

# Dementia in rural settings: examining the experiences of former partners in care

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## **ABSTRACT**

Informal carers, also referred to as partners in care, provide the bulk of care to people living with dementia across a range of community settings; however, the changing experiences and contexts of providing informal care for people with dementia in rural settings are under-studied. Drawing on 27 semi-structured interviews with former partners in care in Southwestern and Northern Ontario, Canada, we examine experiences of providing and accessing care over the course of the condition and across various settings. Our findings illustrate the challenges associated with navigating the system of care, finding people who understand dementia in the surrounding community, negotiating hours of home support, facing resistance to respite from the person with dementia, and feeling pressured into long-term care. We 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.

**KEY WORDS** – dementia, rural, care, settings, transitions, qualitative, Canada.

## **Introduction**

Internationally, approximately 47.5 million people have been diagnosed with some form of dementia (World Health Organization 2015). As dementia progresses, the need for support with everyday activities increases to the extent that many people with dementia require sustained and sometimes constant care. Much of this care is unpaid and typically provided by a family member. The intensity, frequency and duration of caring for someone with dementia are often associated with burnout among partners in care<sup>1</sup> (Adelman *et al.* 2014). The number of caring hours, increased social isolation and confinement for the partner are exacerbated by broader socio-political contexts (*e.g.* ageing at home strategies) that place increasing pressure on partners to provide support without recognising

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their own care needs (Lilly *et al.* 2012). Programmes and services for people with dementia and their partners can help alleviate the burden of care and enhance the quality of life of people with dementia and their partners; however, in many places programmes and services are difficult to find or non-existent and that can be particularly challenging for people with dementia and their partners in care.

Both in the Canadian and international context, rural communities and small towns pose particular challenges to delivering targeted services (Dal Bello-Haasm *et al.* 2014). Low population densities, small numbers of people with particular health conditions, distance, limited or non-existent public transportation systems, weather conditions, shrinking and geographically dispersed family support networks, recruitment and retention of health professionals, and socio-cultural beliefs all affect provision of, and access to, care in rural settings (Skinner, Yantzi and Rosenberg 2009). People with dementia and their partners 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-Haasm *et al.* 2014). Earlier studies suggest that people living in rural areas with dementia typically use fewer community-based services because of competing priorities (*e.g.* farm labour), socio-cultural barriers, stigma and privacy issues (Forbes, Morgan and Janzen 2006; Morgan *et al.* 2002). More recent studies indicate that there is an increasing demand for support in rural communities; however, the range of formal supports required to meet different knowledge and care needs over the course of the illness are under-developed (Forbes *et al.* 2012; Herron, Rosenberg and Skinner 2016; Wiersma and Denton 2013).

In spite of these challenges, people with dementia and their partners actively negotiate the support required to cope with and care for dementia, drawing on positive aspects of rural environments (Blackstock *et al.* 2006; Egdell *et al.* 2010) and developing adaptive coping strategies to meet the demands of care (Branger *et al.* 2014). More information is needed, however, about the place-specific transitions and trajectories of partners in care to help support them and the person with dementia over the course of the condition (Forbes *et al.* 2012). Our paper addresses this gap with a focus on two specific research questions:

1. How do partners negotiate support over time and across different settings?
2. What are the major changes and challenges over the course of the condition?

To examine partners' experiences negotiating support in the community and over time, we take a relational approach.

### **A relational approach to care experiences**

Research on rural dementia has mainly viewed care and rural places in static terms. Rural places, for example, are frequently characterised as homogenous sites for care (*i.e.* all rural places are the same) and care is often described in unidirectional terms, flowing from a partner who provides the care to a person with dementia who receives it. In contrast, a relational approach to care recognises the dynamic, networked and multi-scaled nature of caring relationships (Cummins *et al.* 2007; Wiles 2005). For example, policies and programmes, family structures and dynamics, the opinions and culture of health professionals, and gendered expectations about care come together in the constitution of care at multiples scales (Andrews, Evans and Wiles 2013; Milligan and Power 2010). We draw on a relational approach because we believe it is better suited to examining the dynamics of care over time and across space. Rather than see transitions in care as a part of a linear trajectory that is invariant in time and space, our analysis focuses on how care flows between bodies and across space (Atkinson, Lawson and Wiles 2011). Care is comprised of actions and reactions to people, places and objects which are constantly unfolding (Andrews and Grenier 2015).

