Knowledge Network in
Rural and Remote Dementia Care

Scientific Poster Session

Healthcare Delivery Across the Continuum
for Rural and Remote Seniors with Dementia

1st Annual Summit

November 20 - 21, 2008
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Design of a multidisciplinary memory clinic using telehealth technology to serve a rural and remote population

University of Saskatchewan

Background/Aims: The Canadian province of Saskatchewan has a population of only one million but is larger than the Iberian peninsula. We developed a Memory Clinic to serve rural patients with early dementia.

Methods: Upon referral, a telehealth visit using videoconferencing allows patients and families in rural communities to meet the clinic nurse and neuropsychologist for orientation and preliminary data collection. Blood tests are taken during that visit. Patient and family then travel to Saskatoon for an in-person appointment. The neurologist sees patients in follow-ups at 6 and 12 weeks, 6 and 12 months, and then annually or as needed. Patients are randomly allocated to 6 week appointment either in-person in Saskatoon or via telehealth with subsequent appointments alternating between in-person and telehealth. Patients and family complete questionnaires to rate satisfaction and convenience of visits.

DIAGNOSES (First 200 patients)

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Diagnosis</th>
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<tr>
<td>25%</td>
<td>Alzheimer’s disease</td>
</tr>
<tr>
<td>14%</td>
<td>Mild Cognitive Impairment</td>
</tr>
<tr>
<td>11%</td>
<td>Frontotemporal Dementia</td>
</tr>
<tr>
<td>10%</td>
<td>Normal</td>
</tr>
<tr>
<td>7%</td>
<td>Vascular</td>
</tr>
<tr>
<td>5%</td>
<td>Normal Pressure Hydrocephalus</td>
</tr>
<tr>
<td>4%</td>
<td>Huntington’s Disease</td>
</tr>
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</table>

Mean distance to Telehealth = 78
Mean distance to Saskatoon = 518
Distance saved by Telehealth (kms round trip)

Satisfaction with follow-up appointment

Telehealth 4.45 (0.12)
In-person 4.44 (0.10)
P = 0.125
(1 = very dissatisfied, 5 = very satisfied)

Convenience of appointment

Telehealth 4.77 (0.08)
In-person 3.69 (0.16)
P <0.0001
(1 = very inconvenient, 5 = very convenient)

Conclusions: A multi-disciplinary telehealth-based memory clinic is an effective way to assess and care for dementia patients in remote areas.
Utility of Telehealth for Following Cognition of Memory Clinic Patients in Rural Areas

Wendaline McEachern, Andrew Kirk, Debra Morgan, Margaret Crossley, and Carol Henry, University of Saskatchewan

Abstract

Advances in telehealth have improved access to health care for those in rural areas. Thus, examinations conducted via telehealth must be comparable to in-person testing. A rural and remote memory clinic in Saskatoon provided an opportunity to compare scores on the Mini-Mental State Examination (MMSE) administered in-person and via telehealth.

Method

Research Question: Are Mini-Mental Status Examination scores comparable when the test is administered in-person vs. via Telehealth?

Participants: the first 71 patients followed through the Rural and Remote Memory Clinic at their 6-week and 12-week follow-up appointments.

Patients were randomized to receive either telehealth then in-person follow-up or vice-versa (to prevent bias due to worsening due to progression or improvement due to treatment).

The same neurologist administered each MMSE. MMSE scores were evaluated to see if a difference existed due to mode of delivery.

Patient Characteristics:

- **Telehealth Follow-up**
  - 34 Telehealth, 37 In-person (initially)
  - Mean MMSE score: In person: 22.70 +/- 6.51
  - Telehealth: 22.34 +/- 6.35
  - (No significant difference between groups)

- Analysis method developed by Bland and Altman was used, plotting the differences between in-person and telehealth against their mean:

Discussion

- No statistically or clinically significant difference was observed when comparing telehealth MMSE assessment with in-person MMSE assessment.
- In accordance with this finding, all follow-up appointments of Rural and Remote Memory Clinic patients are now delivered via telehealth.
- Telehealth assessment is a valid way of following cognition in patients referred to a rural and remote memory clinic.
Factors Associated with Falls and Near-Falls in Community Dwelling Older Adults with Early-Stage Dementia

Vanina Dal Bello-Haas, Margaret Crossley, Debra Morgan, Andrew Kirk, Sheri Harder, Jenny Basran
University of Saskatchewan

Introduction

In Saskatchewan, falls and fall-related injuries are a significant health care concern:

- the population is older than the rest of Canada
- the hospital admission rate secondary to falls in people ≥ 65 years is higher than the national average
- Annual incidence of falls in persons with dementia is 40% to 60%, twice the rate of cognitively normal seniors
- In persons with dementia, serious injury is more common and prognosis is poorer compared to cognitively normal older fallers
- 25% sustain a fracture
- 6-month mortality rate post-fracture is more than 3 times that of cognitively intact older adults
- Satisfactory recovery from injury is less likely and institutionalization rate post-injury is 5 times greater

In Saskatchewan, over 30,000 people have dementia, and as the population ages the number of people affected by dementia will rise. The increased incidence of dementia will result in increased fall-related treatment and complications and associated healthcare costs.

Objectives

1. Characterize falls and near-falls in community dwelling older adults with early-stage dementia.
2. Determine which potentially modifiable physical fall risk factors contribute to falls and near-falls in older adults with early-stage dementia.
3. Examine the relationship between dementia subtype, medical and neuropsychological factors, physical factors, balance and gait, and falls and near-falls in community dwelling older adults with early-stage dementia.
4. Identify which tests or measures are most useful in this client population.

