances associated with a partner interview (Forbat & Henderson, 2003). Persons with dementia frequently relied on their partner for confirmation of their responses. Although the interview guide was designed to ask questions about the experiences of persons with dementia, the perspectives of their partners were useful in building a more comprehensive understanding of care needs and challenges. If, however, I observed an imbalance where the partner dominated the discussion, I redirected the question to the person with dementia. By orienting the interview guide and discussion toward the person with dementia, I hoped to challenge the stigma and silence often associated with the disease. In doing so, I risked, however, marginalizing the challenging experiences of the partner in care in the context of the interviews. I managed this dynamic, checking-in with each participant throughout the interview to be sure that they were presented with an opportunity to respond. I noted tensions in the interviews in my field notes (e.g., disagreements about decisions to move or the capacity of the person with dementia to perform specific tasks) and reflected on how best to respond. The group interview may have changed the nature of the data collected and it did add to the complexity of balancing power in the interview; nevertheless, the wishes and well-being of all participants were given primary value. Although I would not suggest that these research encounters were therapeutic or
transformative for participants, many indicated that they hoped that by contributing to the research they might change the circumstances of care for other partners and persons with dementia.

It is important to note that there are perspectives excluded and underrepresented in the study. For instance, the experiences of men as caregivers are relatively underrepresented. In addition, the number of women with dementia does not reflect the incidence of dementia in women. Seventy-two per cent of persons with Alzheimer's disease in Canada are women (Alzheimer Society of Canada, 2010). Data from the Framingham Study also indicate that women are more likely to develop dementia in their lifetime than men (Alzheimer’s Disease International, 2015). The gendered nature of dementia and dementia care both require greater attention. Additionally, the needs and experiences of Aboriginal People living on reserves in the case study areas are not included in this study, despite the fact that the Aboriginal population living on reserves in Ontario is predominantly a rural population. These perspectives should be addressed, but I suggest that the unique history and specific policy context of Aboriginal health and health care requires a separate analysis and a lengthier amount of time to engage in a completely participatory research design (see Jacklin et al., 2012).

Several community based participatory strategies were used in the study following the community-based orientation introduced at the beginning of the chapter. These strategies were employed with the aim of giving voice to and taking direction from community stakeholders. Although community-based strategies have become somewhat of a gold standard in health research that seeks to address social and spatial inequalities, there has been significant criticism of the extent to which studies are participatory, given
the rising popularity of the approach (Cacari-Stone et al, 2014). In this study, community partners helped to verify research priorities, test the appropriateness and usefulness of the study design and instruments, recruit participants, and interpret some preliminary results. They had no involvement in the interpretation of the data or manuscript preparation and the data ownership was not shared. While data sharing and interpretation are common approaches in CBPR, given the challenges of preserving confidentially in small communities, the ACs were only involved in verifying more generalized findings. Individual participants were asked if they would like to have a copy of the interview transcript at the end of the interview; however, most participants did not send back comments or revisions. At the time of the interviews, many people who wanted to receive a transcript expressed a desire to share it with their children or to have it as a record for themselves. Thus, the practice of returning transcripts became more of a practice of memorializing and honoring the particular stories that were shared rather than seeking a more participatory and/or complete account of events.

Throughout the research process, I presented preliminary papers and presentations to the Alzheimer Society staff and boards of governance. One of the ACs has already used some of the findings in grant applications, but the capacity of each chapter to contribute to and leverage community-based research was uneven. Both the research and the communities involved would have benefited from the development of more formal feedback mechanisms and capacity building initiatives such as an advisory council.

3.6 Data analysis

The quantitative information gathered from the surveys was analyzed in an Excel spreadsheet to compare chapters and the populations they served. This database included
information about the per cent of rural clients, total number of persons served, number of volunteers, number of paid staff, and number and type of services. The qualitative data analysis was informed by grounded theory. The term grounded theory refers to both the method and products of a systematic inductive, comparative analysis with a focus on the data as a means of constructing and testing a theoretical framework for a specific social phenomenon (Charmaz, 2006; 2014). Proponents of grounded theory suggest that all research begins with “sensitizing concepts,” guiding interests, and disciplinary perspectives that sensitize the researcher to ask particular kinds of questions, but ultimately data collected in the field should emerge as the foundation for developing theory (Blumer, 1969). Constant comparison analysis is one of the most commonly adapted methods of analyzing qualitative data across disciplines (Charmaz & Belgrave, 2011). Like other qualitative researchers, I draw on this approach to data analysis because it makes explicit the analytical processes involved in qualitative research. In particular, it privileges participants’ voices and actions in the process of coding and developing more abstract themes and theories.

Line-by-line initial coding was employed to analyze open-ended qualitative questions to identify and compare contextual attributes, descriptions, and processes described in the questionnaire (Charmaz, 2006; 2014). The process involved asking the question what is happening for each line of the data. I performed a second round of focused coding to remove redundant codes and identify the most significant categories and group them thematically. Emergent themes within the dataset were compared to the study questions and the existing literature. In Chapter 4, I examine the variation in services available across each AC and the challenges of providing services as they relate
to 1) increasing demand, 2) partner relations, and 3) reaching rural persons in need of services.

The interview transcripts from the second phase of the study were organized and coded along with additional field notes using Nvivo 10 software. Given the depth, length, and number of interview transcripts, the software was an integral aid in the analysis process but the analysis itself was informed by the same manual grounded theory approach. This involved initial familiarization with the transcripts and field notes, line-by-line and incident by incident coding in Nvivo, developing reports of the frequency and relationships between different codes, arranging the codes into larger thematic groups, and writing memos that develop the codes into categories. This approach positions the diverse and particular voices of rural people living with and caring for dementia at the forefront of the research.

3.7 Discussion

I began this chapter with a quotation that challenged me to reflect more deeply about the different ways that one might come to know, care about, and care for dementia. In this chapter, I have attempted to outline the careful steps that were taken to produce rigorous and sensitive research. I explained why a mixed-method approach was appropriate for the research as well as the methodologies that have informed the research design. The remaining sections explained how the research objectives were fulfilled through the development of specific research relationships, instruments, and procedures. The ethical challenges and limitations of the research were addressed before discussing the process of data analysis. The remaining chapters of the dissertation discuss the findings of the research.
Chapter 4

Learning from voluntary organizations: The challenges of providing dementia care across community settings in Ontario

In this chapter, I examine the specific role of the ACs in providing services for persons with dementia and their partners in care in Ontario, Canada. More specifically, I examine 1) what services are available and provided by ACs across the province of Ontario, 2) what challenges do chapters face in delivering services to clients across their regions, and 3) what differences, if any, exist between urban-rural service use and delivery? I draw on information collected from a survey of ACs (described in Chapter 3) to contribute to the literature on dementia care in the community with specific attention to the role of the voluntary sector in rural communities.

As discussed in Chapter 2, the bulk of studies on community care for persons with dementia have focused on informal care by a spouse or family member (Stewart et al., 2014; Egdell, 2013) and the availability and use of formal services including memory clinics, primary health care, emergency care, and community support services such as day care, meals on wheels, transportation, support groups, hospice care, and respite (Neville et al., 2015; Dal Bello-Haas et al., 2014a; Davies et al., 2014). The availability and organization of community support services mainly dependent on volunteers, has not been as well explored in spite of the fact that studies indicate these supports are a valuable resource in alleviating some of the burden of dementia care for persons with, family members, and physicians (Weber et al., 2011). Moreover, the role and capacity of the voluntary sector in providing community support services for persons with dementia is seldom discussed in the larger body of literature on dementia care.
Although gerontologists have long been interested in volunteering and volunteer-based programs as a means of supporting and enhancing community living for older people, it is only relatively recently that geographers and other social scientists have begun to study the potential and limitations of voluntarism across diverse community contexts (Skinner & Power, 2011). Responding to the almost unanimous adoption of voluntarism by Western governments as the answer to fiscal constraints, this growing body of research has focused on voluntary sector reactions to health care restructuring, local service integration, population aging, and community development as well as the benefits and contributions of older volunteers (Hanlon et al., 2014; Winterton et al., 2014). Studies suggest that a healthy voluntary sector is a determinant of healthy aging; however, voluntary organizations differ in their capacity to shape and respond to the changing structure of community care (Hanlon et al., 2014; Skinner et al., 2013). For instance, rural communities in particular, are expected to have a robust voluntary and community sector; yet, key studies have shown that increasing pressure on these organizations may further exacerbate urban-rural service inequities (Cloutier-Fisher & Joseph, 2000; Skinner, 2008). The perspectives of different organizations in various places are essential to further understanding of the capacity of nonprofit organizations (NPO) and their volunteers to provide services, particularly to vulnerable populations that may not be well positioned to navigate the complex system of formal care services on their own (Power & Kenny, 2011).

In the case of dementia, the ACs have become essential service providers as well as advocates for persons living with dementia. In Canada, AS and its various branches and chapters provide education, support, and advocacy in a variety of forms for persons
with dementia and partners in care. Although the AS is named for Alzheimer’s disease, the most common and publically acknowledged form of dementia, it provides support for anyone with or suspected of having any form of dementia. Internationally, Alzheimer organizations have played a role in lobbying governments to develop targeted policies toward dementia care (e.g., Alzheimer Society of Canada 2010; Goodchild, 2009); however, in countries like Canada and the United Kingdom, the primary function of Alzheimer organizations at the local level is to provide education and support services. Little attention has been directed toward understanding the local-regional contexts and challenges of providing support for persons with dementia and their partners in care by organizations mainly dependent on volunteers.

4.1 The community care context

In Canada, the Alzheimer Movement, as it was known, began to form local chapters in Toronto, Hamilton, London and Guelph in the province of Ontario in 1979 with the aim of providing support for partners in care and families of persons with dementia. A three-tier system consisting of a national office, provincial organizations and local chapters was approved in 1986. Since then, the scope of the organization has broadened geographically and in terms of its mandate with an increasing range of supports for partners in care and persons with dementia at various stages of the illness. Ontario is one of the only provinces, however, with chapters: independently incorporated as local units of the Society. Thus, the Alzheimer Societies in Ontario serve as an

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4 In Ontario, the term chapter is used to refer to independently incorporated societies. Some provinces have local branches which have a different relationship with their provincial organizations (e.g., British Columbia). For the remainder of this dissertation I refer only to chapters as that is the organizational structure in Ontario.

5 As is typical of many voluntary sector organizations, the AS chapters generally have a limited number of paid employees and volunteers provide support with governance, fundraising and some service delivery.
important case study of local-regional dynamics of volunteer service provision because of the longstanding existence of relatively autonomous units within a single organizational structure.

The geographic distribution of chapters roughly reflects the population distribution in the province with many more chapters in the south and fewer in the northern regions of the province where populations are smaller and more geographically dispersed. At last count, a network of 34 chapters was delivering a set of free core services to persons with dementia and their partners in care. The core services are broadly defined by the provincial governing body, the Alzheimer Society of Ontario (ASO), to include: information and referral, support, and education for people with dementia and families, as well as general public awareness, and education for health professionals. The specific programs provided to fulfill the core services vary from chapter to chapter and will be described further in the findings section.

4.2 Looking at service variation

All ACs in the study (n=20) who responded to the survey offered support groups to persons with dementia and partners in care, as well as a variety of education sessions, referral to other community services, and additional resources through their lending libraries. One AC offered education services through webinars, but most education and support services were delivered in person. Almost half of the 20 ACs had a First Link program, which links persons with dementia and their partners in care to the AC upon diagnosis; however, not all ACs have staff funding to coordinate the service. Three ACs provide a day program and a quarter of the ACs provide in-home respite. Almost half of the ACs, many of those not offering in-home respite or a day program, have active
volunteer companion programs. Most of these ACs, however, noted that they have a limited number of volunteer companions. Three of the mid-sized urban ACs also offer recreation and leisure therapy in their clients’ homes. Additional services such as men’s cooking classes, caregiver retreats, and music programs for persons with dementia were offered by particular ACs as well. Viewing these trends together (see Table 4.1), there is considerable variation in the number and types of services offered by each AC. I turn to the insights offered in the open-ended survey questions to understand the challenges of services provision across these regions.
<table>
<thead>
<tr>
<th>Alzheimer’s Society</th>
<th>Rural (%)</th>
<th>Services and programs</th>
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<tr>
<td></td>
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<td>Caregiver Support Groups</td>
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<tr>
<td>Chatham-Kent</td>
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<tr>
<td>Sarnia-Lambton</td>
<td>30-50%</td>
<td>x</td>
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<tr>
<td>Windsor and Essex County</td>
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<td>x</td>
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<tr>
<td>Elgin St. Thomas</td>
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<tr>
<td>Grey Bruce</td>
<td>75-100%</td>
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<td>Huron County</td>
<td>75-100%</td>
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<tr>
<td>London and Middlesex</td>
<td>5-30%</td>
<td>x</td>
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<tr>
<td>Perth County</td>
<td>50-75%</td>
<td>x</td>
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<tr>
<td>Guelph-Wellington</td>
<td>30-50%</td>
<td>x</td>
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<tr>
<td>Niagara Region</td>
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<td>Toronto</td>
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<tr>
<td>Peterborough, Kawartha Lakes,</td>
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<td>Northumberland and Haliburton</td>
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<td>Belleville-Hastings</td>
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<td>Kingston</td>
<td>5-30%</td>
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<tr>
<td>Region</td>
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<tr>
<td>Lanark County</td>
<td>30-50%</td>
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<td>Cornwall and District</td>
<td>5-30%</td>
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<tr>
<td>Ottawa and Renfrew County</td>
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<td>North East Simcoe County</td>
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<td>Sault Ste. Marie and Algoma</td>
<td>5-30%</td>
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<tr>
<td>Sudbury-Manitoulin</td>
<td>30-50%</td>
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<tr>
<td><strong>Number of Chapters Providing Service</strong></td>
<td></td>
<td>20</td>
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</table>
4.3 Identifying challenges to service delivery

In the sections that follow, I examine the variation in services available across each AC and the challenges of providing services as they relate to 1) increasing demand, 2) partner relations, and 3) reaching rural persons in need of services.

4.3.1 Growing demand

ACs cited a growing demand for services as one of the greatest challenges with which to keep pace. For instance, one respondent explained, “Our limited human resources are being stretched to the limit to address the growing number of clients coming to us for service” (AC5). In part, the observations reveal the success of specific programs. For instance, ACs with First Link programs noted not only an increase in the number of persons served, but also an increasing demand for early stage support. While the Alzheimer Society was originally envisaged as a support service for families and often at later stages of the illness, many ACs are offering more services to persons with dementia, much earlier in the illness, and for a longer duration. The growth in demand for services results not only in a larger volume of persons served, but also an increasingly diverse population to serve in terms of stage of illness, socio-economic status, race, ethnicity, and gender.

Human and financial resource constraints challenged the ability of ACs to provide services to an increasing population. For example, AC5 observed:

…numerous changes and growth opportunities within the dementia care field have raised the bar in terms of the services we are offering (PIECES, Gentle Persuasive Approach, Behavioural Supports Ontario, primary care memory clinics etc.) Keeping up with these changes is a challenge and puts added pressure on human resources.

Several ACs specifically identified counselling as a human resource need. Only two ACs had trained counsellors on staff; however, all ACs provided family consultations. Finding, retaining,
and re-training paid staff to meet counselling needs was a challenge cited by all of the ACs. In addition, ACs consistently noted that neither fundraising nor provincial funding were increasing to meet the growing demand for services.

ACs also identified lack of respite services for partners in care, transportation, stigma, and denial as barriers to service use. For example, AC10 indicated, “transportation is the biggest problem in [our] region and a huge issue for our clientele as many of them have lost their license.” AC7 explained,

[W]e find that many of our clients lack insight into their condition and are therefore reluctant to accept our assistance. Furthermore, families often feel unable to access services either because they are unable to leave their family member alone or because they do not wish to engage in support activities ‘behind the back’ of the person with dementia.

ACs noted that because of access issues ACs were required to provide more one-on-one and telephone support. The ACs also long engaged in public awareness and education in the community, specifically toward health professionals to improve access and reduce the barriers noted above.

4.3.2 Partner relations

When asked to identify challenges to providing available services to persons with dementia in their region, building relationships with other professionals (e.g., acute care medical providers, family health teams, and primary care providers) was a common response. For instance, AC18, serving a large urban population (pop. 1,010,000), explained, “Many [professionals] aren’t aware of the services (or the quality of services) provided by Alzheimer Societies.” Similarly, AC4, serving a rural population noted “Family physicians that lack knowledge in the area of ADRD [Alzheimer’s Disease and Related Dementias] and may or may not be reluctant to refer on” as a challenge to making services available. A quarter of the ACs
cited some difficulty getting referrals from CCACs as a challenge to delivering available services. Additionally, chapters noted that often “people with ADRD do not qualify for home assistance [through CCAC] because of the nature of their disease;” as a consequence they have a “total reliance” on the Alzheimer Society (AC6). The issues of referral and eligibility arguably make the role of the Alzheimer Society and its education mandate larger as they expend more resources to mend the “system disconnect” as well as reach persons living with dementia (AC6).

4.3.3 Reaching rural service users

ACs noted that reaching rural service users presented additional challenges. Typically, rural service users took advantage of fewer in-office services. From the perspective of the ACs, rural service users consumed more time and resources in transportation and more one-on-one home visits than their urban counterparts. AC7 explained, “Transportation, isolation, and stigma are more evident concerns in the rural areas than in the urban areas”. ACs generally agreed rural service users were more difficult to engage in group support and as such this service went through stop and start cycles in smaller communities. For example, AC12 suggested, “We find people in our more rural areas more reluctant to seek support because ‘everyone knows everyone’ and the risk of others knowing their business.” There was some divergence in this theme with one AC suggesting that rural and urban service users were no different and another AC indicated that rural service users were heterogeneous in their acceptance of group support in their own community:

Privacy is challenging with smaller/rural populations, either people will want to discuss issues in a local grocery store or not want services in their local community at all to protect denial/privacy of the person (AC17).

AC14 noted that some rural service users came to their urban location for support groups, to avoid stigma in their local community. Three rural ACs indicated that they were competing with
urban ACs because doctors did not know about them and referred patients to urban ACs. This speaks to some of the challenges of building relationships with professionals discussed earlier, but it also underlines awareness issues particular to rural areas as barriers to providing and accessing supports.

