

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



CCHSA / CCSSMA



Thursday November 20th 2008
Wine and Cheese Scientific Poster Program
7:00 PM – 10:00 PM at Sheraton Hotel (South Room)

Poster Number	Poster Presenter	Authors & Poster Titles
1	Drew Kirk	Kirk, A., Crossley, M., Harder, S., Basran, J., Dal Bello-Haas V., Morgan, D., Stewart, N., D'Arcy, C., Biem, J., Forbes, D., & Holfeld L. Design of a multidisciplinary memory clinic using telehealth technology to serve a rural and remote population.
2	Wendaline McEachern	McEachern, W., Kirk, A., Morgan, D., Crossley, M., & Henry, C. Utility of telehealth for following cognition of memory clinic patients in rural area.
3	Vanina Dal Bello-Haas	Dal Bello-Haas, V., Crossley, M., Kirk, D., Harder, S., & Basran, J. Factors associated with falls and near-falls in community dwelling older adults with early stage dementia.
4	Carl D'Arcy	Meng, X., D'Arcy C., & Yu Y. Does more education protect against Alzheimer's disease and vascular dementia? A systematic review with meta-analysis.
5	Carl D'Arcy	D'Arcy, C., Morgan, D., Stewart, N., Kirk, A., Biem, J., Forbes, D., McBain, L., Crossley, M., & Cammer, A. Establishing and evaluating an interprofessional rural and remote memory clinic: Making transdisciplinary collaboration work.
6	Allison Cammer	Cammer, A., & Morgan, D., & Stewart, N. Negotiating culturally incongruent systems: The process of accessing dementia care for Aboriginal older adults living in Northern Saskatchewan
7	Leslie Holfeld	Morgan, D., Crossley, M., Kirk, D., D'Arcy, C., Biem, J., Forbes, D., Dal Bello-Haas, V., Harder, S., Basran, J., McBain, L., & Holfeld, L. The development and evaluation of a telehealth-supported Rural and Remote Memory Clinic.
8	Debra Morgan	Morgan, D., Crossley, M., Stewart, N., D'Arcy, C., Forbes, D., Normand, S., & Cammer, A. Physical aggression toward nursing aides: Focussing on caregiver "error" masks systemic and organizational factors.
9	Margaret Crossley	Poock, J., Crossley, M., Dal Bello-Haas, V., Harder, S., Lanting, S., Haugrud, N., Basran, J., Kirk, D., McBain, L & Morgan D. Interprofessional research in a rural and remote memory clinic: The role of neuropsychology in collaborative research on differential diagnosis in early stage dementia.

10	Jocelyn Poock	Lanting, S., Crossley, M., McBain, L., & Morgan D. 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.
11	Mary Ellen Andrews	Andrews, M., Morgan, D., & Stewart, N. Dementia care in remote northern communities: Perspectives of registered nurses.
12	Anita Bergen	Bergen, A., Morgan, D., Green, K., Stewart, N., & Normand, S. Dementia care for residents in rural nursing homes: An evaluation of the enhancing care program.
13	Dorothy Forbes	Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., Henderson, S., Leipert, B., Jansen, L., & Normand, S. Availability and acceptability of Canadian home- and community-based services: Perspectives of family caregivers of persons with dementia.
14	Sheena Walls Ingram & Jane Caulfield	Estabrooks C., Morgan D., Stewart N., Teare G., & Cammer, A. The Translating Research in Elder Care (TREC) Program.
15	Freda Elash	Kosteniuk, J., Morgan, D., & Elash, F. Timeline of questionnaire completion: rural and remote memory clinic.
16	Julie Kosteniuk	Kosteniuk, J., D'Arcy, C., & Morgan, D. A regional analysis of family physicians attitudes toward anxious and depressed patients.
17	Rob Beever & Chandima Karunanayake	Karunanayake, C., & Beever, R. The role of a data analyst and biostatistician roles in an interprofessional research program.
18	Megan O'Connell	O'Connell, M. Diagnosing dementia with cognitive tests: Are demographic corrections useful?

Design of a multidisciplinary memory clinic using telehealth technology to serve a rural and remote population

A Kirk, M Crossley, S Harder, J Basran, V Dal Bello-Haas, D Morgan, N Stewart, C D'Arcy, J Biem, D Forbes, L Holfeld.
University of Saskatchewan

Background/Aims: The Canadian province of Saskatchewan has a population of only one million but it 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 their own 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-up 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.

ORGANIZATION OF DAY FOR PATIENT 1 & FAMILY

0830: Arrive at clinic:
Coffee.
Oriented to day, consent obtained.
Patient and family begin completing questionnaires.