Preliminary Data

- 46 males and 49 females (mean age = 73.7 ± 10.8) have been evaluated in the Rural and Remote Memory Clinic (RRMC)
- Diagnoses include: Alzheimer’s dementia (47.6%), Vascular Dementia (6%), Dementia Lewy Body (7.1%), Fronto-temporal Dementia (6%), Mild Cognitive Impairment (9.5%), mixed dementias (4.8%)
- Mean Mini Mental Status Exam and 3-MS scores = 23.2 (SD = 4.6) and 73.8 (SD = 15.7)
- Percentage of those retrospectively reporting falls or near falls = 23% and 24%, respectively

Methodology

Sample: 80 community-dwelling males or females older adults over the age of 50 who have consented to be enrolled in the RRMC, and who have early-stage dementia (Global Deterioration Scale levels 2, 3, 4 or 5)

Knowledge Translation

- Understanding factors, especially potentially modifiable factors that increase the risk of falls in people with early-stage dementia, such as those related to physical factors, balance and gait, may assist in the identification of those individuals who would benefit from interventions.
- Examining factors related to near-falls may provide insight into natural adaptive strategies used by people with dementia to maintain balance, and may serve as the basis for formal and informal caregiver education and training programs.
- Resources to minimize the frequency and severity of falls could be appropriately allocated, and subsequent prevention programs could result in substantial health care cost savings, significant improvement in quality of life for people with early-stage dementia, and decreased caregiver burden.

References


SHRF New Investigator Establishment Grant (2006)
SHRF New Investigator Equipment Grant (2006)
Does more education protect against Alzheimer’s Disease and Vascular dementia?
A systematic review with meta-analysis.

Xiangfei Meng1, Carl D’Arcy2, Yaqin Yu1

1Jilin University, Changchun, China and 2University of Saskatchewan, Saskatoon, Canada

The Challenge
- Globally, with increasing life expectancy the number of people affected by dementia is estimated to double every 20 years to 81.1 million by 2040.
- Alzheimer’s disease (AD) causes 50%–70% of dementia. Vascular dementia (VaD) causes approximately 30% of dementia cases.
- A variety of biological and social attributes have been implicated as risk factors for developing dementia. A hypothetical construct, “cognitive reserve” or brain reserve hypothesis has been widely used to explain how, in the face of neurodegenerative changes that are similar in nature and extent, individuals vary considerably in their cognitive aging and manifestations of clinical dementia.

The Study Question
- Is education associated with the occurrence of AD and/or VaD?
- What kind of robust evidence can be derived on this matter from current studies?

Methods

Search Strategy
- Retrieve relevant articles: Alzheimer’s OR VaD AND education
- Include studies identified from PubMed, PsychINFO, EMBASE, HealthSTAR, and Scopus (N=7988)
- Studies excluded after reviewing titles (N=6974)

Inclusion Criteria
- Cross-sectional and case-control study designs
- Used clear diagnosis criteria for AD or VaD, i.e. DSM and its updates, NINCDS-ADRD, ICD-10 or other generally accepted criteria.
- Use of clear definition of educational attainment
- Provide a comparison of dementia incidence or prevalence in different educational levels
- Give the clear information about education of subjects;
- Control the potential confounds.

Data Synthesis
- Quantitative Analyses Contents
  - Mortality
  - Cognitive Decline
  - Clinical Performance
  - Onset of Age
  - Risk Factor
  - Educational attainment

Quantitative Analyses: Meta-analyses Procedures

Results

Quantitative Results
The pooled OR of prevalent dementia for individuals with low compared to high education was 2.67 (95%CI 1.53-3.13, p<0.001), indicating a low level of education increased the risk of dementia by 67% for incident studies the pooled OR was 1.92 (95%CI 1.36-2.44, p<0.001).

Sensitivity tests
- Further analyses omitting one study at one time, which takes influence of study into account, did not change the results.
- Sensitivity results, Table 2, show that only incidence studies with case-control designs (4 articles in total) yielded negative results.
- None of the study characteristics examined globally, with increasing life expectancy the number of people affected by dementia is estimated to double every 20 years to 81.1 million by 2040.

Conclusion
- A high level education is significantly related to a reduction both in the prevalence and incidence of dementia, either AD and VaD.
- Our study results are in accordance with the cognitive reserve hypothesis, which suggests that higher educated individuals have a later age of onset, better clinical performance and slower cognitive decline, but greater likelihood of mortality from the disease.
- Further studies are required to identify how education functions in this context.
- It is important to recognize the potential policy implications of the role of education in prevention of dementia.
Establishing and Evaluating an Interprofessional Rural and Remote Memory Clinic: Making Transdisciplinary Collaboration Work


The Challenges

- Providing timely specialist diagnosis and treatment to a dispersed rural and remote population
- Melding together a variety of specialized health care providers to work as a well-functioning group
- Evaluating the impact of a service demonstration project

The Clinic

Goals:
- A state-of-the-art transdisciplinary memory clinic serving rural and remote areas
- Streamlined assessments
- Targeted non-institutional population 50+ referred to clinic by a physician, living more than 100 km from the two tertiary care centres in the province (Saskatchewan and Regina) - northern communities were defined as remote

Structure:
- Clinic is coordinated by a nurse case manager
- A pre-clinic assessment is done by TeleHealth (30 mins)
- Necessary blood tests are done and results forwarded prior to clinic visit
- One-day assessment clinic (in Saskatchewan). Patient is seen by neurologist, neuropsychological team, geriatrician, neuro-radiologist & physical therapist
- CAT scan and/or MRI are conducted if not previously done
- One patient is discussed at Interdisciplinary Teaching Rounds at the end of the day
- All clinical teams, residents and graduate students attend, plus the referring physician is invited to participate by telephone conference call
- Case conference – Patient and family members meet with neurologists and neuropsychologists, and other clinicians to provide information on probable diagnosis, clinical assessments and recommendations regarding management and care
- Reports from the individual clinicians are collated and sent to the referring physician usually within 1 week

Evaluation - Indicators of Impact and Outcome

For the collaboration – continuation and accreditation:
- All principals are still involved 3 years into the project
- Have added new team members with complementary expertise
- Teams are looking for ways to expand clinic and secure alternative funding
- Clinic training experience for medical residents and graduate students
- Research training and experience for medical residents and graduate students

For the clinic – an RCT was not ethical or practical - have used both qualitative and quantitative measures of growth of demand, satisfaction and impact on the psychological status of caregivers and comments as outcome measures

