

# RESEARCH CONNECTION

## Improving rural dementia care

By Rachel Herron, Ph.D.



### Why this research is important

In Canada, over 500,000 people live with some form of dementia. Dementia refers to a range of complex progressive degenerative conditions, such as Alzheimer's disease and vascular dementia, which affect a person's memory, language, judgement, and attention. People with dementia and their partners in care experience different needs depending on the severity of the condition; however, in many places, people with dementia and their partners in care do not experience the quality and kind of support they need. This study focused on rural and small town Ontario because rural people, in Canada and internationally, typically face additional challenges getting appropriate health and social care. It provides a foundation for Dr. Herron's ongoing research about supporting people with dementia and their partners in care in rural Manitoba.

### What you need to know

Voluntary organizations play an important role supporting people with dementia and their partners in care. However, there is variation in volunteer capacity across different rural communities and over the course of the condition. Overall, one of the most underdeveloped areas of support is meaningful support for people in the early stages of dementia. Future research and programming need to examine the development of a wider range of opportunities for people with dementia to contribute and participate more actively in their communities.

### How the research was conducted

The findings of the study are based on the experiences of people caring for, and living with, dementia. To collect these first-hand accounts, Dr. Rachel Herron conducted a province-wide survey of Alzheimer Society (AS) chapters in Ontario and 73 semi-structured interviews with partners in care (both present and former) and people with dementia living in rural and small town settings. The survey of AS chapters provided information about the services available across the province of Ontario and identified challenges related to delivering appropriate support, specifically to rural populations. The survey information was then used to select study sites to explore experiences of dementia through in-depth interviews.

The interviews with people with dementia and partners in care provided personal evaluations of care needs and challenges in particular community contexts. They took place in partnership with three AS chapters: Kingston, Frontenac, Lennox and Addington; Grey-Bruce, and Sault Ste. Marie Algoma. Overall, the research participants identified both challenges and opportunities to improve dementia care in rural and small town settings.

### What the researcher found

The study found variation in the services available across the province of Ontario. In general, support services for people with early stage dementia were underdeveloped in many of the chapters outside of major urban centres. The majority of AS chapters in the survey served rural populations and they identified particular challenges in reaching these populations. AS chapters observed that rural service users typically took advantage of fewer in-office services. However, they consumed more time and resources in transportation and more one-on-one home visits than their urban counterparts. People with dementia in the study delayed seeking formal support because they did not feel they were “there yet.” They suggested that the services available did not reflect their interests or abilities. They expressed a strong desire to continue to contribute to their communities, homes, and surrounding environments. On the other hand, partners in care were more likely to initiate and encourage service use than people with dementia. Partners in care explained a number of ways in which they were constrained by the lack of available support in the home and community settings. Lack of early stage support and consistent services places increasing demands and constraints on partners in care.

### How this research can be used

Ultimately, the key findings from the study identify the challenges and potential of caring for dementia in rural and

small-town settings. Significant work remains to improve the accessibility and acceptability of care across rural and small town settings and over the course of the illness. Many successful programs exist but they need to reach rural people and respond to their interests and capacities. Dr. Herron’s ongoing research in Manitoba draws on the gaps identified from this broader research project to focus on innovative program solutions and the needs of isolated partners in care.

### About the researcher

Dr. Rachel Herron is an Assistant Professor at Brandon University who specializes in health geography and rural health and aging research. She is also a member of the Gender and Women’s Studies Department at Brandon University.

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### Keywords

dementia, care, rural, voluntary sector

### Publications based on the research

Herron, R. V., Rosenberg, M. W., & Skinner, M. W. (2016). The dynamics of voluntarism in rural dementia care. *Health & Place, 41*, 31-41.

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