Patient Interview:
Life Concerns Scale
IADL
Memory Scale
Perceived Stress Scale
Quality of Life
CES-D
Pleasant Events Scale -AD

Family/Caregiver:
Functional Activities Questionnaire
Bristol ADL
Quality of Life
Neuropsychiatric Inventory
Zarit Burden
Brief Symptom Inventory
Short Form Health Survey (SF-12)

0940: Neurological examination of patient
Family continue discussion with neuropsychology.

1200: Lunch for patient and family

1300: Further assessment by geriatrician.

1400: CT scan

1500: Physiotherapy gait assessment.

1630: Patient and family meet with neurologist, neuropsychologist, geriatrician

1700: Patient and family head home.

Neuropsychological assessment:

Cognitive Screens:

Modified Mini-Mental State (3MS)
Clock Test

Estimates of Premorbid Intelligence:
WRAT-III
WAIS-III (4 subtests)

Repeatable Battery for the Assessment of Neuropsychological Status (RBANS):

Immediate Memory
Visuospatial/Constructional
Language
Attention
Delayed Memory

Orientation & Freedom from Distraction:
Mental Control
Digit Span (Forward & Backward)

Attention/Executive Functions:
Stroop Test
Memory & Learning:
Prairie Buschke
Modification of Buschke Cued Recall Test

Language:

Token Test
Letter Word Naming
Animal Naming
Grasshoppers & Geese (Modification of Pyramids & Palm Trees Test)

Manual Strength & Dexterity:
Grooved Pegboard
Grip Strength
Finger Tapping

Additional:
Behavioral Rating Scale
Saskatchewan Mood Inventory

Community Screening Interview for Dementia (CS1'D):
Where necessary due to language/cultural differences.

Original Buschke Cued Recall Test



Pictorial Prairie Buschke



DIAGNOSES (First 200 patients)

35% Alzheimer's disease
14% Mild Cognitive Impairment
11% Frontotemporal Dementia
11% Mixed Vascular/Alzheimer's
10% Normal
7% Vascular 35% Alzheimer's
14% MCI
11 Dementia
6% Dementia with Lewy Bodies
3% Vascular Cognitive Impairment
1% Normal Pressure Hydrocephalus
1% Huntington's Disease

Travel saved by Telehealth (kms round trip)

Mean distance to Telehealth = 78
Mean distance to Saskatoon = 518
Distance saved by Telehealth = 440

Satisfaction with follow-up appointment

Telehealth 4.65 (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)

Conclusion: 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 Saskatchewan provided an opportunity to compare scores on the Mini-Mental State Examination (MMSE) administered in-person and via telehealth.

After an initial one day assessment in Saskatoon, patients were seen in follow-up at 6 and 12 weeks, either in-person in Saskatoon or by telehealth assessment in their home community. Patients who initially received in-person assessments were seen by telehealth for their next follow-up visit and vice-versa. The same neurologist administered all MMSEs. The first seventy-one patients with both 6 and 12 week follow-up assessments were included. The scores of in-person and telehealth MMSE administrations were compared using the methods of Bland and Altman as well as a paired t-test. MMSE scores did not differ significantly between telehealth (22.34 +/- 6.35) and in-person (22.70 +/- 6.51) assessments. Telehealth provides an acceptable means of assessing mental status of patients in remote areas.

Background

- *Aging demographic in rural, remote areas*
- *Growing prevalence of dementia*
- *Elderly affected by dementia*
- *Harder for elderly to travel*
- *Telehealth available*

But:

- *Sensory impairments may make telehealth difficult*
- *Unfamiliarity with videoconferencing in elderly with cognitive impairment may hinder performance*

However:

- *Greater convenience and reduced travel time may improve performance*

So:

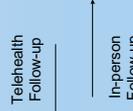
- *It is important to evaluate whether cognition can be adequately assessed and followed via Telehealth*

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

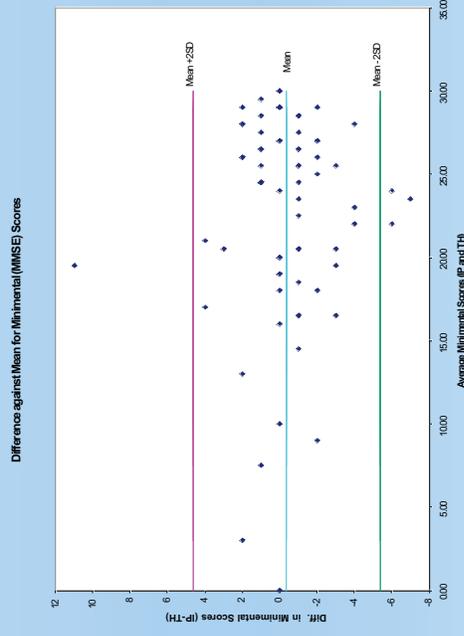
Patient Characteristics:

Total Number of Patients in Study	71
Age at Initial Clinic Day	
Mean +/- SD	72 yrs +/- 11
Range	42-89
Gender	
Male	34 (48%)
Female	37 (52%)
Initial Clinic Day - Neurologist Diagnosis	
Alzheimer's Disease	37 (52.1%)
Mild Cognitive Impairment	11 (15.5%)
Normal	9 (12.7%)
Vascular Dementia	4 (5.6%)
Mixed Vascular/Alzheimer's Dementia	3 (4.2%)
Vascular Cognitive Impairment	1 (1.4%)
Dementia with Lewy Bodies	1 (1.4%)
Parkinson's Disease	1 (1.4%)
Huntington's Disease	1 (1.4%)
Frontotemporal Dementia	1 (1.4%)
Normal Pressure Hydrocephalus	1 (1.4%)
Status Post -Hyponic Encephalopathy	1 (1.4%)

Results

- 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 Canada¹
- > the hospital admission rate secondary to falls in people ≥ 65 years is higher than the national average²

Annual incidence of falls in persons with dementia is 40% to 60%, twice the rate of cognitively normal seniors^{3,4}

In persons with dementia, serious injury is more common and prognosis is poorer compared to cognitively normal older fallers

- > 25% sustain a fracture^{3,5}
- > 6-month mortality rate post-fracture is more than 3 times that of cognitively intact older adults⁶
- > satisfactory recovery from injury is less likely⁶ and institutionalization rate post-injury is 5 times greater⁴

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

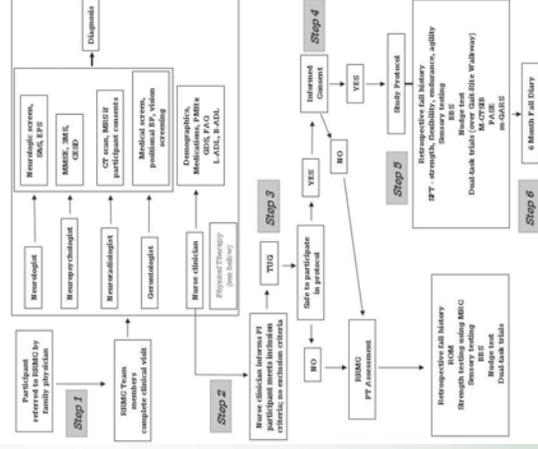
1. Characterize falls and near-falls in community dwelling older adults with early-stage dementia.
2. Determine which potentially modifiable physical fall risk factors contribute to falls and near-falls in older adults with early-stage dementia.
3. Examine the relationship between dementia sub-type, 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)⁸
- 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

1. Health Quality Council. A Picture of Health in Saskatchewan: System Characteristics, Health Determinants, and Outcomes. Saskatoon: HQC; March 2003.
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3. Tinetti ME, Speechley M, Ginter SF. Risk factors for falls among elderly persons living in the community. N Engl J Med. 1988;319:1701-1707.
4. Morris JC, Rubin EH, Morris EJ, Mendel SA. Severe dementia of the Alzheimer's type: an important risk factor for serious falls. J Gerontol. 1987;42:412-417.
5. Buchner DM, Larson EB. Falls and fractures in patients with Alzheimer-type dementia. JAMA. 1987;257:1482-1485.
6. Baker BR, Duckworth T, Wilkes E. Mental state and other prognostic factors in femoral fractures of the elderly. J R Coll Gen Pract. 1972;22:557-559.

• The RRMC is the "flagship" initiative of a CHR New Emerging Team grant ("Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas," Dr. Debra Morgan, P.I.) that aims to improve the availability, accessibility, and acceptability of dementia care services in rural and remote regions



SHRF New Investigator Establishment Grant (2006)
SHRF New Investigator Establishment Grant (2006)

Does more education protect against Alzheimer's Disease and Vascular dementia? A systematic review with meta-analysis.



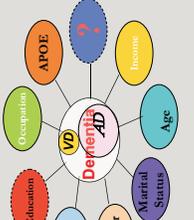
Xiangfei Meng¹, Carl D'Arcy², Yaqin Yu¹

¹ Jilin University, Changchun, China and ² University 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

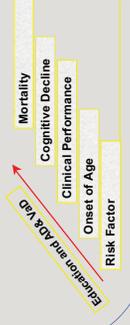
- Search Strategy**
 - Retrieve keywords: (Alzheimer* OR vascular dementia) AND education
 - Study abstracts retrieved for assessment (N=1014)
 - Studies excluded after screening abstracts (N=4513)
 - Full text articles retrieved for assessment (N=201)
 - Studies excluded after assessment of full text articles (N=110)
 - Full text articles for review (N=91)
 - Data on author, published year, journal, subjects, methods, outcomes, adjustments, study design, and results were extracted.
 - Qualitative Analyses (N=35) Quantitative Analyses (N=56)

Inclusion Criteria – include studies that:

- Used case-control, cross sectional, cohort designs;
- Used clear diagnosis criteria for AD or VaD, i.e. DSM and its updates, NINCDS-ADRDA, ICD-10 or other generally accepted criteria;
- Give the clear information about education of subjects;
- Provide an index (odds ratio, etc) or original data to allow meta analysis;
- Control the potential confounders.