Quantitative:
- There has been an increase in demand for service and growing waiting list
- Patients and caregivers very satisfied with TeleHealth experience - all clients would use TeleHealth again
- Positive experience of family with One-day assessment clinic:
  - Dementia is a disease of aging - 8% of the Canadian population 65+ have AD versus 34.5% of those 85+
  - Canada has an aging population - currently 13.7% are 65+
  - Remote and rural areas have higher % of seniors (65+), 16.1% versus 13.1% in cities
  - In Saskatchewan, 14.7% of the general population, and 22.4% of small towns and 21.7% of villages are 65+
  - Specialist care difficult to provide in rural and remote areas – “It was like climbing a mountain to get a diagnosis,” a rural resident noted. Multiple visits for specialist assessment is onerous in terms of time and money
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Qualitative comments:
- “I couldn’t believe we were going to get all those services in one day and in one place – incredible.”
- See Touching Lives document below

Ingredients for a successful collaboration

In theory

MEMBERSHIP
- Feel sense of ownership
- Clear roles & policies
- Adaptability - Appropriate pace of development
- Favorable climate - Ability to compromise
- Concrete, realistic & attainable goals & objectives
- Informal relationships & communication
- Open and frequent communication
- Positive experience of family with One-day assessment clinic:
- Continuous via email, weekly clinic meetings, monthly project research rounds & periodic retreats

EMPIRICAL
- Members have established membership and access to funding agencies
- Dedicated seed money provided by Banting Foundation, Health Canada, and University of Saskatchewan
- Dementia is a disease of aging - 8% of the Canadian population 65+ have AD versus 34.5% of those 85+
- Canada has an aging population - currently 13.7% are 65+
- Remote and rural areas have higher % of seniors (65+), 16.1% versus 13.1% in cities
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Purpose:
- Members had established trust & respect among team members
- Each member makes a unique & valuable contribution
- Team includes individuals with diverse skills & abilities
- Cross-disciplinary & collaborative

Negotiating Culturally Incongruent Systems: The Process of Accessing Dementia Care for Aboriginal Older Adults in Northern Saskatchewan

A. Cammer², D. Morgan¹, N. Stewart²

¹Canadian Centre for Health and Safety in Agriculture, College of Medicine, University of Saskatchewan, Saskatoon, Canada; ²College of Nursing, University of Saskatchewan, Saskatoon, Canada

Background

• Rural and Remote health-service is limited, particularly specialized services and long term care in Northern Aboriginal communities
• The population of Aboriginal seniors a growing demographic
  • Dementia prevalence on the rise, greatest risk factor is increased age
  • Little is known about Aboriginal groups’ experience of dementia care
  • Aboriginal refers to First Nations, Status and Non-Status Indians; Inuit; and Métis

Research Question

• What is the process of accessing formal healthcare for dementia from the perspective of Northern Saskatchewan Aboriginal communities and what factors specifically impede or encourage accessing formal healthcare?

Setting

• Setting: Northern Saskatchewan Aboriginal communities in Keéwatin Yatthe Regional Health Authority and Meadow Lake Tribal Council
• Communities of focus: Île à la Crosse, Buffalo Narrows, Beauval, and English River First Nation

Methods

• Grounded theory methodology: postcolonial (Browne, 2005), feminist (Wuest, 1995), constructivist (Charmaz, 2006)
  Consent Process
  Community: Regional Health Authority, Tribal Council
  Academic: Behavioural Research Ethics Review Board, Thesis Committee
  Personal: Each individual at every point of contact

Data Generation Strategies:

• Semi-Structured Individual Interviews (18)
• Semi-Structured Group Interviews (2)
• Focus Group Discussions with Participant-Directed Activity (3)

“Swimming the River of Care”

• Participants self-led an activity conceptualizing barriers to access as ‘boulders’, supports as ‘waves’ and persons affected as ‘fish’, then arranged the figures to represent negotiating access as navigating a river

Results

Emergent Theory:
The Process of Negotiating Culturally Incongruent Healthcare Systems

Social Context:

• Lack of Awareness of Dementia
• Unfamiliar Milieu
• Difficulty in Travel

Managing in Spite of Systems:

Accounts for the processes people engage in when confronted with a potential dementia diagnosis:
  • Subverting the System
  • Kinship and Family Caregiving
  • Sacrificing to Care for Others

Submitting to Culturally Insensitive Systems:

Activities that reinforce negative aspects of social context:
  • Long Term Care as a Last Resort
  • Perceived Failure on the Part of the Caregiver/Community

Participating in and Affecting Systems:

Activities that transform and affect the social context in a positive way:
  • Increasing Awareness
  • Building Local Care Capacity

Discussion

• Context is a key factor in understanding care access
• Focus on enhancing and supporting informal care
• Development of culturally-informed and affirming care protocols is imperative

Acknowledgements

Table 1: Summary of Participant Characteristics

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<tr>
<th>Participant Characteristic</th>
<th>N</th>
<th>%</th>
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<tr>
<td>Participants who are women</td>
<td>29</td>
<td>96.7%</td>
</tr>
<tr>
<td>Participants identifying Aboriginal</td>
<td>22</td>
<td>73.3%</td>
</tr>
<tr>
<td>Participants identifying First Nations</td>
<td>14</td>
<td>46.7%</td>
</tr>
<tr>
<td>Participants identifying Métis</td>
<td>9</td>
<td>26.7%</td>
</tr>
<tr>
<td>Participants whose work is related to dementia</td>
<td>29</td>
<td>96.7%</td>
</tr>
<tr>
<td>Participants with personal experience caring for a loved one with dementia</td>
<td>7</td>
<td>23.3%</td>
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</tbody>
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Table 1: Summary of Participant Characteristics
Development and Evaluation of a Telehealth-Supported Rural and Remote Memory Clinic


1Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; 2College of Arts and Science, University of Saskatchewan; 3College of Medicine, University of Saskatchewan; 4College of Nursing, University of Saskatchewan; 5Department of Applied Research, University of Saskatchewan; 6School of Nursing, University of Western Ontario; 7School of Physical Therapy, University of Saskatchewan; 8First Nations University of Canada

Background

- Rural and Northern Saskatchewan has a low population density resulting in large travel burdens for medical visits.
- Rural SK is older, on average, than urban and is home to many older adults.
- Risk for dementia increases with age.

