Summary of the Saskatchewan Rural and Remote Memory Clinic

The Rural Dementia Action Research (RaDAR) team came together in the early 2000’s as a group of researchers at the University of Saskatchewan who had a common interest in dementia care. The original impetus came from Dr. Debra Morgan PhD in the Canadian Centre for Health and Safety in Agriculture but researchers in sociology, human geography, neuropsychology, nutrition, nursing, radiology, and neurology were amongst the original members. Our flagship project was the Rural and Remote Memory Clinic which is ongoing.

There are several reasons why this project was important:

1. The prevalence of dementia is increasing as the population ages.

2. There is a large rural population in Canada (30% of the population) and particularly in Saskatchewan (49% of the population) who often have difficulty accessing the same variety and quality of health care available in cities.

3. Saskatchewan has a large elderly population (14.6% of the population is over 65).

4. Seniors are more likely than younger persons to live in rural areas.
5. A large geographic area. Saskatchewan is almost the size of Texas but has only 1 million people whereas Texas has a population of 27 million people. Across Canada we have plenty of wide open spaces that are sparsely populated.

The Alzheimer’s Society of Saskatchewan in 2004 put together a strategy for Alzheimer’s disease and related dementias and a focus group member said “it was like climbing a mountain to get a diagnosis”. Our aim was to make that mountain much easier to ascend.

The goal of the Rural and Remote Memory Clinic was to bring the resources of a large tertiary care hospital, Royal University Hospital at the University of Saskatchewan, to people living more than 100 km away from Saskatoon or Regina. The goal was to develop and evaluate a streamlined interdisciplinary “one stop shopping” clinic for patients from rural and remote Saskatchewan for diagnosis and management of dementia and to evaluate telehealth as a means of delivering follow-up care to patients and their family.

Patients are referred to the clinic by their family physician or nurse practitioner and the referrals are reviewed by a neurologist to ensure that they are appropriate. There is an initial telehealth visit with the clinic nurse and neuropsychologist who orient the patient and family to the clinic process. The patient’s blood work is also done at this visit. On clinic day the patient and family travel to Saskatoon for a one day assessment. There patients are assessed jointly and individually by a neurologist, neuropsychologist, physiotherapist and dietician. They also have their neuroimaging performed.

Our original neuropsychologist, Margaret Crossley, recognized that many popularly used neuropsychological assessments were not necessarily appropriate for people in a prairie environment particularly for those in the north and particularly for those living on reserves. For example, the Buschke cued recall test was adapted by her into a pictorial prairie Buschke which instead of using urban objects like buses and foreign objects like elephants uses prairie objects like canoes, baskets and deer.
At the end of the clinic day there is an interdisciplinary meeting of all the professionals involved. The family doctor is welcome to be present at the discussion via telephone. There is then a meeting with the patient and family to discuss diagnosis and treatment. Follow-up is then via telehealth with the clinic neurologist. Patients remain in their home community and are assessed via video-conferencing.

Of our first 500 patients seen 44% had Alzheimer’s disease, 15% mild cognitive impairment, 14% could be reassured that they were normal, 10% had frontotemporal dementia, 5% Lewy body dementia, 5% vascular dementia, 3% mixed vascular/Alzheimer’s dementia. These have been the most common diagnoses to date.

For our first 363 patients the mean round trip distance to telehealth was 71 km. The mean round trip distance to Saskatoon was 529 km for a distance saved of 458 km per visit. 100% of families and patients said they would use telehealth again and 97% said that they would recommend telehealth to another person.

The clinic began as a Canadian Institutes of Health Research (CIHR) project and, as this was the world’s first clinic of its type, it was important to show that telehealth was a valid way of following patients with dementia. Although all of our follow-up visits are now done via telehealth, patients were initially seen in follow-up at six weeks, twelve weeks, six months, twelve months, and annually thereafter plus visits as required and were randomly assigned to have their first visit either in person in Saskatoon or via telehealth and visits then alternated between telehealth and in person. After our first 58 patients were seen we examined satisfaction with appointments and found that there was no significant difference in satisfaction between telehealth appointments and in person appointments. However, when we looked at convenience of appointments telehealth appointments were rated as highly significantly more convenient.

We next needed to show that it was possible to do simple neuropsychological follow-up testing over telehealth. The mini mental state examination (MMSE) is a commonly used cognitive screening test.
When we compared in-person versus telehealth scores for our first 71 patients there was no significant difference between MMSE scores, demonstrating that telehealth is a valid way to follow mental status.

It has been said that Canada is a nation of pilot projects. This project began with funding from CIHR for five years. At the end of this research funding, although our health region recognized the value of the project they were not willing to fund it. Fortunately the provincial government recognized that this was an important service and has since been funding it directly at a level that enables us to do this clinic one day a week. More funding could enable more patients and families to be seen.

We thus have shown that a multidisciplinary “one stop shopping” rural and remote memory clinic with telehealth follow-up is a convenient, valid, effective, and transferrable way to improve the care of those with dementia and their families.

Dementia is very common and there are a large number of people affected by it across the country. A clinic like ours does not have the capacity to see every person with dementia and we focus on community dwelling individuals with cognitive concerns whom primary care practitioners have found difficult to diagnose or manage. Thus, as part of the Canadian Consortium on Neurodegeneration in Aging (CCNA), we are now focusing on improving primary health care approaches to dementia. Most current approaches to dementia care are urban, based in areas with a high density of patients. Rural primary health care teams thus may not have best practices to guide them. Our current research is therefore evaluating strategies to support functional interdisciplinary rural primary health care teams that can deliver coordinated dementia care, education and support. We are developing dementia education resources to deliver to family physicians and nurse practitioners over telehealth in a rural health region in Saskatchewan and are adapting point-of-care decision support tools developed in another province to the rural Saskatchewan environment.