ACs cited public knowledge of them and their services as a barrier to reaching potential rural service users. They explained that awareness-raising was more difficult in rural areas, since most promotional material and events were located in more urban centres where it was more cost effective. Several ACs noted that few of their rural service users communicated by e-mail; all correspondence had to be done by phone or regular mail. Additionally, respondents from ACs in rural agricultural communities felt that standardized education material was “intimidating” to some of their service users (AC5). They also identified socio-economic status, particularly the lack of private pensions among potential rural service users as a barrier to accessing supports (AC6). Overall, getting rural service users to come to an AC location and getting information out to reach them presented additional challenges to service provision. Distance issues extended to operational matters. For example, those ACs operating friendly visiting programs found it more difficult to “match [their volunteers] to rural areas” (AC11). Moreover, ACs observed that rural services users had access to fewer services from other formal providers (e.g., day programs) than their urban counterparts and many were not well-positioned (in terms of transportation, socio-economic status, education etc.) to navigate the complex system of care on their own.

4.4 Discussion

The findings illustrate the uneven development and availability of AS services across Ontario, which is significant because NPOs are expected to provide an increasing share of support for persons with dementia and their partners in care in the community. In some
communities, it appears that they are filling the gap and in others, it appears that they are, at the very least, not as well-resourced to do so. Roughly, half of the ACs identified themselves as having a First Link program that would connect clients to information and services at diagnosis. Fewer still, identified having the resources to offer programing to persons in earlier stages of dementia such as recreation and leisure therapy, counselling, and transportation. Although such services could be used later in the course of the illness and by partners in care, it is worth noting that there were fewer services and fewer ACs offering services for persons with dementia. Services such as day programs and respite were not commonly offered by ACs. To some extent, this variation may reflect local funding decisions. Leadership and the ability of individual ACs to compete for program funding against other NPOs and for profit service providers may also be at play in explaining the variations in resource funding. The uneven pattern of available services suggests that the concerns of earlier scholars about the long-term implications of depending on local-level voluntary organizations, without consideration of their differing capacities, may already be taking effect, forming or reinforcing disparities across space (Skinner, 2008).

The increasing demand for services, in terms of the number of service users and duration of care, was identified as one of the primary challenges of service delivery. In addition, providing targeted support for persons with and partners in care at all stages of the illness and across the communities in catchment areas of ACs was a significant human and financial resource challenge. Consistent with previous studies, providers noted that lack of respite services for partners in care, transportation, stigma, and denial acted as barriers to service use and placed increasing demand on resources as one-on-one support was often the preferred means of reaching service users (Forbes et al. 2006). Although studies have documented the benefits of support groups for attending partners in care as well as some of the predictors for continuing
support groups (Steffen & Mangum 2012, Chein et al., 2011), the service providers in the study suggested that many people are reluctant to access group services, in particular, and to acknowledge their condition, more generally. Further research might explore if this reluctance could be mitigated through online or telehealth support groups (e.g. O’Connell et al., 2014); however, the respondents in this research suggest that some service users (particularly in rural areas) might not feel comfortable with computer-based technologies. It is also worth noting that in some rural areas internet services remain unavailable or are only available at significantly higher costs than in urban areas. All such interventions, therefore, need to be attentive to local-level contexts and cultures.

Although ACs and their parent organizations are well-recognized as dementia advocates, they face awareness issues within the health and social service system itself. They are positioned as the primary community support service for persons with dementia, yet they identify referral issues from other health care partners as a challenge to providing available services. In suggesting that other health care professionals do not understand the services or the quality of services they provide, ACs identified a hierarchy in which formal service providers are still likely to act as gatekeepers to a broader range of supports. As Davies et al. (2014) have pointed out in their research on hospice care for persons with dementia, these communication difficulties and integration issues disadvantage NPOs and persons living with dementia.

Consistent with previous studies of rural services use, the ACs noted that rural service users typically used fewer services (Forbes et al., 2006); however, they often placed greater demands on ACs in terms of one-on-one support. The ACs indicated that home visits are essential to overcoming stigma, transportation issues, competing demands with farm and other labour, and intimidating education material in rural communities. Some of these issues may be
similar from the perspective of urban ACs; however, the costs in time and human resources tend to be greater in rural areas. ACs suggested that these demands were also related to individuals’ desires to maintain their sense of independence and privacy in their rural community.

Privacy issues in relation to rural and small town settings have been well-documented (Forbes et al., 2006). ACs reported that some rural service users drive to larger centres to maintain their sense of privacy and confidentiality in their local community while accessing support. The findings calls into question the tendency to characterize rural populations as being more caring or willing to look after their own while illustrating diverse pathways to care amongst the rural population. Indeed, some rural chapters noted that they faced challenges competing with urban ACs for service users. We need to explore how this spatial variation is influenced by the needs and socio-cultural attributes of particular rural populations. In addition, more research is required to look at the migration patterns of persons with dementia to receive different types of support.

Excluded from survey are the views of support service providers other than the ACs that may play a role in providing support for persons with dementia and partners in care. As previously stated, however, the scope and specificity of the ACs, as well as the increasing expectation that they will be able to offer the bulk of support is what draws my attention to them. Also missing from this account are the views of the service users themselves. More work is needed to examine how persons with dementia connect with or withhold from using services at various stages of the illness and in various places. This is the focus of Chapter 5. The survey does, however, offer important insights for the development of policy and programming for persons with dementia and their families.
4.5 Implications for policy and programming

My findings may help various levels of government, policy makers, communities, and NPOs by contributing to the growing body of research on dementia care with evidence of the local level challenges and opportunities for community service providers. For example, the progressive degenerative nature of the illness makes early contact with persons with dementia much more critical, as their ability to advocate for themselves and make decisions about how their needs might best be met will decline over time. The findings illustrate several strategies for connecting with potential service users early (i.e. First link programs, home visits, and telephone consultations). Early contact, however, places increasing demands on service providers to offer a greater range of services for a longer period of time. Financial resources are essential to making early engagement possible across and within community settings.

Strengthening the relationship between community partners is also essential to making early engagement possible. At the regional level, different types of planning and programming may be required to reach rural populations. Even if technology can connect urban service-providers to rural service users, my findings suggest that one-on-one time is equally if not more valued by rural service users. These temporal and spatial dimensions need to be taken into account to make community supports available and suitable across catchment areas, but also to make equitable service provision sustainable.

4.6 Concluding comments

The findings corroborate the existing geographic and social science literature on voluntarism, which has pointed to the geographic variation in the capacity of voluntary organizations to meet the needs of the aging population. In spite of the national and provincial scope of the Alzheimer Society in Canada, the local and regional capacity of ACs might be
characterized as a complex and uneven geography. As organizations who provide services for persons with dementia and their partners in care face increasing demand for a broad range of services from persons with dementia and their partners in care, they will continue to be confronted by the complex and particularistic nature of the illness, the need to improve partnerships with other formal service providers, and the challenges of relatively high proportions but small numbers of geographically dispersed rural service users.
Chapter 5

“Not there yet:” Examining community support for persons with dementia in rural and small-town settings

In this chapter, I examine the experiences and needs of persons living with dementia in rural and small town settings. I focus on their relationships to and within their communities as well as their use and perceptions of particular services. The narratives of persons with dementia provide a rich resource for understanding the suitability and availability of services at community and regional scales. They indicate the factors that influence delayed service use and service uptake. Beyond the service landscape, such stories elucidate the broader desires and contributions of persons with dementia. They highlight the challenges and potential of organizing and finding support, formal and informal, to live with dementia in rural and small-town settings. This chapter presents different versions of, and limitations to, community care across the case study areas and participants. I argue that support in the community is “not there yet” for the vast majority of persons in the earlier stages of dementia. I discuss the implications of limited and delayed service use for persons with dementia, their partners in care, and their communities.

I begin the chapter by examining how persons with dementia described their communities as social and physical spaces that shape and are shaped by their daily activities. I focus on their continued contributions to the community, family, and friends while discussing the limits of these relationships in providing care. In the subsequent section, I link these relationships to people and place to patterns of delayed service use and perceptions of particular kinds of support. The following section details experiences of initial service use and participants desires for the future. I conclude with a discussion of the implications of delayed service use and the challenges
of negotiating social space in rural communities. The major themes within each section, the research questions to which they respond, and their contributions to the literature are outlined in Table 5.1.
<table>
<thead>
<tr>
<th>Category</th>
<th>Themes in the category</th>
<th>Research question</th>
<th>Research contributions</th>
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| Relationships to and in the community | • Routine and attachment to the physical and social environment  
• Getting help from neighbours and friends  
• Negotiating social space and experiencing stigma | • How do persons living with dementia experience care services and sites of care in rural places?  
• What services do people living in rural areas with dementia, including partners in care, need and use?  
• How can the lives of rural people with dementia and their caregivers be improved by taking into account their experiences over the course of dementia and at different sites of care? | • Examines the diversity of rural experiences with attention to people-place relationships  
• Identifies the value of the physical environment in rural communities  
• Corroborates literature on the extent and limitations of family/friend care for persons with dementia  
• Identifies social and cultural factors related to delayed service use in rural Ontario  
• Identifies structural/organizational issues related to delayed service use  
• Examines early service use, needs, and desires for the future  
• Contributes to understanding of program and policy issues  
• Identifies significant issues of isolation and lack of community space for persons with dementia |
| Delaying service use           | • “Not there yet”  
• “Keeping busy”  
• Clinging to independence  
• Inappropriateness of services  
• Barriers to accessing care |                                                                                                                                  |                                                                                                                                       |
| Initial service use           | • Alzheimer Society education and information  
• Day program  
• Home maintenance  
• Safety devices  
• Support group  
• Identifying desires for the future |                                                                                                                                  |                                                                                                                                       |
| Negotiating social space      | • Staying away from activities  
• Mobility and being “house-locked”  
• Being alone and feeling isolated |                                                                                                                                  |                                                                                                                                       |
5.1 Recognizing community connections and contributions

In recent decades, social gerontologists have sought to draw attention to the contributions of older adults to their communities to counter negative and alarmist discourses about the costs of caring for an aging population (Hennessy et al., 2014). Studies indicate that older people make significant contributions to community development, social care, and civic life in rural communities, in particular, where they make up a greater proportion of the population (Hanlon et al., 2014). Few scholars, however, have focused on the continued contributions and barriers to participation for persons with dementia. My focus on such connections and contributions emerges from the insistence of persons with dementia in the study that they were not in need of care. Instead, they identified themselves as “self-sufficient,” “independent” and “keeping busy.” They defended this position by describing their contributions to their communities and families through volunteering, outdoor work, and household work. While their participation and contributions were at times fraught, these connections in and to their communities require specific attention; they offer examples of contextually specific and meaningful informal support while at the same time identifying broader challenges to organizing more inclusive community care.

Persons with dementia identified a range of volunteer activities through which they contributed to their communities as well as barriers to continuing volunteer commitments. They helped with community events, fundraised for local charities, spoke on behalf of the Alzheimer Society, and assisted with church activities. Some people identified challenges remembering, recording, and showing up at meetings for volunteer groups to which they belonged. To manage
these challenges, they relied on calendars, digital and paper, and often reminders from a spouse. Others explained that they were no longer able to volunteer because they had too many doctor’s appointments and could not commit to a consistent volunteer schedule. In addition, transportation presented a barrier to getting to volunteer activities, as the majority of persons with dementia were no longer able to drive. Beatrice’s (65, Person with dementia, GB) reflection captures many of these challenges:

I would love to just sit and read to somebody and just talk to them or take them for a walk or whatever um I really enjoyed getting to know the people and getting to do things for them and with them but I, I don’t think I would commit myself because I wouldn’t know how much time I could give or how long I could be there and I wouldn’t want to leave somebody else in a bad state because I wasn’t able, like I was going to volunteer at one of the soup kitchens but there’s no bus to get me home [she laughed].

Not all persons with dementia desire, nor are they necessarily able, to volunteer throughout the entire course of their illness. However, their responses to questions about involvement in community activities and service planning indicate that certainly they wish to be included and to participate in caring, not only for themselves, but also for others.

Persons with dementia described the ways in which they contributed to care in the home through cleaning, home maintenance, and helping to prepare meals. For example, Sam (79, Person with dementia, KFLA) described himself as “an in-house chief and dish-washer.” He explained that his wife was having surgery that week and he would be looking after her. Other persons with dementia discussed the ways in which they support their adult children and their grandchildren, although many people indicated that their children were not geographically proximate. Three of the persons with dementia cared for an adult child with a disability who still
lived with them or within the same community. Their stories of caregiving, call into question the assumption that persons with dementia are, or ever can be, dependent on their adult children for support. Samantha (64, Person with dementia, KFLA) explained that she had cared for a son with schizophrenia steadily throughout his adult life; she said, “…my son phones and he’s crying and that. He says mom I need you and I want you to come and I can’t get nowhere so what do I do?” Her driver’s license had been taken away and she had not yet told her husband about her diagnosis. She relied on her sister for support to get to doctors’ appointments and continue to care for her son. Her duties to clean, cook, and help with chores on the farm had not changed. Samantha’s experience illustrates the tremendous privilege involved in assuming that persons with dementia share the same ability to make demands for their care needs. Some persons with dementia (disproportionately women) may continue to work and care for others because they have long been expected to do so and they feel they have few other choices.

Within agricultural communities, in particular, participants identified their gendered contributions to the home as well as resistance to depending on other community members. Wayne (66, GB), a farmer and partner in care to his wife reasoned, “well, right now we’re pretty well coping with what we have. Farther down the road, if there’s a disability takes place well then we’re going to have to I guess rely on the girls [daughters] more.” He elaborated further that his wife, like Samantha, still cooked and even drove the tractor on the farm, in spite of having her license taken away. His comments reveal strongly entrenched ideals about women’s caring role in the farm family. On the other hand, they point at a tenuous balance between the dangers of rural resilience and the opportunities of a silent work ethic. The farm may present an opportunity for continued participation and connectivity with longstanding lifeways for the
person with dementia, at least until they experience significant functional impairment. Such impairment may be ameliorated for some time by the routine and familiarity of farm activities and environments.

For many persons with dementia, routines facilitated work, not only in the home, but also in other community spaces. For instance, Emma (75, Person with dementia, GB) explained her long-engrained routines at the church:

   I have done a lot in the church…There’s things I can’t do as well as I used to, but there’s still something I can do [she laughed]. Well, if they decide they don’t need me, I won’t go back to that church. I’ll go somewhere else that will take me [she laughed].

She clarified further that she had difficulties working in her daughter’s kitchen, but she could still cook in the home as well as the church without trouble because she had done so for 45 years. Her reflections illustrate the value of being embedded in a physical space over time. Certainly, not all persons with dementia live such physically embedded lives and the social relationships within those physical spaces are not always as supportive. Her connection to the home and church illustrate a particular life course as a farmer’s wife, mother, and member of the church. Nonetheless, the attempt to establish a routine embedded in place was a common coping strategy for persons with dementia.

In discussing their contributions to the families and communities, persons with dementia and their partners in care sometimes cast work as a coping strategy or even a form of therapy. Elizabeth (77, Care partner, Spouse, KFLA) suggested, “We feel, and so does the doctor actually eh, that because we’re busy out here—Sam chainsaws the wood down, you can see it, Sam’s done all that … This is one way of dealing with Alzheimer’s [she laughed].” Persons with
dementia described their attachment to the physical landscape surrounding them and pleasure in continuing to live and work on the land. A number of persons with dementia indicated that walking in the countryside was something that helped them to cope with their diagnosis by getting the exercise their doctors suggested, but also giving them a way of getting out of the house to visit with neighbours and friends.

5.2 Negotiating social space in rural and small town settings

In describing their communities and support within them, many participants indicated that they had “good neighbours.” They clarified that their neighbours were willing to help with tasks such as clearing the laneway of snow, cutting the grass, and driving the person with dementia to a medical appointment. When probed further, participants often indicated that their neighbours offered, but seldom provided such support. William (89, Person with dementia, GB) reasoned that he never accepted support, saying, “I’m still old fashioned. I don’t like to ask.” Another care partner reasoned that he would not ask his neighbours for help because they were all too old; he described the situation saying, “It’s a splint for a crutch” (Harold, 84, Partner in care, Husband, KFLA). Other participants indicated that the neighbours they had known had all passed away. Nonetheless, persons with dementia expressed appreciation for friendly neighbours who made offers of tangible support in the case of an emergency or extreme event. Even if those tangible offers were never realized, they gave persons with dementia and their partners in care a sense of the availability of informal support that was consistent with their values of work and independence.
Although persons with dementia appreciated their neighbours’ offers of support, they were somewhat wary of their neighbours watchfulness and concern. Partners in care sometimes interjected that the attention of neighbours gave them peace of mind; however, some persons with dementia referred to this concern as being “nosy” (Terry, 64, Person with dementia, SSMA). They indicated that particularly in small communities, word travelled fast about their diagnosis. Samantha explained that she had not told anyone except her sister, but neighbours had started to ask questions:

I don’t want them thinking that you know what I mean. Then they’ll go around telling people and that puts me in, that makes it worse. I get thinking about because somebody asked me the other day I don’t see you driving anymore, what’s wrong? I said what do you mean driving? They said I don’t see you going any place. I said no I’m just depressed.

Samantha explained that she and her husband had workers on the farm and she did not want them going around telling everyone “yah her husband’s got a wife that’s, she’s nuts—got a mental problem.” She reasoned that her neighbours would be more accepting and understanding of depression. Persons with dementia described a range of reactions from others when disclosing their diagnosis. Sally (56, Person with dementia, GB) explained that she didn’t tell many people at first:

It’s a small town thing and ah I don’t like the pity party that goes on when people find out you have short term memory loss. Oh, it’s ok. We’ll take care of it for you. Don’t! I’ll do it myself. I’m going to forget something, but I do not want a pity party here. I can take care of myself.

Sally resisted the loss of autonomy that coincided with neighbours’ and friends’ concerns. Other persons with dementia identified a sense of pity and “othering” associated with sharing their
diagnosis. They noted that neighbours were sometimes a bit standoffish once they knew and they felt that they expected them to be different when they did not feel different.