New Emerging Team (NET) Grant:

1. Improve the availability of specialized personnel and services providing assessment and management of dementia.
2. Improve the accessibility of programs supporting formal and informal caregivers of persons with dementia.
3. Improve the accessibility of services for persons with dementia and their caregivers.

Full-Day Coordinated Assessment

Pros and Cons

**CONS:**
1. Long day onerous for some patient families.
2. Labor-intensive & time-consuming for staff.
3. Must be funded.
4. Necessity of all testing hard to judge in advance.
5. More difficult to establish and maintain rapport in groups and via telehealth.

**PROS:**
1. Savings in travel time & money for patients & families.
2. "Get it all over with."
3. Detailed assessment
4. Well-studied group of patients for study.
5. Referring physician involvement.
6. Team-building.

Evaluation

The clinic is evaluated in a number of ways including:

1. Regularly scheduled Clinic Team meetings to plan and discuss clinic process, examine issues, and make decisions.
2. Annual NET retreat workshops.
3. Systematic monitoring of Clinic attendance and 'drop-outs'.
4. Comparison of travel time and estimate of costs saved:
   - Travel time to Saskatoon = 7.6 hours
   - Travel time to local hospital = 0.6 hours
   - Distance saved by telehealth = 640 km

5. At each Telehealth Appointment:
   - Family/Client Telehealth Satisfaction Questionnaire
   - Telehealth Coordinator Evaluation Form

6. After full-day clinic visit in Saskatchewan:
   - Structured scale and semi-structured telephone interview with informal caregiver.
   - At Telehealth and In-Person Follow-up Appointments:
     - Follow-up Evaluation Form (Patient and Family)

Discussion

The Rural and Remote Memory clinic has seen approximately 200 patients/caregivers to date.

The success of this clinical service is due to:

1. Clinical need.
2. Research productivity.
3. Teaching value, capacity building.
4. Focus on rural residents.
5. Focus on needs of elderly patients.
6. Focus on Aboriginal residents.
7. Focus on technology, telehealth, savings $.
8. Increasing service access.
9. High satisfaction of patients and caregivers.

Acknowledgements

Funding and in-kind support is generously provided by:

- CIHR
- IRSC
- Saskatoon Health Region Foundation
- Catholic Health
- Health
- First Nations University of Canada
- Health
- Telehealth
- Health
- Telehealth
- Health
- Telehealth
Interprofessional Research in a Rural and Remote Memory Clinic: The Role of Neuropsychology in Collaborative Research on Differential Diagnosis in Early Stage Dementia


Introduction: Collaborative Research at the RRMC

The Rural and Remote Memory Clinic (RRMC) is an interprofessional, research-focused memory clinic established to improve dementia assessment and care.

• Our understanding of cognitive decline in early stage dementia is enhanced by successful collaborations between clinical neuropsychology and related disciplines.

• The integrative transdisciplinary research at the RRMC includes nursing, geriatric medicine, neurology, neuroradiology, physical therapy and human geography.

Neuropsychology and Physical Therapy

• Dual-task methodology is extended to an evaluation of “talking while walking” within the context of a physical therapy analysis of gait in dementia subtypes.

• Gait dual-task performance also contributes to a prospective study of risk factors for falls and “near falls” in individuals with dementia.

• Conversely, physical therapy gait assessment contributed to the development of the “talking while walking” dual-task that is used to investigate attentional capacity in early stage dementia.

Neuroradiology

• Successful collaboration between neuropsychology and neuroradiology enable the careful investigation of mild cognitive impairment using magnetic resonance spectroscopy (MRS).

• Neuropsychological tests help to highlight the cognitive correlates of MRS and structural imaging.

Behavioral Medicine

Neurology

• Differential patterns of performance on neuropsychological tests complements the neurological exam by helping to distinguish among stages and subgroups of dementia when diagnosis is unclear.

• Performance on cognitive screening measures can often help determine the stage of illness and inform potential pharmacological therapies.

Fig. 2 Dr. Drew Kirk (Neurology: far left) and Dr. Sherri Harder (Neuroimaging: far right) conducting research linked to the RRMC

• Dr. Harder has received funding to evaluate the potential of magnetic resonance spectroscopy (MRS) to improve diagnostic accuracy in early AD and MCI.

Fig. 1 The interdisciplinairy team at the RRMC

Human Geography

• The interprofessional setting at the RRMC and team travel to northern communities guides the cross-cultural research and culturally sensitive test development that is informed by human geography and cultural anthropology.

Conclusions

• The RRMC is generating a rich, shared database which is fostering complementary research projects among team members.

• Transdisciplinary research is also attractive to graduate students and has fostered collaborative studies on attentional processes and verbal fluency strategies in dementia.

• Successful collaboration between psychology and associated disciplines can improve assessment and differential diagnosis in early-stage dementia.
Modifying Neuropsychological Assessment Protocols for Individuals Referred to a Rural and Remote Memory Clinic: Incorporating Insights and Research Methods from Human Geography and Cultural Anthropology

S. Lanting, M. Crossley, L. McBain, & D. Morgan

Introduction

- Performance on neuropsychological tests is influenced by culture, language, and educational level (e.g., Manly, 2006; Ferraro et al. 2002).
- Developing assessment and consultation services for older adults with cognitive impairment and dementia who reside in rural and remote regions must address cultural bias of existing assessment protocols.
- Little is known about normal aging and prevalence of dementia in Aboriginal seniors.
- Interdisciplinary team allowed for incorporation of different research approaches to inform development of a culturally appropriate assessment protocol.
- Human Geography
  - Facilitated the generation of stimuli that is geographically and historically relevant to prairie and Northern regions of North America.
  - Added to our understanding of geographical and social barriers in accessing specialized health care services.
- Cultural Anthropology
  - Highlighted the importance of ethnographic fieldwork in understanding northern communities and forming effective partnerships prior to collecting normative data.
  - Informed development of translation protocols and attention to cultural relevance of test stimuli.

