



# “Not there yet”: Examining community support from the perspective of people with dementia and their partners in care



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## ABSTRACT

People with dementia can live meaningful and engaged lives with the appropriate social and physical supports in place. There has been relatively little research, however, on the experiences and desires of people with dementia *themselves* as they negotiate informal and formal support in rural and small town settings. In this article, we draw on semi-structured interviews with 46 community-dwelling people with dementia and 43 partners in care in rural Ontario, Canada to examine how people with dementia relate to and within their communities as well as their perceptions of community support services. We identify the continued contributions of people with dementia to their own care and the care of others as well as common social, cultural, and organizational factors related to delayed service use and refusal to use particular services. We argue that care is “not there yet” for people in the earlier stages of dementia and that more attention needs to be paid to what people with dementia can offer their communities as well as the role of culture and gender in developing support. Our findings make an important contribution to understanding the experience of dementia in rural and small town Canada, which is relevant to rural healthcare and community support in other industrialized countries.

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## 1. Introduction

World-wide, approximately 35 million people live with some form of dementia (Prince et al., 2013). Dementia refers to a range of complex progressive degenerative conditions—Alzheimer's disease, vascular dementia, and mixed dementia are the most common—that affect a person's cognition (i.e., memory, language, judgement, and attention). People with dementia experience different needs depending on the severity of their cognitive impairment, functional limitations, and neuropsychiatric symptoms such as depression and “reactive behaviours” (Alzheimer Society of B.C., 2011). For example, their needs may range from education and information, to meaningful activities, to support with bathing and other personal care tasks. Moreover, as the disease progresses people with dementia need a supportive social and physical environment; this includes formal services as well as a responsive network of family, friends, and community members.

There is an extensive body of research on formal service use and

unmet needs for both people with dementia and partners in care (i.e., family or friends who are supporting a person living with dementia). Studies have identified barriers to service use including stigma, lack of privacy, lack of information, costs associated with accessing services, problems navigating the system, and inappropriate supports (Boots et al., 2015; Innes et al., 2011). Black et al. (2013) report that 99 per cent of people with dementia in their Maryland-based study experienced at least one unmet need and 42 per cent experienced eight or more unmet needs. In the Canadian context, Forbes et al. (2006) found that people with dementia were more likely to report that their health needs were unmet than those without dementia 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. Although barriers to service use and unmet care needs have been identified in both urban (Tam-Tham et al., 2016) and rural contexts, people living in rural areas face additional challenges to accessing formal health services and they often express specific socio-cultural barriers to service use (Innes et al., 2005; Morgan et al., 2002).

As indicated in the broader literature on rural health service delivery, there are longstanding challenges to providing targeted

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health services to a small and geographically dispersed population with diverse health needs, particularly in large countries such as Canada (Joseph and Cloutier-Fisher, 2005; Kulig and Williams, 2012; Skinner and Rosenberg, 2006). For instance, lack of health professionals affects the availability of care in rural and remote regions. Consequently, people with dementia and their partners in care living in rural settings face added challenges getting a diagnosis, long wait times to see specialists, and a lack of community support services including respite, home care, day programs, long-term care, and early stage support (Dal Bello-Haas et al., 2014; Herron et al., 2016). In addition, service provision often works on the assumption that people living in rural places have close ties to family and friends that will fill gaps in services (Parr et al., 2004). Put simply, the range of supports required to meet different needs over the course of the condition are typically underdeveloped in rural communities (Forbes et al., 2012; Wiersma and Denton, 2013).

Failure to meet the needs of people with dementia can have many impacts including social exclusion, early placement in a long-term care facility, and caregiver burnout (Forbes et al., 2011; Lilly et al., 2012). However, the assessment of needs and the consequences of unmet needs are often evaluated from the perspective of partners in care or formal service providers (Dal Bello-Haas et al., 2014; Morgan et al., 2011). Increasingly, scholars have called for greater inclusion of the perspectives of people with dementia to address issues of vulnerability and stigma, recognize the personhood and citizenship of people with dementia, provide appropriate support, and understand dementia as a social experience (Murphy et al., 2015). To date, there are less than a handful of studies that focus on the perspectives of people with dementia and their experiences finding support in rural and small town settings (Blackstock et al., 2006; Clarke and Bailey, 2016; Forbes et al., 2011). In addition, few studies have sought to understand the place, both physical and social, of the person with dementia while examining their needs (for notable exceptions see Blackstock et al., 2006; Clarke and Bailey, 2016; Egdell et al., 2010).