Othering was felt and experienced in a variety of community spaces. For example, Dorothy (81, Person with dementia, KFLA) described people’s reactions when she bumped into them on the street saying, “Oh my gosh, Alzheimer’s stay away, it’s contagious. You get sometimes that feeling. They don’t do that. That feeling you get sometimes.” Her husband Larry (84, Partner in care, KFLA) added:

Now very often we meet people and they know she has Alzheimer, yah, and they talk to me alone they say, “oh yah you don’t notice it, she just blah blah.” They don’t believe it. They talk to me like they say, “oh she’s just like normal” [pause]…the word Alzheimer is completely misunderstood by so many people.

Other persons with dementia corroborated this experience of being talked about rather than being talked to. They added that others seemed to expect them to be less intelligent. They noted, on the other hand, that comments about their seeming normal undermined the legitimacy of their illness. To address these issues, they called for continued public education about dementia that would target, for example, local businesses. Beatrice (66, Person with dementia, GB) explained that she found the staff at the grocery store hostile when she asked questions about where produce was located. She decided to create a “business card” with her name and diagnosis to give to people so that they might understand why she was having difficulties finding things in the store. Persons with dementia understand that changes to their social and physical environments presented challenges to their independence and mobility. Some individuals developed coping strategies to navigate these spaces and others began to avoid them and the embodied experience of feeling out of place. Overall, participants’ descriptions of their communities and their
experiences within them highlight the importance of independence and work in rural lives. They make evident the diversity of individual’s resources in navigating community support. Understanding and respecting diversity and independence is important if services are to be appropriate for persons with dementia across the care continuum.

5.3 Identifying care needs and delays

Given the importance of independence described above, it is not surprising that many persons with dementia and their partners in care delayed accessing formal services. During the interviews, partners in care and persons with dementia responded to questions about service use with a common refrain, “we’re not there yet,” “I’m not there yet,” “no, not yet.” Although some persons with dementia and their partners in care had information about, and had started to use some community support services, there was a general reluctance to accept external support. Persons with dementia acknowledged that they would need some support eventually, but they clung to their sense of independence. Many persons with dementia responded to questions about their most important needs, by identifying their spouse. They made statements such as, “She does everything for me, really” (Robert, 62, KFLA), “My wife, I don’t know how much she charges [we laughed]” (Thomas, 81, GB), “well as long as I have this guy…” (Dorothy). Persons with dementia identified a need for guidance and to have someone around, rather than requiring a specific service. Even in the earlier stages of the illness; however, partners in care carried out a broad range of essential activities such as driving, cooking, cleaning, laundry, booking appointments, banking, administering medication, and making decisions. Notably, two women in the study were single and lived alone. For these women, sticky notes, calls and visits from adult
children, occupational therapists, and personal support workers were essential to their remaining at home. They made use of more services, earlier in the disease progression. While their diagnosis facilitated access to functional support, they lacked both the companionship and consistency of care that coupled people experienced. As Beatrice made clear in her comments “You know all the fellows in our [support] group have a wife that is there and will be there.” Beatrice’s circumstances draw out the social vulnerability of those who are single and living alone, many of whom are women.

The majority of partners in care added to these responses that if they were not in good health themselves, the situation would be very different. Several partners in care were still working during the day. They explained that that they felt safe leaving their spouses at home alone, although they feared having to leave work to provide full-time care. One woman in particular was working three jobs to support her husband. She left him at home during the day and took him with her to the church where she cleaned during the evening. Work commitments acted as barriers for both partners in care and the person with dementia for whom they cared to access support services.

Partners in care acknowledged a greater need for external support than persons with dementia, often carefully citing safety concerns. For example, many partners encouraged the person for whom they cared to go walking, but were sometimes wary when the person for whom they cared took off without telling them. One partner in care even suggested trying to find a GPS chip, so he could find his wife if she had not returned. While over half of the persons with dementia in the study had a medic alert or safely home bracelet, partners in more remote regions found such identification less useful. There was also tension surrounding the continued use of
larger tools and doing home maintenance work, which involved climbing a ladder or being on the roof. Although safety was a concern, partners in care recognized that “keeping busy” was important to the person for whom they cared. Patricia (70, Partner in care, Spouse, GB) expounded, “I’m getting frustrated trying to think of what can I come up with to occupy his time.” Larry corroborated this concern saying, “Here is the big question. She’s, she’s her brain is active enough to know that she has to do, she wants to do things. There is nothing she can do!” Both partners in care indicated that there was a lack of opportunities to “keep busy” outside the home and they found themselves searching for things that they might be able to do.

Several persons with dementia explained that community support services were inappropriate for persons in the earlier stages of dementia. For example, Dorothy explained her experience going to an AC day program:

[They think] that you’re mentally so ill that your folding little pieces of paper in a little thing and you make a wave [she made a fanning motion in the air] and what do you call them…well something to wave in the wind…anyway I’m not that childish that I can do kindergarten work, you know.

Dorothy stopped going to the day program. Other persons with dementia identified a series of reasons why they did not think they were ready, or would not try, attending a day program. Sam reasoned, “Yah if I could take my chainsaw in and carve out some figurines or something or the axe but not, you know, not writing poetry or something.” To Sam the activities associated with day programming were emasculating. Edward, a 71 year-old partner in care to his wife explained that he found the circumstances of persons with dementia attending such programs “really sad” and he did not think it would be good for his wife to attend. In their evaluations persons with dementia resisted and internalized the stigma associated with the image of terminal dementia—
an image of weakness and dependence. They saw these images reflected back to them as they perceived and experienced day programming for persons with dementia in their areas. Although they and their partners in care identified a need for places to go and things to do, their perceptions of these places did not support their sense of dignity and independence.

In general, participants revealed a degree of aversion to group support, including day programs and support groups. This aversion was not only linked to a sense of privacy and independence, but also to gender and embedded life ways. A number of persons with dementia described themselves as “loners,” “not joiners,” and not a “group person”. They linked this sense of themselves to their histories and place. Wayne (Partner in care, 66, GB) poignantly explained:

We milked cows for 20 years. In 20 years, I missed 7 milkings. We’ve never taken a holiday. We concentrated on the farm and didn’t take holidays and now…. We’re actually not comfortable going out to social stuff. We used to go to the [community name] church. A couple of the old farmers there, I’d corner them and we could talk but the rest were old teachers and what not. They had a computer and everything like that and they were talking their language. I could talk farming with the old guys [he laughed].

Wayne’s remarks give lie to the assumption that rural communities take care of one another by exposing the isolation that particular individuals and groups may experience over time, particularly in the face of community change. His reticence to engage in social activities, in general, and support groups specifically raises questions about the accessibility and acceptability of formal support services for rural men as partners in care and for the persons for whom they care. As Jack stated more bluntly, “Support groups are not a normal rural solution, when you’re raised on the opposite side of the snow storm to everybody else you learn how to fix it yourself.”
Each of these comments further illustrate the links between rurality, independence, and gender in the culture of rural communities.

Persons with dementia identified additional barriers to using services including transportation, being too busy, costs, and not knowing how to access programs and services. The majority of persons with dementia relied on a spouse or relative for transportation and had no independent means of transportation. Their participation in programming was contingent on the support of a family member, as the majority had no access to public transportation. Samantha explained that she relied on her sister to drive. In addition, she reasoned, “I don’t have time because he [husband] doesn’t have anyone to help him…. So I have to help him. Yah I help him on the farm so I can’t.” Negotiating transportation involved mediating competing time demands, distance, and poor weather conditions. Some partners in care were at times reluctant to drive as well. Marie (83, Spouse, KFLA) indicated that she did not go to support groups because they were too far away, but she would look into them once she and her husband moved into the city. Many rural participants indicated that they did not have an additional pension; thus, the costs of or associated with programming were prohibitive. Although most participants recognized the AC as a resource, they indicated that their doctors gave them little direction about where to go to find support and they felt that there should be more information at diagnosis; this was particularly the case in the south east case study where the First Link program was not funded (see Chapter 4). Underlying these explanations was a sense of pride and privacy. However, the majority of persons with dementia in the study were starting to make use of some services.
5.4 Using services

Typically, partners in care initiated and encouraged the use of services. For instance, some partners in care visited the AC by themselves to get information about dementia and see what support was available. Several female partners in care indicated that they had thought about going to the AC, sometimes before their spouse had a formal diagnosis, but they were afraid that they might upset their spouse in doing so. Many were referred by a GP or specialist, but not necessarily at the time of diagnosis. Advertisements in the newspaper and on television prompted a few people to engage with their AC. Judith (82, Spouse, GB) explained that she drove by the AC office fairly regularly and she finally stopped one day two or three years after her husband’s diagnosis:

I went in and I said I don’t know if I should be in here or not and I told her and she said do you think he would talk to me here in the office or if I came to your home… I went home and talked to him and I said I don’t know if you’re going to be very happy with me or not but I went to the Alzheimer’s because I said if we need help, I guess we got to go.

Consistent with the service provider survey detailed in Chapter 4, partners in care were afraid to betray the person for whom they cared by seeking formal support. This seemed to be particularly the case when the partner in care was a female spouse. Adult children were more likely to encourage and actively facilitate meetings with the AC, if they were close enough (physically and socially) to observe significant changes in their parent’s functioning and well-being. Another couple explained that they drove to an outside community to access support. Sam said:

You know if you go down here [referring to local chapter] and it doesn’t work out really well then it’s kind of insulting if you leave. Well these people don’t have anything to offer us, so we started to go to [name of city] and after one or two meetings we were
hooked, or I was at least. They’re a very compassionate and caring group.

Sam reasoned that by going to a larger centre he avoided everybody in town knowing about his diagnosis. His comments corroborate findings from the survey (see Chapter 4), which identify privacy as a barrier to accessing services in the community in which people live. Looking at the experiences of persons with dementia who leave their immediate community to access services raises questions about the influence of physical and financial mobility on service use. Sam and his partner in care were both still driving and they had appointments in the city, so they did not view transportation and distance as barriers to accessing support in an urban area. Although information was not collected about participants’ incomes, they indicated that they had assets and were not concerned about their finances. If persons with dementia who are able to go to urban centres to access a greater range of services do so, this may impact the development of support in smaller rural chapters.

Other partners in care indicated that they were aware urban centres had more to offer than their local chapter, but it was not feasible for them to access this support. Patricia described her initial expectations and disappointment regarding the services available in her community:

I thought there would be a group or something for [Mike] to attend one day a week or whatever just so that he could have an outlet. Something for him to do, an outlet that he could enjoy that would be helpful to his condition…. I was quite disappointed and basically expressed my disappointment that there wasn’t something for, I’m going to say the guys, but I realize a lot of them are women too but there wasn’t anything in place… our area being smaller and more of a rural area ah they just didn’t have anything set up.
Patricia went on to explain that shortly after voicing her disappointment, the chapter set up a memory café where persons with dementia could meet in a reserved room at a local coffee shop with one another and their partners in care. An AC facilitator attended the group, but the discussion was largely led by the persons with dementia. Other persons with dementia in the case study indicated that they enjoyed the café, but they unanimously agreed that they would like to have more frequent meetings. Although they acknowledged that there were seniors’ centres with games to play and groups to join, the majority of persons with dementia and their partners in care had begun to avoid those types of activities because they feared the judgements of others. Joseph (70, Person with dementia, KFLA) explained, “Well, when you get one of those days when you can’t find the right word for anything, the easy way of doing it is don’t go, that way you won’t be singled out.” Many persons with dementia had started to avoid going to church, playing cards, and engaging in other group activities with friends. They described themselves as being more “house-locked” (Larry). While persons with dementia were defensive of their independence, they exposed their vulnerability in their growing experiences of social isolation.

Persons with dementia explained that they felt increasingly isolated because they lacked places to go, ways to get there, and people to visit them. Although some persons with dementia provided examples of their contributions to their communities, these hopeful and empowering stories were tempered by a more predominant sense of social isolation. Isolation was often precipitated by the loss of a driver’s license and amplified by their rural and small-town locations. Robert explained, “It would be nice to have somebody to drop in and talk or something because it’s kind of lonely. After so many trips around the corner, you’re not getting anywhere” and Gloria (81, Person with dementia, KFLA) suggested, “I could stand more enrichment as I see
it. Time to find a lot.” Persons with dementia were not the only ones to feel this isolation. Steven (73, KFLA), a partner in care to his wife explained:

The majority of the people that we chum with. They know the situation and basically most of them don’t even phone now… . Walk around and we bump into different people and they’re very friendly and that but they never say why don’t you guys come over. And if we invite them um they come up with some excuse. When I take my wife over to church, she’s actually overheard one woman telling another not to get close to her that she has that disease. Some people are very naive.

Both the physical and social space of rural communities can be particularly isolating for persons with dementia and their partners in care as their ability to connect with once familiar others changes.

In spite of their feeling of isolation, the majority of persons with dementia expressed a desire to remain in their own homes for as long as possible and to bring support into the home as needed. Consistent with their descriptions of themselves as independent and not yet being in need of support, most persons with dementia regarded this as a distant, or not yet pressing, concern. They commented, “I hate to think about it,” (Ruth, 77, Person with dementia, KFLA) “It’s not a priority” (Peter, 79, Partner in care, KFLA), and “I hope that’s down the road quite a piece. It’s a case of we’re going to make do as long as we can out here (Emma).” At times, partners in care became teary-eyed when they were asked about the future, particularly the prospect of long-term care. The very nature of responses to questions about the future displays the tensions, fears, and negotiations involved. In many of the interviews, questions about future care needs created a dialogue rather than a single answer. Persons with dementia asked for confirmation from their partners in care and qualified their answers, like Sam saying, “I think,” and “I can’t speak for [my partner in care]…” In this dialogue they acknowledged that the care
that they hoped their partner in care would provide was “more than duty sort of thing. It’s a great expression of love” (Sam). Some persons with dementia suggested that the expectation that they be cared for at home by a spouse was unfair. Robert said, “I would like her to look after me but in the same breath I think it’s not fair to her to look after me because it’s not her spot to have to be looking after nonsense I don’t think [pause].” Most persons with dementia explained that they would not ask their children to care for them as the disease progressed. The common refrain was, “they have got lives” (Sally). At times these dialogues were humorous:

Mike: I don’t want to go to a nursing home, but I will when I have to….Yah, I’m planning to get to 80. [He laughed]

Patricia: See my shoulders drooping? I don’t know if I’ll make it [we laughed].

Mike: 90 would be nice.

Patricia: Fat chance.

Underlying such humorous exchanges, were legitimate concerns about caregiver burnout chafing against perceptions of long-term care. Participants described long-term care as noisy, lacking privacy, and not having enough staff or other resources to provide adequate care. Dorothy and Larry suggested that they had heard too much about people being “doped” so that they would be easier to handle and that was not the life they wished to live. Larry suggested that if they could not stay in their country home they would move into a smaller home in a nearby city. Four couples in the study had moved into a small or mid-sized city in the last year from their rural homes and two were planning to move in the next year. They described their rationale for moving and some of the challenges they faced. Partners in care, in particular, were interested in downsizing and minimizing their responsibilities of caring for a large home and property.
alongside caring for a person with dementia. Many were concerned about the isolation that the person for whom they cared faced when they left them home alone to go into town. Several partners in care suggested that their doctors had advised them to think about moving so that the person for whom they cared had more opportunities for independence and socialization, although they noted that building new social support networks did not necessarily come easily. Moving also radically altered the routine and familiarity of the home on which many persons with dementia rely. Persons with dementia typically held mixed feeling about the move. Some of them talked about the convenience of being able to walk for a coffee or through the park in a more urban setting. Norm (77, Person with dementia, KFLA) on the other hand was openly disappointed about his future move; he said, “I don’t know. I’d like to stay right here.” Although only a small number of people in the study made a move that was directly related to a dementia diagnosis, these moves are worth noting. For one thing, the small number may reflect the small number of people that can afford to move into an urban setting. They may also indicate that these individuals did not have strong ties in and to their communities. The caring community often associated with rural places was not there for them. Lastly, these moves highlight the scope of caring for a person with dementia in a rural setting alongside all the physical demands and time constraints associated with such a setting.

5.5 Discussion: Including persons with early stage dementia in community care

The narratives of persons with dementia draw attention to the actual and potential contributions that they make to their communities. In particular, they identify an opportunity to rethink the structure of voluntary organizations, including those that are directed at supporting
persons with dementia specifically and those that have a broader community mandate. For persons with dementia to feel like services are appropriate for their stage and circumstances, their capacity to contribute needs to rise to the forefront of early service provision. Indeed, the question for many persons with dementia was not what do we need, but rather what can we do? They identified barriers to participation in their communities while at the same time demonstrating their resistance to being framed as dependent. Their strong relationships in and to their communities contributes to the growing interest in dementia friendly communities and the activities of persons with dementia (Innes et al., 2015; Wiersma & Denton, 2013). Consistent with previous studies, persons with dementia identified their neighbours as being a potential resource for support. However, further probing indicated that most people had not actually received help from their neighbours, nor did they feel comfortable asking them for help. Persons with dementia and their partners in care preferred to remain independent. They suggested that there is a continued need for public education to make their encounters on the sidewalk, in the grocery store, and with their neighbours and friends more positive. At the same time, they indicate that physical environments at a range of scales can be supportive, from the familiarity of the kitchen cupboards to the tranquility of rural roads and paths for walking.

This research takes place at a time when early stage support is being developed. The positive assessments and experiences of those engaged with the memory café provide evidence of the possibilities of developing new places for persons with dementia in rural and small town contexts. However, only one of the case study areas had such a program at the time of the study. Furthermore, those involved in the memory café expressed a desire for more frequent meetings. Consistent with Chapter 4, the development of programs and services in rural and small town
settings is variable across the province. Put simply, the range and frequency of support that persons with dementia desire is not there yet. Formal and informal supports as well as individual resources vary too. Women, in particular, may still be providing support to their families long after a diagnosis. Consistent with the broader literature on rural women’s health, participants’ stories indicate that rural women face additional barriers to accessing support, including responsibilities in the home and resistance from male partners in care toward accepting help, at least in its current format (Leipert et al., 2012). This is a particularly important finding, given that partners in care often initiate service use. Although men with dementia may have a female partner in care encouraging them to use support services, support groups and day programs are viewed as more appropriate for women; this disadvantages their partners in care (typically women) who may be afraid to access support for themselves or as a couple. The gendered nuances of programing and program use reflect traditional gender norms that are deeply embedded in particular rural lives and places (i.e., farming), but are not necessarily generalizable to all persons living with dementia in rural and small-town settings. The trends reflected in this study do not include, for example, homosexual couples living in rural and small-town settings who may share the responsibilities of care differently. However, the analysis reveals diverse versions of community care across the case study sights and participants. Although information was not collected about income, it is clear that some individuals have more resources both to access services and to access a better care environment in general. Future research should explore the diverse mobilities of persons with dementia in rural places. In particular, how might imaginative and virtual travel ameliorate social isolation? Indeed, for some individuals who have
lived relatively isolated and less communal lives in rural places, technology may present a number of opportunities to enhance their connectivity with a community and support.

The pattern of delayed service use across all case studies illustrates the resilience and resourcefulness of at least some persons who have dementia. Upon closer inspection, participants’ evaluations of services highlight significant gaps in the services available. The stories of persons living alone, or left alone during the day, lay bare this gap in support for early stage dementia because nobody else is there to fill the void of the full-time partner in care. Partners in care play a central role in providing informal support and initiating formal service use, particularly getting information about services available. The subtle tensions emerging in this chapter between partners in care and persons with dementia, underline the tremendous demands placed on partners in care. In this chapter, I have tried to focus on the voices of persons with dementia, although their partners in care were present and contributed to the interviews that form the empirical foundation of this analysis. In the subsequent chapter, I will focus on the perspectives of former partners in care to examine their needs and experiences.
Chapter 6

Constraining care: Examining the experiences of partners in care

“I just hope that people like you can really work on this and make them see…”

In this chapter, I examine the experiences of former partners in care providing and accessing care over the course of the illness and across different settings. In doing so, I seek to contribute to the literature on the transitions and trajectories involved in living with and caring for dementia, with attention to a range of rural and small-town settings (see Chapter 2). More importantly, I aim to make visible the hopes and challenges expressed by partners in care. As the epigraph above indicates, many participants in the research gave their time to this study because they believed that there is a lot of work to be done to adequately support persons with dementia and their families. Indeed, partners in care have and continue to shoulder the bulk of this work in their families and communities. I argue that partners’ time, bodies, and choices are spatially constrained within rural and small-town settings and the current systems of home, community, and long-term care.

Building on the findings in Chapter 4, the first section examines partners’ reported service use over the course of the illness. To understand patterns in service use, the second section explores the ways in which partners moved through and navigated the system of care. In the third section, I focus on the temporal, spatial, and emotional constraints identified by partners

6 Unlike Chapter 5 where the analysis was based on interviews from all three case studies, this chapter is only based on interviews in Grey-Bruce and Sault Ste. Marie Algoma. All efforts at recruiting former partners in care in Kingston were unsuccessful (see Chapter 3).
in care. Key themes in this section include the challenges of negotiating support within the care relationship, the challenges of responding to behavioural changes of the person with dementia, and the limited choices associated with end of life care. In the final section, I summarize these findings and my argument. Each of these sections encompasses overarching categories and subthemes that emerged from partner’s narratives and in response to specific research questions. Table 6.1 outlines the relationship between the categories and themes, the research questions, and the existing literature.
Table 6.1: Overarching categories and themes in relation to research questions and contributions

<table>
<thead>
<tr>
<th>Category</th>
<th>Themes in the category</th>
<th>Research question</th>
<th>Research contributions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Navigating the system</td>
<td>• Getting a diagnosis&lt;br&gt;• Accessing AS&lt;br&gt;• Finding people who understand&lt;br&gt;• Accessing CCAC&lt;br&gt;• Negotiating more hours&lt;br&gt;• Making decisions about end of life care</td>
<td>• What services do people living in rural areas with dementia, including partners in care, need and use?</td>
<td>• Confirms enduring challenges of system navigation&lt;br&gt;• Identifies demand for socio-emotional support in rural areas (not just stoicism)&lt;br&gt;• Identify central role of AS across the continuum of care&lt;br&gt;• Contributes to understanding of the complexity of care relationships and the socio-emotional barriers to service use&lt;br&gt;• Challenges perceptions of cared for as passive and willful participants in care as well as idyllic conceptions of family care&lt;br&gt;• Contributes to understanding of the spatial and temporal dimensions of care&lt;br&gt;• Identifies factors associated with uptake and changes in service use&lt;br&gt;• Identifies vulnerability and variable capacity of partner in care&lt;br&gt;• Elucidates the role of fear and other emotions in care decisions&lt;br&gt;• Identifies limited end of life care options and repercussions for partners in care&lt;br&gt;• Contributes to understanding of program and policy issues</td>
</tr>
<tr>
<td>Negotiating available support and experiencing constraints of care</td>
<td>• Being unsure of persons safety&lt;br&gt;• Facing resistance to services&lt;br&gt;• Negotiating more hours&lt;br&gt;• Having difficulties sleeping&lt;br&gt;• Experiencing isolation</td>
<td>• How do persons living with dementia experience care services and sites of care in rural places?</td>
<td></td>
</tr>
<tr>
<td>Responding to behavioural change</td>
<td>• Defending PWD/explaining behaviour&lt;br&gt;• Feeling pressured into LTC&lt;br&gt;• Ceasing use of services&lt;br&gt;• Admitting PWD to hospital and/or LTC</td>
<td>• How can the lives of rural people with dementia and their partners in care be improved by taking into account their experiences over the course of dementia and at different sites of care?</td>
<td></td>
</tr>
<tr>
<td>End of life care and LTC</td>
<td>• Advocating for PWD&lt;br&gt;• Identifying staffing/training issues&lt;br&gt;• Identifying need for better communication&lt;br&gt;• Having a “horrible experience”&lt;br&gt;• “Failing fast”&lt;br&gt;• “Getting emotional”&lt;br&gt;• “Dying with dignity”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6.1 Retrospective accounts of service use

During the interviews, each partner in care was asked about the services they and the person for whom they cared used, how they got information about these services, and when they started using them (see interview guide in Appendix J). This information was compared to the service provider information in the first phase of the research and across interviews and case studies to examine patterns in service use and the factors that might influence these patterns at particular times and places. The following section describes the most commonly used services in relation to dementia. It should be noted that many people with dementia have other co-morbidities that may require support services; however, the focus here is mainly on those services directed at managing day-to-day needs associated with dementia. These services include home care provided by the CCACs (e.g., personal support, occupational therapy, and home nursing care), services provided by the ACs (e.g., education and information, support groups, friendly visiting, and recreation therapy), other community-based services (e.g., day programs, meals on wheels, transportation) and private or pay-for-use services.

Across both case study areas, the most commonly used type of support was publicly funded personal support in the home, accessed through the CCACs, usually to help with bathing and respite. Two partners in care did not have the support of a personal support worker (PSW) because the person for whom they cared refused service. Margaret’s mother and Betty’s husband would not “allow” the PSW in the home. In both cases, the partners in care indicated that the person with dementia lacked insight into their condition (i.e., they did not believe they needed support) by the time the partner in care tried to arrange home care. In general, the partners in care reported accessing CCAC services later on in the progression of the illness. Participants typically had the support of a PSW for 6 months to two years. The number of weekly hours of support
ranged from 2 to 12 hours per week, often beginning with several hours once a week and adding on subsequent hours of support as the illness progressed. Along with support from a PSW, 13 participants reported seeing an occupational therapist (OT) during the initial CCAC assessment. Some partners in care, however, were unaware of what an OT was or how they might provide support. Most of the OT support that was received was focused on the physical layout of the home (i.e., tripping hazards) and physical condition of persons with dementia (i.e., fall prevention), rather than more holistic strategies for maintaining meaningful activities with a dementia diagnosis. Moreover, the CCAC provided support for the medical, physical, and long-term care needs of the person with dementia as well as some respite for the partner in care. Indeed, as other scholars have noted, CCAC services privilege “health” needs over “social” needs (Daly, 2007). Thus, the majority of partners in care went to the ACs for information, support with system navigation, and social and emotional support.

Partners in care typically accessed AC services earlier in the disease progression and made use of these services for a longer period of time. Partners in care noted that they had seen commercials on TV or read advertisements in the newspaper about the society. Some individuals living in small town settings knew staff or volunteers working with the local AC and they explained that this influenced their willingness to go there for help because they knew people involved in the organization. In total, 18 partners in care accessed information and educational materials through the AC lending libraries, their websites, and education seminars. In this way, education was very much a multisite service, rather than merely an office-based service. AC support groups, on the other hand were usually held in the office or community buildings (e.g., churches). Of the 27 partners in care, 16 went to monthly support groups and one partner in care took the person for whom they cared to a support group for persons with dementia. Several
partners in care went to support groups for over five years. Partners involved with the ACs also talked about visiting and phoning staff in the office when they had questions or felt overburdened. Many partners also used the Safely Home program through the ACs or other safety devices (e.g., Life Line) and they installed special locks or door handles as per information received from AC staff.

In Sault Ste Marie and Algoma, four partners in care had a recreation therapist come to the home for an hour a week through the AC and others noted that they were on the waiting list and would like to have received the service. The Grey-Bruce AC did not offer recreation therapy. Both the ACs, however, have small friendly visiting programs aimed at decreasing the social isolation of persons with dementia and increasing their access to meaningful activities. As such, only two partners in care had access to the service. One partner mentioned that they would have liked to have had friendly visiting, but there were not enough volunteers available. This corroborates the findings in Chapter 4 about the limited availability of volunteers, particularly those that might already live in, or travel to, rural areas. Other partners in care commented that the person for whom they cared would not have “allowed” (Joan, 70, Spouse, SSMA) a friendly visitor, they were “private” (Elizabeth, 60, Daughter, SSMA) people, or they had generally stopped “interacting with people” altogether (Debra, 65, Spouse, GB). In general, those engaged with the ACs tended to use a greater range of community support services.

In both case studies, a total of 12 participants made use of a subsidized day program. Ellen (77, Spouse, GB) noted that the cost of the program did “add up” presenting barriers to more intensive use. Persons with dementia sometimes refused to try or continue this service, a point to which I will return later in this chapter. Most partners in care paid for transportation to get the person with dementia to the day program. In addition to transportation and day program
costs, 12 partners paid for support for house cleaning, shovelling snow, and other home maintenance. Two partners in care also used meals on wheels, although sparsely and generally in the case of emergencies. Moreover, the bulk of available and most frequently used services were free, but partners in care paid for support to maintain the home and have space alone in the home, usually in the later stages of the illness.

Table 6.2 summarizes the service use patterns. While there were some difficulties collecting information about the number of hours and duration of support for each service, since partners’ recall of these details was sometimes imprecise, several patterns were certainly clear. The majority of partners in care relied on publically funded personal support on a weekly basis in the latter part of the illness. That is consistent with other studies on the rural aging population, more broadly, which indicate that older people in rural settings typically wait longer to access support but often demand more support than their urban counterparts when they engage with the formal health and home care systems (Cloutier et al., in press). In contrast, those who engaged with ACs for support did so over a longer period of time and often accessed other community-based services (e.g., day programs). For many partners in care, the ACs played a central role in helping them navigate the complex system of community-based care, which I examine in the following section.

Table 6.2: Service use patterns over the course of the illness

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of care partners using service</th>
<th>Hours/week</th>
<th>Duration of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Support Worker</td>
<td>25</td>
<td>2-12 hours/week</td>
<td>6 month-2 yrs.</td>
</tr>
<tr>
<td>AS</td>
<td>18</td>
<td>As needed/typically</td>
<td>Up to 6 yrs.</td>
</tr>
</tbody>
</table>

7 Some care partners shared diaries and notes during the interview that they had kept throughout the illness, which provided rich detail and exact dates for events.
6.2 Navigating the system of care

Navigating the system of care was not a straightforward linear trajectory for partners in care, nor was it the same trajectory for everyone. As evidenced above, there are differences in the type, number, and timing of services used by partners in care and persons with dementia. In this analysis, I seek to uncover the experiences and perceptions underlying these pathways and to identify common temporal and spatial nodes (Atkinson et al., 2011). Atkinson and colleagues, use the term node to describe the relational, intersecting, and dynamic nature of care. Rather than focus on stages and settings along a linear trajectory, they suggest that geographers should focus on how care flows between bodies and across space. As such, I shed light on a number of factors influencing pathways to support, illustrating the ways in which care flows and is delayed over the course of the illness. Following the partner’s narratives, the nodes I identify are not necessarily fixed in time and space; they are processes that stretch across time and space. They include getting a diagnosis, getting support from the ACs, finding people who understand, accessing the CCAC and negotiating home care hours, and making decisions about end of life care. The sequence of the nodes reflects a common pattern of contact with particular people, settings and services, but I do not mean to suggest that partners’ experiences of care follow a
linear trajectory. Instead, I elucidate the ways in which the timing and spacing of the nodes of care were configured in relation to one another.

The starting point for the dementia journey often began with noticing problems and changes for several years before there was a formal diagnosis; however, there were delays in seeking and receiving a diagnosis. Linda (50, Daughter, GB) explained “we knew she [mother] was forgetting things and she might say there was somebody in the house, but there really wasn’t anybody in the house, so we knew there, we assumed it was Alzheimer’s.” As was the case in this instance, some partners in care coped with and compensated for memory problems until the symptoms of dementia progressed further. Jean (65, Spouse, SSMA) described her experience saying, “we always just managed and laughed…we were a team. People didn’t notice ah for quite a while because…here, you go places together, and I had always helped [husband] with names and things.” Routine in relationships and community settings enabled numerous couples to manage memory loss, and avoid seeking a diagnosis. Moreover, discourses of marital responsibility and rural resilience were sometimes used to justify delayed help-seeking. However, such narratives were not universally taken up by the rural residents in either case study. In fact, there were also partners in care that “pushed for a diagnosis,” particularly when it was complicated by co-morbidities such as depression, Parkinson’s, or stroke. Anna, a spouse and 65 year old retired nurse recalled telling the doctor, “I would really like a CAT scan done just to make sure.” In this case, work experience, experience with navigating the health care system, and experience mediating inter-personal tensions in the care relationship were all assets in initiating diagnosis.

Following these delays, numerous partners in care identified challenges receiving a diagnosis from their general practitioner. As Joan (70, Spouse, SSMA) recounted, “I had
mentioned it to his doctor at the time and she just said, ‘it’s just age, it’s just age,’ like the
general public does. But I was surprised at it from a doctor.” Other partners in care discussed
similar disagreements with the doctor and additional challenges related to not having a GP. The
extent to which people were able to cope together without a diagnosis, access to and
responsiveness of a GP, and knowledge of other health professionals and resources shaped
pathways to a diagnosis. In addition, they often shaped broader service use, particularly
engagement with ACs and CCAC.

The ACs were generally the first point of contact for partners in care seeking information
about dementia. They also provided a more fluid space for ongoing support with a range of
services and settings in which these services occurred. For the majority of partners in care in the
study, ACs played a central role as a system navigator by explaining service options, discussing
eligibility, and identifying when specific services might be appropriate as well as who to contact.
For example, Jean explained, “Because I went to the Alzheimer Society, I learned about the day
program. I don’t think I would have known that was available.” Other participants detailed the
ways in which the ACs helped them to access home care services and making decisions about
long-term care placement. Such information sharing took place over the phone, during home
visits, at education sessions, and at support groups over the course of the illness. A few partners
started going to ACs before they had a diagnosis because they wanted more information about
signs and symptoms and some were referred to an AC by their GP or through the First Link
program (see Chapter 4). While partners in care were likely to seek information from the ACs
earlier in the illness, only a few started going to support groups as soon as they got a diagnosis.
The majority of partners in care who went to support groups suggested that frustration or an
event at home propelled them to pursue more support. Jean, explained, “…the thing that upset
me and made me go to the Alzheimer Society was he went out to water the beets and he used gasoline!” Partners in care who did not engage with an AC until near the end of their caregiving role did not find it as helpful as those who had gone there at an earlier stage of the illness. Overall, timing and frequency of contact with an AC shaped partners’ sense of satisfaction with community care services and their access to social support more broadly.

Notably, most of the partners in care identified as the sole carer, with limited tangible support from family or friends, whether family was geographically proximate or distant. This is in direct contrast to the perception that some care providers (see Chapter 4) held about people living in rural areas being more oriented toward family care or “looking after their own”. Joan indicated, “The biggest challenge was that I didn’t have any family around” and Betty (77, Spouse, SSMA) reasoned “I have three kids in town, but they have their own families and things too so, I didn’t rely on them. I guess I could say it that way.” Typically other family members offered support through emails, phone calls, and visiting. Given family members’ distance from the day-to-day demands of care, many partners felt that other family members did not fully understand the experience or needs of the person with dementia, let alone their needs as partners in care.

