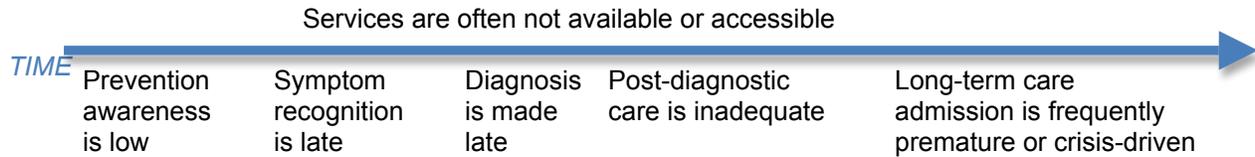


KEY MESSAGES

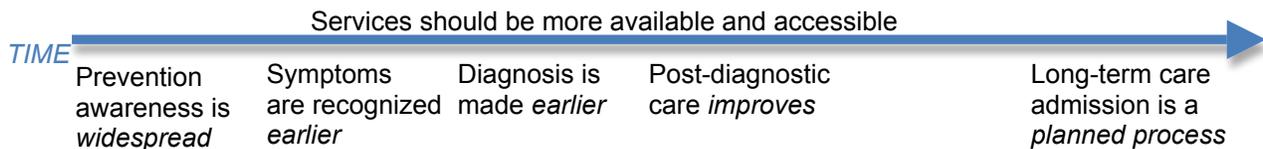
The current picture of healthcare services for rural people with mild cognitive impairment and dementia and their caregivers, according to Planning Session participants:



Gaps in healthcare

- ✦ Symptoms of mild cognitive impairment (MCI) and dementia are challenging to recognize early in the disease for families and healthcare professionals, and may be attributed to normal aging. Some people feel that a diagnosis of dementia carries a stigma.
- ✦ Families typically seek help when they have reached a crisis point. As a result, diagnosis is frequently delayed.
- ✦ Post-diagnostic care services are not consistent across the province and can be difficult to access, such as primary care and home care services.
- ✦ Long-term care admission is frequently either premature or crisis-driven. Individuals with dementia and their caregivers do not receive the range of services they need in order remain as independent as possible and to stay in their own homes for as long as possible.

The way healthcare services should look for rural people with mild cognitive impairment and dementia and their caregivers, according to Planning Session participants:



Improve healthcare by:

- ✦ Improving early recognition of mild cognitive impairment (MCI) and dementia symptoms among the public and healthcare professionals.
- ✦ Improving access to early diagnosis of MCI and dementia among the rural and remote population.
- ✦ Improving post-diagnostic care for rural and remote people with MCI and dementia and support to their caregivers throughout the continuum of care.
- ✦ Supporting caregivers to allow people with dementia to stay in their homes longer, reduce caregiver distress, and delay admission to long-term care.

Key recommendations by participants:

- ✦ Develop dementia care facilitators to provide case management and system navigation
- ✦ Offer education and training to improve the knowledge base of healthcare professionals
- ✦ Establish guidelines to improve prevention, early detection, and diagnosis
- ✦ Introduce care pathways for primary healthcare professionals
- ✦ Support a provincial and national strategy for dementia
- ✦ Lobby provincial government to recognize dementia as a chronic disease

1. EXECUTIVE SUMMARY

Team Objectives

Our team's objectives are to develop and implement an interdisciplinary and cross-jurisdictional (national and international) program of research to improve the delivery of healthcare to persons with mild cognitive impairment (MCI) and dementia and their caregivers in rural and remote primary healthcare settings.

Background

Our team has been working together since 2003 to deliver services, in person and by telehealth, to persons with dementia in rural and remote (northern) Saskatchewan through the Rural and Remote Memory Clinic in Saskatoon and related projects (e.g. telehealth support group for caregivers). With Dr. Debra Morgan as Principal Investigator, the team was originally funded in 2003 by Canadian Institutes of Health Research (CIHR) as a "New Emerging Team (NET)." Saskatchewan Health has continued to fund the Rural and Remote Memory Clinic's services since the research demonstration project ended in 2009. Since then, the NET team has continued its momentum with research funding from CIHR and the Saskatchewan Health Research Foundation, with guidance from a 27-member Decision-Maker Advisory Council. Other funding organizations have also provided support for research, trainees, and research-related travel.

The Rural and Remote Memory Clinic in Saskatoon provides diagnostic support, management, and follow-up for rural and remote patients presenting with atypical and complex cases of dementia and mild cognitive impairment. However, the clinic also receives referrals for relatively uncomplicated patients, indicating that family physicians are not sufficiently prepared to meet the current need for diagnosing and managing patients with Alzheimer's disease and other dementias. In addition, our team's research over the last several years points to a significant need for new ways to deliver care to people with mild cognitive impairment and dementia, as well as to their caregivers.

The impetus for the October 17th Planning Session was supported by a call from CIHR for Planning Grant applications of \$25,000, to enable researchers and stakeholders to meet face-to-face and develop plans for a full Community-Based Primary Healthcare (CBPHC) Innovation Team Grant. CIHR plans to fund a number of CBPHC Innovation Teams in the area of primary healthcare for a minimum of five years, with the possibility of extension to ten years.

