

From Beginning to End: Perspectives of the Dementia Journey in Northern Ontario*

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RÉSUMÉ

La recherche sur les soins de la démence continue à se développer, mais peu d'attention est accordée à l'expérience de la démence dans les lieux ruraux et nordiques. Cette étude explore la démence à travers les points de vue des services de santé, les soignants, les membres de la communauté, et les personnes atteintes de démence. Les résultats mettent en évidence la complexité de la prise de conscience et la compréhension de ce phénomène dans des lieux ruraux. La perspective des gens vivants avec une démence, la compréhension des services disponibles et une prise de conscience communautaire, sont essentiels à la prise en charge rural. La nécessité d'accroître les connaissances et l'emphase sur le développement des services de santé et bien-être en milieux ruraux sont discutées.

ABSTRACT

Research on dementia care continues to develop, yet little attention has been given to the dementia experience in rural, northern communities. This study explored the dementia journey through the viewpoints of health service providers, caregivers, community members, and people living with dementia. The findings highlight the complexity of dementia awareness and understanding. Sound awareness and knowledge of dementia itself, the community services available, as well as of the perspectives of individuals living with dementia and care partners specifically in rural, northern Ontario are fundamental to quality care and support of individuals with dementia. Practical service implications and the need for greater developments with respect to the awareness and understanding of dementia in rural, northern communities are discussed.

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Dementia is a condition that is becoming widely recognized as a global health concern (World Health Organization [WHO], 2012). In Canada, approximately 500,000 people are currently living with dementia, and as the aging of the population continues, these numbers are expected to accelerate to over one million Canadians with dementia within one generation (Alzheimer Society of Canada, 2010). In northwestern Ontario, over 3,200 people are living with dementia, and within one generation, this number is projected

to double (Alzheimer Society of Thunder Bay, 2013). Because of the predicted prevalence of dementia, attention must turn to understanding the needs of this population in order to plan, and to provide appropriate and effective health and social care services, particularly within the rural northern community context.

For the purposes of this study, we defined *rural* or *small town* as referring to a town or municipality with fewer than 150 persons per square kilometre and

which exists outside the commuting area of an urban centre with a population greater than 10,000 (Statistics Canada, 2001). As this definition implies, rural communities are isolated and often far removed from urban centres. Several studies have suggested that there is less accessibility to, and less variety of, health care services for rural seniors in comparison to their urban counterparts (Andrews, Morgan, & Stewart, 2010; Coward, Netzer, & Peek, 1996; Forbes, Morgan, & Janzen, 2006; Krout, 1994; Morgan, Semchuk, Stewart, & D'Arcy, 2002). Rural communities in northern Canada face unique challenges and limitations related to the level of service and support that they are capable of providing, thereby creating additional barriers for aging populations, particularly for people with dementia (Andrews et al., 2010; Hanlon & Halseth, 2005). Accessing care in the rural north entails several challenges, including geographic remoteness, long distances, low population density, less availability of services, and harsh weather conditions (Ontario Ministry of Health and Long Term Care, 2011).

Canada's rural population is aging faster than urban populations. Seniors comprise approximately 15 per cent of rural residents over the age of 65 in comparison to 13 per cent of people living in urban areas (Dandy & Bollman, 2008). Canadian rural populations have both a higher old age dependency ratio as well as a higher child dependency ratio, indicating increasing pressures on the working cohort to provide care for both young and old (Dandy & Bollman). In rural regions, youth typically migrate for employment to urban centres, even as increasing numbers of seniors relocate from urban to rural communities because smaller communities are perceived to be more appealing for retirement (Forbes & Hawranik, 2012). Wenger and Keating (2008) noted that widespread misconceptions exist concerning rural communities as ideal retirement settlements, in particular the belief that individuals are encircled by family, friends, and community members who will provide support and care to them as they grow older. Those who have resided in their communities for many years may have had time to establish relationships and social networks that affect the likelihood of their receiving care, but recent migrants may not have had those opportunities.

The rural environment is also shaped by the changing socioeconomic context (e.g., forestry and mining industries). The depletion of natural resources underlies significant changes in many small rural communities (Williams & Cutchin, 2002). The broader political context framing rural health care also contributes to a "double burden" for many rural Canadian residents as the lack of availability of and accessibility to professional health care workers are compounded by government policies that often fail to account for the

diversity of communities, particularly of rural communities (Halseth & Williams, 1999; Hanlon & Halseth, 2005; Joseph & Cloutier-Fisher, 2005; Joseph & Hallman, 1998).

Senior residents in rural northern communities often rely on support services to be able to remain living in their own homes as their health declines (Wilcox, Jones, & Alldrick, 1995). When these support services are unavailable or unable to sustain aging-at-home, relocation may occur to urban centres, removing seniors from the comfort and familiarity of their homes and communities (Sims-Gould & Martin-Matthews, 2008). As important as support services are to rural senior residents, research in rural northern environments appears to be limited, and studies often focus on access to physicians including medical care recruitment, distribution, retention, availability, and accessibility (Williams & Cutchin, 2002). Cummins, Curtis, Diez-Roux, and Macintyre (2007) have noted that although more recent studies have investigated a person's experiences and perceptions of place related to particular health conditions, dementia has not been considered.