Methods

1) Initial telehealth meetings and travel to communities
2) Ethnographic fieldwork with individuals residing in remote communities
3) Normative data collection in remote communities
4) Focus groups with Aboriginal seniors

Results

- All data collection methods highlighted importance of:
  - Incorporating colour, humour, and familiar images into assessment stimuli.
  - Engaging aboriginal seniors through informal conversation, use of humour, and relevant assessment stimuli for activities of daily living.
  - Obtaining functional data from caregivers (e.g., activities of daily living, changes in functional status).
  - Modification of specific assessment measures incorporated these findings:
    - Pyramids and Palm Trees (Howard & Patterson, 1992)
    - Buschke Cued Recall Test (Buschke, 1984)
    - Community Screening Interview for Dementia (Hall et al., 1993)

Discussion

- An assessment protocol informed by diverse methodology from different disciplines resulted in converging data on the importance of culturally grounded assessment procedures.
- The modified measures and assessment procedures are highly acceptable to clinic patients and found to be engaging for participants from diverse cultural backgrounds.
- Clinical and normative data collection is ongoing to determine the utility of measures in detecting cognitive impairment and dementia.

Supporters

- CIHR IRSC
- CCHSA / CSSSMA
- Northern Scientific Training Program
PURPOSE OF THE STUDY
The purpose of this study was:
• to explore the nature of health care services available to older adults with dementia in northern Saskatchewan from the perspective of RNs who work in northern health care facilities.
• to provide contextual data on dementia care in rural and remote nursing practice by contrasting the location of nursing practice in northern compared to southern Canada.

RESEARCH QUESTION
What do northern RNs in Saskatchewan perceive as key issues and concerns associated with the care of older adults with dementia?

SEQUENTIAL MIXED METHOD DESIGN
Phase 1
Interviews with 14 RNs employed in northern health regions and Grounded Theory analysis.
Phase 2
Descriptive analysis of survey component from the multi-method study, The Nature of Nursing Practice in Rural and Remote Canada (MacLeod et al., 2005). Survey north-south sample selection based on definition of rural and location of community.
Study sample N = 2751
North: n = 597, South: n = 2154

FINDINGS PHASE ONE
Conditions were conceptualized as insulating or expanding the RNs’ awareness of dementia and dementia care in northern nursing practice.

Conditions Insulating an Awareness of Dementia
• The acute care clinical focus of northern health care and recruitment of RNs in the north based on acute care knowledge and skills versus Long Term Care, Home Care and Primary Health Care knowledge and experience.
• The RNs unfamiliarity with the culture and inability to speak the language of the older adults in the community.
• The lack of dementia as a clinically documented diagnosis and the limited availability of culturally sensitive assessment tools.

Conditions Expanding an Awareness of Dementia
• Communities with programs for older adults.
• Clinical contact with older adults with dementia in northern communities.
• Having a small or northern community of origin and a personal comfort living in a northern community.
• The length of time a RN spent in a community and the RNs relationship with the Community Health Representatives and Licensed Practical Nurses working with older adults in the community.

FINDINGS PHASE TWO
Descriptive analysis of the survey was conducted based on the themes that emerged from the grounded theory analysis.

• Northern RNs were found to perform more expanded scope clinical procedures than southern RNs.
• Large proportion of northern RNs (42.9% versus 21.0% of southern participants) had an urban community as their community of origin.
• A large proportion of northern RNs (58.3% versus 9.9% of southern participants) reported that they used interpreters in their practice. The participants working in nursing stations were more often found to use interpreters within each of the northern (63.1%) and southern (36.8%) subsets.
• A smaller proportion of northern participants (41.7%) reported plans to continue working in the same location in the next five years compared to the southern participants (67.7%).
• In the northern subset: 70.3% were in their current primary position less than 5 years; 22.0% of the RNs expected to stay in their current position less than one year. In the southern subset: 50.2% were in their present primary position for less than 5 years; 10.7% of the RNs expected to stay in their current position less than one year.

CONCLUSIONS
The findings identified that dementia care services are limited in northern Saskatchewan and in the broader context of northern Canada. Supporting a wider representation of health care services at a community level for older adults is one avenue that may support an increased awareness of dementia in northern health care. Using a primary health care approach, and a nursing staff with varied nursing skills and previous experience, may allow for a broader development of northern health care services. The amount of time in a position was suggested as indicative of the knowledge of the community and the ability to become aware of older adults with dementia.

ACKNOWLEDGEMENTS
Dr. Debra Morgan for the Canadian Institute for Health Research doctoral scholarship associated with the New Emerging Team Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas, the Northern Scientific Training Program, Northern Medical Services, Telehealth Saskatchewan and the Saskatoon Health Region Telehealth Staff.
### Background

**Introduction:**
- Rural SK is older, on average, than urban and the risk for dementia increases with age.
- Little is known about dementia care in rural long-term care facilities, nor about how programs are implemented in rural settings.
- As a component of a CIHR New Emerging Team grant, an evaluation of the Alzheimer's Society's Enhancing Care Program was undertaken in rural Saskatchewan.

**Enhancing Care Program:**
- The Enhancing Care (EC) Program was developed by the Alzheimer Society of Canada in 1998.
- The EC Program is based on the Alzheimer Society of Canada’s 11 Guidelines for Care, created in 1992.

**Research Objectives:**
- To determine which parts of the EC program were operating as they were intended.
- To develop a theory regarding change in small, rural organizations.

**Setting:**
- Research took place in the Heartland Regional Health Authority in southwest Saskatchewan.
- Two long-term care facilities with similar characteristics were selected for the evaluation:
  - **Facility #1**
    - Town population < 1000
    - Integrated healthcare facility: Health clinic attached to LTC
    - 35 residents
    - 21 full-time staff
    - 24 part-time staff
    - Facility does not have a Special Care Unit
  - **Facility #2**
    - Town population < 1000
    - Integrated healthcare facility: Health clinic attached to LTC
    - 32 residents
    - 12 full-time staff
    - 26 part-time staff
    - Facility does not have a Special Care Unit

### Process Evaluation

**Research Objectives:**
- To determine which parts of the EC program were operating as they were intended.
- To develop a theory regarding change in small, rural organizations.