Planning Session Objectives

We had three specific objectives for the October 17th Planning Session:

- bring together researchers, stakeholders, family caregivers, and international experts to identify important issues in primary healthcare for people with MCI and dementia and their caregivers living in rural and remote areas
- identify innovative and feasible service delivery models to improve primary healthcare for people with MCI and dementia and their caregivers living in rural and remote areas
- establish relationships with stakeholders who are interested in working with our team to implement future intervention projects in Rural Dementia Care

Method

The one-day Planning Session was held at the Sheraton Cavalier Hotel in Saskatoon on October 17, 2011. A number of stakeholder groups were invited to the Planning Session, including family physicians and Nurse Practitioners; health region directors of primary healthcare, chronic disease

management, long-term care, and Home Care; and selected past participants of the Annual Knowledge Network in Rural and Remote Dementia Care Summit, including family caregivers of Rural and Remote Memory Clinic patients. Prior to the Planning Session, we mailed a binder of meeting documents by post to each participant.

The Planning Session included brief presentations in the morning by Dr. Debra Morgan (Team Principal Investigator), Dr. William Albritton (Dean of College of Medicine, U of S), and Sheila Achilles (Director, Primary Health Care and Chronic Disease Management, Saskatoon Health Region). A session of focus groups and a facilitated panel discussion followed. During the afternoon session, our Team's international collaborators, Dr. Sridhar Vaitheswaran (Consultant Old Age Psychiatrist, Scotland) and Alan Murdoch (Dementia Services Development Manager, Scotland), presented their program of telepsychiatry in dementia service delivery in the remote Shetland Islands in Scotland. This presentation was followed by a second session of focus groups, a facilitated panel discussion, and a self-administered survey of Planning Session participants that identified challenges and solutions to implementing interventions.

Planning Session participants were asked to discuss the following five questions during the morning and afternoon session of the focus groups:

Thinking of people with dementia and their caregivers in rural and remote areas:

- *What are the gaps in primary healthcare (i.e., pressing issues or challenges)?*
- *What are the reasons for these gaps?*
- *How can these gaps be resolved?*
- *What objectives should be kept in mind when designing services to provide primary healthcare to this group?*
- *What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?*

Ethics approval was obtained from the University of Saskatchewan Behavioural Research Ethics Board (BEH# 11-192) to collect focus group and survey data during the Planning Session.

Results

The Planning Session was attended by 53 stakeholders and 13 co-investigators, collaborators, and research assistants. Stakeholders included health region directors, family physicians, nurse practitioners, family caregivers, the Alzheimer Society of Saskatchewan, Health Quality Council, and health region employees.

Participants identified the following gaps in primary healthcare for people with dementia and their caregivers in rural and remote areas:

- Symptoms of MCI and dementia are challenging to recognize early in the disease for families and healthcare professionals, and may be attributed to normal aging. Some people feel that a diagnosis of dementia carries a stigma.
- Families typically seek help when they have reached a crisis point. As a result, diagnosis is frequently delayed.
- Post-diagnostic services are not consistent across the province and can be difficult to access, such as primary care and home care services.
- Long-term care admission is frequently either premature or crisis-driven. Individuals with dementia and their caregivers do not receive the range of services they need in order remain as independent as possible and to stay in their own homes for as long as possible.

The following reasons for gaps in primary healthcare for people with dementia and their caregivers in rural and remote areas were singled out by participants:

- Insufficient education for healthcare professionals and the general public resulting in inadequate public awareness and stigma
- Rural isolation and a need for travel to access diagnostic and supportive management services in cities
- Human resource shortages
- Rigid health region boundaries, and services that are inconsistent across health regions
- Inadequate public funding for services and costs to rural patients and families to access private services

According to participants, the objectives that should be kept in mind when designing services to provide primary healthcare to persons with dementia and their caregivers include:

- Improving early recognition of MCI and dementia symptoms among the public and healthcare professionals
- Improving access to early diagnosis of MCI and dementia among rural and remote populations
- Improving post-diagnostic care for rural and remote people with MCI and dementia and support to their caregivers throughout the continuum of care
- Supporting caregivers to allow people with MCI and dementia to remain functionally independent, in order to stay in their homes longer, reduce caregiver distress, and delay admission to long-term care

The specific interventions that should be included in rural primary healthcare for persons with dementia and their caregivers, as identified by participants:

- Develop dementia care facilitators to provide case management and system navigation
- Offer education and training to improve the knowledge base of healthcare professionals
- Establish guidelines to improve prevention, early detection, and diagnosis
- Introduce care pathways for primary healthcare professionals
- Support a provincial and national strategy for dementia
- Lobby provincial government to recognize dementia as a chronic disease

Next Steps

Based on the results of this Planning Session and subsequent meetings, our team intends to develop innovative ways to improve the delivery of healthcare to persons with mild cognitive impairment and dementia and their caregivers in rural and remote settings. Our team intends to:

- ✦ Consult with individual stakeholders to identify primary healthcare interventions that build on existing resources (e.g., Alzheimer Society of Saskatchewan)
- ✦ Lobby the provincial government to provide funding for pilot interventions
- ✦ Work with health regions to further develop feasible and effective primary healthcare interventions
- ✦ Conduct a baseline provincial (and regional level) study to determine current rates of healthcare and social service use, identify gaps in care and support services, and target potential areas for quality improvement
- ✦ Develop a CBPHC Innovation Team Grant proposal to submit to CIHR in Fall of 2012

Suggested citation format: Morgan D., Kosteniuk J., Crossley M., O'Connell M., Kirk A., Stewart N., Dal Bello-Haas V., Forbes D., Innes A., Keady J., Vaitheswaran S., & Murdoch A. *Report on the Community-Based Primary Healthcare Team Grant Planning Session, October 17, 2011, Planning for the Rising Tide: New Models of Rural Primary Healthcare for Persons with Dementia*. Saskatoon, Saskatchewan: University of Saskatchewan