A search of the literature revealed that the investigation into the dementia experience in rural northern communities has been largely untouched, with the exception of a few pockets of research occurring in Canada and elsewhere (Edelman, Kuhn, Fulton, & Kyrouac, 2006; Morgan et al., 2002). McDonald and Heath (2008) examined the provision of health and social services for people with dementia in three rural communities in the United Kingdom and found an underdevelopment of dementia care services and policies. Interestingly, the authors pointed out that carers were also quite aware of the "rationing" of services and, although discouraged by the limited availability of professional supports, had an expectation and sense of entitlement to support from within the community that was fulfilled by family, volunteers, and other community members (McDonald & Heath).

Morgan et al. (2002) suggested that there is also a rural culture that further embodies reluctance on the part of rural seniors to use formal services, contributing to their reliance on informal social networks and family members as central sources of assistance. Reliance on these individuals for support can be problematic for individuals with dementia because informal social ties and family members can lack knowledge about dementia, also creating a barrier to obtaining service (Edelman et al., 2006; Morgan, Innes, & Kosteniuk, 2011). According to Morgan et al. (2002), these barriers encompass dementia stigma, beliefs, attitudes, service acceptability, and general lack of dementia awareness and understanding. According to the World Health

Organization (WHO, 2012), a lack of awareness and understanding of dementia reflect the common belief that cognitive decline is a normal part of the aging process, and few people are able to recognize the symptoms of dementia. Informal and family caregiving was also studied by Innes et al. (2011), who found that education opportunities were limited, contributing to insufficient information and an overall lack of knowledge about dementia and rural dementia services for care providers.

Lack of knowledge and awareness were also dominant themes relating to service needs and disparities in formal services in a review by Morgan et al. (2011). They noted that professional health service providers often lack awareness of service availability as well as an understanding of the influence that rural social contexts and beliefs can contribute to impeding a person's ability to seek care (Innes et al., 2011). In addition to insufficient education opportunities for informal care providers, Forbes and Hawranik (2012) have noted that formal, rural health care providers are also quite limited in the availability of, and opportunities for, education and dementia training.

Overall, current literature reveals that a lack of dementia awareness and understanding is evident in rural communities encompassing informal carers, family, and community members and that it also extends to the formal service providers caring for rural residents living with dementia. Research has been largely restricted to the perspectives of formal care providers or informal caregivers, often excluding insights and viewpoints from others who have a presence within an individual's dementia journey in providing indirect support and care. As has been illustrated in the aforementioned literature, community and social networks in rural communities provide support to aging seniors (Andrews et al., 2010; Coward, Netzer, & Peek, 1996; Wiersma & Denton, 2013; Wilcox et al., 1995), and examining dementia in rural communities, as we did in our study, requires a comprehensive analysis that includes the perspectives of various groups.

Dementia is an ongoing progression, and as the disease progresses, the changes highlight milestones along the dementia journey. Individual experiences vary throughout this journey; and the progression of dementia in northern rural communities intersects with unique challenges that encompass a concept of *rural* that is both geographic and social. It is necessary to recognize and understand how these milestones are experienced from the perspectives of people living in rural northern Ontario. These key milestones, as discussed by research participants in our study, include recognition of signs and symptoms, dementia diagnosis, care requirements, and long-term care (LTC) placement.

Our findings describe community members' perspectives of dementia innovatively on two key fronts: exploring the progression of dementia through different stages in the disease journey, and analyzing how these pivotal points are experienced within the rural context of northern Ontario. The heterogeneity of rural northern communities and the individuality of each community can only be understood through exploring the lived experiences of its members (Williams & Cutchin, 2002). Accordingly, the purpose of this study was to explore the stages of the dementia journey in the context of rural northern Ontario through the perspectives of formal health service providers, informal and family carers, as well as other community members, such as neighbours, friends, volunteers, business owners, and clergy.

Methods

Using an interpretivist, constructionist paradigm (Lincoln & Guba, 2000; Schwandt, 2001), we sought to understand the context of dementia from the perspectives of various groups of people in four communities in northern Ontario. The four communities were situated within two regions. In each region, the two communities were located within 50 kilometres of one another and were several hundred kilometres from the nearest urban centre. Each of the two regions had several support services available including a hospital, pharmacy, LTC home/beds, home care, family health teams, community support services, public health centres, and community health centres. In addition, each community had numerous other community supports available including transportation, grocery stores, seniors' apartments, seniors' centres, and various opportunities for recreational activities. In order to ensure the anonymity and confidentiality of all participants, we gave each community a pseudonym – Dakota, Dawson, Perry, and Trenton.