Data Synthesis

- Qualitative Analyses Contents
 - Published articles have different view about education. Most of them support that low education is a risk factor to dementia, except the mortality.



Quantitative Analyses : Meta-analyses Procedures



Robust evidences for relationship between education & dementia

Results

Quantitative Results

The pooled OR of prevalent dementia for individuals with low compared to high education was 2.67 (95%CI 2.15-3.31, p<0.001), indicating a low level of education increased the risk of dementia by 87%; for incident studies the pooled OR was 1.92 (95%CI 1.52-2.41, p<0.001).

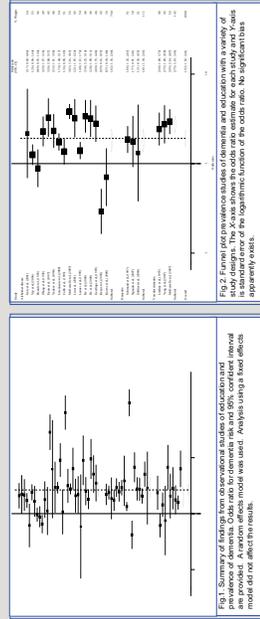


Fig. 1. Summary of findings from observational studies of education and the risk of dementia. A random effects model was used. Analysis using a fixed effects model did not affect the results.

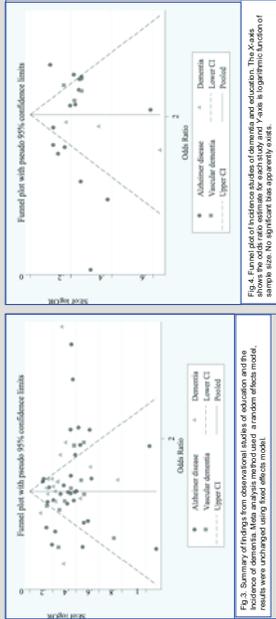


Fig. 2. Funnel plot of incidence studies of dementia and education. The x-axis shows the odds ratio estimate for each study and y-axis is logarithmic function of the odds ratio. No significant bias apparently exists.

Heterogeneity tests

- Funnel plots, Fig 2 and Fig 4, show that most of studies are located in the domain, although some lie outside the boundary.
- Egger tests were employed for the prevalence and incident studies separately. Only prevalence studies with observation designs yielded significantly result (t= 4.42, p=0.01).
- The "trim-and-fill" method was only adopted for prevalence studies, the estimate of corrected OR was 1.85 (95%CI 1.45-2.37 p<0.001), indicating that those with lower education levels were 85% more likely to have dementia compared to those with higher education.

Sensitivity tests

- Subgroups results, Table 2, show that only incidence studies with case-control designs (4 articles in total) yielded negative results.
- Further analysis omitting one study at one time, which takes influence of study into account, did not change the results.

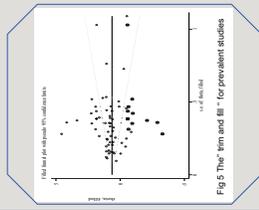


Fig. 5. The "trim and fill" for prevalent studies

Group	AD	VaD	Unspecified	Total
Prevalence	2.74 (2.02-3.73)	1.99 (1.29-3.05)	2.96 (1.95-4.51)	2.67 (2.15-3.31)
Incidence	1.82 (1.36-2.44)	2.75 (2.19-3.45)	1.81 (1.52-2.41)	1.92 (1.52-2.41)

Table 2 Pooled OR& 95%CI in Subgroups

Group	Cross-sectional	Case-control	Cohort	Total
Prevalence	3.50 (2.68-4.57)	1.64 (1.19-2.27)	2.02 (2.15-3.31)	2.67 (2.15-3.31)
Incidence	1.47 (0.93-2.34)	1.47 (1.57-2.60)	2.02 (1.52-2.41)	1.92 (1.52-2.41)

What this Systematic Reviews adds:

- Study Designs included**
 - Cross-sectional study
 - Case-control study
 - Cohort
- Heterogeneity Tests**
 - Funnel plots
 - Egger tests
- Sensitivity Tests**
 - Subgroup analysis based on study design and different diseases
 - Omitting one study each time
- Meta-regression**
 - Explore the characteristics of study quality
 - Low education was a risk for dementia, either for AD & VaD. Education may also influence the clinical process including age at onset, clinical performance, cognitive decline, mortality, etc.
- Findings**
 - Subgroup analysis for one review
 - Subgroup analysis for different or unpublished studies and for education categories.
 - Not employed
 - One review found that low education may be a risk factor for dementia.
 - Another review found that high education can decrease the incidence of dementia.