The need to find people who understood the mundane experiences of living with dementia was a common theme amongst partners in care. Many partners found this understanding through the AC, their support groups and staff, and informal support groups. Margaret explained:

These other people are going through exactly what you’re going through. It’s so easy to relate to these other people and their situations and it’s the sharing of information that’s so, so important… you just feel very comfortable sharing what you are going through. You can vent and rant and rave [she laughed] (73, Daughter, GB).
In both case studies, several women started informal support groups to augment the AC meetings with more frequent support. The one group included former partners in care, current partners in care, and persons with dementia who would regularly meet at a local diner together as well as organize other outings. The group provided partners in care with reassurance and support to continue to be social at various stages of the illness and after the death of the person with dementia. Diane (72, SSMA) explained that, even after her husband passed away, doing activities with the group helped her to feel that she was not alone. Another informal support group drew together partners in care for persons experiencing different illnesses and emerged from conversations amongst three friends about the need to “unload.” Debra explained that the groups had found a psychologist to volunteer his services once a month, but they met twice a week. She recounted, “…we learned how to deal with each other and be a support without criticizing.” She suggested that many people in her community did not want to hear about or talk about the “hard places.” The two informal support groups demonstrate different social spaces of understanding that partners in care desired. The first group, helped partners to get out of the house with the person with dementia and navigate potentially unusual social encounters as, and within, an understanding group. The second group demonstrates the desire to break the silence and express the personal challenges of being a partner in care in a place where judgment and the potential to harm the person with dementia are suspended. In small town settings, Debra observed that this was particularly difficult. Moreover, the space of the support group can serve a range of purposes that are potentially at odds with one another. In fact, ambiguity and misunderstanding about the precise nature of formal AC support groups sometimes served as a barrier to their use.
In the Grey-Bruce case study, Mary, Anna, Fred, Linda, and Darl explained that they did not want to go to a support group. Fred suggested there wasn’t anything more to learn and Anna said “It wasn’t my thing. And whether I could have been any help to anybody I truly think that the group in [name of village] …is hardly /maybe three people.” Anna’s comments, in particular, underline the pride and sense of resilience that some people living in smaller towns espoused. They expressed a desire for more “practical” support from the AC (Linda). Mary commented: “I guess my idea about Alzheimer’s is that they would maybe offer some respite, but I know they are more into education and that sort of thing, but I think in some areas they must have stuff like that, don’t they?” The variation observed in Chapter 4 created a degree of misunderstanding about the ACs and their services. In addition, partners in care cited lack of respite or alternative care arrangements as a barrier to attending support groups. Linda, who was working full time, explained that she “dealt with the internet” and Ellen explained that because of the constraining nature of her caregiving role, “The last thing you want to do is go sit at an Alzheimer’s meeting if you’ve got this hour or two hours because you’ve got groceries to get and just your own time.” While engaging with the AC and finding people who understand were closely connected with one another, the use of AC services was also linked to the use of home care.

A noted earlier, home care was the most commonly used service across the case studies in terms of the number of partners in care relying on it and the frequency with which it was used. When asked how they found out about CCACs, partners in care indicated that they were referred by a doctor, the AC, or a friend. A few partners in care also had prior experience accessing services through CCACs. Not knowing about the CCAC did not appear to be an issue for persons with a doctor and/or accessing services from the AC; however, the compatibility of home care in terms of eligibility, scheduling, and consistency and quality of workers affected use over time.
Initially, some partners in care indicated that they put off calling CCAC because they “were managing ok” (Anna) or the person with dementia “was fine” (Mary). They emphasized their ability to do the work of caring while rejecting the notion that they might need help. Some partners were encouraged by the AC to call the CCAC for an initial assessment, particularly when it became more difficult to leave the person with dementia at home alone. Those seeking support before this point identified eligibility criteria as a barrier. Sandra suggested,

If you tell them that you leave them alone, ever, you’re done. You will not get respite care…that’s not right, because sometimes it is ok to leave for you know, half an hour to run to get milk or bread or you still would like a couple of hours to do a big grocery shop you know?

Such comments indicate that the later use of home care services may also be a product of the ways in which care needs are evaluated by the CCAC. Partners in care expressed frustration that their needs were assessed in relation to the person with dementia, who often had different needs and different perceptions of their needs than their partner. Kathy recounted her CCAC assessment experience with her husband saying, “He was at his most charming, and his most witty, and his most alert; and I would sit there and I could kill him [she laughed].” Like Kathy, other partners in care explained that the person for whom they cared always seemed able to perform at their best during assessments and with family members, undermining the sense of need and stress that they felt as partners in care. As a strategy for dealing with this issue, Jean began collecting her own “data.” She wrote down the “down side” of things that she had previously tried to ignore. She commented that this process, although it was “awful,” helped her to answer CCAC questions and advocate for what she thought was needed. Taken together, these accounts illustrate a range of socio-cultural, inter-personal, and institutional barriers to accessing home care in the beginning and negotiating long-term care placement toward the end.
In addition to qualifying for certain kinds of support, partners in care identified issues related to scheduling and geography. For instance, Jean and Linda were frustrated with care workers showing up late or leaving early to get to their next appointment. Jean reasoned that this was largely a scheduling issue with the CCAC: “I don’t think they have any idea about geography.” Others explained that scheduling did not take into account long-established daily routines such as bathing in the morning rather than the evening, which made the experience of having the PSW in the home more stressful. Joyce (60, Daughter, SSMA) who cared for her mother summarized this situation: “…you had to be on their schedule and sometimes that didn’t really work.” As a consequence of the inconsistency in terms of timing and personnel, several partners in care stopped having support with bathing and decided to do it themselves. In relation to respite hours, numerous partners in care explained that the scheduling would not allow them to do the basic tasks such as banking and grocery shopping because the block of time allotted was too short. Again, this was seen as an issue of not understanding rural geography.

In talking about scheduling issues, partners in care also identified problems related to staffing consistency. Many partners praised “good workers” for the relationship that they were able to establish with the person with dementia. However, they identified challenges getting the same worker to come on a consistent basis. This was often an issue when it came to bathing support, as partners in care felt that having the same staff member to do this intimate task would help make the person with dementia more comfortable. Several partners complained that some staff providing respite did not make an effort to get to know the person with dementia and this was complicated when the person with dementia was themselves withdrawn. For instance, Jean explained, “he [her husband] would pretend that they weren’t there and he would just go and withdraw, so by the time that I got there he was well-rested and ready to go, go, go [I laughed].”
She tried to prepare for the PSW by laying out activities that might engage her husband in a positive and meaningful way in advance. Such accounts underline the importance of the overall fit—timing, sensitivity, and responsiveness—of home care to the needs of persons with dementia and their partners in care living in rural communities. Moreover, inadequacies in home care precipitated long-term care placement and often forced decisions about long-term care that were against the wishes of the person with dementia.

End of life care played an extensive and powerful role in partners’ experiences. It influenced, and was influenced by, other sites and services along the care trajectory. It is important to note that end of life care is not located in a single space and the time period to which it refers can be difficult to define. End of life care and long-term care are not synonymous. Home, hospice, and a range of long-term care facilities, often outside of one’s immediate community, figure into thinking about end of life care. So too, do the wishes expressed by persons with dementia, sometimes long before a dementia diagnosis, the current conditions of care at home, and the physical, psychological, and emotional condition of the person with dementia and the partner in care.

Across both case studies, the majority of persons with dementia died in long-term care; one person died at home, two died in hospital, and one died in hospice. Notably, the one person who died in hospice also had terminal cancer. Some partners in care had actively researched alternative settings of care such as residential hospices. For example, Elizabeth recalled, “I got told, get papers ready; we got to do something and then that woman went into the nursing home under severe stress. I was trying to get her into Pathways [hospice].” The majority of partners in care felt pressured into and “fought” long-term care placement (June, 84, Spouse, SSMA). This pressure came from both family members and health care professionals. For instance, June
recounted, “…my children thought he was ready, but I didn’t… ‘cause he used to say to me not to put him in a home.” For spouses in particular, end of life care and long-term care decisions were associated with intimate and longstanding knowledge of the person. Jean poignantly described her husband’s end of life wishes and her own limitations to fulfill them saying,

He still knew he wanted to end his life. He just didn’t know how so um and legally I couldn’t. I mean we had always talked about this. I said I cannot go beyond a certain point so um you know so he’d go storming out of here saying well I’m going to the dam and I knew that, that was where he intended to end things… but he just couldn’t conceive of the way to do it in the state his mind had reached.

Numerous partners in care indicated that the person with dementia they cared for had expressed a desire to end their own lives. Few partners in care, however, felt as certain about the intent and capacity of the person with dementia in expressing these wishes as Jean. For a number of partners in care, these expressions were linked to going into or being in long-term care, which would not have been the choice of the person with dementia at an earlier stage or had there been other alternatives.

In the final stage of dementia, partners in care were constrained by a lack of choices with regards to end of life care. In spite of fatigue and behavioural challenges, most care partners sought to keep the person they cared for at home for as long as they could. Mary explained:

I knew what would happen if he went to a nursing home. He couldn’t tell anybody what he wanted. He had to be toileted. He couldn’t tell when he needed to go to the bathroom. He would just be put in a wheelchair and when they could get to him, they would get to him.

Most partners in care became tearful and relayed feelings of guilt and regret when discussing long-term care. Many described it as a “horrible experience.” Spouses, in particular, felt they had betrayed their partners’ wishes; this feeling was heightened by the sense that their partner failed
quickly in long-term care, often dying within 6 months of moving. Partners in care reasoned that they might have been able to care for the person with dementia at home, had they known how little time was left. The partners’ sentiments reflect the complex relationship between home and long-term care. They highlight the lack of alternative residential care settings as well as the lack of home care hours available to keep a person with final stage dementia at home. Structural issues such as these are not isolated to rural and small-town settings. The reluctance of spouses to move their others into long-term care is a common theme even outside the dementia literature (Milligan, 2005). Nevertheless, partners in care, identified concerns specific to dementia (e.g., persons be non-communicative). Most importantly, they identified the ways in which end of life decisions shape and were shaped by earlier stages of the illness and encounters with the system of care.

Consistent with Chapter 5, delays in seeking and receiving care were common, not only at the beginning, but also across the care continuum to end of life care. There was some indication from partners in care in Grey-Bruce that such delays are, in part, influenced by a rural culture of resilience and silence wherein individuals refrained from talking about their troubles, particularly if it involves exposing their vulnerability (Parr, 2008). However, the composition of rural communities is diverse and attachment to such values are not universal. The relational nature of the care continuum is also an essential factor in understanding these delays. Later diagnosis, later engagement with ACs and CCACs, and later placement in LTC are certainly connected to one another. More than that, ideas about the end of the dementia journey and the stigma associated with the illness shape each of these nodes of care and reinforce the need to find people who understand or experience isolation. The emergence of informal support groups in each case study speaks to the demand for this support and its potential at the community level.
Recognizing this potential involves mediating the constraining experiences of care that entrap partners in care in other settings, mainly the home. I explore these constraining experiences in the following section.

6.3 Negotiating care and experiencing its constraints

As partners in care navigated the complex system of care they negotiated constraints within their relationships, the home, and the community. The ways in which partners in care talked about the constraints of caring revealed social and structural limitations of care, as it is currently organized. That care, in general, can be constraining or oppressive is not a new paradox (see Brown, 2003), but the particular forms of these constraints require attention if care is to be made less constraining. My intention is not to cast care as inherently bad, but rather to contribute to the literature that exposes the consequences of particular social and political constructions of care. In the following section, I explore the ways in which partners’ time, bodies, and choices are constrained by care across different spaces.

In the first instance, partners’ sense of constraint was heightened by safety concerns in the home and community. Partners began to feel uneasy about leaving the person with dementia at home alone. In particular, the kitchen became a site of contention. Margaret described her mother trying to cook things as "frightening” and Linda explained that one night her mother had put the electric tea kettle on the stove and melted off its bottom. Particularly for partners in care who were cohabitating with the person with dementia, such safety concerns changed their experiences of the home disrupting rhythms, routines, and the division of responsibilities. They described a need to be watching the person for whom they cared on a constant basis. As Evelyn poignantly put it, “you go and lay down but you’re really not resting because you’re listening to every noise” (75, Spouse, SSMA). Evelyn explained that her husband had started a fire in the
kitchen once when she was sick with bronchitis. She had lain down to take a nap and her husband had turned on an element on the stove setting fire to a pan of grease left from dinner. In an effort to prevent similar incidents, Linda sought out devices that would calibrate household appliances so that they could only be used at a certain time when someone else was there to watch. In spite of such technologies, the home became much less of a place of rest for partners in care as the illness progressed.

Partners in care recognized, however, that the person for whom they cared should be supported in continuing to maintain their lifeways and routines. For instance, Jean explained:

…we heat with wood. He wanted to still do that sort of thing. He was high energy…He wanted to be doing, so by the end, I would go for a walk here. I would leave him um and he didn’t want to be alone either. It’s not just that I would be afraid to leave him but I would go around this little block and he would stand at the window and wave each time I did a loop so that I could get some exercise and then when the caregivers came [from CCAC], I would, when the bath lady came I often went and split kindling or something just to get out of the house.

Jean’s reflection illustrates the tensions between safety concerns and meaningful activity in the home for the person with dementia. She and others noted that the persons for whom they cared were physically able and insistent on continuing certain activities. At the same time, she points to her husband’s increasing dependence on her, not just because she felt she had to watch him, but also because he did not want to be alone. Furthermore, she had limited hours of home care to get out of the house, so she used even 15 minutes of bathing time to “get out.” Indeed, Jean’s movements were often constrained within a circle around the home or negotiated within the context of the support of the community and the availability of home care.

Consistent with findings in Chapter 5, partners in care identified ways in which the social and physical environments in which they lived sometimes helped to facilitate their movement
and space from the person with dementia. Jean recounted taking her husband with her to get her hair cut because her respite had been cancelled. He had wanted to stay in the car, but he got out and started walking when she was still getting her hair cut: “A neighbour came in and said [your husband] is walking down the street. I just want you to know I’ve chatted with him. He’s now with so and so. He thinks he wants a snack, so they are walking him down to the restaurant…” She explained that the small community in which she lived was very supportive. She felt that this was especially the case with her husband because he had given a lot to the community. Similarly, Debra, whose husband had been a GP explained that the “whole community” helped her because she had taken pamphlets to local stores and she had been featured in an article in the local newspaper. In both of these examples, partners in care felt that community watchfulness was a positive feature of their small town setting. They also played a significant role in constructing supportiveness for themselves from a position of privilege. These anecdotes display the potential of rural and small-town community support; however, I would cautiously note that they are more the exception than the rule. Furthermore, there are some temporal parameters to community support to which I will return later in this chapter. Certainly, community settings did not always feel comfortable and supportive.

In the earlier stages of the illness, friends and family sometimes played a role in getting the person with dementia out of the house and helping them to maintain longstanding interests. For instance, Debra explained that her husband’s friends would take him to band practice once a week; however, as the illness progressed many partners experienced their social worlds “shrinking” (Ellen). Mary explained that she and her husband stopped going to church and doing many of the things they had done together throughout their marriage: “When it got to a point that he would start speaking out or talking or whatever I said well, this, we can’t do this anymore.”
Most partners in care withdrew from activities as means of dealing with behavioural changes in the person with dementia. Kathy explained that she stopped going out to dinner with friends because she could never be sure what her husband would do:

I mean I think it’s within me…I’m sure nobody else was looking but I was sure they all were and my son said, “Mom, Dad has Alzheimer’s. People have got to get used to it.” He sort of felt, if they don’t like it, too bad, but I didn’t find it that way. It wasn’t a relaxing thing to do, which is what I used to find [she began to cry].

Kathy’s reflection, particularly her sense of guilt and shame, illuminate the constraints of the partner discourse itself. While her son expected her to set an example and challenge the stigma associated with dementia, she sought a place that she had long associated with relaxation. This place was transformed by the pressure to be an advocate. She blamed herself for her own sense of isolation and for not overcoming the stigma of the illness. Her story also illustrates the limitations of family support in alleviating isolation for the person with dementia and their partner in care. Corroborating this theme, Linda expressed frustration with her siblings for the ways they interacted or failed to interact with her mother. She explained that her mother complained that they did not talk to her. Anna explained that it was difficult to have visitors in the home because “they couldn’t have a conversation because [her husband] would be rambling.” She found that visits from family members shortened. Furthermore, those without family nearby expressed considerable loneliness and isolation.

To some extent, the physical environment facilitated the movement of the person with dementia and some space for the partner in care. Some partners in care described a sense of relief from caring when the person for whom they cared “wandered off.” Jean explained that her husband would wander to a friend’s house and she would watch after him, but take her time to get to him, knowing that he would be sitting comfortably in the company of friends. Others
explained that the physical environment provided a scenic and safe place for the person with dementia to walk. Ellen described her husband’s weekly walk with the PSW saying, “they walked down to the lake, and they’d walk along the lake shore, and then they’d walk to the library…” To her, it seemed that her husband’s relationship with the PSW was bolstered by the routine and excitement that he had for their walks together. In talking about walking and wandering, partners in care identified the potential freedom, and even therapeutic value, of rural and small-town settings. Again, however, the freedom and security that the physical environment offered declined as partners in care became increasingly uncertain of what the person for whom they cared might be doing while in their own space.

Given these concerns, partners in care identified lack of any time and space to one’s self as a common and increasing constraint in the later stages of the illness. Some partners in care found that even in-home respite felt constraining. Kathy expounded, “well you don’t want to leave or you’d really rather that he could have gone and give me the house to myself.” Kathy, like many partners in care, identified an increasing tension between her own desires and needs and her husband’s, for whom she cared. This tension was illustrated most poignantly in partners’ narratives about residential respite. The majority of partners in care experienced some resistance in getting the person for whom they cared to go and continue going to such day programs. A number of partners in care could not get the person they cared for to agree to try such a program. For instance, Joan resigned herself, “he just wouldn’t go.” Anna poignantly explained her husband’s resistance:

To send him was just awful. He didn’t want to go and he said you know you’re a traitor pushing me out the door there’s no reason why I have to go. Just awful. I was crying after and I called the program to see how he was doing. Needless to say, he was fine down there, but it was always a battle to get him out the door. (68, Spouse, GB)
Although Anna was offered two days of day programming a week, she explained that her husband only went one day a week because of the emotional stress of getting him there. Her story elucidates the emotional and interpersonal barriers of negotiating care, particularly with a spouse. Indeed, whether accused of being a “traitor” or not, partners in care often felt guilty about sending the person for whom they cared to a day program. They viewed resistance as a valid response to what looked like more of a “sitting service” than meaningful activity (Jean). Some partners in care called on sons and daughters to help them get the person with dementia ready and take them to the day away program, alleviating some of the stress of getting there. Partners in care also identified successful strategies used by the program staff such as counselling partners in care to refer to the program as a “coffee club,” being flexible with regards to drop-off and pick-uptimes, and being welcoming. Over time, some partners in care found that the persons for whom they cared came to look forward to the day program, but often they required increased hours of support at home.

Many care partners found that the hours of home care available to them were inadequate. Anna, for instance, was told that she was “maxed out” and Linda reasoned, “…if Dad didn’t have me, then you would need a lot more care than what we were able to get…there isn’t that care available.” In addition, partners in care identified the need for respite hours during the night. Although some partners in care felt comfortable with wandering during the day, they were concerned about falling at night when they felt they could not call neighbours or other family members to help them get the person up off the floor, as they sometimes did during the day. In addition, the need for assistance with toileting resulted in “broken sleep” for partners in care. Pam (78, Spouse, SSMA) recounted,
I used to get up with him every night for a year and a half because he couldn’t find the bathroom... He only wet the bed once and he was scared he was going to wet it. He got up every hour and a half for that reason.

Partners in care described the night work of listening, following, and leading the persons they cared for back to bed as well as bathing them and re-making the bed. In doing so, they negotiated competing bodily rhythms of sleeping and toileting, often for extended periods of time. Such demands ultimately placed constraints on their capacity to continue caring for the person with dementia at home as they experienced increasing fatigue.

### 6.4 Responding to behavioural changes

As partners in care described their experiences of caring in the later stages of the illness, they identified challenges responding to behavioural changes. In particular, seven partners in care identified aggressive behaviours as a challenge to both their providing and accessing appropriate care (e.g., day programs and long-term care). Aggression is a relatively common symptom and response to personal, social, and environmental challenges experienced by persons with dementia. While Dupuis and colleagues (2012) have advocated for the use of the terms “responsive behaviours” and “personal expressions,” to refer to these behaviours and ultimately place greater emphasis on understanding the person with dementia and their intent, I refer to these expressions as aggression. In doing so, I seek to draw attention to the position of the partner in care, not just as one person responding to another person in a particular time and space, but also as persons living within invisible spaces of violence. Here, I understand violence as a process of harm that “inhibits the self-development and self-expression of individuals.”

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8 There is some debate about what terminology should be used to discuss “aggression.” Dupuis and colleagues (2012) argued that “aggression,” “violence” and “challenging behaviours” are phrases that reinforce the stigma associated with dementia.
(Fleming, 2012, p. 486). It is not exclusively uninvited physical harm to which I refer; it also includes social and emotional harm, which take place across a range of spatial scales (DeVerteuil, 2015). I argue that partners in care experience the threat of interpersonal violence and they are constrained by a degree of structural violence, feeling entrapped in their position of caring. Indeed, partners’ narratives about aggression reflect the ways in which health care workers and places of care outside the home reinforce such conditions of care.

First, I note that aggression is an emergent theme within this dataset. Some partners in care used the word “aggressive,” but many were reticent to give the behaviour a name. Partners in care who spoke candidly about their experiences of responding to aggression did so with great sensitivity to the person with dementia’s personal histories and the context in which this aggression took place. Many used these histories to defend the person with dementia and distinguish the behaviour as uncharacteristic. They described their partners as “agreeable,” (Ellen) and having “a good personality” (Pam) before discussing their anger and aggression. Many partners in care displayed considerable capacity to understand the person with dementia, while also reflecting on their own vulnerability. For instance, Anna described an incident that led to her husband’s hospitalization saying,

I guess thinking back I was pushing him a bit. You know, he had to go to the bathroom and he had gone into the bathroom, but at that point often he couldn’t remember what to do when he got in there. But he knew where to go… I was easing him down but he just punched my shoulder a couple of times on the way down. He had a wild look in his eyes and I had never seen that before. I thought you know maybe, maybe we better call and get an ambulance because I’m just not sure what happens after that.

Anna explained that, as a retired registered nurse, she felt certain that her training would allow her to keep her husband at home, but she also expressed a sense of uncertainty in this situation.
She reasoned that once her husband’s medication was adjusted, he should come home. Similarly, other partners in care identified strategies for avoiding and managing aggression. For instance, Mary described how she managed her husband in these situations saying,

…if I’d said something that made him aggressive then I stopped, waited, and it was/it passed. It was gone or if I was showering him and he didn’t want me to do certain things or whatever I would just say you stop that and he was fine, but I just felt they [PSW] didn’t really know how to deal with it or they didn’t want to…

Mary explained that she stopped getting help to bath her husband because she felt “there was this undercurrent that this man should be in a nursing home, you shouldn’t be looking after him.” She had tried taking her husband to a long-term care facility for a weekend of respite, as well, but staff called the police when he became aggressive and he was transported to the nearest psychiatric ward. She was frustrated that they called the police and not her and when she was finally able to see him he was “sitting in this Geri chair with nothing from his waist down.” Her knowledge of her husband was not taken into account. In addition, the doctor on call did not want to release him. Her experiences of other people’s responses to her husband’s aggression left her feeling that there was no better alternative to her own care. In fact, all the partners in care responding to aggression at home, were adamant that the person for whom they cared should stay at home. They feared that other places and people would not have the time or training to understand these behaviours; however, their capacity to manage these behaviours also varied.

Not all partners in care had the experience and information to manage as Mary and Anna. For instance, Evelyn explained that her husband would get “very, very angry…and he’d beat me up.” She had some advice from one of her doctors to “be careful… don’t be close to the stairs when he is around;” however, nobody discussed the role of medication or techniques in managing her husband’s aggression. Furthermore, some partners in care suggested that the
person for whom they cared had always had a temper and it became worse as the illness progressed. Pam explained nervously,

I figured I’d get beat up before I got out of this situation…. One day he went out to the bedroom and said he was going for his walk. He put on his shirt, couldn’t get it buttoned up properly I guess. I heard the buttons flying. He pulled every button off the shirt. He put another one on and the buttons went on that one and I locked myself in the bathroom because I wasn’t going to say one word about it.

She explained that she had a “burnout” when her husband went into long-term care and she was medicated for anxiety. She reasoned, “…how I feel, if I would have kept him home and not put him in the home, he would still be alive, maybe I wouldn’t be though.” Each of these narratives illustrates ways in which violence is not just a threat within an interpersonal relationship; it is nested in broader structures of violence, which deny the needs and vulnerability of partners in care. In this case, the state plays a role in making aggression invisible in private homes and institutional settings. Fear of institutional settings, guilt, and negative encounters with health professionals entrap ‘partners’ in care in the home as the best settings of care amongst less than ideal choices.

6.5 Discussion: Caring places and partnerships?

As the quotation at the start of the chapter indicated, there is work to be done to make visible the needs and challenges of partners in care and persons with dementia in rural communities. The experiences of former partners in care are an invaluable resource in evaluating the range and fit of services for persons with dementia and their families over time and across space. Partners’ accounts of service use contribute to the literature on transitions and trajectories of caring for dementia. They confirm the enduring challenges of system navigation for persons with dementia and their families. Such challenges often begin with getting a diagnosis from a GP
and persisted as partners in care negotiated pathways to support in the community and the home. On the other hand, the findings point to the positive role that AC can play in helping persons with dementia and their families navigate the system. Corroborating the findings in Chapter 4, partners’ narratives indicate that the AS is the only organization to provide support to persons with dementia and partners in care from diagnosis to death. Notably, the use of formal support groups and creation of informal support groups, points to the potential and capacity of some individuals and groups to develop local solutions. In contrast to earlier studies, the findings indicate that there is a demand for socio-emotional support in spite of the typical characterization of rural people as stoic and not wanting to share their personal business with others in the community. It would seem that engagement with the ACs and support groups in particular, is far more nuanced. Gender, education, and social embeddedness in the community have an impact on persons existing support networks as well as the networks that they are able to make after diagnosis. The findings corroborate the suggestions of Egdell et al. (2010) that persons with dementia and their partners in care seldom have support networks in place before diagnosis. This may be even more likely in a rural context where family members are less likely to be geographically proximate. While some examples of tight kinship groups exist in my research, most partners in care did not receive consistent support from family members.

Partners’ knowledge adds depth and scope to the current literature on care and caregiving. Reflecting back on their experiences of providing and receiving care, partners in care offer a dynamic view of care in various contexts and at different times. Their narratives shed light on the multiple spaces that constitute care in rural and small town settings and beyond the landscape of service provision. While partners in care shared a sense of despair and grief about their experiences, they also identified the potential of rural communities to support persons living
with dementia and their partners. To some extent, the social and physical environments in which they lived offered both support and freedom in the earlier stages of the illness. However, as the illness progressed, partners in care identified the limitations of their existing social support networks and challenges associated with safety in the surrounding environment. They identified the constraints in their relationships, their homes, the community, and the broader system of care. In particular, long-held wishes and emotional responses to day programming and long-term care acted as barriers to service use for persons with dementia and their partners in care. Partners’ evaluations of day programs and long-term care challenge perceptions of the cared for as passive and willful participants while raising questions about the availability of meaningful care for persons in the later stages of dementia. In fact, the lack of meaningful supports available was not only linked to service uptake, but also linked to terminating service use. The responses of personal support workers and case managers to behavioural changes, led some partners in care to cease service use as they feared the person with dementia might be forced into long-term care. In spite of their vulnerability, partners in care for persons who had become aggressive sought to keep the person with dementia at home for as long as they could. The capacity of partners in care to cope with aggressive behaviours and the outcomes of these experiences in the home were variable. The narratives of partners in care elucidate the role of fear in decisions about care. Fear of long-term care placement and fear of betraying the person with dementia were reoccurring themes in discussions of end of life care.

The constraining experience of care extends beyond the life of the person with dementia. It affects the social lives of former partners, the spaces they inhabit, the spaces where they do not want to go, and their relationships with others. The majority of partners in care identified struggles regaining a normal social life with friends and their community. Several partners in
care suggested that general bereavement groups did not meet their needs; they felt their experiences of loss were too difficult for those not having experienced dementia to understand. One woman expressed a sense of alienation by her peers who suggested that she should be over grieving and another talked about experiencing anxiety and having to go on medication to manage her anger. One partner in care continued to attend support groups, but the majority felt that it was no longer their place. However, limited research, policy, and programming exists to target grief for current and former partners in care of persons with dementia (Chan et al. 2012). Further research is required to explore the experiences, needs, and interventions for grief in former partners in care.

The constraining experiences of partners in care troubles movements within the social sciences literature on dementia to adopt the language of partnership. Can a relationship, marked by constraints and aggression, be characterized as a partnership? It would seem that framing the relationship in terms of partnership obscures the felt injustices and naturalizes the work of those supporting a person with dementia. While scholars have sought to recognize the agency of persons with dementia, at all stages of the illness, through the partnership discourse; partners’ needs are not given equal consideration. Instead, partners in care are expected to be advocates and providers of care at a time when many of them also need care. The system of care is not designed for partners. Often services are for persons with dementia or for caregivers; they are usually not designed with both in mind. I would argue, however, that partnership should not be abandoned. In fact, partnership should be taken more seriously in policy and programming, so that, for instance, respite might be geared toward both partners in care and persons with dementia across a range of settings and scales with sensitivity to the diversity of relational contexts that shape care.
Taken together, these findings contribute to program and policy issues around aging in rural communities and dementia care specifically. Most importantly, they illustrate the potential negative consequences of aging at home policies for partners in care. While partners in care and the persons for whom they care want to stay at home, the fit and frequency of support is not enough for most people live out this goal. Experiences of care as constraining and “horrible experiences” are linked not only to the rationing of resources, but also the lack of discussion about alternative places of care. Recognizing the changing feelings and experiences associated with care and caregiving is essential if support is to be accessible and acceptable across the continuum.
Chapter 7
Conclusions: Improving dementia care in rural and small town settings

Although public and academic interest in dementia has grown significantly in the last few decades, researchers and policy makers have paid limited attention to the contexts and experiences of dementia in rural and small town settings. In response to the lack of current research in this area, I aimed to achieve four broad objectives in this thesis. First, and most broadly, I sought to understand and examine the relationship between living in rural places and experiences of dementia care. Secondly, I sought to examine how living in rural places affects service availability and service use from diagnosis with dementia to death. Thirdly, I examined the relationships between specific sites of care, care needs, and experiences of care and caregiving. My final overarching objective was to contribute in a meaningful way to the lives of persons with dementia, their partners in care, and their communities by building on current knowledge about service organization and service experiences at the community level. In this final objective, I hoped to inform policy and practice. Each of these objectives was informed by the academic literature on health and health service provision, rural aging, and rural dementia care. Conceptually, the research employed a relational approach (Andrews et al., 2013; Cummins et al., 2007; Skinner et al., 2014) to understand the dementia experience, the diversity of rural and small town settings, and care more broadly (see Chapter 2). In this final chapter, I discuss the benefits of a relational approach and I summarize the research findings as they address each of the research questions contributing to specific bodies of literature as well as policies and programs. I then review the limitations of the research and highlight important research directions for the future.
7.1 Revisiting the research approach, questions, and major findings

Relational thinking has not been highly visible in research on aging and dementia (Skinner et al., 2014). In using a relational approach, this dissertation seeks to expand geographical, gerontological, and social science research on experiences of dementia. Much of the current research on dementia care has adopted relatively conventional approaches to understanding dementia, rural places, and care. Although social gerontologists have engaged with a range of social theories to explore the diverse positionings of persons with dementia (e.g., O’Conner et al., 2010), there is still a tendency to view persons with dementia solely in terms of their health behaviours, needs, and demands for services. This is particularly the case in research on service provision and use. However, thinking relationally about how persons with dementia are positioned within their communities and broader networks of giving and receiving provides a richer understanding of their lives and perceptions of care. It offers new perspectives on alternative spaces, places, and practices of care. A relational view of dementia care explores the complex meaning of different settings of care in relation to one another. It makes evident the non-linear flow and timing of care across the continuum. The home, the surrounding social and physical environment, day programs, AC offices, churches, and long-term care facilities are all interconnected in individuals’ care experience and care decisions. Rather than view these settings as bounded within a particular rural area, the dissertation explores how persons with dementia and their partners in care move between these sites in rural and regional contexts. By looking at multiple settings and scales in relation to one another and over time, the dissertation offers a more thorough analysis of the cumulative consequences of particular structures of care from the micro scale (e.g., feelings within particular settings) to the macro scale (e.g., aging at home policies).
R1: What services are available to persons with dementia and their caregivers across the province of Ontario?

Drawing on traditions in health geography and health service research, more broadly, I conducted a survey of the largest and only dementia-specific service provider in the province of Ontario to examine what services are available to persons with dementia and their partners in care across the province. The focus of the survey makes a significant and original contribution to the study of community support services for persons with dementia by focusing on the roles and challenges faced by the voluntary sector, which are seldom discussed in the larger body of literature on dementia care. The findings confirm the essential role of nonprofit service providers in meeting the needs of the aging population, and persons with dementia specifically, in rural and small town settings. At the same time, the findings illustrate the uneven development and availability of community support services for dementia care across Ontario. With regards to development and service provision, ACs identified challenges associated with increasing demand, partner relations, and reaching rural populations. While some ACs have developed strategies for connecting with persons with dementia at diagnosis through the First Link program, phone calls, and home visits, few ACs had meaningful activities and programming to offer at these earlier stages; those that did, were typically in larger urban centres. The uneven pattern of available services suggests that the concerns of earlier scholars (e.g., Cloutier-Fisher & Joseph, 2000, 2003; Skinner, 2008) about the long-term implications of depending on local-level voluntary organizations, without consideration of their differing capacities, may already be taking effect, forming or reinforcing disparities across space with particular implications for rural and small town settings.
Consistent with previous studies of rural services use, the ACs noted that rural service users typically used fewer services (Forbes et al 2006); however, rural service users often placed greater demands on ACs in terms of one-on-one support. The ACs indicated that home visits are essential to overcoming stigma, transportation issues, competing demands with farm and other labour, and “intimidating” education material in rural communities. Some of these issues may be similar from the perspective of urban ACs; however, the costs in time and human resources tend to be greater in rural areas. ACs suggested that these demands were also related to individuals’ desires to maintain their sense of independence and privacy in their rural community. Service providers’ evaluations of barriers to rural service use were largely consistent with those living with dementia.

**R2: What services do people living with dementia in rural places need and use?**

In the last 30 years, qualitative dementia research has focused primarily on the perspectives of formal and informal care partners to inform policy and practices regarding service use and needs. Over the last decade there has been a significant shift in thinking and practice concerning the voices of persons with dementia themselves (Murphy et al., 2014). Understanding the embodied and emotional lives of persons with dementia is essential in developing programs and policies that are meaningful while also recognizing fully the personhood and citizenship of persons with dementia (Cahill et al., 2012). Still, limited research on rural dementia care has included the voices of persons with dementia (Blackstock et al., 2006; Dal Bello-Haas et al., 2014b; Forbes et al., 2012). Research that has done so, has been relatively small in scale. The scope of this project, both the number of participants and its geographic extent, is a significant contribution to the research on rural dementia care in Canada and elsewhere.
The experiences and perceptions of persons with dementia corroborate earlier Canadian and international studies which indicate that those living in rural and small town settings face unique barriers to service use including socio-cultural barriers, being too busy or lacking time, transportation, and privacy (Forbes, 2006; Morgan et al. 2002). Over a decade later, these barriers persist. Notably, knowing where to go to access support did not appear to be a significant barrier, rather perceptions of particular types of support (e.g., support groups and day programs) contributed more to delayed service use. An important finding in this regard was the willingness and ability of some individuals to go outside of their communities to maintain their privacy and access a greater range of supports in urban centres. This finding calls into question the tendency to characterize rural populations as being universally vulnerable and more caring or willing to look after their own. It exposes diverse pathways to service use while raising questions about those less physically and financially mobile in the same case study area. To be sure, vulnerable groups and vulnerable circumstances are evident across the case studies. Consistent with the broader literature on rural women’s health, rural women faced additional barriers to accessing support, including responsibilities in the home and resistance from male partners in care toward accepting help (Leipert et al., 2012). Indeed, the gendered nuances of service use require more attention in rural and community settings as rural men typically identified community support services as being inappropriate for their needs and interests. Women, on the other hand, seemed more willing to go to support groups and day programs. Overall, persons with earlier stage dementia, however, regarded the supports available as being inadequate for their needs and/or geared towards later stages of the disease progression. They hoped that when they reached the later stages themselves, they would be able to stay in their homes and bring the support that they needed into the home.
One of the original contributions of the research was the use of retrospective interviews with former partners in care to reflect on transitions and trajectories throughout the course of the illness. Former partners in care confirmed the enduring challenges of system navigation from getting a diagnosis to accessing adequate home and community care (Dal Bello-Haas et al. 2014a). Although early stage support was limited, partners in care typically accessed AC services earlier in the disease progression for education and information and they made use of these services for a longer period of time than any other support service. For over two thirds of partners in care, the ACs played a crucial role as a system navigator by explaining service options, discussing eligibility, and identifying when specific services might be appropriate as well as who to contact. The interviews with former partners in care identified much less resistance to accessing support than those with persons with dementia. In fact, partners expressed a demand for socio-emotional support, at least retrospectively. Their reflections identify a range of relational and emotional barriers to accessing services, specifically in-home and residential respite, in the later stages of the illness. The reflections of partners in care illustrate the complex dynamics and consequences of delayed service use as well as the lack of home care available to keep persons with dementia at home. In the latter stages of the illness, almost all partners in care accessed publically funded home care; however, many suggested that there were not enough home care hours, scheduling was inflexible and inconsistent, and formal care providers were constantly changing. Moreover, partners in care face inter-personal and structural constraints, caring for persons with dementia at home.