**Data Collection and Analysis**
- Data was collected and analyzed according to the principles of Grounded Theory.
- A total of 44 participants.
- Data were collected in three ways:
  - Observation (7 months of EC team meetings)
  - Focus Group Discussions (with EC team members)
  - Individual Interviews (with non-EC team members)

### Preliminary Findings

- EC team members unanimously endorsed the program as having a positive impact in their facilities, and would recommend it to other facilities.
- Communication between departments improved due to the EC program.
- EC team members felt that important changes had been made despite frustrations with the process.
- Ongoing support from the Alzheimer Society was identified as a need.

**How were team members chosen?**
- "I think we were all asked"  
- "I was conscripted"

**Did team members understand what was expected of them?**
- "We weren't adequately informed as to what to expect or what was required"

**How did you find the meetings with the Alzheimer Society facilitator?**
- "The meetings she was here for, it was just great. She guided us but didn't... she let us find out what it was we needed. But she just helped keep us focused..."
- "You didn't know whether you were upside down, turned around, if you were doing it right. You could go back over it and change it again. And still you didn't know if that was right. It was really difficult.
- "I think the more times you do it now, maybe the little easier it gets"

**What effect did the EC program have on the group?**
- "I think there has been a great amount of opportunity to be real, to share, and in doing that, everybody wins... I think this has been really good"
- "We were kind of a dysfunctional facility and now we're sort of on to functioning"

### Summary

- EC team members unanimously endorsed the program as having a positive impact in their facilities, and would recommend it to other facilities.
- Communication between departments improved due to the EC program.
- EC team members felt that important changes had been made despite frustrations with the process.
- Ongoing support from the Alzheimer Society was identified as a need.

### Acknowledgements

Funding generously provided through the NET grant.
Availability and Acceptability of Canadian Home and Community-Based Services: Perspectives of Family Caregivers of Persons with Dementia

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1University of Western Ontario, 2McMaster University, 3University of Manitoba, 4University of Alberta, 5University of Saskatchewan, Canada

Funded by Alzheimer Society of Canada; CIHR Institute of Gender & Health and Institute of Aging; Canadian Nurses Foundation; Nursing Care Partnership of the Canadian Health Services Research Foundation

Background

• Eight percent of Canadians 65 years of age and older and 35 percent of persons over the age of 85 have dementia.1 Baby boomers reach the age of greatest risk for dementia in 2010. Thus, we have a narrow window of opportunity to prevent a dementia crisis.2
• Caregivers of a family member with dementia are more likely to experience social isolation, chronic health problems and depression than those caring for cognitively intact elderly.3
• Home care services have shifted to clients with greater physical needs and services have become medically focused.4,5 Responsibility and costs have shifted to clients and family members.6

Purpose

To explore the experiences of family caregivers who received Canadian home and community-based services that aim to assist them in caring for a family member with dementia.

Methods

• Interpretive descriptive approach7,8
• Focus groups (n=6) and in-depth interviews (n=3)
• Thematic content analysis9

Participants

Family caregivers (N=39) in rural and urban areas of Ontario, Manitoba, and Saskatchewan, Canada.
• Female (82%), married (87%)
• <60 years (44%), >80 years (23%)
• Spouse (56%), adult child (28%)

Findings

Availability of Home and Community-Based Services

Definition: the continuum of home and community-based services that are able to assist family caregivers in their care work (i.e., services that fully meet their clients’ needs, that partially meet their needs, to services that are unavailable).

Available Services:
respite, assistance with daily living such as personal care and meals on wheels, health professional monitoring, and caregiver support groups.

Insufficient Amounts of Available Services:
I want to have some respite, I need more than an hour or two. I didn’t use VON.

Geographic Location:
A private care home would be the best place. But the closest one was too far and just out of the question.

Unavailable Services:
in-home respite care through mental health services, assistance with lawn maintenance, snow shoveling, and information on the disease process, how to manage difficult behaviours, and support resources.

Acceptability of Home and Community-Based Services

Definition: caregivers’ perceived quality of service and includes relevant dimensions of the service considered important to them.

Comprehensive Assessments, Treatments, and Provision of Dementia Care:
Family caregivers became well informed about assessment procedures and treatments and found it unacceptable when providers were misinformed or lacked expertise. They wanted to be involved in the assessment and care planning to ensure that accurate assessments were completed and that their own needs were included in the assessment process.

Consistency of Care Providers:
If they (persons with dementia) need any one thing, it’s consistency of one person.

Attributes of Trusting Partnerships:
professional conduct, consistency of care provider, respectful and sensitive approach.

Flexible Care:
if the service was inflexible and not able to meet their individual needs, (i.e., “a customized plan”), then the family caregivers occasionally found the service to be more of a burden than a help.

Cost of Services:
While professional services are 100% covered by publicly funded home care programs, there is a fee for supportive services (e.g., homemaking assistance) needed by persons with dementia. Caregivers expressed a desire to be better compensated for the financial costs incurred due to their care work.

Conclusion

The findings suggest a need for an integrated continuing care model10 that includes the person living with dementia and their family caregivers as partners in care, addresses all of the determinants of health, and embraces sensitivity, diversity, flexibility and supportive services to enhance the availability and acceptability of Canadian home and community-based services.

Funded by Alzheimer Society of Canada; CIHR Institute of Gender & Health and Institute of Aging; Canadian Nurses Foundation; Nursing Care Partnership of the Canadian Health Services Research Foundation
The Translating Research in Elder Care (TREC) Program

BACKGROUND
- An estimated 22% of Canadians will be 65 years of age or older (senior) by 2031
- 43% of Canadian seniors will live 3-4 years in a long-term care facility
- Care provided in long-term care facilities is sub-optimal
- Majority of care is provided by healthcare aides with limited educational preparation

THEORETICAL FRAMING

PURPOSE OF THE RESEARCH PROGRAM
- To address the impact of context on knowledge translation and the subsequent impact of knowledge translation on resident, provider and system outcomes in long-term care facilities in the three Canadian Prairie Provinces

PROGRAM AIMS
1. To build knowledge translation theory (using a multi-method design) about the role of context in influencing knowledge use in long-term care settings and among non-professional care givers
2. To pilot innovative knowledge translation interventions
3. To contribute to improved outcomes and enhanced use of new knowledge in long-term care