Within relational approaches there has been a burgeoning interest in the emotional interconnectedness of people and places, which also informs our analysis. Emotions have a powerful influence on the processes and decisions involved in care. Conceptions of 'good care' often include assumptions about the way it should be performed affectively and the way an individual 'receiving' care should feel (Milligan 2005). Emotions are integral to care work, but they are also integral to understanding settings of care (Herron and Skinner 2013a). For example, older people typically feel a deep sense of personal attachment to their homes and a fear of losing independence when entering a long-term care facility (Wiles 2005). Such reactions reveal how sentiments about place shape relationships to and within space, but also affect the quality of care and often the wellbeing of those involved in the care relationship. Although the emotional nature of peoples' attachment to place and relations of care are at least implicitly acknowledged in research on care, few studies have sought to explore the changing nature of these emotions and their influences over time and in relation to dementia care.

The third and final component of our relational approach to examining care experiences is attention to time. Time can be thought of in terms of the

rhythm of everyday life or as significant events throughout the lifecourse, in terms of routines, in terms of linear expectations related to work, and in relation to bodily needs (Bowlby 2012; Wiles 2003). These conceptions of time are not just quantitative; they acknowledge multiple time scales as overlapping in the lived experiences of care and caregiving. Ultimately, this article seeks to integrate relational perspectives on places of care, emotion, and time to examine how former partners negotiated caring over the course of the condition.

## **Methods**

A qualitative case study approach was used to examine partners' experiences. Case studies are an ideal methodology for exploring complex phenomena, in depth, and with particular attention to contexts and processes (Baxter 2016). In this study, the selection of case study sites was based on information from a larger research project, including information on the proportion of rural service users accessing services from an associated Alzheimer Society (AS)<sup>2</sup> and the socio-cultural characteristics of the rural communities (Herron, Rosenberg and Skinner 2016). Two case study sites were chosen to represent different types of rural regions: one in Southwestern Ontario, a predominantly agricultural region of the province; and the second in Northern Ontario, where resource industries such as forestry and mining have historically been the main economic drivers. In the first site, the associated AS indicated that more than 75 per cent of its clients resided in rural areas and in the second site less than 30 per cent of the AS clients lived in rural areas. As is typical of many rural areas in Canada and elsewhere, both case study sites had proportionately larger ageing populations than the provincial and national average.

Across the two study areas, a total of 27 semi-structured interviews were conducted with former partners (*i.e.* the primary carer for a person with dementia who had died more than one year ago and less than five years ago at the time of the study). Former partners were chosen as informants in this study because of their unique ability to comment on the course of dementia, as a progressive degenerative illness, and transitions in care. Although some research on service needs and use has included former partners as a part of its study design (often alongside current partners), to our knowledge, no other studies have focused specifically on former partners' knowledge and experience as a means of understanding transitions in care. Recruiting partners whose spouse or parent with dementia had died between a year and five years at the time of the study was a crucial part of the research design. We wanted to ensure that participants had sufficient

time to mourn the loss of the person with dementia, but were now in a position to reflect critically on their experiences as partners in care before those experiences became too distant in their thoughts.

With ethics approval from the Queen's University Research Ethics Committee, the partners were recruited through local service providers ( $N = 23$ ) as well as snowball sampling ( $N = 4$ ) in 2013 and 2014. All partners who were approached agreed to participate in the study; many noted that more work needed to be done to improve care for both partners and people with dementia, and they saw research as an important step towards change. The majority of partners were spouses ( $N = 22$ ) to a person with dementia, four were daughters and one was a son. They ranged in age from 46 to 89 years and the majority were female ( $N = 21$ ). On average the partners reported providing care for seven years (ranging from two to 13 years).