Conclusions

- A high level education is significant related to a reduction both in the prevalence and incidence of dementia, either AD and VaD.
- The evidence suggests, albeit less strongly, that those with higher education will have a later age of onset, better clinical performance and slower cognitive decline, but greater likelihood of mortality from the disease.
- Our study results are in accordance with the cognitive reserve hypothesis, which assumes some aspects of life experience such as greater levels of education may protect against the dementia.
- More 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

C. D'Arcy⁽¹⁾, D. Morgan⁽²⁾, N. Stewart⁽²⁾, A. Kirk⁽³⁾, J. Biem⁽⁴⁾, D. Forbes⁽²⁾, L. McBain⁽⁵⁾, M. Crossley⁽⁶⁾, A. Cammer⁽⁷⁾
 (1)Medical Sociologist, (2)Nursing, (3)Neurologist, (4)Internist, (5)Geographer, (6)Neuropsychologist, (7)Dietitian/Epidemiologist

The Challenges

- Providing timely specialist diagnosis and treatment to a disperse 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 Context



Saskatchewan:

- Is a Canadian prairie province
- One million people spread out over 665,000 km² or 262,000 sq. miles
- (In comparison England has an area 1/5 that of Saskatchewan with 50 times the population)
- Median population density is 1.67 persons per km²
- Has a universal single payer medical care system



Impetus for a Rural and Remote Memory 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

Development process:

- Many meetings and seed money to develop proposal
- Consultation meeting with primary care providers in rural and remote areas

The Clinic

Goals

- A state of the art transdisciplinary memory clinic servicing 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 (Saskatoon and Regina) - northern communities were defined as remote

Structure

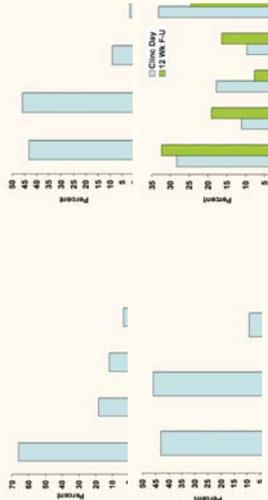
- Clinic is coordinated by a nurse case manager
- A pre-clinic assessment is done by TeleHealth (30 mins)
- Necessary blood tests are done and results forwarded prior to clinic visit
- One-day assessment clinic (in Saskatoon), patient is seen by neurologist, neuropsychological team, geriatrician, neuro-radiologist & physical therapist
- CAT scan and/or MRI are conducted unless recent imaging available
- Each patient is discussed at Interdisciplinary Teaching Rounds at the end of the day
 - all clinical team members, residents and graduate students attend, plus referring physician is invited to participate by telephone conference call
- Case conference - Patient and family members meet with neurologist and neuropsychologist, 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 accretion:
- All principals are still involved 3 years into the project
- Have added new team members with complementary expertise
- Team is looking for way to expand clinic and secure alternative funding
- Clinic training experience for medical residents and graduate students
- Research training and experience for residents and graduate students.

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

- 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:



"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

Making Transdisciplinary Collaboration Work

Defining transdisciplinarity:

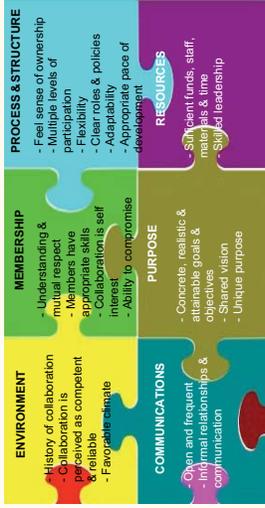
A transdisciplinary approach pools and integrates ... the expertise of team members so that more efficient and comprehensive assessment and intervention services may be provided... Professionals from different disciplines teach, learn, and work together to accomplish a common set of intervention goals. The role differentiation between disciplines is defined by the needs of the client, not discipline-specific characteristics. Assessment, intervention, and evaluation are carried out jointly...."

Why are some collaborations successful and others not?
 You can't just throw people together
 Successful collaboration requires:

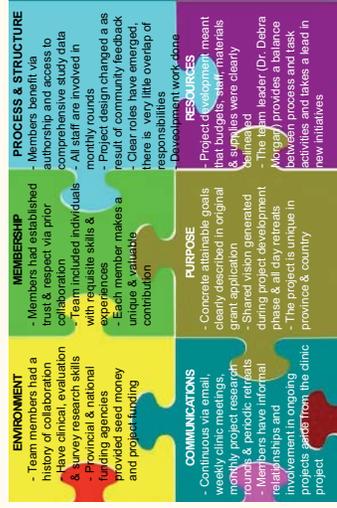
- work
- time
- money
- resources
- leadership
- involvement
- commitment



Ingredients for a successful collaboration ? In theory



And in the Rural and Remote Memory Clinic



References: Berman, M.B. (1984). Working with members of other disciplines. Collaboration for success. In M. Wolcott & J.S. Wilkes (Eds.), Including children with special needs in early childhood programs (pp. 4-70). Washington, DC: National Association for the Education of Young Children. 4. Wolcott, M.P., Murray-Coker, M., & Wolcott, S.P. (2001). Collaboration. In: Stakeholder Work, 2nd Edition. St. Paul: AmeriStar, Wolcott Foundation.

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



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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 Keéwaítin Yatthe Regional Health Authority and Meadow Lake Tribal Council
- Communities of focus: Île à la Crosse, Buffalo Narrows, Beauval, and English River First Nation



Participants

- Participants (N=30): Healthcare Providers, Informal Caregivers, Community Members (overlapping roles)



Participant Characteristic	N	%
Participants who are women	29	96.7%
Participants identifying as Aboriginal	22	73.3%
Participants identifying as First Nations	14	46.7%
Participants identifying as Métis	8	26.7%
Participants who work in healthcare	28	93.3%
Participants with personal experience caring for a loved one with dementia	7	23.3%

Table 1: Summary of Participant Characteristics

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

Key Concepts

Social Context:

Speaks to the contributing circumstances in which dementia care is accessed and can be further divided into 6 contributing areas:

- Lack of Awareness of Dementia
- Unfamiliar Milieu
- Difficultly in Travel
- Competition for Limited Resources
- Distrust of Western Systems
- Fear

Managing in Spite of Systems:

Accounts for the processes people engage in when confronted with a potential dementia diagnosis:

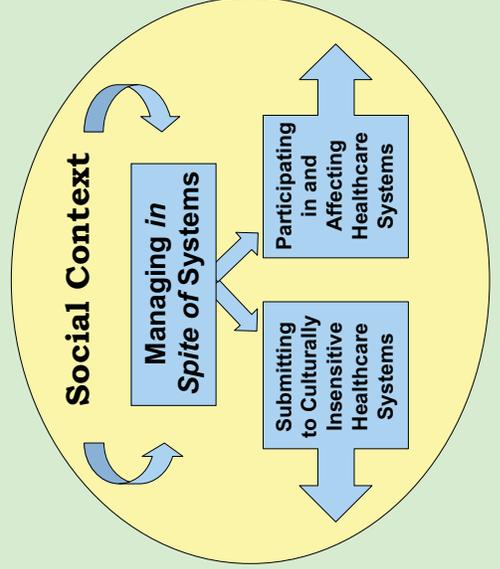
- Subverting the System
- Kinship and Family Caregiving
- Sacrificing to Care for Others



Results

Emergent Theory:

The Process of Negotiating Culturally Incongruent Healthcare Systems



Submitting to Culturally Incongruent Healthcare 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



Development and Evaluation of a Telehealth-Supported Rural and Remote Memory Clinic

D. Morgan¹, M. Crossley², A. Kirk³, N. Stewart⁴, C. D'Arcy⁵, J. Biern³, D. Forbes⁶, V. Dal Bello-Haas⁷, S. Harder³, J. Bastran³, L. McBain⁸

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

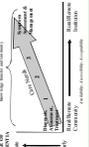
Introduction:

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

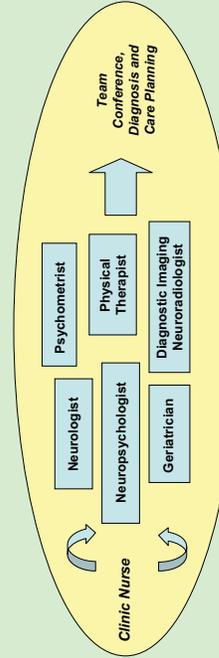
New Emerging Team (NET) Grant:

- NET grant, "Strategies to improve the care of persons with dementia in rural and remote areas", was developed to:

- Improve the **availability** of specialized personnel and services providing assessment and management of dementia
- Improve the **accessibility** of programs supporting formal and informal caregivers of persons with dementia
- Improve the **acceptability** of services for persons with dementia and their caregivers



Full-Day Coordinated Assessment



Pros and Cons

CONS

- Long day onerous for some patients.
- Labor-intensive & time-consuming for staff.
- Must be funded.
- Necessity of all testing hard to judge in advance.
- More difficult to establish and maintain rapport in groups and via telehealth?

PROS:

- Savings in travel time & money for patients & families.
- 'Get it all over with.'
- Detailed assessment
- Well-studied group of patients for study.
- Referring physician involvement.
- Team-building.

Interview Analysis

- Interview comments proved to be the best source of feedback for full-day clinic evaluation
- Relatively few concerns and complaints but, when reported, concerns and suggestions discussed and addressed at regular clinic meetings
- Examples of concerns: lack of support bar in washroom, poor wheelchair accessibility, length of day and need for rest breaks, too many questionnaires (all addressed)
- Overall, the positive feedback showed acceptability and satisfaction with clinic
- Thematic analysis of interview comments produced 3 main areas of satisfaction:

Reduced Travel Burden

• For us it's quite a trip so it was a relief to have it all done in one day - I can't imagine having to see all those people in their own clinics on different days - would have been too stressful

• It was a long day but not as exhausting as we'd anticipated

• It was easier than going many times because after the travel she's already worked up

Timely Diagnosis

• Such a relief to have a diagnosis and start planning, taking the next steps and not wondering

• A big thing is just knowing, just knowing what the problem is so we can start dealing

• (My husband) was relieved to have everything finished that day and know the results - not have it hanging over his head

• It was really great to go in and have the tests and get the results and diagnosis right away without waiting or worrying

Team Approach to Care

• Everyone went out of their way to make us comfortable, we were very friendly and knowledgeable

• All the doctors can talk to each other right there rather than having us as the go-between saying, 'well this Dr. told us this last month...'

• I just can't imagine doing this any other way - it's how healthcare should be

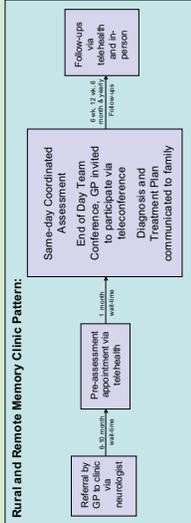
• I've never been to a place where everyone worked so well together

• We were respectful and didn't expect? attitude we often do

Rural and Remote Memory Clinic

Clinic Goal:

- To develop and evaluate a streamlined integrated clinic for patients from rural and remote Saskatchewan for diagnosis and management of dementia and to evaluate telehealth as a means of delivering follow-up care to patients and their families



- Pre-assessment of patient and caregivers is conducted via telehealth to prepare them for the one-day assessment, familiarize them with the clinic nurse who will be their care liaison, order blood work or other necessary tests, and gather information to assist with planning the one-day assessment
- Coordinated assessment takes place in Saskatoon, is approximately 8 hours, and involves the patient and their informal caregivers and/or family members

Discussion

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

- The success of this clinical service is due to:
- Clinical need
 - Research productivity
 - Teaching value, capacity building
 - Focus on rural residents
 - Focus on needs of elderly patients
 - Focus on aboriginal residents
 - Focus on technology, telehealth, saving \$
 - Increasing service access
 - High satisfaction of patients and caregivers



Acknowledgements

Funding and in-kind support is generously provided by:



Evaluation

- The clinic is evaluated in a number of ways including:
- Regularly scheduled Clinic Team meetings to plan and discuss clinic process, examine issues, and make decisions
 - Bi-annual NET retreat workshops
 - Systematic monitoring of Clinic attendance and 'drop-outs'
 - Comparison of travel time and estimate of costs saved:
 - Mean distance to Telehealth = 78
 - Mean distance to Saskatoon = 518
 - Distance saved by Telehealth = 440
 - At each Telehealth Appointment:
 - Family/Client Telehealth Satisfaction Questionnaire
 - Telehealth Coordinator Evaluation Form
 - After full-day clinic visit in Saskatoon:
 - Structured scale and semi-structured telephone interview with informal caregiver
 - Follow-up Evaluation Form (Patient and Family)
 - At Telehealth and In-Person Follow-up Appointments:
 - In-depth interview with informal caregiver 1-3 years after initial clinic contact



Interprofessional Research in a Rural and Remote Memory Clinic: The Role of Neuropsychology in Collaborative Research on Differential Diagnosis in Early Stage Dementia



J. Poock, M. Crossley, V. Dal Bello-Haas, S. Harder, S. Lanfing, N. Haugrud, J. Basran, D. Kirk, L. McBain & D. Morgan



Joelyn Poock (graduate student: psychology) and Dr. Vanina Dal Bello-Haas collaborating on a prospective study of fall risk

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.