A variety of participants were recruited from each region to take part in this study. These participants were divided into four categories: (a) individuals living with dementia, (b) care partners, (c) health and social service providers, and (d) other community members. Initially, we recruited key individuals in the community, including health service providers and community members, for the study. We used snowball sampling as these individuals suggested other key individuals to contact for the study. Care partners and people living with dementia were then contacted by key health service providers who asked if they would be willing to have their contact information shared with the research team. If the individuals agreed, their contact information was passed on

to the research team, who then described the study and asked if individuals would be interested in participating in an interview.

In total, 71 participants were recruited including two people living with dementia, 15 care partners, 37 health and social service providers, and 17 other community members (see Table 1). In the first region, a total of 40 participants were recruited, including one person with dementia, seven care partners, 24 health and social service providers, and eight other community members. In the second region, a total of 31 participants were recruited, including one person with dementia, eight care partners, 13 health and social service providers, and nine other community members. Health service providers included persons working in community care, primary care, acute care, and long-term care. Although we did not focus on content saturation, we conducted interviews until no additional participants in the community were recommended.

Individual and group interviews were conducted with participants in order that we would better understand the dementia experience. All interviews were conducted by the principal investigator (EW) and a research assistant. The interview questions covered experiences of Alzheimer's disease and related dementias, experiences of community, and issues and challenges associated with living with Alzheimer's disease and related dementias in the community.

The study was approved by two research ethics boards. Participants were given an information letter and signed a declaration of informed consent prior to participating in the interview. Interviews were audio recorded with participants' permission. Most interviews were conducted at people's homes or places of employment. Once all interviews were completed, they were transcribed verbatim and entered into QSR International's NVivo 8 qualitative software analysis program.

The principal investigator and two research assistants coded the interviews. Initial coding was used to attach a word or phrase that summarized a sentence or idea

in the data, and broke the data down into discrete parts (Charmaz, 2006; Saldana, 2009). Initial coding was used as a starting point to allow researchers to be open to the direction of the study and analysis (Saldana). Focused coding was then used to develop prominent themes from the initial codes (Saldana).

A second level of coding was then conducted by additional researchers (DD and SF) along with the principal investigator. For the purposes of this study, the methodology applied was an iterative process that involved a continuous review of the data, individual transcripts, and literature throughout the research project. In order to gain a strong understanding of the data, the researchers continuously examined the coding and original transcripts in order to understand both the data and the context in which it was being discussed. This ensured that all researchers were fully immersed in the data and had a trustworthy and authentic comprehension. The researchers analyzed the data by reading, describing, classifying, and making interpretations. The original line of inquiry of dementia in rural northern Ontario was pursued, and after feedback from the principal investigator and further analysis of the data, it was apparent that a common theme of knowledge and awareness was emerging in the data. Next, the researchers examined how the different participant groups conceptualized the themes of knowledge, understanding, and awareness.

It was evident that the participants discussed knowledge and awareness along the dementia journey and that there were specific milestones. As a result, we felt it appropriate to structure the findings around the pivotal milestones encountered along the dementia journey. In order to advance the research process further, regular meetings and discussion with the principal investigator took place; this also ensured that the findings were both grounded in the data and trustworthy. It was also important that a constant comparative method was used to explore consistencies and contradictions between different communities and groups, as well as the similarities and differences that existed about these themes in the literature.

Table 1: Characteristics of study participants

Region #1	Region #2	Total
24 health and social service providers	13 health and social service providers	37 health and social service providers
7 care partners	8 care partners	15 care partners
1 person with dementia	1 person with dementia	2 people with dementia
8 other community members ^a	9 other community members	17 other community members
40 Total Participants	31 Total Participants	71 Total Participants

^a other community members = includes neighbours, friends, volunteers, business owners, and clergy.

Findings

Awareness and understanding of dementia are common themes transcending the dementia journey from the first recognition of signs and symptoms to seeking assistance and obtaining a diagnosis, informal and formal supports, and eventual progression to LTC placement. Awareness is the first step in which one begins to have knowledge of the phenomenon: in this case, the signs and symptoms of dementia, the available resources, or people who have dementia. Understanding is an in-depth knowledge of how dementia impacts one's life and experiences and how circumstances become framed by the experience of dementia. Awareness and understanding can be complex, and can occur in varying degrees. Although study participants may be aware of certain aspects of dementia, other aspects may be unknown. Awareness and understanding, then, centered on three main things: (1) dementia as a physical and neurological condition; (2) resources and services; and (3) the person living with dementia.