A semi-structured interview guide was used to ensure the reliability of data collected. The guide consisted of demographic and contextual questions (*e.g.* How old are you? What was your relation to the person with dementia? How long did you provide care? Did you live with the person?), questions about service use (*e.g.* What services did you use? How did you find out about them? When did you start using the service? How long did you use the service?), and open-ended questions asking participants to describe the settings in which care took place, their experiences negotiating support in each setting, major changes and challenges over the course of the condition, and how partners coped with these changes. All interviews took place in the partners' homes or an AS office and lasted approximately 45–90 minutes. After discussing the purpose of the study, the format and their right to withdraw, partners provided written consent including consent to record the interviews digitally. In addition to standard ethics procedures in qualitative research (*i.e.* informed consent), the first author drew on feminist care ethics to respond to the highly emotional nature of the research with sensitivity to context the consequences of her choices, and her role in responding to participant needs (Herron and Skinner 2013*b*). Although the participants wanted to tell their stories and they were generally calm, most of them became tearful when they were talking about challenges they faced as partners in care. Feminist care ethics provided a framework for thinking through these interactions and responding empathetically rather than focusing on being neutral and objective.

All of the interviews were transcribed verbatim and participants were given the option to review their transcripts to clarify and confirm their accounts. NVivo 10 software was used to store, organise, and code the interview data as well as additional field notes. The first phase of analysis involved initial coding whereby each line or section of the text was coded with a

phrase that captured the meanings and actions (implicit and explicit) of the partners (Charmaz 2014). An iterative constant comparison approach was used to evaluate codes within and across each transcript to ensure that the results were shaped by all the partners' narratives and that the interpretation was both confirmable and credible. A second phase of focused coding was then conducted to synthesise the codes into broader conceptual categories. In the sections that follow, we briefly describe participants' patterns of service use; then we explore how partners moved through the system as well as the temporal, spatial and emotional constraints that emerged in their narratives. The names of people and places have been removed to preserve the anonymity of partners and each partner is identified using a pseudonym, followed by their relation to the person they cared for and their age.

### **Experiencing care-giving over time and across space**

Over the course of the condition, partners identified a series of challenges that included learning how to navigate the system, finding people who understood dementia, seeking support at home, negotiating respite and resistance to care, and making decisions about end-of-life and long-term care. The specific sites and services that addressed these needs changed over time; some services were gradually accepted and others were rejected. Our focus is on the general movement of partners through formal and informal support systems and the changing relationships among different types of support. To begin, we describe which services were most commonly used and the length of time they were used.

#### *Service use over time*

Partners used a range of support services over the course of the condition, including publicly funded home care, services provided by the AS, other community-based services, and private or pay-for-use services. Across both case study areas, publicly funded personal support in the home was the most commonly used support. Partners reported accessing home care later on in the progression of the illness; they used such support for six months to two years. The number of weekly hours of support ranged from two 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 Personal Support Worker, 13 partners reported seeing an occupational therapist in their initial home care assessment, four partners had a recreation therapist come to the home for an hour a week, two partners used a friendly visiting service and 12 partners

made use of a subsidised day programme in the later stages of the condition. Notably, partners beyond those described above were placed on waiting lists for recreation therapy and friendly visiting in the home, but they never received the service. Eighteen partners accessed information and educational materials through the AS lending libraries, their websites and education seminars, and 16 partners went to monthly support groups. Several partners went to support groups for over five years. Moreover, those who engaged with the AS for support did so over a longer period of time in comparison to any other support service and often accessed more community support services in general (*e.g.* day programmes).

### *Navigating the system*

Navigating the system of care was not a straightforward linear trajectory for partners, 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. The AS was generally the first point of contact for information about dementia. For partners who engaged with the AS, the AS 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, one participant explained, 'Because I went to the Alzheimer Society, I learned about the day programme. I don't think I would have known that was available' (Jean, spouse, 65). Other participants explained that the AS helped them to access home care services and 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. Unlike the other support service above, the AS provided a fluid space for ongoing support with a range of services and settings in which these services occurred.