In this article, we address this under-researched area by asking how people with dementia experience their communities and support within them. Specifically, we ask three questions: 1) in what ways do people with dementia connect with and contribute to their communities, 2) how do people with dementia negotiate space outside the home, and 3) what support services do people with dementia desire and use? In doing so, we take a relational approach to the study of care in rural and small town settings, which we outline in the following section. We then discuss the methodological and ethical challenges associated with doing research with people with dementia. We argue that support in the community is “not there yet” for the vast majority of people in the earlier stages of dementia. In our analysis, we draw particular attention to the contributions of people with dementia as well as the importance of rural cultures and gender in their experiences of care.

### 1.1. A relational approach to care in the community

To examine people's experiences of care in the community, we draw on a relational approach that begins by recognizing how people with dementia are positioned in place and connected to sites and experiences across space. In doing so, we respond 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., 2015). We have chosen this approach because we believe it provides us with a more comprehensive view of the potential and limitations of care in the community for people living with dementia.

A large proportion of the social science literature on dementia

care has tended to look at people with dementia, their care, and rural places in relatively static and discrete terms. For example, people with dementia are often defined by their needs and demands for service (e.g., Black et al., 2013). In contrast, gerontologists have increasingly taken a more relational approach to understanding older people's experiences arguing that they are positioned within networks of giving and receiving (Andrews et al., 2013; Milligan and Wiles, 2010). Studies have noted that older people make significant contributions to community development, social care, and civic life in rural communities (Hennessy et al., 2014). Social sciences research on rural dementia care has not, however, explored the everyday contributions of people with dementia. There is a growing body of research on citizenship in ordinary places such as the home and community settings, (e.g., Bartlett, 2016); however, more empirical work is needed to understand how people contribute to, and desire to contribute to, these ordinary places. The paucity of research on the contributions of people with dementia is, in part, because of the way care needs and services have traditionally been conceptualized.

Care is not simply a unidirectional activity and it cannot be reduced to a set of tasks or a single setting, particularly for people living in the community (Milligan and Wiles, 2010). Care is a complex relationship imbued with cultural meanings, power relations, and emotions (Lawson, 2007). People's use and experiences of different kinds of health and social care are influenced by their feelings and practices in other places (Andrews et al., 2013; Cummins et al., 2007). A more relational approach to the study of care starts by understanding that settings of care and decisions about care are interconnected. Increasingly, dementia care studies have acknowledged that there are diverse pathways to care (Blackstock et al., 2006; Egdell et al., 2010). Such pathways to care are shaped by the social and cultural characteristics of people and places.

Place, “as a meaningful segment of space,” is often taken for granted in research on rural dementia care (Cresswell, 2013: 280). Blackstock et al. (2006) contend that research on dementia care in rural areas has tended to view rural settings as a study site without exploring the diverse meanings of rurality for the people living in rural places. Subsequent reviews of the literature indicate that, in most studies, rural is either not defined at all or defined by population size and density (Morgan et al., 2011). However, rural places cannot be conceived as simply a single, bordered study site with unchanging characteristics. In the discipline of geography, there is a longstanding interest in the socially constructed, contested, and diverse nature of rurality (Cloke, 2006). For the purposes of this study, rural and small town Canada is understood as a social construct grounded in material and geographic realities (i.e., distance, relative isolation, and worse access to specialist medical services), economic factors (i.e., agricultural or resource-based economies), and perceived rural identity (Kulig and Williams, 2012). From a relational perspective, rural places contain multiple settings that may function as supportive or unsupportive, which are connected to other settings inside and outside of rural communities. Therefore, to understand support for people with dementia in rural settings, we look at how people with dementia connect with the other people and places around them as well as their perceptions of services.

### 1.2. Research design

Our research design involved a qualitative case study approach—a methodology well-suited to exploring social phenomenon in depth and with particular attention to context (Baxter, 2016). The case study sites were selected using information about the percentage of rural clients and descriptions of the rural areas

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