It was important that we placed awareness and understanding in a local context in our study, explicating how the rural northern environment structured and impacted awareness and understanding. In addition, we conceptualized different milestones along the dementia journey as emerging from participants' experiences in which awareness and understanding were relevant. These milestones were as follows: (a) seeking assistance and obtaining a diagnosis, (b) acquiring informal supports, (c) acquiring formal supports, and (d) progressing to LTC placement. At each of these milestone stages, awareness and understanding of dementia, resources, and the person with dementia permeated and impacted people's experiences. Consequently, we have presented our findings through the words of our participants, illuminating the awareness and understanding of dementia in rural northern communities and the impact of the dementia experiences on these participants.

Community Awareness of Dementia

The study participants described awareness of dementia as often being limited within rural northern communities and as a significant barrier to the identification of the disease. In contrast, dementia was also described as becoming more visible within these communities. Many individuals described having little awareness of the signs and symptoms of dementia; however, they noted that the size of the community also contributed to greater visibility as increasing numbers of people, particularly prominent community members, had dementia and continued to live within the community. As a result, the complexity of awareness comes to the fore – where individuals

may know that someone in the community has a form of dementia yet are unable to explicitly identify the specific signs and symptoms of the disease.

Community awareness of dementia as a condition, with associated signs and symptoms, was the first stage in the dementia journey experienced by the study participants. To be aware of the signs and symptoms of dementia meant that participants were then able to filter their own experiences through this knowledge. For an individual to receive a diagnosis of dementia and receive appropriate care, awareness of the individual's dementia was essential.

When access to information about dementia is challenging, as is often the case in rural northern communities, this first stage becomes particularly problematic. Although information is available online about dementia, the presence and visibility of organizations which provide education about and services specific to dementia is limited. As an example, due to the large geographical area that these organizations in northern Ontario cover, many small communities do not have a local organization providing services and education in the community; this typically comes from a larger centre. The lack of such awareness was evident in this care partner's words:

"When they first mentioned dementia, I didn't realize. I thought that was old age – forgetfulness – which I guess is what it is. But I never thought of Alzheimer's; and I asked somebody what the difference was. But nobody ever told me." (care partner)

Although many care partners were not aware of dementia, one health service provider discussed the general attitude towards dementia:

"I think memory loss is taken as sort of a light-hearted attitude that anywhere after middle age you sort of expect it, that your memory fails and a lot of people just sort of laugh it off. So I don't think it's treated as a serious medical problem." (health service provider)

In addition, one health service provider commented on how living in the rural northern environment, in particular a small town, might contribute to a lack of awareness of dementia.

"... and a lot of people in these communities have lived here forever, so they have a small-town mentality, which isn't rude to say, but there's different experiences in life that people don't venture out. That's my polite way of saying it. My parents were born and raised here. My grandparents were born and raised here. They're just different. My mother has a different outlook on things – way different than I do – because she hasn't moved from here. You know, it's true. And they think they have that

mentality. They're just becoming forgetful ... but don't understand the seriousness of how it will develop and what it develops into." (health service provider)

Despite lack of awareness of the signs and symptoms of dementia, people who were diagnosed with dementia were often more visible in rural northern environments.

"I guess one grateful thing about being in a small community is that the community does know, for instance, who has dementia, who has Alzheimer's." (health service provider)

An interesting part of the dementia journey, unique to rural northern communities, was the increased awareness of the prevalence of dementia within the community. Frequent and familiar interactions between community members promoted the sharing of such information. Neighbours and friends often recognized when people were experiencing difficulty adapting and coping as they aged, and as they struggled with their cognition. Many study participants commented on how people were closely connected in small communities. It is hard to conceive that this same level of familiarity and concern would be present in an urban centre. For example, a community member described how word of mouth created greater dementia recognition and visibility in the community because of her family member's struggle with dementia:

"For the last year, it's been out in the open and that would be by word of mouth, by her circle of friends, neighbours, and family put that word out, and then it spreads in a small town. But prior to that – no, I don't think people did know. Certainly, it's been going on longer than a year. I can probably think that it's been five years, you know, that the first sort of signs of things happening or that were overt and people weren't aware of that." (community member)

People living with dementia were visible in rural northern communities due to the small population. Since frequent contact occurred, and many if not most community members were familiar with each other, recognition of dementia was more pronounced within the community, which also assisted community members in acknowledging and recognizing signs and symptoms. This was especially true with prominent community members:

"... and I don't know whether it's because some very important people in the community have come and gotten it and you become more aware. Or is it something that's just happening, you know? I'm sure that's not true, but it's all of a sudden been very much forefront. Like [people living with dementia] would've been very prominent seniors in town. So that could've been what it is." (community member)

Receiving a Diagnosis

Receiving a dementia diagnosis was a milestone in the journey that was regarded by care partners and health service providers as difficult, due to a lack of broad awareness and education even by health service providers. Awareness and understanding at this milestone typically focused on health service providers' knowledge of dementia, and on an individual's denial of having received a diagnosis of dementia. Participants described the diagnostic process as being vague; if an individual received a diagnosis at all, contact with a medical specialist was made only when families were aware of, or knowledgeable about, dementia and requested a referral. Health service providers described being unable to respond to the unique needs of the different types of dementia, which impacted the quality of care a person with dementia might receive. Family members also discussed how a diagnosis was often questioned by other community members since it was a difficult disease to understand, which contributed to further denial in the diagnosis and a struggle to arrange supports.