Dr. Julie Kosteniuk, a RaDAR team member, is also leading work in collaboration with the Saskatchewan Health Quality Council to examine
dementia incidence and prevalence, as well as patterns of health service use in Saskatchewan administrative health databases. This work will inform health service planning and policy.

Dr. Megan O’Connell, a neuropsychologist with the Rural and Remote Memory Clinic, pioneered the use of caregiver telehealth support groups for spouses of patients with frontotemporal dementia. This has been very helpful as the distances between these people dealing with a less common form of dementia are vast. Dr. O’Connell has also, in collaboration with Dr. Vanina Dal Bello-Haas, a physiotherapist who was a team member, piloted exercise intervention as well as cognitive rehabilitation via telehealth.

Challenges for patients and families with dementia that are particular problems in a rural environment:

1. Transportation. Dementia often results in loss of driving privileges. This is difficult enough in cities where taxis and buses are usually readily available. In rural areas those living on farms have long distances to travel even for routine shopping. Taxis and buses are not available.

2. Isolation: Rural patients are more likely than urban patients to have children who have moved away from the area and are therefore unavailable to be of much help in day to day care. This increases the need for other forms of care such as home care.

3. Access to Diagnosis. It is more difficult for rural patients to travel to see specialists and several studies have shown that rural patients are less likely to be referred to specialists than are urban patients for dementia assessment. Specialist physicians are generally clustered in larger urban centers resulting in long travel times. Persons with dementia are not at their best when assessed after travelling hundreds of kilometers. Research is important to improve primary care as many rural patients will have little access to specialist physicians.

4. Cultural Issues. It needs to be recognized that patients from the non-majority culture may need more culturally sensitive assessments.
For example, neuropsychological tests often include items that are not terribly relevant to persons living in a northern aboriginal community.

5. Access to Caregiver Programs. In cities caregiver support groups are common and, because of the high density of people with dementia, are relatively easy for caregivers to attend. In remote areas, especially for caregivers of those with less common types of dementia such as frontotemporal dementia, the nearest person with similar issues may be hundreds of kilometers away. Telehealth support groups can help fill that gap. Investment in the Alzheimer’s Society’s First Link program also helps with patient and caregiver support.

6. Primary Care Education. Physicians and nurse practitioners in rural areas often have more difficulty attending educational events. Our surveys have demonstrated that rural family physicians often rate themselves as not confident in diagnosing dementia or in having some of the difficult conversations that are needed such as those around driving.

7. Diabetes and other medical conditions that are risk factors for development of dementia are increasingly common in First Nations communities. There is thus a looming wave of dementia in this relatively young population. It can be difficult to eat well in many rural and northern communities as fruits and vegetables can be much more expensive than in cities.

**Recommendations to help with some of these issues:**

1. Transportation. Subsidized and/or free transportation would be a boon to persons with dementia who are no longer able to drive.

2. Caregiver Support. Telehealth support groups are a demonstrated means of delivering caregiver support over large areas.

3. Homecare. It is much less expensive to care for persons with dementia at home rather than in institutions and better availability of homecare is important. Increasing the number of home care staff as well as the hours of service allotted to individuals with complex needs, such
as older adults with dementia particularly with other chronic conditions would be a real boon to these patients and their families.

4. Culturally Relevant Assessment Tools. As discussed above.

5. Chronic Disease Management Plan. In many provinces chronic disease management plans enable primary health care workers to use best practices to better track and manage chronic health conditions. These programs often include fee incentives to primary care physicians who use them. Development of such a tool for dementia would be useful.

6. More Primary Care Education on Early Diagnosis and Management of Dementia. This is important for health care professionals across all health sectors as is continuing education. Many patients with dementia unfortunately are going undiagnosed. In Scotland, a successful national strategy to improve diagnosis involved quotas requiring family doctors to make more diagnoses of dementia.

7. Research on Dementia Care. There appears to be no imminent cure for dementia. Therefore, in the meantime it will be important to fund research into better models of care.

8. Task Sharing. There is a strong need for excellent primary care but at the same time there is a strong need for excellent specialist support to primary caregivers. Training and assistance provided by specialists can be invaluable in rural primary care. These specialists include neurologists, geriatricians, and geriatric psychiatrists.

9. Tracking Quality Indicators. If we don’t know how we are doing in a given health region in meeting the health care needs of those with dementia, it is difficult for us to improve. Tracking indicators of quality may be useful in ensuring quality.

10. More use of telehealth technology. Our clinic has shown that telehealth is a useful way of following patients with dementia. This is relevant in many other areas of Canada and the world where there are large numbers of rural patients with dementia.
11. Investment in control of diabetes and other dementia risk factors in First Nations.

12. A national dementia strategy would be very useful in planning for the rising tide of dementia, rural and urban.

13. Better funding mechanisms for innovative programs with demonstrated effectiveness such as the Rural and Remote Memory Clinic which came very close to becoming one of those discontinued pilot projects. Our clinic almost became another successful pilot project that fell by the wayside due to lack of funding. We’re fortunate to be funded by the province of Saskatchewan but the level of funding limits us to a clinic one day a week. With funding for a full-time neuropsychologist, for example, we could help many more people and families dealing with dementia.

I recognize that many of these issues are a complex combination of provincial and federal responsibilities.

Further Reading:


