



Rural Dementia Action Research (RaDAR) Team
and
Health Quality Council



2015

A Multi-Method Investigation
of Dementia and Related Services
in Saskatchewan
FINAL REPORT AND RECOMMENDATIONS

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Abbreviations used throughout the report:

AD = Alzheimer's disease
ADI = Alzheimer's Disease International
ADRD = Alzheimer's disease and related dementias
AM Care = Morning care
ASOS = Alzheimer Society of Saskatchewan
CM = Case Manager
HC = Home Care
HQC = Health Quality Council
HS Care = Bedtime care
LTC = Long-term Care
MMSE = Mini Mental State Examination
MoCA = Montreal Cognitive Assessment
PAR = Population at risk
PCH = Private Care Home
PRN = When necessary
PT/OT = Physical Therapy/Occupational Therapy
RaDAR Team = Rural Dementia Action Research Team
RN = Registered Nurse
SW = Social Worker
WHO = World Health Organization

This study was conducted, in part, with data provided by the Saskatchewan Ministry of Health to the Health Quality Council. The interpretations and conclusions herein do not necessarily represent those of the Saskatchewan Ministry of Health or Government of Saskatchewan.

Executive Summary

Background

Worldwide, it is estimated that there is one new (incident) case of dementia every 4 seconds, or 7.7 million incident cases each year (WHO and ADI 2012). The most recent estimates show that 44 million people now live with dementia (prevalence), projected to increase to 135 million by 2050 (Prince et al. 2013a). Among individuals aged 60 years and over in 2010, dementia prevalence was between 5-7% worldwide; dementia onset before the age of 65 (i.e., early onset dementia) was estimated to account for 6-9% of all prevalent cases (WHO and ADI 2012). International recognition of the association between population aging and the growing numbers of individuals with chronic and degenerative diseases has resulted in greater attention on dementia as a significant global health challenge (WHO and ADI 2012).

In 2011, a planning session hosted by the Rural Dementia Action Research (RaDAR) Team and attended by key stakeholders highlighted some stark deficiencies in our knowledge about the epidemiology of dementia in the province of Saskatchewan and the nature of related services available to individuals and their families. To date, little research has been carried out to examine the scope of dementia and dementia care across the province. Although published *estimates* of dementia incidence and prevalence for Saskatchewan do exist, the most recent estimates are based on a combination of 1991 data from the Canadian Study of Health and Aging and 2005 data from a review of European Union studies (Smetanin et al. 2009).

Epidemiological data that is as current as possible, and that combines both community-based and long-term data, can inform policy decisions that affect individuals with dementia and their families living in every corner of the province. To this end, this study provides an up-to-date comprehensive picture of the epidemiology of dementia in the province of Saskatchewan - based on physician, hospital, prescription drug, and long-term care data - as well as an overall scan of the availability and quality of local services for individuals with dementia in the province.

Objectives

In partnership with the Saskatchewan Health Quality Council, this report involves a comparison of actual to best practices in dementia care, with three components:

- 1) A review of best practices across the care continuum of health and social services for individuals with dementia and their families
- 2) An analysis of administrative health data to determine the 12-month incidence and prevalence of dementia among individuals aged 45 and older in the province of Saskatchewan by database of identification, demographic characteristics (age group, sex, and rural/urban residence), and health region
- 3) An environmental scan of dementia-related services and resources across the continuum of care, specifically service availability and primary health care orientation of such services, provincially and by health region

Methods

For the **best practice review**, 12 national dementia plans were identified from the Alzheimer Disease International website; nine plans were evaluated with a qualitative narrative approach to identify the common themes in best practices in each country's plan. For the **administrative data analysis**, data were extracted from

10 provincial health databases linked by a unique health services number. The cohort included individuals aged 45 years and older at their first-ever recorded identification of dementia in one of four administrative health databases (Hospital Discharge Abstracts, Physician Service Claims, Prescription Drug, and RAI-MDS, i.e., Long-term Care). The numbers of incident (new) and prevalent (existing) dementia cases were calculated for the 12-month period from April 1, 2012 to March 31, 2013. The environmental scan data were collected June to December, 2013 using a cross-sectional survey of Home Care Assessors serving communities in Saskatchewan. We evaluated the availability of services across the care continuum (health promotion, primary health care, post-diagnostic care, home care, and long-term care) and the orientation of dementia-related services toward key dimensions of primary health care, in communities served by the Assessors.

Key Findings

The main findings for each of the three components of this study are reviewed below.

Best Practice Review

Nine national dementia plans were included in the review of best practices: Australia, England, Finland, France, Norway, Scotland, Northern Ireland, United States, and Wales. The 6 best practice themes identified in the nine national dementia plans were as follows:

- **Expanding Dementia Research** involves an increased emphasis on growing the dementia research field
- **Quality improvement in Care Services** encompasses improved access, availability, and coordination of current and future services throughout the disease stages along the continuum of care
- **Raising Public Awareness** includes recommendations to assist with the recognition of symptoms and reduction of stigma
- **Early/Timely Diagnosis and Treatment** emphasizes disseminating information to the public and health care professionals, to improve early diagnosis and encourage help seeking in early stage
- **Staff Training** involves increasing resources to improve awareness, knowledge, and training among health care professionals responsible for providing care to individuals with dementia
- **Family Support** emphasizes the need to improve the availability and appropriateness of community support and respite options to caregivers and families of individuals with dementia

Administrative Data Analysis

The administrative data analysis employed linked administrative databases in the province of Saskatchewan to determine the 12-month incidence and prevalence of dementia among individuals aged 45 and older in the province of Saskatchewan by database of identification, demographic characteristics (age group, sex, and rural/urban residence), and health region. Key findings regarding the incidence and prevalence of dementia as identified in the administrative data analysis are reviewed below.

Incidence of dementia (2012/2013) - Province of Saskatchewan*

- A total of 3,270 incident (new) cases of dementia were identified among adults 45 years and older in Saskatchewan during the 12-month period of 2012/13. The unadjusted incidence rate of dementia was 7.28 per 1,000 population at risk (PAR).
- There were 1,887 incident cases among females and 1,383 incident cases among males aged 45 years and older. The unadjusted incidence rate was 31% higher among females than males (8.25 vs. 6.28 per 1,000 PAR). This difference was statistically significant ($p < 0.05$).
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- Within every health region, similar to the province overall, the unadjusted incidence rate of dementia was higher among females than males. In 6 health regions, these differences were statistically significant ($p < 0.05$).
- **Adults 45 to 64 years of age contributed 8% of incident cases (247/3,270), those aged 65 to 84 contributed 41% (1,343/3,270), and 51% (1,680/3,270) were contributed by adults aged 85 years and older.** The unadjusted incidence rate increased 152 times between the group aged 45 to 54 and those aged 85 years and older (0.46 vs. 69.73 per 1,000 PAR).
- The greatest proportion of all 12-month incident cases in 2012/13 was first identified in long-term care (34.98%), followed closely by a diagnosis in physician services claims (29.94%), and a diagnosis in hospital (28.53%). Of note, 6.54% of all incident cases were first identified as a result of a cholinesterase inhibitor prescription.
- Of the incident cases that were *first identified in long-term care* in 2012/13, 79.72% (912/1,144) were identified at the point of admission. The remaining 20.28% (232/1,144) were admitted to long-term care prior to April 1, 2012 (in some cases by many years) and were not identified as having dementia until 2012/13. Therefore, of *all* incident cases of dementia, 27.89% (912/3,270) were first identified with dementia at the point of admission to long-term care.
- There were 1,133 incident cases among rural residents and 2,105 incident cases among urban residents. Among those aged 85 years and older, the unadjusted incidence rate was 14% higher among rural than urban residents (a statistically significant difference $p < 0.05$). Within all other age groups, the differences in unadjusted incidence rates between rural and urban residents were not statistically significant.
- The incidence (and population at risk) was highest in Saskatoon Health Region, where a total of 880 new cases were identified for the 2012/13 12-month period. The incidence (and population at risk) was lowest in the Northern Health Regions, where a total of 32 cases were identified for the same 12-month period.
- The age- and sex-adjusted incidence rate was highest in Sun Country Health Region (8.77 per 1,000 PAR) and second highest in Heartland Health Region (8.63 per 1,000 PAR). These adjusted incidence rates were 15-17% higher than the adjusted rate for all health regions combined (7.51 per 1,000 PAR). The difference between each of these adjusted rates and the adjusted rate for all health regions combined was statistically significant ($p < 0.05$).
- The age- and sex-adjusted incidence rates were lowest in Prince Albert Parkland (6.59 per 1,000 PAR) and the Northern Health Regions (6.66 per 1,000 PAR). These rates were 13-14% lower than the adjusted rate for all health regions combined (7.51 per 1,000 PAR). The difference between each of these adjusted rates and the adjusted rate for all health regions combined was not statistically significant.

Prevalence of dementia (2012/2013) - Province of Saskatchewan*

- A total of 13,012 prevalent (existing) cases of dementia were identified among adults 45 years and older in Saskatchewan during the 2012/13 12-month period; the unadjusted prevalence rate of dementia was 28.16 per 1,000 population at risk (PAR).
- Overall, the 12-month unadjusted prevalence rate among individuals aged 45 years and older was 3.9 times the unadjusted incidence rate (28.16 vs. 7.28 per 1,000 PAR).
- There were 8,099 prevalent cases among females and 4,913 prevalent cases among males aged 45 years and older. The unadjusted prevalence rate was 57% higher among females than males (34.19 vs. 21.82 per 1,000 PAR). This difference was statistically significant ($p < 0.05$).
- Within every health region, similar to the province overall (34.49 vs. 22.09 per 1,000 PAR), the prevalence rate of dementia was higher among females than males. These sex differences were statistically significant in every

health region ($p < 0.05$) except the Northern Health Regions, ranging from a difference of 73% in Kelsey Trail (41.46 vs. 23.96 per 1,000 PAR) to a difference of 29% in Prairie North (28.08 vs. 21.79 per 1,000 PAR).

- **Adults 45 to 64 years of age contributed 8% of prevalent cases (1,087/13,012), those aged 65 to 84 accounted for 39% (5,078/13,012), and adults aged 85 years and older accounted for 53% (6,847/13,012).** Overall, the unadjusted prevalence rate was 160 times higher among adults aged 85 and older than among those 45 to 54 years of age (221.30 vs. 1.38 per 1,000 PAR).
- The greatest proportion of all 12-month prevalent cases in 2012/13 was first identified by a diagnosis in physician services claims (40.16%). A further 24.72% were first identified in long-term care, 23.84% by a diagnosis in hospital, and 11.28% by a cholinesterase inhibitor prescription.
- Of the prevalent cases *that were first identified in long-term care* in 2012/13, 68.89% (2,216/3,217) were identified at the point of admission to long-term care, and 31.12% (1,001/3,217) were identified 30 days or longer after admission. Therefore, of *all* prevalent cases of dementia, 17.03% (2,216/13,012) were first identified with dementia at the point of admission to long-term care.
- Among all adults aged 45 years and older, there were 4,394 prevalent cases among rural residents and 8,497 prevalent cases among urban residents. Among those younger than 85 years, the unadjusted prevalence rates were higher among urban than rural residents; among those aged 85 years and older, the unadjusted prevalence rate was 13% higher among rural than urban residents. Among all age groups combined, the unadjusted prevalence rate was 6% higher among urban than rural residents. All rural vs. urban differences were statistically significant ($p < 0.05$).
- Prevalence (number of existing cases) ranged from 126 to 3,286 across the health regions. The prevalence (and population at risk) was highest in Saskatoon Health Region, where a total of 3,286 existing cases were identified for the 2012/13 12-month period. Regina Qu'Appelle Health Region had the second highest prevalence at 3,041 cases. The prevalence (and population at risk) was lowest in the Northern Health Regions, where a total of 126 cases were identified for the same 12-month period.
- The age- and sex-adjusted prevalence rates ranged from 25.87 to 31.91 per 1,000 PAR across the health regions. The adjusted prevalence rate was highest in Prince Albert Parkland Health Region (31.91 per 1,000 PAR) and second highest in Sun Country Health Region (30.55 per 1,000 PAR). These adjusted prevalence rates were 8-13% higher than the adjusted rate for all health regions combined (28.16 per 1,000 PAR). Two additional health regions also had adjusted prevalence rates that were statistically significantly higher ($p < 0.05$) than all health regions combined: Sunrise at 29.40 and Regina Qu'Appelle at 28.75 per 1,000 PAR).
- The age- and sex-adjusted prevalence rate was lowest in the Northern Health Regions (25.87 per 1,000 PAR). This adjusted rate was 9% lower than the adjusted rate for all health regions combined (28.16 per 1,000 PAR), which was not a statistically significant difference. The adjusted prevalence rate in the Saskatoon Health Region (26.45 per 1,000 PAR) was 6% lower than the adjusted rate for all health regions combined; this difference was statistically significant ($p < 0.05$).

* Results are also presented by health region within the current report, as listed in the Table of Contents.

Key conclusions

The incidence and prevalence of dementia found in the current study likely underestimate the true epidemiology of dementia, since previous studies have shown that between 31% and 69% of *primary care patients with dementia* do not receive a documented diagnosis (Boustani et al. 2003; Bradford et al. 2009; van den Dungen et al. 2012). Therefore the true number of incident cases over a 12-month period in Saskatchewan may vary between 4,700 and 10,500. As shown in Tables 105 and 106 (see Discussion section of this report), the *Rising Tide* report (Smetanin et al. 2009) projected 4,154 incident cases and 18,332 prevalent cases of dementia in

Saskatchewan in the year 2012, based on previous field studies of individuals living in the community and long-term care. When compared to these *Rising Tide* projections, our findings would suggest that only 79% of incident cases (3,270/4,154) and 71% of prevalent cases (13,012/18,332) were diagnosed or otherwise identified; 21% of incident cases and 29% of prevalent cases were not diagnosed or otherwise identified.

Please refer to the Discussion section of this report (p. 135) for additional key conclusions regarding the administrative data analysis.

Environmental Scan

The purposes of the environmental scan were to determine, within each of the 13 health regions of the province of Saskatchewan and for the province as a whole: 1) the availability of dementia-related services and resources across the continuum of care, and 2) the orientation of dementia-related services toward key dimensions of primary health care. The key findings from the environmental scan are reviewed below.

Availability of Dementia-related Services – Province of Saskatchewan*

- **Health Promotion Programs** related to dementia care were reported to be widely unavailable according to more than half of respondents.
- **Primary Health Care** Multidisciplinary team assessment and Nurse Practitioners were unavailable in approximately half of the communities served by respondents.
- **Post-diagnosis Support** More than half of respondents reported that post-diagnostic support in the form of private caregiving, caregiver support groups, and counselling for diagnosed individuals was not available in their communities.
- **Home Care** services that were unavailable, according to the majority of respondents, were night respite, transportation to health care, and weekend respite.
- **Long-term Care** counselling for individuals with dementia and caregivers was reported to be widely unavailable. Long-term care housing that was more likely to be unavailable included assisted living options and special care units.

Primary Health Care Orientation of Dementia-related Services – Province of Saskatchewan*

- **Information and Education.** Overall, respondents perceived community-level dementia-related information and education to be inadequate.
- **Accessibility.** Overall, respondents held somewhat negative perceptions on the dimension of *Accessibility* of dementia-related services.
- **Population Orientation.** Respondents held somewhat negative views overall on *Population Orientation*, (i.e., community fit).
- **Coordinated Care.** Perceptions on overall *Coordinated Care* were in the neutral range.
- **Comprehensiveness of Care.** Of the 6 dimensions considered, *Comprehensiveness of Care* fared the most favorably with somewhat positive views overall.
- **Quality of Care.** *Quality of Care* overall was viewed neutrally.
- According to a **single summary item**, environmental scan respondents perceived the amount of supportive resources and services available in the community to be somewhat *inadequate* overall.

* *Results are also presented by health region within the current report, as listed in the Table of Contents.*

Please refer to the Discussion section of this report (p. 139) for key conclusions regarding the environmental scan.

Recommendations for Action

Recommendations for action to improve dementia care in Saskatchewan are offered below, based on the report findings. The recommendations were developed over two steps. In the first step, the RaDAR Team workshopped 10 draft recommendations with participants of the 7th Summit of the Knowledge Network in Rural and Remote Dementia Care. Participants revised the recommendations, ranked the top 5, and suggested plans for action (see <http://www.cchsa-ccssma.usask.ca/ruraldementiacare/summit2014.html>). In the second step, the RaDAR-HQC Steering Committee endorsed the top 5 recommendations and provided further suggestions for revision.

These recommendations acknowledge the evidence presented in this report, that over a single 12-month period, 3,270 adults in Saskatchewan were diagnosed or otherwise identified with dementia and 13,012 were living with dementia (aged 45 years and over). These recommendations address the challenges associated with providing appropriate services to individuals with dementia and their families. These challenges will intensify over the coming years as our population ages if we do not develop long-term plans.

1. **Include dementia in the provincial Chronic Disease Management Quality Improvement Program**, thereby establishing a patient registry and decision support tools (standardized care) for health care professionals similar to other chronic conditions (e.g., Diabetes Mellitus, Chronic Obstructive Pulmonary Disease, Coronary Artery Disease, Congestive Heart Failure).
2. **Track quality indicators of dementia care provincially and by health region**, to ensure that individuals are properly assessed, diagnosed, and managed within the health care system.
3. **Improve and encourage access to a timely and accurate diagnosis.**
4. **Ensure that individuals with dementia and their families are adequately supported.**
5. **Review the *Provincial Strategy for Alzheimer Disease and Related Dementias in Saskatchewan* (released in 2004) and consider aligning with the proposed national strategy while reflecting the needs of individuals with dementia and their families living in Saskatchewan.**

These recommendations are presented in full at the end of the report (p. 141).

About the RaDAR Team

The Rural Dementia Action Research (RaDAR) Team is an interdisciplinary group of researchers from Ontario, Alberta, and the United Kingdom, based at the University of Saskatchewan.

Dr. Debra Morgan, Professor in the Canadian Centre for Health and Safety in Agriculture, College of Medicine (U of S), leads the RaDAR Team and is a founding member of the Gateway to Rural International Initiatives in Dementia (GRIID).



Since 2004, the RaDAR Team has been working together to improve rural and remote dementia care. RaDAR's flagship project is the Rural and Remote Memory Clinic, which began as a CIHR-funded demonstration project and is now funded by the Saskatchewan Ministry of Health. The Rural and Remote Memory Clinic focuses on diagnosing and managing atypical and complex cases of suspected dementia in patients living in rural and remote communities outside of Saskatoon and Regina.

The RaDAR Decision-Maker Advisory Council provides guidance to the team, meeting annually at the Summit of the Knowledge Network in Rural and Remote Dementia Care. The Council includes health care providers, family members, health region representatives, and governmental and community-based organizations.

To learn more about the research and activities of the RaDAR Team, visit their rural dementia care website: www.cchsa-ccssma.usask.ca/ruraldementiacare. To learn more about GRIID, visit www.ruraldementia.com.