Participants described many issues experienced by people receiving a diagnosis of dementia specific to the knowledge of health service providers. The knowledge of health service providers about dementia and cognitive impairment was described as being generic and at times non-existent, and participants clearly described a lack of knowledge on the part of rural health service providers in diagnosing dementia.

"[T]here's a gap in how you're going to be diagnosed as to where you might be if you think you might have a dementia problem. And this just isn't the doctors down here, because I've been other places where you go and you start saying this and that. "Well, that's because you're getting old." That isn't just because you're in a small place. The GP's and that in other places say the same thing. They do not take it seriously." (community member)

However, typically most individuals did not have a specific diagnosis.

"Very few of our residents have a specific diagnosis to go along with their dementia. Very, very few." (health service provider)

Referrals to specialists were not common, which further impacted the quality of care that people with dementia in rural northern communities received. This same health service provider explained how not getting a specific diagnosis could impact quality of care:

"Yeah. You know, if I've ... you'd have to actually say, "Okay. I want to know what kind of dementia",

most people don't even know there's another kind of dementia out there. You know, dementia and Alzheimer's is the same thing to them, and Lewy body. You know, they have no idea: "What is that? I've never heard of that before." You know? So you're not getting ... which, of course, affects your care plan because with all the different ones, their needs are different. So we're not getting any of that information, or very little of it." (health service provider)

While awareness enhanced early help-seeking behavior and provided opportunity for prompt initial education, denial was described as a barrier to seeking help. A number of health service providers described the reluctance of family members to seek help in specific situations. A health service provider commented on the need for further education:

"I mean, like I think it's the education part of it. Their awareness of it is not, you know... and like I said, it's hard to get everybody to get involved because some would rather not know, maybe. I don't know what it is, but they just don't want to know; and then it comes to the point where they need to figure it out and find out what's going on." (health service provider)

A community member also stated:

"I don't know if that's changed a lot, you know, despite the education that's out there. I think family members – I'll use family members as a reference – are reluctant to admit that that's what's going on with their loved ones. Friends – the same, are reluctant to vocalize those kind of things that they see going on and just put it down to, "Oh, well, she forgot this." Or, "Oh, well, she's getting short-tempered in her old age", that kind of thing. I don't think people are quick to want to put that handle on." (community member)

Denial of people's diagnoses was also an issue. Denial of the symptoms of dementia was described earlier in the section on community awareness; in addition, study participants described the denial of a person's diagnosis once it had been received by an individual. In particular, if individuals acted "normal" and not out of the ordinary, many people found it difficult to believe that a diagnosis of dementia had been given. A community member stated that although the small community intimacy contributes to people's being more aware of someone experiencing the symptoms of dementia, they sometimes are only capable of seeing someone in a limited way. This makes it difficult for community members to fully recognize and accept a person's dementia and can contribute to a denial of the diagnosis.

"But I've had friends say, "Yeah. Gees, I talked to her in the grocery store. You'd never know there was anything wrong with her". So even though

people are aware of it and they see, like I said, with [community member's] wife. It was like, if I didn't know, I'd think [he] was a liar, even though I know about it. Because it's kind of, how can you be this way here and then an hour later at home you're this way? People don't realize that." (care partner)

Community Support Networks

An interesting component of awareness and understanding of dementia that was unique to rural communities was the breadth of community and informal supports that existed. Although the awareness and understanding of dementia as a condition was described as minimal, the process of caring for people living with dementia in the community was very clearly seen as a community responsibility (Wiersma & Denton, 2013). Awareness of whom in the community was living with dementia and of his or her needs was evident in how community members responded to caring for those people, and it only necessitated awareness or knowledge of the person, not the disease, for these supports to occur. Community members provided invaluable supports and assistance for people with dementia which was described as playing a significant role in the person's ability to remain in his or her own home. A health service provider reported familiarity among community members as a benefit of living in a rural northern community:

"Yeah, I think that's a huge benefit for our area, the small little communities, is everybody knows everybody and everybody takes care." (health service provider)

Another health service provider stated:

"Benefits. Well, I don't know that there are benefits to living with Alzheimer's. But I think that maybe living in the smaller community where people know each other and have known each other oftentimes for many, many years allows for people to stay longer in their homes and still connect on a social dimension with the public. People who have Alzheimer's move within our community. We might know that they are forgetful. We'll check if we see them downtown where they're headed, where they're going. Do they need a ride? Are they lost? Do they need a ride to their son's? And I find that the public in our communities, because we know each other so well, often supports the patients with early Alzheimer's; and even later stages of Alzheimer's." (health service provider)

As these responses suggest, living within a small rural community can be a favourable environment for people living with dementia. Community members were aware of the incidence of the disease and valued the safety of their fellow community members. A health

service provider described past situations where, for example, the community watched out for people who might be found on the street in the middle of winter not dressed for the weather, and bring them home or call their family. This level of community vigilance and support would typically not be witnessed in a larger, urban centre, where little effort may be made to get to know one's neighbours. A small community may be better able to be attentive in the care and safety of their community members:

"... when you've got a small community and people see So-and-So wandering the street knowing that he's demented, they will bring him back home." (health service provider)

Beyond providing a sense of safety and security, the community members were also described as contributing to the day-to-day needs of a person with dementia:

"Yeah, and out in the community, they'll make sure they have rides to the stores and back to their homes, and neighbours are excellent. Neighbours will check on people, you know." (health service provider)

Health and Community Care Services

After a diagnosis was received, an individual's dementia journey progressed to accessing formal health and community care services. Whether support was in-home or hospital based, receiving formal support was considered beneficial for those with dementia as well as for their family members and care partners. Although the benefits of formal supports were obvious, awareness played an influential role in facilitating access, perceptions of the supports that were received, and how these supports were provided in rural northern communities.

While living in a small rural community poses some geographical barriers to receiving formal support, a common lack of awareness was described about the supports that did exist, and how to use those supports.

"And there's a lot of older couples that are going through it – a wife with a husband and a lot of confusion in the home, and not knowing the next step to take." (community member)

Our study suggests that improved access to formal services, a greater emphasis on dementia awareness, and increased knowledge of formal services and programs would have greatly increased the standard of support that a person received.

Although some of the quotes included in this article indicate a lack of awareness and existence of health and community care services, an awareness and

understanding of the person, outside of the disease, ensured that the provision of care within these rural communities embodied a more personal, relational, and holistic approach to the person with dementia. Not only did service providers deliver necessary medical attention, but they also offered a unique, personal approach to this care based on their familiarity with the person living with dementia. As one health service provider stated:

"I think I just have some more knowledge about the person. So it's easier for me to make conversation because I remember, "Oh, when So-and-So ...", "Oh, I remember when we used to do this", so it's easier to carry a conversation as opposed to ... but I'm not shy, so I can talk to somebody and then ask them and they have to tell me what they've done and then they'll talk, you know, if I have somebody that's new. So I have to carry on a conversation, but the conversation probably would be a little easier because I have some knowledge of the person ahead of time." (health service provider)

Progression to Long-Term Care

Throughout the dementia journey, many supports, both formal and informal, were sought by the study participants in an attempt to help a person remain living in his or her home. However, a time eventually came for many when the individual was no longer considered capable of living in the home and LTC facility placement was considered. Family and community members were aware that the progression of dementia often meant that relocation to an urban centre for long-term care was necessary. In some rural communities, LTC beds are located in hospitals, rather than in separate facilities. As a result, hospital bed shortages can impact LTC placement. Rural northern Ontario has limited facilities that provide this type of care, and bed shortages make this transition an enormous challenge:

"They're living in their homes. They're using their stoves. Some of them are probably sleeping in the basement close to the furnace if they have an oil furnace because it's expensive to heat. The upstairs is closed if they're in an old house. ... and where are they going to go? This hospital here right now ... It's full of the alternate level of care." (community member)

Instead, long wait times meant that responsibility for care often remained with the family and formal support systems that they may have reached out to along the way. A family member described her experience with her mother:

when her assessment had been done, we were told it was still another 2-½ year wait. And that was a bit of a scare for me because I thought, I don't

know what to expect. We've never had anybody in our family that has had dementia ..." (care partner)

As this suggests, caring for someone with dementia can be an overwhelming task for both those unfamiliar with the condition and family members struggling to cope with the diagnosis and prognosis. Facilities specializing in the treatment and care of persons with dementia were imperative resources at the advanced stages of the condition, and the shortages that existed in rural northern Ontario only seemed to exacerbate the issue. Unfortunately, placement into long-term care, whether it was within the community or in an urban centre, was often as a result of a crisis situation:

"At the hospital, like over the years, I've noticed that we seem to have more and more patients with Alzheimer's. And I've looked after them, like in the hospital when basically they've been admitted to acute care because there are absolutely no resources or very few resources in the community to help them stay in their homes. And they come to the floor and they're just so totally lost. It's kind of terrible. And in Emerg, of course, at the crisis point where friends or family will bring them in because, you know, they can no longer care for themselves but they've stayed at home as long as they can." (health service provider)

If LTC beds are not available in the community, people with dementia can be relocated to urban centres or other communities with available beds. Because of geographic distances in rural northern Ontario, this can mean that family and friends have to travel significant distances to visit loved ones.

While in long-term care, health care staff also described their limited knowledge about the behaviours of people living with dementia, which contributes to an earlier placement in long-term care.