HYPOTHESIS
- Context (organizational setting/environmental factors)
- Successful knowledge translation
- Improved outcomes (resident, provider, system level)

PROJECT 1
An Organizational Monitoring Program
Purpose: To explore the effectiveness of context upon knowledge translation among providers and decision makers in long-term care
Design: Interrupted time series
Sample: 36 long-term care facilities
- Alberta (urban)
- Manitoba (urban)
- Saskatchewan (mixed urban and rural)
Methods:
- Survey data collection (Alberta Context Tool)
- RAI-MDS 2.0
- Facility and unit level data
- Regression modeling
Analysis:
- Convergent evidence will be sought and considered across multiple cases

PROJECT 2
A Case Study Program
Purpose: To explore how context mediates the use of knowledge in long-term care
Design: Longitudinal, case study
Sample:
- 3 in-depth case studies (1 province) from 36 facilities in Project 1
- 6 focused case studies (2 provinces) from 33 facilities not involved in in-depth case studies
Methods:
- Participant observation
- Interviews
Analysis:
- Convergent evidence will be sought and considered across multiple cases

PROJECT 3
Enhanced Audit and Feedback Intervention
Purpose: To assess feasibility, costs, and effectiveness of an audit and feedback intervention enhanced with education
Design: Interrupted time series
Sample:
- 12 intervention facilities
- 18 control facilities
Methods:
- Monthly feedback reports developed based on RAI-MDS 2.0 data with educational outreach sessions
- Intensive evaluation in first 3 months
Analysis:
- Survey and interviews to assess responsiveness to feedback reports
- Interrupted time series analysis to assess impact of feedback reports and educational outreach sessions

THE TREC RESEARCH TEAM
Principal Investigator: Carole Estabrooks
Co-investigators: Greta Cummings, Lesley Degner, Sue Dopson, Heather Laschinger, Kathy McGilton, Debra Morgan, Peter Norton, Joanne Profetto-McGrath, Jo Rycroft-Malone, Valerie Menzies, Anne Sales, Malcolm Smith, Norma Stewart, Gary Teare
Collaborators: David Hogan, Chuck Humphrey, Michael Leiter, Charles Mather
Scientific Advisory Committee Chair: Dorothy Pringle

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k n o w l e d g e  i n  p r a c t i c e...
A Regional Analysis of Family Physicians’ Attitudes toward Anxious and Depressed Patients

Julie Kostenki1, Carl D'Arcy1, Debra Morgan2

1Applied Research
2Canadian Centre for Health and Safety in Agriculture
College of Medicine, University of Saskatchewan

Background

Several studies indicate that the majority of physicians subscribe to the biological/medical model of mental disorders and a minority believe that there is a social causation theory [Donat, 2002; Anderson et al., 2015, Chiew-Graham et al., 2012]. However, these views are not necessarily mutually exclusive (Thomas MacBride & Stoppe 2014). Furthermore, mental illness is a public health phenomenon of significant concern in Canada. The mental disorders model identifies illnesses with which individuals are usually not concerned. It is the focus of this paper to examine the mental health among low-income Saskatchewan residents.

Methods

A cross-sectional survey of 6,000 Saskatchewan family physicians was conducted by the Saskatchewan Medical Association and the College of Family Physicians of Saskatchewan in 2016. Data collection occurred at the 2016 annual meeting of the Saskatchewan Medical Association and the College of Family Physicians of Saskatchewan in 2016. The survey was administered to the physicians in the form of an online questionnaire. The response rate was 92%.

Results

Table 1 Responses to Depression Attitude Questionnaire by region: percentage of family physicians agreeing with statements

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<tr>
<th>Region</th>
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Table 2 Component of Depression Attitudes by region: means (standard deviations)

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Discussion

Family physicians’ responses to specific questions regarding patients with depression and anxiety indicate that physicians are likely to believe that these disorders are more likely to be caused by social factors rather than biological factors. However, when asked about the reasons for the exam, they are equally likely to exhibit attitudes consistent with both the social and biological models of mental disorders and the biological model.

Family physicians (no) likely to exhibit attitudes consistent with both the social and biological models of mental disorders and treat the mood and anxiety disorders. Hence, the attitudes of family physicians do not vary by region.

Table 3 Responses to Anxiety Attitude Questionnaire by region: percentage of family physicians agreeing with statements

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Table 4 Component of Anxiety Attitudes by region: means (standard deviations)

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The Role of a Data Analyst and Biostatistician in an Interprofessional Research Program

Chandima Karunanayake, Ph.D. and Rob Beever, M.Ed.

Canadian Centre for Health and Safety in Agriculture
Applied Research/Psychiatry

Context
The role of a data analyst and statistician within a research program depends on the type of study, resources available, and needs of the project. This can range from being a full collaborator or partner, a technical advisor, or a team member.

Participation as a collaborator or partner means that the data analyst or statistician are involved in identification and development of a research topic, conducting literature searches and reviews, writing proposals, ensuring all human or behavioral ethical requirements are met, collecting and entering data, writing the final report, and disseminating research results to stakeholders in the form of technical reports, poster presentations, and scholarly journal submissions.

Alternatively, the data analyst and statistician can maintain distance from the research program and act more as a technical advisor who is available to answer questions that might arise from those that are conducting the research. Finally, the data analyst and statistician can act as a team member, who is available to offer advice on procedures and interpretation of results.

A Statistician is helpful when …
1. A researcher is looking for assistance in designing a study that will answer their research question(s), determining how large a study to perform, and how many different groups to compare.
2. Different types of data are analyzed in different ways. A statistician can determine appropriate methods of analysis for each type.
3. Interpreting the results of an analysis and helping to publish the final reports.

A Data Analyst is helpful when …
1. Ensuring that there is no missing data, outliers, and data entry errors in the database before any analysis takes place.
2. Researchers need to describe and explain various characteristics of the sample that makes them unique for a particular study.
3. The analysis needs to be conducted and reporting the results.

The Rural and Remote Memory Clinic Project

Involvement During Data Collection

The data analyst is involved in creating the database that will be used for data entry and data management. Additional responsibilities of the data analyst include confidentiality of participant information, data integrity and security, coding guidelines and documentation, and managing computer software and hardware specifically to analyze the data.

After Data Collection

The data analyst and statistician examine data validity and reliability of specific questionnaires. Additionally, any data that is missing or that could be an outlier are re-checked to ensure that the values are correct.

Once this is completed, data that is missing on certain scales can be imputed (substitution of a missing value with value based on the scores of the scale, like the mean or median) by using syntax that the statistician has written in SPSS. Syntax is a written command describing the functions that are to be carried out in SPSS. For example, syntax is used to assign labels and values to the numbers in the SPSS database. After all checks have been completed on the dataset, the data analyst and statistician can determine what information can be extracted for the required analysis and perform any suitable statistical analysis for specific research questions.

Fig 1: Database created for data entry (Filemaker)
Fig 2: Data is moved from Filemaker to SPSS for analysis
Fig 3: Data analysis derived from SPSS

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Acknowledgments
The Rural and Remote Memory Clinic Project

Diagnosing Dementia with Cognitive Tests: Are Demographic Corrections Useful?*

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\textsuperscript{a}University of Saskatchewan \textsuperscript{b}Centre on Aging, University of Victoria

Abstract
Demographic corrections should improve the classification accuracy of cognitive tests by reducing the diagnostic biases of advanced age or few years of education, but empirical support for this improved classification is inconsistent. We sought to test factors that could underlie these inconsistent data. Age corrections for cognitive test performance were hypothesized to be inappropriate because age is a risk factor for a dementia diagnosis. Using simulated data, we found increasing the association between demographic variables and dementia diagnosis compromised the diagnostic classification accuracy of demographically corrected scores relative to raw, uncorrected test scores. We also tested the hypothesis that demographic corrections for skewed tests were inappropriate due to the effect of skew on the bivariate relation between demographic variables and scores. Indeed, we found that increasing the skew of simulated test scores caused the classification accuracy of demographically corrected scores to decrease relative to raw, uncorrected scores. Importantly we found some support for these simulation-based findings using archivally collected clinical data.

Relevant Literature
Demographic corrections - advanced age or few years of formal education - are related to older adults' performance on neuropsychological tests (e.g., Bank et al., 2000; Bravo & Hébert, 1997; Brown et al., 2003; Marcopulos et al., 1997; Marcopulos et al., 1998; Nabors et al., 1997; Nystrom et al., 1997).

Due to the demographic variables/test score relation, older adults with advanced age and/or low level of attained education are more likely to be misclassified as impaired (e.g., Folstein et al., 1975; Mangione et al., 1993; Marcopulos et al., 1997; Tombar, McClell, & Knopp, 1996).

Demographic corrections should reduce the error in classifications and improve classification accuracy. Emerging research suggests, however, the use of such demographic corrections does not improve dementia classification accuracy (Bank et al., 2003; Sliwinski et al., 1997; 1999).

Age corrections for test scores may be inappropriate because age is a risk factor for a dementia diagnosis (Sliwinski et al., 1997; 2003).

Corrections may be inappropriate for skewed tests due to non-linear and heteroscedastic relations between these test scores and demographic variables (Flinn et al., 1991; O’Connell et al., 2004).

Data Simulation Method
Overview of simulated data
\begin{itemize}
  \item random numbers to simulate ‘test’ scores
  \item ‘age’ and education based on raw ‘test’ scores
  \item ‘dementia’ or ‘no dementia’ based on ‘test’ score accuracy
\end{itemize}

Manipulations in simulated data generation
Hypothesis re: use of demographic corrections when these demographic variables are also risk factors for dementia 
\begin{itemize}
  \item kept test score \( r \) with age and education constant
  \item varied \( r_{pb} \) between demographic variables and dementia 
    \begin{itemize}
      \item trivial magnitude \( r_{pb} \)
      \item small magnitude \( r_{pb} \)
      \item medium magnitude \( r_{pb} \)
    \end{itemize}
\end{itemize}

Hypothesis re: skew of test scores
\begin{itemize}
  \item varied skewness of ‘test’ scores
    \begin{itemize}
      \item no skew
      \item slight skew
      \item moderate skew
      \item severe skew
      \item kept all other factors constant
    \end{itemize}
\end{itemize}

Statistical Comparisons
For the 100 iterations of each experimental condition; 
\( \% \text{Diff} = \text{AUC for raw} - \text{demographically corrected test scores} \)

Results

Figure 1. \% difference in AUCs of raw minus demographically corrected scores plotted by demographic variable/diagnosis association.

Figure 2. \% difference in AUCs of raw minus demographically corrected scores plotted by degree of skew simulated in ‘test’ scores.

Clinical Data Method
Participants
Of the 10,263 participants in phase 1 of the Canadian Studies of Health and Aging (CSHA-1) we selected 1,252 participants;
\begin{itemize}
  \item with complete demographic data &
  \item interdisciplin consensus diagnoses based on:
    \begin{itemize}
      \item physician’s assessment
      \item nurse’s assessment
      \item neuropsychologist’s assessment
    \end{itemize}
\end{itemize}

Procedure
Participants were grouped based on diagnosis:
\begin{itemize}
  \item No dementia (\( n = 1,039 \))
    \begin{itemize}
      \item diagnoses of no cognitive impairment & cognitive impairment but no dementia
    \end{itemize}
  \item Dementia (\( n = 213 \))
    \begin{itemize}
      \item diagnosis of any subtype of dementia
    \end{itemize}
\end{itemize}

For 20 test scores, difference in AUCs were compared for:
\begin{itemize}
  \item raw scores vs demographically corrected scores
  \item regression based demographically corrected
  \item demographically stratified from published normative data
\end{itemize}

Conclusions
\begin{itemize}
  \item Use of demographic corrections for test scores is cautioned when these test scores are very skewed
  \item Use of age corrections is likely not clinically relevant when association between age and dementia diagnosis is of a small magnitude. At specific cutoffs for impairment demographic corrections compromise sensitivity, but in a test battery approach this is less of a clinical concern because use of multiple tests increases sensitivity.
\end{itemize}

*This work was supported by a Dr. Janet Bews and Alzheimer Society of Canada/CIHR Institute of Aging Doctoral Award.