Partners engaged with the AS for different reasons and at different times. A few partners started going to the AS before they had a diagnosis because they wanted more information about signs and symptoms, and some were referred by their family doctors. Although partners were likely to seek information from the AS earlier in the condition, 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. For instance, Jean (spouse, 65) 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!' Such events were often tied to disruptions in long-held routines and/or safety concerns associated with rural work and leisure (*e.g.* concerns that

the person might get lost in a rural area with few or no other people watching or concerns about using heavy farm equipment). Partners who did not engage with the AS until near the end of their caring role did not find it as helpful as those who had gone there at an earlier stage. Partners' narratives highlighted the need for support to navigate the system of care and the importance of receiving that support early in the disease progression.

### *Finding people who understand*

Although rural communities are often associated with strong family and community support networks, most of the partners had limited tangible support from family or friends, whether family was geographically proximate or distant. Joan (spouse, 70) indicated, 'The biggest challenge was that I didn't have any family around' and Betty (spouse, 77) 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.' While Joan's response highlights the changing geography of the family, particularly in rural areas, Betty's response reveals a preference for independence. Typically, other family members offered support through emails, phone calls and occasional visiting. Given family members' distance from the day-to-day demands of care, many partners felt that other family members did not understand fully the experience or needs of the person with dementia, let alone their needs as partners in care.

Outside the family, partners identified a need to find people who understood dementia within their communities. For some people, support groups provided a structure for this kind of support. Margaret (daughter, 73) 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 (laughs).

At both case study sites, several women started informal support groups to augment the AS meetings with more frequent social support. One group included former partners, current partners and people with dementia. They met once a week at a local diner and organised other outings. The group provided partners with reassurance and support to continue to be social at various stages of the illness and after the death of the person with dementia. For example, Diane (spouse, 72) explained that, even after her husband passed away, doing activities with the group helped her to feel that she was not alone. The other group emerged from conversations amongst three friends about the need to 'unload' (Debra, spouse, 74). They



found a psychologist to volunteer with the group once a month, but they met twice a week. These informal groups demonstrate the need for social and emotional support groups in rural communities as well as the agency of some partners to organise effective supports for themselves and others.

Although all partners expressed a need to find people who understood dementia, some partners expressed more traditional rural views about not sharing their experiences with other members of the community. Mary (spouse, 75), Anna (spouse, 68), Fred (son, 61), Linda (daughter, 50) and Daryl (spouse, 89) explained that they did not want to go to a support group. Anna (spouse, 68) 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.' Her comments 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 AS (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?' Partners were aware of variation in services on a regional basis and sometimes expressed frustration about the limited support available in their particular community.

Partners cited lack of respite or alternative care arrangements as a barrier to attending support groups and socialising in general. Linda, who was working full time, explained that she 'dealt with the internet' and Ellen (spouse, 77) explained that because of the constraining nature of her care-giving 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.'

Overall, partners identified a general lack of pre-existing support networks and a need to find people in their communities who understood dementia. They developed a range of strategies to fulfil these needs, from attending organised support groups, to creating informal support groups (often to augment formal groups with more frequent support), to finding practical solutions on the internet. They also identified persistent barriers to accessing support, particularly the need for more home care hours.

### *Seeking home care hours*

As 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 community care access centres (CCACs<sup>3</sup>), partners indicated that they were referred by a doctor, the AS or a friend. A few partners also had

prior experience accessing services through CCACs. Not knowing about the CCAC did not appear to be an issue for people with a doctor and/or accessing services from the AS; however, the compatibility of home care in terms of eligibility, scheduling, and consistency and quality of workers affected use over time.

Initially, some partners indicated that they put off calling the CCAC because they 'were managing ok' (Anna) or the person with dementia 'was fine' (Mary). They emphasised their ability to do the work of caring while rejecting the notion that they might need help. Some partners were encouraged by the AS 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 (daughter, 46) 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 might 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 (spouse, 86) 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 (laughs).' 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. One partner explained that she started recording the 'down side' of things that she had previously ignored, so she could continue to cope and care for her spouse (Jean, spouse, 65). These 'data' helped her to advocate far more effectively for support from the CCAC. Taken together, these accounts illustrate a range of institutional, interpersonal and emotional barriers to accessing home care, which are not necessarily specific to rural and small-town settings.

In addition to qualifying for certain kinds of support, partners identified issues related to their rural geography. For instance, Jean (spouse, 65) and Linda (daughter, 50) were frustrated with care workers showing up late or leaving early to get to their next appointment. Jean (spouse, 65) reasoned that this was largely a scheduling issue with the CCAC: 'I don't think they have any idea about geography.' She believed that distance between

clients and poor weather conditions were not accounted for when scheduling home care and that these were consistent reasons for late and shortened hours. 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 Personal Support Worker in the home more stressful. Joyce (daughter, 60), who cared for her mother, summarised 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 scheduling would not allow them to do 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.

Over time, many partners found that the hours of home care available to them were inadequate. In particular, partners identified the need for respite hours during the night. Although some partners 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. Pam (spouse, 78) 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 described the night work of listening, following and leading the person 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 affected their capacity to continue caring for the person with dementia at home as they experienced increasing fatigue.

### *Resistance to respite*

The majority of partners experienced some resistance in getting the person for whom they cared to go to a residential respite programme. Some partners could not get the person they cared for to agree to try such a programme. For instance, Joan resigned herself, 'he just wouldn't go'. Anna poignantly explained her husband's continued resistance to the programme:

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 programme 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.

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 (relevant to urban and rural contexts). 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 programme. They viewed resistance as a valid response to what looked like more of a ‘sitting service’ than meaningful activity (Jean, spouse, 65). Moreover, partners identified lack of any time and space to one’s self as a common and increasing constraint in the later stages of the condition. They 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 and other partners felt unable to relax at home. Evelyn (spouse, 75) explained, ‘you go and lay down but you’re really not resting because you’re listening to every noise’. Partners struggled to negotiate meaningful activities for the person with dementia and realise their own desires for respite.

### *Making decisions about end-of-life care*

End-of-life care played an extensive and powerful role in partners’ experiences. It influenced, and was influenced by, other relationships, sites and services along the care trajectory. 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’. Indeed, the wishes of the person with dementia, sometimes long before a dementia diagnosis, placed significant strain on partners as they made end-of-life care decisions. Most partners sought to keep the person they cared for at home for as long as possible. Mary (spouse, 75) explained her choice, saying:

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.

Many partners felt pressured into and ‘fought’ long-term care placement (June, spouse, 84). As one daughter caring for her mother 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 [hospice]’ (Elizabeth, daughter, 65). Most partners 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. They reasoned that they might have been able to care for them at home, had they known how little time was left. The partners’ sentiments reflected the complex relationship between home and long-term care and the lack of alternative residential care settings in rural areas, as well as the lack of home care hours available to keep people in the later stages of dementia at home.

## Discussion

Our findings identify a range of supports that partners use, including the most common support services (*i.e.* publicly funded home care), and the most wide-ranging supports in terms of length of use and qualitative impact on partners’ experiences (*e.g.* AS). Partners’ narratives identify a lack of availability of home care and other home-based supports (*e.g.* recreation and leisure therapy and friendly visiting). They also confirm the enduring challenges of system navigation for people with dementia and their partners (Forbes *et al.* 2012; Morgan *et al.* 2002). Some system navigation issues appear to be ameliorated for partners who engaged with organisations focused on community services for people with dementia (*e.g.* the AS), particularly early in the disease progression. The AS provided long-term support and helped connect partners to other community resources. Future policies and programmes should continue to facilitate early contact with organisations such as the AS to help to address system navigation issues. The bigger questions are how and whether governments are willing and able to support organisations to play this role or whether governments should provide services directly to people with dementia and their partners. At present, the AS occupies a liminal space in the care trajectory as a non-profit organisation outside the formal health-care system with public funding for different services from one health region to the next (*see* Herron, Rosenberg and Skinner 2016).

In negotiating support, partners identified a need to find people who understood dementia in their communities. The emergence of informal support groups developed by partners in an attempt to fulfil their need for more regular social and emotional support is both a positive story of community resilience, but is also a negative story in that it reflects the lack of formal support and the precarious nature of voluntarism in rural communities. Consistent with other research, rural partners did not always have existing support networks in place; however, they drew together other AS clients and friends to form informal support networks (Egdell *et al.*

2010). Future research should explore the contextual factors that influence the capacity and sustainability of informal support groups and how organisations such as the AS can encourage the development of such groups as a means of extending their own capacity for community support. It is, however, important to note that some people in rural communities are reluctant to access group support and certainly not everyone is well-positioned to create their own group.

Over time, partners' experiences of care were constrained within rural and small-town settings and the current systems of home, community and long-term care. In particular, partners identified limited and inflexible home care hours as constraints to their getting out of the house and caring for themselves. They also identified significant emotional barriers in negotiating more support with the person with dementia for whom they cared. Partners limited their use of home care and respite in relation to experiences of emotional strain in their care relationships. In spite of fatigue and behavioural challenges, they felt obligated to keep the person with dementia at home, citing the wishes of the person with dementia as well as staff training and shortages as reasons why their care would be better than long-term care. None of these particular findings are exclusive to rural contexts; they reflect issues and changes that would benefit partners in care across a range of geographic contexts.

Previous studies have failed to acknowledge the continued knowledge and contributions of former partners in care as well as the complex relational dynamics of negotiating support. Taking a relational approach, we demonstrate how the use of services is inter-related. AS support influences use of other community supports; home care influences access to support groups and social support more broadly; and the emotional dynamics of care influences access to services such as respite and end-of-life care. Moreover, the experiences of partners in this study reflect the range of care needs, constraints and choices in rural settings, all of which are relational in nature. Although the majority of care for dementia takes place in the home, the ability of partners to cope with the demands of caring over time is strongly related to external supports. The emotional geographies and temporalities of caring at home can have detrimental effects on the mobility and health of partners.

## **Limitations**

Although some researchers suggest that there is a recall bias in asking participants to reflect on their needs and challenges, particularly after an extended period of time (*e.g.* more than a year), studies have found that

these accounts have a high degree of consistency and credibility (Morse 2011). Particularly for individuals who have dealt with bereavement, we suggest that the waiting period allowed partners to grieve, participate when they had more time and comment critically about services without feeling threatened that such criticisms might influence the support they received. The experiences of former partners are an invaluable resource in evaluating the range and fit of services for people with dementia and their families over time and across space. They reveal the lasting emotional impact of caring for and about dementia.

There are several groups which are under-represented in this study. First, there were only a small number of male partners in care in the study. Secondly, 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. The perspectives of Aboriginal people should be included in rural dementia care research through a separate community-based participatory research project. Finally, although not all participants were recruited through the AS, the experiences of those who are perhaps most in need of support (*i.e.* those without a diagnosis or access to services) are not reflected in this study.

## Conclusions

The findings of this research contribute a unique understanding to the challenges faced by partners in care using a relational approach to the study of older people and the services they require in rural communities. Most importantly, the findings highlight the potential negative consequences of ageing at home policies for partners in care. While partners and the people for whom they care want to stay at home, the fit and frequency of support is not enough for most people to achieve this goal without paying high costs, emotionally and physically (*see* Herron and Rosenberg 2017). Furthermore, some programming fails to appreciate the sometimes diverging needs of both partners in the care relationship. Looking at how partners negotiate support over time, we see the need for more frequent and earlier social support services, as well as major changes and challenges in relation to navigating the system, finding people who understand dementia, getting more home care hours, managing resistance to respite and making end-of-life care decisions. Solutions to these issues must take into account the dynamic nature of care and the importance of rural contexts. Without greater sensitivity to the emotional and temporal dynamics of caring for dementia, partners in care will continue to be trapped within the systems

of home, community and long-term care that fail to satisfy the needs of people with dementia or their partners in care.

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## NOTES

- 1 We use this term to refer to family or friends who are supporting a person living with dementia, as suggested by some interviewees and consistent with the Alzheimer Society of Canada and scholars in the dementia care field (see Dupuis *et al.* 2012). A language of partnership recognises the interrelated needs, challenges and contributions of people with dementia and those supporting them.
- 2 The Alzheimer Society is a non-profit organisation that provides support for persons with dementia and their families through information sessions, support groups, educational resources and a range of locally specific services. For more information, see <http://www.alzheimer.ca/en/on>.
- 3 Community care access centres are provincially funded organisations which are mandated to assess the service needs (medical and non-medical) and provide the services for people in need of home care in Ontario.

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