"Like even just to have some basic knowledge about how to manage dementia people. But when the patient becomes ... a resident becomes too aggressive, it does cause some kind of concern to the staff and, of course, safety. Everyone's trying to protect themselves first. So that is one of the challenges of management is educate the staff, make them more aware, how to handle those aggressive behaviours, and how to recognize the signs and symptoms." (health service provider)

Although health service providers in the LTC setting lacked knowledge about dementia as a disease, what they offered was a unique, personal approach to care based on their familiarity with the person living with dementia:

"Yeah, or "They really liked this or they liked when their hair was styled like this", and so there's a lot of added little things that the nurses here can do

because they do know. Or the patients have been here for so long that they remember them in their earlier stages when they just got admitted and they know what they liked and everything. So I guess that's good." (health service provider)

As these quotes suggest, awareness and understanding of dementia are common themes that are evident throughout the dementia journey in rural northern Ontario. Participants discussed obvious milestones beginning with the recognition of signs and symptoms, to seeking supports and finally, advancement to long-term care. While awareness is necessary in order to have knowledge about the existence and impacts of dementia, understanding requires a more comprehensive perspective of the complexities that a person with dementia experiences. Awareness and understanding are significant in the perceptions of dementia signs and symptoms, in the resources that a small community has to offer, and most importantly, they are significant to the people experiencing dementia. Dementia is a process that evolves over time, where awareness and understanding are fundamental within the pivotal points emerging throughout the journey. Furthermore, the construction of place through the environment, socialization, and interdependence influences how people are aware of, understand, and make sense of dementia in a rural northern community.

Discussion

Addressing a gap in the literature, this study focused on rural northern Ontario health service providers, care partners, and community members' perspectives and experiences of providing care and support to people living with dementia in their communities through the lens of awareness and understanding. Awareness and understanding emerged as themes through which dementia as a disease was known, what services and supports were available, and through community interactions and knowledge of people living with dementia in the community. Unique to the literature on rural dementia is recognition of milestones, or pivotal points, that are typically experienced throughout the dementia journey in a rural northern Ontario community. Although ours was not a comparative study, historical research would suggest that there is a relationship between awareness and service use. Based on centrally located services in urban areas, rural community members may be unaware of the process involved in accessing needed supports, despite having knowledge about the existence of these services (Koller et al., 2010).

The different community groups provided diverse perspectives and insights about what it meant to live with dementia in the community, rather than solely focusing on health care providers and care partners as

previous studies have done. Including the views of diverse community members contributes to building knowledge and understanding of a rural dementia experience that currently exists exclusively from the health care perspective. A viewpoint from northern Ontario has not been included in previous studies, and its exploration suggests a unique and novel construct of the dementia experience. The findings of this study exemplify distinctive experiences that rural communities in northern Ontario have with regards to dementia. These experiences characterized the dementia journey in our study, from the initial recognition of signs and symptoms through to the eventual progression to long-term care.

Lack of awareness and understanding permeated experiences encompassing the recognition of signs and symptoms of dementia. Participants became aware of dementia through encounters with people visible within the community rather than by knowledge or awareness of dementia itself. The "generalist" practice of health service providers perpetuated the lack of knowledge and understanding of dementia and was an obstacle that contributed to difficulties in obtaining a diagnosis, as suggested by previous studies (Forbes & Hawranik, 2012; Morgan et al., 2002; Szymczynska, Innes, Mason, & Stark, 2011). Lack of knowledge and awareness of dementia as a disease, coupled with familiarity and expectations of individuals in the community appeared to influence the challenges of recognizing dementia during this initial milestone in the dementia journey. The apparent lack of knowledge, awareness, and understanding of dementia as a disease has implications for how people in rural northern communities experience the first recognition of signs and symptoms, and how they experience their diagnosis.

Accessing formal supports and services relied heavily upon awareness of the need for services, and the awareness of what services were available. By identifying the importance of service awareness, our study adds to previous findings where underutilization in rural areas has been attributed to such factors as distance, transportation, caregiver time and resources, smaller families, different lifestyles and beliefs in rural areas, as well as stigma (Koller et al., 2010). As the findings suggest, these services are highly valued, but unfortunately there are often limited supports in rural communities (Forbes et al., 2006; Innes et al., 2011). This study further supports previous literature regarding the discrepancy that exists between service needs and the underutilization of services in rural communities (Jansen et al., 2009; Williams, 1996). Whereas previous Canadian research points to stigma, privacy issues, possibility of strong social networks, and reluctance towards service use (Coward, Cutler, &

Mullens, 1990; Forbes & Hawranik, 2012; Morgan et al., 2002; Stoller & Pugliesi, 1988) as key determinants of reduced access and service use, our findings indicate the importance of knowledge and awareness. However, it is not known whether the degree of service use varied with length of residency in a community.

Familiarity with the person living with dementia was also central to the provision of care. Community members living with dementia were integrated within their communities, where the experience of dementia was felt by many. Although people with dementia in rural northern communities were not universally supported, a sense of community often resulted in common bonds uniting community members. Despite other findings in the literature describing rural obligations for caring (Innes, Blackstock, Mason, Smith, & Cox, 2005; Keating, 2008; Morgan et al., 2002; Wenger, Scott & Seddon, 2002), the community members in this study were profoundly aware of the needs of others and demonstrated a sense of commitment to supporting their fellow community members. Unity and collective responsibility were part of the underlying rural culture within the communities. In contrast to previous research indicating that privacy issues could be problematic when it comes to providing formal care services (Magilvy, 1996; Morgan et al., 2002), the participants in the present study expressed the view that knowledge and awareness of the person living with dementia were beneficial to the quality of care provided as these qualities encouraged a more personal and holistic approach to care. Familiarity, for these communities, was the essence of fostering the blending of professional and personal boundaries that strengthened the caring relationship and optimized the quality of care that community members received.

This study has several practical implications for health and social service organizations, rural northern Ontario communities, policy makers, and health service providers. Awareness of supports and services in the early stages of the dementia journey is crucial to enabling a person with dementia to make decisions related to their care and future. Lack of awareness, as in the case of rural communities in northern Ontario, contributes to the increased vulnerabilities of those requiring care. It would therefore be beneficial for organizations providing dementia awareness, education, and services to enhance awareness and increase the education provided to communities, particularly those in rural areas. Due to the lack of supports and services that often exist in these communities (Morgan et al., 2002), it is recommended that these organizations expand their reach and the support that they provide to surrounding rural communities.

Similarly, health service providers and policy makers must acknowledge the unique challenges that exist in providing dementia care services to rural communities. Our study lends support to existing literature regarding rural dementia care with findings that emphasize a lack of information and awareness of services from the perspectives of the public, those who provide informal care, and health care professionals (Coward et al., 1996; Krout, 1994; Morgan et al., 2002). Ensuring that community members are educated and fully informed about services that are available necessitates further consideration of how services are delivered in rural communities and reflection on the opportunities available for community members to engage in learning about dementia.

Dementia care is an ongoing challenge for rural communities in northern Ontario (Andrews et al., 2010). These communities must be aware of the unique opportunities and challenges that they face. Although isolation may limit the scope of services that rural areas can provide, the sense of community provides support to residents living with dementia.

These communities exhibited an interesting and unique mosaic of interrelated values that contributed to improved cohesion and commitment to care throughout the community. Although previous studies (e.g., Morgan et al., 2002) have indicated the isolation and burden of care that rural caregivers experience, the participants in this study emphasized community cohesion and responsibility in caring for community members living with dementia (see also Wiersma & Denton, 2013). Northern communities have traditionally lacked formal services and have adapted to caring for community members through their commitment and dependence upon one another in providing informal assistance (Coward et al., 1990).

Although the communities represented in our study focused on the benefits of community support networks, the findings also revealed a clear lack of awareness of the services available. There was, however, an acute awareness of rural service allocation being less than that available to the communities' urban counterparts. Despite literature indicating that a general widespread lack of awareness in dementia exists, our findings revealed that this lack of awareness encompasses several areas in the dementia journey that are most exacerbated in rural communities. This may influence the acceptance of informal assistance and encourage community members to focus positively on the community contributions in caring for a person living with dementia. Caution, however, must be exercised in interpreting these communities' positive expressions of social networks and informal supports relevant to caring for a person living with dementia in

a rural community. Although there was acceptance and appreciation for the care that a person received, the availability of rural services has been shown to fall significantly short in comparison to what Canadians living with dementia receive in an urban centre (Andrews et al., 2010; Coward et al., 1996; Forbes et al., 2006; Krout, 1994; Morgan et al., 2002).

While the intent of this study was not to generalize to other populations and was specific to the communities in which the research took place, the findings can provide insight into the rural experience. Further studies incorporating a longitudinal design would assist in expanding an understanding of the changing needs, or milestones, of an individual progressing through the dementia journey in a rural northern Ontario community that this study has brought to light. Although the present study provided a unique understanding of the dementia journey and the experiences of people with dementia, a limitation of the study is that only two people living with dementia were able, or willing, to participate. In addition, the recruitment method limited the diversity of participants, and this may have influenced the results. Because participants were often engaged with someone living with dementia, the perspectives of individuals who have some awareness of dementia have been solicited. Future research might endeavour to interview people with limited understanding or awareness of dementia. Both dementia stigma and the signs and symptoms of dementia being attributed to aging rather than a disease may have contributed to few people with dementia participating in the study.

In order to gain a more in-depth understanding of the dementia experience, we recommend that future studies endeavour to reduce stigma by encouraging and inviting greater participation of individuals living with dementia. Additional research is necessary in order to contribute to a better understanding of the unique experiences of people living with dementia so their respective needs can be met regardless of where they live.

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