As partners in care described their experiences of caring in the later stages of the illness, they identified challenges responding to behavioural changes, particularly aggressive behaviours. Aggression is a common symptom and response to personal, social, and environmental
challenges experienced by persons with dementia. Although previous research has emphasized the importance of acknowledging the meaning of these expressions (Dupuis et al., 2012) and the challenges of responding to them in long-term care settings (Chappell et al., 2014), little attention has been given to the insights, ethics, and management of aggression at home and the support required to transition to alternative settings of care. The emergent findings of the thesis reveal the variable capacity of some partners in care to manage such behavior at home, as well as their vulnerability and lack of choice. These stories elucidate the role of fear in decision making about long-term care placement as well as the linkages between negative experiences of service provision in different settings and times. The lack of desirable alternatives to long-term care, the lack of home care hours, and the lack of meaningful respite activities effectively constrain partners’ time, space, and bodies. Arguably, this amounts to a form of structural violence, as described by Banerjee and colleagues (2012), preventing care partners from meeting their basic needs and realizing their potential.

**R3: How do persons living with dementia experience care services and sites of care in rural places?**

Stories of dementia are not always, and do not have to be characterized as violent, constraining, and isolating. In writing this thesis, I have attempted to share the humour, lightness, and hopefulness in the stories of persons with dementia and their partners in care. A significant finding in this regard was the insistence of persons with dementia that they contribute to the care of their communities, families, and broader environments. They enact and are embedded within particular understandings of community, personhood, and citizenship and linked to rural life ways. Independence and work are at the centre of these understandings for the majority of persons with dementia in the study. The importance of work on the land contributes to the
literature on therapeutic landscapes with further evidence of the subjective value of walking and working outdoors for persons with dementia (Milligan, 2004; Williams, 2010). Such everyday sites and movements of therapeutic value have implications for the development of more inclusive community care as well as health care sites and services. Outdoor work and exercise have long been seen as a useful tool in managing persons with mental health problems (Foucault, 2006). More recently, such places and activities have been recast with the potential of empowering persons with complex mental health issues (Wood et al., 2013; Parr, 2008). In this case, working provides persons with dementia with a sense of connection and contribution to people and place, but it may also entrench them in places of isolation and ableism.

The limited experiences of persons with dementia with formal care sites and services illustrates the implications of a rural culture of resilience and silence (Parr, 2008). In retrospective accounts, this culture is less apparent; instead, former partners in care identified significant delays in service use. Nonetheless, the stories of persons with dementia and the partners in care both confirm the need for more caring social spaces and not just more services. They identify the challenges of navigating social space in rural and small town settings from the grocery store to the side walk. While examples of resistance to stigma and isolation exist across the cases studies, social isolation remains a significant issue for persons with dementia and their partners in care.

**R4: How can the lives of rural people with dementia and their partners in care be improved by taking into account their experiences over the course of dementia and at different sites of care?**

Taken together, these findings may help various levels of government, policy makers, communities, and NPOs by providing examples of the limitations of current structures of care as
well as opportunities for development across the continuum of care. For NPOs, the findings illustrate several strategies for connecting with potential service users early (e.g., First link programs, home visits, and telephone consultations). Early contact, however, places increasing demands on service providers to offer a greater range of services for a longer period of time. Sustainable financial resources are essential to making early engagement possible across and within community settings. If meaningful support services are not there, low service use and service delays may be further exacerbated. With the knowledge from this thesis, various levels of government and community organizations might work together to fill the gap in service provision for and with persons with early stage dementia. Rather than being guided by an assumption that persons with dementia are necessarily in need of services, communities must acknowledge and facilitate the contributions of persons with dementia. Admittedly, communities and individuals have different capacities to engage with and develop comprehensive and inclusive programs, as the findings from all phases illustrate. However, the narratives of persons with dementia shine new light on a range of possibilities for their inclusion. They also point to the continued need for public education and awareness to facilitate more inclusive community spaces.

The findings contribute to program and policy issues around aging in place more broadly. They expose a fundamental contradiction between support in principle and support in practice for aging in place. Indeed, partners in care are expected to provide the bulk of support without enough support for themselves. The idea of partnership should be taken more seriously in policy and programming, so that, for instance, respite might be geared toward both partners in care and persons with dementia across a range of settings and scales. While partners in care and the persons for whom they care want to stay at home, the fit and frequency of support is not enough
for most people live out this goal. Furthermore, partners’ “horrible experiences” of long-term care call attention to the need for alternative spaces and models of end of life care for persons with dementia and their partners.

7.2 Limitations

The insights of service providers, persons with dementia, and their partners in care provide a rich resource for examining the provision, experiences, and contexts of caring for dementia in rural and small town settings. In Chapter three, I outlined several limitations of the research to which I now return. First, I note that the views of support service providers other than the ACs that may play a role in providing support for persons with dementia and partners in care were not included in the survey results. Initially, the CCACs were included in the study design. However, only four CCACs completed the survey. Although there were few questionnaires returned from the CCACs, the responses confirmed the predominant role of the ACs in providing support specifically targeted toward dementia and from diagnosis to death. As previously stated, the scope and specificity of the ACs, as well as the increasing expectation that they will be able to offer the bulk of support is what drew my attention to this organization. In addition, the ACs played an important role in verifying research priorities, testing the appropriateness and usefulness of the study design and instruments, recruiting participants, and interpreting some preliminary results.

Although some would argue that recruitment of participants for the second phase of the study through ACs might create some bias, particularly in the former partner in care interviews, as they were recruited almost exclusively through the ACs, participants were both grateful and critical of support received from the ACs. Another limitation with regards to recruitment is that I was unable to find former partners in care to participate in the KFLA case study. No former
partners in care responded to notices or emails through the AC. The majority of persons with dementia in the KFLA case study were recruited through a memory clinic. Overall, snowball sampling and additional recruitment through memory clinics produced a more diverse sample of persons with dementia in the study and a more comprehensive story of service delays.

One of the limitations of interviews with former partners in care was the variation in their recall of the timing of events. For example, some partners had difficulty answering questions about how long they, or the person with dementia, used particular services. A number of other partners, however, consulted detailed diaries suggesting another rich source of data from which to examine transitions and trajectories of care. Nonetheless, studies have shown that such retrospective accounts have a high degree of consistency and credibility (Morse, 2011). Particularly for individuals who have dealt with bereavement, I suggest that these reflections and evaluations are certainly meaningful. Retrospective interviews allow partners in care to reflect critically on their experiences without fearing that any negative comments might influence their access to, or quality of, service provision. They contribute to a deeper and richer understanding of the geographies of dementia care. They reveal the enduring emotion and temporality of caring for and about dementia within home and family settings as well as through voluntarism and advocacy.

The majority of the interviews with persons with dementia took place with a partner in care present. While the partner in care was presumably there to support the person with dementia, the person with dementia may have been reluctant to say things that might hurt the care partners’ feelings. On the other hand, partners in care played a role in eliciting responses to questions, sometimes providing additional prompts and encouraging the person with dementia. In spite of the inter-personal and ethical challenges associated with this dynamic (see Chapter 3),
the information collected was far more comprehensive in the interviews with partners in care present than those without a partner in care.

It is important to note that there are perspectives excluded and underrepresented in this study. Although the findings of the research point to the importance of gender in caregiving and service use, the findings reported herein are not based on a representative sample. The sample, however, is indicative of gendered trends in service use and caregiving. Additionally, the needs and experiences of Aboriginal People living on reserves in the case study areas are not included in this study, despite the fact that the Aboriginal population living on reserves in Ontario is predominantly a rural population. These perspectives should be addressed, but I suggest that the unique history and specific policy context of Aboriginal health and health care requires a separate analysis and a lengthier amount of time to engage in a completely participatory research design (see Sandoval et al. 2012).

7.3 Future research directions

Looking forward, attention to the routines and affinities of persons with dementia and their partners in rural communities might guide future studies on the development of age-friendly and dementia-friendly communities. In addition, the role of the ACs and other community groups in shaping these initiatives requires further exploration. As indicated in Chapter five, individuals can draw on the resources and their experiences with the ACs to develop groups and spaces of their own. The structural and individual level factors influencing these developments in rural communities require greater attention. In examining the diversity of rural and small town experiences, this thesis makes evident degrees of vulnerability. Further research is required to examine what and how dementia-friendly initiatives might enhance the lives of the most vulnerable people in rural and small town settings.
Looking at vulnerability, more work needs to be done to explore the role of gender in rural community contexts and in community service provision specifically. Studies suggest that older men are more likely to experience social isolation and loneliness, have greater difficulty in accessing effective social support and making new friends, and are often resistant to participating in voluntary and community support activities, which tend to be dominated by, and geared towards, older women (Milligan, 2015). Future research needs to explore more explicitly what community spaces and places men identify as supportive or unsupportive.

Looking at community spaces, hospices present a model and a setting of care that is relatively under-researched in the rural dementia literature (Davies et al., 2014). Given the strong aversion toward long-term care and the relatively small time frame persons with dementia spend in such settings, more work needs to be done to explore the suitability of such places for end of life care for persons with dementia as well as the suitability of the hospice model for transforming long-term care.

Across care settings, aggression can present risks to the safety of persons with dementia and partners in care and it often precipitates long-term care placement and “bad experiences” therein. The lack of education and research on behavioural (aggression) issues at home is a significant issue because of the fact that many persons with dementia want, and are encouraged, to stay at home for as long as possible. Future research should examine the support services available to persons with dementia experiencing aggression and strategies for partners in care in different environments (e.g., home, community, and long-term care) with the aim of reducing the threat of aggression and improving care for all persons with dementia.
7.4 Concluding comments

I started this thesis with a story about Ron, a person with dementia who did not want to go back to the day program he had been attending. His wife, who told the story, missed her time alone. Although this narrative propelled the thesis, and it has certainly been revisited through the stories of others, I am hopeful that there are alternative stories that might become more common. Social isolation and constraining care do not have to be a part of experiences of dementia in rural and small town settings, or elsewhere. Improving dementia care involves making visible and taking seriously the desires of persons with dementia and their partners in care. It involves creating different versions of community care that are not centred solely on the home, but make it possible to live more connected lives in a range of community settings over the course of the illness.
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(http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf)


Appendix A

Queen’s University Research Ethics Board, letter of approval

November 19, 2012

Ms. Rachel Herron
Ph.D. Candidate
Department of Geography
Queen’s University
Kingston, ON K7L 3N6

GREB Ref #: GCEO-144-12; Romeo # 6607463
Title: "GCEO-144-12 Caring Places for Alzheimer's Disease and Related Dementias: Examining the Continuum of Care in Rural Ontario"

Dear Ms. Herron:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GCEO-144-12 Caring Places for Alzheimer's Disease and Related Dementias: Examining the Continuum of Care in Rural Ontario" for ethical compliance with the Tri-Council Guidelines (TCPS) and Queen’s ethics policies. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REE, of any adverse event(s) that occur during this one year period (access this form at https://services.queensu.ca/romeo_researcher/ and click Events - GREB Adverse Event Report). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To make an amendment, access the application at https://services.queensu.ca/romeo_researcher/ and click Events - GREB Amendment to Approved Study Form. These changes will automatically be sent to the Ethics Coordinator, Gail Irving, at the Office of Research Services or Irvingg@queensu.ca for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

[Signature]

Jean Stevenson, Ph.D.
Professor and Chair
Appendix B

Letter of information for service provider survey

Caring Places for Alzheimer’s Disease and Related Dementias

Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(613) 533-6000 (ext. 75279) e-mail: 4rh11@queensu.ca

Dear Participant

I am writing to request your participation in the *Caring Places for Alzheimer's Disease and Related Dementia's* project, based out of the Department of Geography at Queen’s University and funded by the Canadian Institute of Health Research.

The importance of the project is that it examines the range of available services for persons living with Alzheimer’s disease and dementia, and their caregivers, in rural communities across the province of Ontario. The first phase of the project focuses on service organization and provision across the province of Ontario. The primary source of information for this phase of the research is a survey of representatives from Alzheimer Society Chapters and Community Care Access Centres.

You are receiving this letter of information because you indicated an interest in participating in the survey. Your participation is completely voluntary and involves filling out the attached questionnaire, which should take no more than 30 minutes to complete. You can refuse to answer any question and you may withdraw from the study at any time. Your name and identifying information will be kept confidential and information from the questionnaire will be kept in a secure location at Queen’s University and will be destroyed following completion of the project. The project has been approved by the Queen’s University General Research Ethics Board.

Information from the survey will be used to understand better the availability and use of services for persons with dementia and their caregivers in rural areas across the province. A general summary of the findings will be made available to you in the form of a participant report, and results will be presented at conferences and published in scientific journals.

If you have any questions, please telephone or e-mail me at the contact information provided at the top of the page. Attached are two copies of an Informed Consent Form, one for you to complete and return with the survey and another for your own records. If you want to speak to a representative of the Queen’s University General Research Ethics Board, please contact Professor Joan Stevenson, chair, at chair.GREB@queensu.ca, or 613-533-6081.

Thank you, sincerely, for your consideration.

Rachel Herron
PhD Candidate
Appendix C
Survey consent form

The Caring Places for Alzheimer’s Disease and Related Dementias project examines the range of available services for persons living with Alzheimer’s disease and dementia, and their caregivers, in rural communities across the province of Ontario. The first phase of the project focuses on service organization and provision across the province of Ontario. The primary source of information for this phase of the research is a survey of service coordinators from Alzheimer Society Chapters and Community Care Access Centres. The project is funded by the Canadian Institute of Health Research and it has been approved by the Queen’s University General Research Ethics Board.

I, ____________________________ (please insert your name) have read the attached Letter of Information and have had all questions answered to my satisfaction, and I agree to participate in an interview under the following conditions:

1) I understand that my involvement in the project consists of answering a 4-part questionnaire.

2) I understand that the purpose of the project is to examine the range of available services for persons living with Alzheimer’s disease and related dementias, and their caregivers, in rural communities across the province of Ontario.

3) I understand that my participation is voluntary and I can refuse to answer any question.

4) I understand that I can terminate my participation at any time and any information provided by me to the research project will be destroyed.

5) I understand that my name and identifying information will not be used in any presentation or publication of the research.

6) I understand that all information from the survey will be kept in a secure location restricted to Rachel Herron, and destroyed after seven years.

7) I understand that I can contact Rachel Herron, (613 533-6000 ext. 75279, or 4rh11@queensu.ca) or Dr. Mark Rosenberg, thesis supervisor, (613 533-6046, or mark.rosenberg@queensu.ca) with general questions about the project and Dr. Joan Stevenson, chair of the General Research Ethics Board (chair.GREB@queensu.ca or 613-533-6081) with any concerns about research ethics.

Name: ____________________________
Signature: ____________________________
Date: ____________________________
Appendix D
Questionnaire for service providers

Caring Places for Alzheimer’s Disease and Related Dementias

Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(613) 533-6000 (ext. 75279) e-mail: 4rh11@queensu.ca

Thank you for agreeing to participate in Caring Places for Alzheimer’s Disease and Related Dementias project. Your participation will involve completing a questionnaire, which will take approximately 30 minutes. Your answers will be kept strictly confidential. While participation in this survey is voluntary, your cooperation is important to ensure that the information collected is as accurate and as comprehensive as possible. The questionnaire is divided into a number of sections. Please answer all questions as best you can. If collaborating with other members of your organization to complete the questionnaire is desirable, please do so. Create as much space as you require to answer each question.

Section 1: Contextual Information

1) What organization do you work for?
   a) Alzheimer’s Society
   b) CCAC
   c) Other, please specify __________________

2) What is your position in the organization (if you need to collaborate with other individuals in your organization to fill this survey, list all participants’ positions)?

3) How many staff work for your CCAC/chapter?

4) How many volunteers work with your CCAC/chapter?

5) On a yearly basis, approximately how many clients do you serve?

6) What region are you responsible for servicing?

7) Please briefly describe the region in which you co-ordinate/provide services (i.e. size, location, population etc.). What is distinctive about this region?

8) Approximately what percentage of your clientele lives in a rural community?

   Less than 5%
Greater than or equal to 5% but less than 30%
Greater than or equal to 30% but less than 50%
Greater than or equal to 50% but less than 75%
Greater than or equal to 75% but less than 100%
Section 2: Services Provision and Use:

9) Identify the services that you provide or co-ordinate that may be used by persons with Alzheimer’s Disease and Related Dementias (ADRD) in your region using the table below. Please fill out all fields as accurately as possible and indicate when services are not applicable to your organization.

<table>
<thead>
<tr>
<th>Service offered</th>
<th>Where service occurs</th>
<th>Eligibility criteria</th>
<th>Per cent costs to client</th>
<th>Per cent of costs paid by organization</th>
<th>Per cent costs paid by LHIN</th>
<th>Per cent of all ADRD clients who use this service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal support worker</td>
<td>Home</td>
<td>Other, please specify</td>
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<td>Nursing</td>
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<td>Occupational therapy</td>
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<td>Physical therapy</td>
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<td>Alzheimer’s education and information</td>
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<td>Service Type</td>
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<td>Friendly visiting</td>
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<td>Meals on wheels</td>
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<td>Home maintenance</td>
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<td>Safely home program</td>
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<td>Transportation services</td>
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<tr>
<td>Other services, Please specify</td>
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</tbody>
</table>
10) What challenges do you face in providing the available services to people with ADRD across your region?

Section 3: Rural Communities and Clients

11) Please describe any additional challenges your organization faces in providing services to people with ADRD who live in rural areas or small towns across your region?

12) Comparing your urban and rural clients are there any different patterns of use which you can describe. For example, do urban clients use some services and rural clients use others or do urban clients use services more often and on a regular basis while rural clients use fewer services and use them on a less regular basis.

Concluding Questions

13) Are there any other comments you would like to share about providing services for persons with ADRD?

14) Can you suggest any other organizations that might provide important information about services for persons with ADRD?

15) Would you like to receive a final summary of the results of this research project and, if so, to what address (e-mail or post) would you like the summary to be sent?

Thank you for your time and consideration. Please return the completed questionnaire and informed consent form to Rachel Herron by e-mail at 4rh11@queensu.ca.
Appendix E

Letter of information for persons with dementia

Caring Places for Alzheimer’s Disease and Related Dementias

Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(613) 533-6000 (ext. 75279) e-mail: 4rh11@queensu.ca

Dear Participant:

I am writing to request your participation in the Caring Places for Alzheimer’s Disease and Related Dementias project, based out of the Department of Geography at Queen’s University and funded by the Canadian Institute of Health Research. The importance of the project is that it seeks to understand how people living with Alzheimer’s disease and dementia experience care and draw on specific services and support systems in rural communities. The project focuses on the experiences of individuals living with and caring for persons with dementia, like you, and the primary source of information for this phase of the research is interviews with persons who self-identify as having early dementia.

You are receiving this letter of information because you indicated an interest in participating in an interview. If you are willing to participate, your participation will be voluntary and would involve three short interviews, approximately a half hour in length, conducted by the researcher, Rachel Herron, at the time and location most convenient to you. During the interviews, you can refuse any question that makes you uncomfortable and you may end your participation at any time. With your written consent, the interviews will be recorded. Your name and identifying information will be kept confidential and information from the interviews will be kept in a secure location at Queen’s University and will be destroyed following completion of the project. The project has been approved by the Queen’s University General Research Ethics Board.

Information from interviews with you and other persons living with early dementia will be used to better understand the challenges and needs associated with living with dementia and finding suitable care in rural communities. A summary of the findings will be made available to you in the form of a participant report, and results will be presented at conferences and published in scientific journals.

If you are willing to participate or if you have any questions, please telephone or e-mail me at the contact information provided at the top of the page. Attached are two copies of an Informed Consent Form, one for you to complete and return at the beginning of the first interview and another for your own records. If you want to speak to a representative of the Queen’s University General Research Ethics Board, please contact Joan Stevenson, chair, at chair.GREB@queensu.ca, or 613-533-6081.

Thank you, sincerely, for your consideration.

Rachel Herron
PhD Student
Appendix F
 Consent form for persons with dementia

Caring Places for Alzheimer’s Disease and Related Dementias
Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(613) 533-6000 (ext. 75279) e-mail: 4rh11@queensu.ca

The Caring Places for Alzheimer’s Disease and Related Dementias’s project examines how people living with Alzheimer’s Disease and Related Dementias, including family and support networks, experience and use care in different settings, over the course of the illness. The source of information for this phase of the research is semi-structured interviews with persons who self-identify as having early dementia and persons who identify as caring or having formerly cared for someone with dementia. The project is funded by the Canadian Institute of Health Research and it has been approved by the Queen’s University General Research Ethics Board.

I, ____________________ (please insert your name) have read the attached Letter of Information and have had all questions answered to my satisfaction, and I agree to participate in an interview under the following conditions:

1) I understand that my involvement in the project consists of a 1-2 hour interview.
2) I understand that the purpose of the project is to examine the range of services, needs and challenges associated with living with and caring for dementia in rural communities.
3) I understand that my participation is voluntary and I can refuse any question at any time.
4) I understand that I can end my participation in the interview at any time and any information provided by me to the research project will be destroyed.
5) I understand that my name and identifying information including any contextual information or commentary likely to identify me will not be used in any presentation or publication of the research; however, I understand that, given the small size of the community, there is the possibility that other community members may know about my participation in the project.
6) I understand that all information from the interview will be kept in a secure location restricted to Rachel Herron and a research assistant, and destroyed after five years.
7) I understand that I can contact Rachel Herron, (613 533-6000 ext. 75279, or 4rh11@queensu.ca) or Dr. Mark Rosenberg, thesis supervisor, (613 533-6046, or mark.rosenberg@queensu.ca) with general questions about the project and Dr. Joan Stevenson, chair of the General Research Ethics Board (chair.GREB@queensu.ca or 613-533-6081) with any concerns about research ethics.
8) I understand that, whether I agree to participate in the study, or not, will have no effect on the care I receive at the memory clinic or from my doctors.

I agree that:

8) This interview may be digitally recorded. Yes _____ No _____
9) My responses in this interview may be used in the presentation and publication of results with the use of a pseudonym (false name) and without attribution to me personally. Yes _____ No _____

Name: ____________________________________________
Signature: _________________________________________
Date: ____________________________
Appendix G

Interview guide for persons with dementia

Caring Places for Alzheimer’s Disease and Related Dementias

Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(613) 533-6000 (ext. 75279) e-mail: 4rh11@queensu.ca

Thank you for agreeing to participate in the Caring Places for Alzheimer’s Disease and Related Dementias Project. I want to begin by asking a few questions about you and the community in which you now live. Please remember that you do not have to answer any questions that make you uncomfortable. The interview will begin only after you have had the chance to read and sign the informed consent form and any questions or concerns about the research project have been addressed.

Part A: Demographic information

1) What is your age?

2) When did you first start having memory problems?

3) When did your doctor confirm your diagnosis?

4) What is your marital status?
   Married               Common Law               Widowed               Separated
   Divorced              Single                  Never Married

5) What is your highest level of education?
   Less than secondary school
   Secondary school graduation
   Post-secondary education
   Graduate or post-graduate

6) What are your living arrangements?
   Lives alone            Lives with partner       Lives with spouse
   Lives with children    Lives with sibling        Other

7) How long have you lived in your home? How long have you lived in this community?

Part B: Background information and community context

8) What is it like living in this community?
9) How has your experience living in this community changed since your diagnosis?

10) What kind of support do you currently benefit from living in this community (ex. Church, neighbours, formal health services)?

11) Is there anything that would make living in this community better for you?

Part B: Service use
We have finished the first part of the interview. Would you like to continue? I have a series of questions about the services available in this community. I want to know if you have used any services.

12) Please identify the health and community services that you are currently using.

<table>
<thead>
<tr>
<th>Services</th>
<th>Where service occurs</th>
<th>How often</th>
<th>How many hours</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Home</td>
<td>Other, please specify</td>
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<tr>
<td>Personal support worker</td>
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<tr>
<td>Nursing</td>
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<td></td>
<td></td>
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<tr>
<td>Occupational therapy</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Physical therapy</td>
<td></td>
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<tr>
<td>Alzheimer’s education and information</td>
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<td>Support groups</td>
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<td>Recreation and leisure therapy</td>
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<tr>
<td>Friendly visiting</td>
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</tr>
<tr>
<td>Meals on wheels</td>
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<tr>
<td>Home maintenance</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Safely home program</td>
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<tr>
<td>Transportation services</td>
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<td></td>
</tr>
<tr>
<td>Other services, Please specify</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Part B: Service Use
13) How did you find out about these services?

14) Has any organization or group been helpful to you since your diagnosis?
   a) What do they help you with?
   b) Where do you get this help (home, community setting, hospital etc.)?

15) Are there any other individuals that have been helpful to you?
   a) How have they helped you?

Part C: Care needs and challenges
We have finished the second part of the interview. Would you like to continue?

16) We all need different kinds of care from health professionals, family and friends, what would you say are your most important care needs?

17) How have your needs changed since your diagnosis?

18) How would you like your needs to be met in the future (i.e., where and with/by whom)?

19) Some people find that it is difficult to find the services and support that they require from their family and community, what challenges do you face meeting your needs in this community?

20) How do you deal with any challenges?

21) Do you have anything else that you would like to add that you feel is important to understand experiences of living with Alzheimer’s disease and dementia in this community?

22) Would you like to review a typed copy of our conversation today to confirm, add or edit any of your comments? This copy will not be viewed by anyone except for me and a research assistant and your name will not be associated with any of your comments.

23) Is there anybody else that you think I should talk to about living with Alzheimer’s disease and dementia in this community?

24) Do you have any questions for me?

Thank you for your time and consideration.
Appendix H

Letter of information for former care partners

Caring Places for Alzheimer’s Disease and Related Dementias

Department of Geography, Queen’s University,
Mackintosh-Corry Hall, Kingston, Ontario K7L 3N6,
(705) 987-9857, e-mail: 4rh11@queensu.ca

Dear Participant:

I am writing to request your participation in the Caring Places for Alzheimer’s Disease and Related Dementia’s project, based out of the Department of Geography at Queen’s University and funded by the Canadian Institute of Health Research. The project looks at how people living with Alzheimer’s disease and dementia experience care and what services and support systems they use in rural communities. The primary source of information for this phase of the research is interviews with former caregivers (persons who have cared for someone with a diagnosis of Alzheimer’s or dementia, who is now deceased).

Your participation will involve an interview which will last less than two hours conducted by me, Rachel Herron, at the time and location most convenient for you. During the interview, you can refuse to answer any question. You may end your participation in the interview at any time without any consequences and your responses to that point will not be used. With your written consent, the interview will be recorded. Your name and identifying information will be kept confidential and information from the interview will be kept in a secure location at Queen’s University and will be destroyed following completion of the project. The project has been approved by the Queen’s University General Research Ethics Board.

Responses from the interview with you and other former caregivers will be used to develop a better understanding of the challenges and needs associated with living with and caring for someone with dementia in rural communities. A summary of the findings will be made available to you in the form of a participant report, and results will be presented at conferences and published in scientific journals.

If you are willing to participate or if you have any questions, please telephone or e-mail me at the contact information provided at the top of the page. Attached are two copies of an Informed Consent Form, one for you to complete and return at the beginning of the interview and another for your own records. If you want to speak to a representative of the Queen’s University General Research Ethics Board, please contact Professor Joan Stevenson, chair, at chair.GREB@queensu.ca, or 613-533-6081. I understand that your experiences of caregiving may be very personal and sensitive in nature. I appreciate your trust in sharing them with me. Should you feel the need to talk more about your experiences after the project, I can direct you to counseling resources in your community.

Thank you, sincerely, for your consideration.

Rachel Herron PhD Candidate
Appendix I

Consent form for former care partners

The Caring Places for Alzheimer’s Disease and Related Dementias project examines how people living with Alzheimer’s Disease and Related Dementias, including family and support networks, experience and find care in rural communities, over the course of the illness. The source of information for this phase of the research is semi-structured interviews with persons who self-identify as having early dementia and persons who identify as having formerly cared for someone with dementia. The project is funded by the Canadian Institute of Health Research and it has been approved by the Queen’s University General Research Ethics Board.

I, ____________________________ (please insert your name) have read the attached Letter of Information and have had all questions answered to my satisfaction, and I agree to participate in an interview under the following conditions:

1) I understand that my involvement in the project consists of a 1-2 hour interview.
2) I understand that the purpose of the project is to examine the range of services, needs and challenges associated with living with and caring for dementia in rural communities.
3) I understand that my participation is voluntary and I can refuse any question at any time.
4) I understand that I can end my participation in the interview at any time and any information provided by me to the research project will be destroyed.
5) I understand that my name and identifying information including any contextual information or commentary likely to identify me will not be used in any presentation or publication of the research; however, I understand that, given the small size of the community, there is the possibility that other community members may know about my participation in the project.
6) I understand that all information from the interview will be kept in a secure location restricted to Rachel Herron and destroyed after seven years.
7) I understand that I can contact Rachel Herron, (613 533-6000 ext. 75279, or 4rh11@queensu.ca) or Dr. Mark Rosenberg, thesis supervisor, (613 533-6046, or mark.rosenberg@queensu.ca) with general questions about the project and Dr. Joan Stevenson, chair of the General Research Ethics Board (chair.GREB@queensu.ca or 613-533-6081) with any concerns about research ethics.

I agree that:

8) This interview may be digitally recorded. Yes _____ No _____
9) My responses in this interview may be used in the presentation and publication of results with the use of a pseudonym (false name) and without attribution to me personally. Yes _____ No _____

Name: ____________________________
Signature: ____________________________
Date: ______________________________
Appendix J

Interview guide for former care partners

Caring Places for Alzheimer’s Disease and Related Dementias

Thank you for agreeing to participate in the Caring Places for Alzheimer’s Disease and Related Dementias Project. I want to begin by asking a few questions about you and the nature and duration of your caregiving role. Please remember that you do not have to answer any questions that make you feel uncomfortable. You can stop the interview at any time. The interview will begin only after you have had the chance to read and sign the informed consent form and any questions or concerns about the research project have been addressed.

Part A: Demographic information

1) What is your age?
   - 49 years or less
   - 50 to 54 years
   - 55 to 59 years
   - 60 to 64 years
   - 65 to 69 years
   - 70 to 74 years
   - 75 to 79 years
   - 80 years or more

2) What is your marital status?
   - Married
   - Common Law
   - Widowed
   - Separated
   - Divorced
   - Single
   - Never Married

3) What is your highest level of education?
   - Less than secondary school
   - Secondary school graduation
   - Post-secondary education
   - Graduate or post-graduate

4) What is/was your occupation?

Part B: Care Relationships

5) What was your relationship to the person for whom you provided care?

6) Did you live with the person for whom you cared?
   a) If so, how long did you live with them?
b) If not, how far did you travel to care for them?

7) How long did you care for them?

8) Who else helped you to care for them?

9) What did they do to help you?

Part B: Service Use

10) Please fill out this table to identify what health and social services you, yourself, and your loved one used over the course the illness experience.

<table>
<thead>
<tr>
<th>Services</th>
<th>Where service occurs</th>
<th>Stage of illness (year)</th>
<th>How many times per week</th>
<th>Cost</th>
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<td>Personal support worker</td>
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<td>Physical therapy</td>
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<td>Recreation and leisure therapy</td>
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<td>Friendly visiting</td>
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<td>Meals on wheels</td>
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<td>Safely home program</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Part C: Care Time and Place:**

11) Please describe the settings in which you provided care.

12) What was it like for you providing care in these settings?

13) What do you think it was like for (person with ADRD)?

**Part D: Changes and Coping Strategies:**

14) Some people talk about the challenges of being a caregiver. What challenges did you face in making decisions about care for (person with ADRD)?

15) What were the major changes that occurred over the course of your time caring for (person with ADRD)?

16) How did you cope with these changes?

17) How did you and the person with ADRD decide what support was necessary?

18) Some people find that the services they receive are not helpful or they are difficult to access. Did you find the services helpful? Why or why not?

19) Did you or the person for whom you provided care have any unmet needs during the illness?

20) Do you have anything else that you would like to add that you feel is important to understand experiences of living with ADRD in this community?
21) Would you like to review a typed copy of our conversation today to confirm, add or edit any of your comments? This copy will not be viewed by anyone except for me and your name will not be associated with this record.

22) Is there anybody else that you think I should talk to about living with Alzheimer’s disease or dementia in this community?

23) Do you have any questions for me?

Thank you for your time and consideration.
Appendix K

Telephone script for recruitment in Sault Ste Marie Algoma

Hello (Client name)

I am calling you to let you know about a research project based out of Queen’s University and funded by the Canadian Institute of Health Research. We have been approached to help identify potential participants for the project. Whether you agree to participate in this study, or not, will have no effect on the support that you receive from the Alzheimer Society.

The project is important because it seeks to understand how people living with Alzheimer’s disease or related dementias experience care and draw on specific services and support systems in rural communities. It focuses on the experiences of individuals living with and caring for persons with dementia, like you. The primary source of information for the research is interviews with persons who self-identify as having early dementia or having formerly cared for someone with dementia.

If you are interested in participating in a one hour interview at a time and place convenient to you, you can contact researcher Rachel Herron at (local phone number). If it would be easier to have the researcher contact you, we will pass along your contact information, with your consent.
### Appendix L

**Characteristics of persons with dementia**

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<th>Age</th>
<th>Gender</th>
<th>Care partner</th>
<th>Yrs. Since diagnosis</th>
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</thead>
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## Appendix M

**Characteristics of partners in care**

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<th>Gender</th>
<th>Care Partner</th>
<th>Yrs. Since death</th>
<th>Duration of care</th>
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<tbody>
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<td>69</td>
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<td>&lt;1 yr.</td>
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<td>6</td>
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<tr>
<td>82</td>
<td>M</td>
<td>Spouse</td>
<td>1 yr.</td>
<td>4</td>
</tr>
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<td>F</td>
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</tr>
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<td>M</td>
<td>Spouse</td>
<td>1 yr.</td>
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</tr>
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<td>82</td>
<td>M</td>
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</tr>
<tr>
<td>88</td>
<td>F</td>
<td>Spouse</td>
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</tr>
<tr>
<td>65</td>
<td>F</td>
<td>Spouse</td>
<td>1 yr.</td>
<td>4</td>
</tr>
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</tr>
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<td>86</td>
<td>F</td>
<td>Spouse</td>
<td>&lt; 1yr.</td>
<td>2</td>
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<tr>
<td>72</td>
<td>F</td>
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<td>79</td>
<td>F</td>
<td>Spouse</td>
<td>&lt;1yr.</td>
<td>9</td>
</tr>
<tr>
<td>83</td>
<td>F</td>
<td>Spouse</td>
<td>&lt;1 yr.</td>
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</tr>
<tr>
<td>63</td>
<td>F</td>
<td>Daughter</td>
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<td></td>
</tr>
<tr>
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<tr>
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<td>7</td>
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<tr>
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<tr>
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<tr>
<td>50</td>
<td>F</td>
<td>Daughter</td>
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</tr>
<tr>
<td>89</td>
<td>M</td>
<td>Spouse</td>
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<td>8</td>
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