Fig. 1 The interdisciplinary team at the RRMCM

Introduction: Collaborative Research at the RRMCM

- The Rural and Remote Memory Clinic (RRMCM) 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 RRMCM includes nursing, geriatric medicine, neurology, neuroradiology, physical therapy and human geography.



Shawnda Lanfing (graduate student) meeting with Aboriginal seniors in the development of a culturally appropriate test protocol

Human Geography

- The interprofessional setting at the RRMCM 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.

Behavioral Medicine



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

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.

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.



- Successful collaboration between psychology and associated disciplines can improve assessment and differential diagnosis in early-stage dementia

Conclusions

- The RRMCM is generating a rich, shared data base 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.



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

Methods



Figure 1: Travel to northern communities

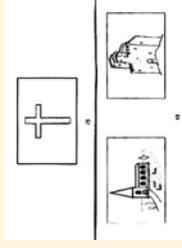


Figures 2 and 3: Examples of prevalence of colour in Aboriginal communities

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)

Results-con't



Example of Pyramids and Palm Trees triad



Example of Modified Measure: "Grasshoppers and Geese" triad

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



Dementia care in remote northern communities: Perspectives of Registered Nurses.

Mary Ellen Andrews RN, PhD¹; Debra Morgan RN, PhD²; Norma Stewart RN, PhD¹
College of Nursing, University of Saskatchewan¹; Canadian Center for Health and Safety in Agriculture²



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 northern 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 *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

INSULATING AND EXPANDING THE AWARENESS OF DEMENTIA IN NORTHERN NURSING PRACTICE

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. 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.



Dementia Care for Residents In Rural Nursing Homes: An Evaluation of the Enhancing Care (EC) Program

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¹Department of Community Health and Epidemiology, University of Saskatchewan; ²Institute of Agricultural, Rural & Environmental Health, University of Saskatchewan; ³College of Nursing, University of Saskatchewan;



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



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

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

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

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 ..."

How did you find the meetings without the facilitator?

"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:



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

11 Guidelines for Care:

1. Specialized Training and Education for Caregivers
2. Support for Caregivers
3. Individualized Assessment
4. Individualized Care Planning
5. Meaningful Programs and Activities
6. Specialized Human Resources
7. Supportive Physical Design
8. Transportation
9. Decision Making: Respecting Individualized Choice
10. Prevention of and Response to Abuse
11. Use of Restraints

- The EC Program is based on a multidisciplinary team approach
- Includes a facilitator from the Alzheimer Society, and on-site coordinator, and representatives from each department within the facility
- The EC team meets to assess the current abilities of their facility to meet the 11 Guidelines for Care, then develop and implement specific measurable goals to improve care
- The Alzheimer Society facilitator participates in 2 meetings then the team operates independently



Forbes D¹, Markle-Reid M², Hawranik P³, Peacock S⁴, Kingston D², Morgan D⁵, Henderson S², Leipert B¹, Jansen L¹, Normand S²
¹ University of Western Ontario, ² McMaster University, ³ University of Alberta, ⁴ University of Manitoba, ⁵ University of Saskatchewan, Canada

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 approach^{7,8}
- 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

HYPOTHESIS

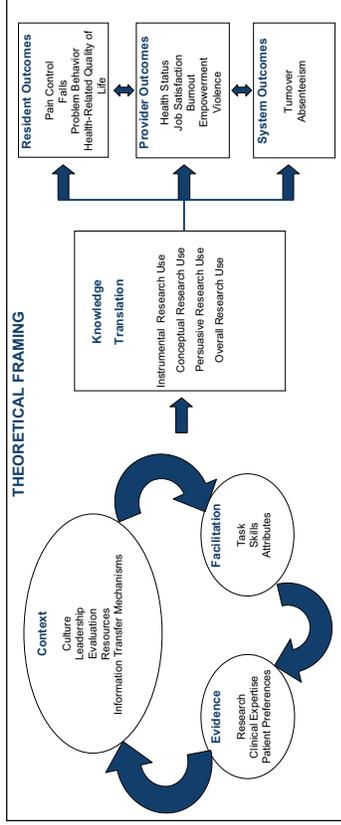
Context (organizational setting/environmental factors) → Successful knowledge translation → Improved outcomes (resident, provider, system level)

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

- 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
- To pilot innovative knowledge translation interventions
- To contribute to improved outcomes and enhanced use of new knowledge in long-term care



PROJECT 1

An Organizational Monitoring Program

Purpose: To explore the effect of context upon knowledge translation among providers and decision makers in long-term care

Design: Longitudinal, descriptive

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

Analysis:

- Regression modeling
- Multi-level modeling
- Structural equation modeling

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:

- 5 in-depth case studies (1/province) selected from 36 facilities in Project 1
- 6 focused case studies (2/province) selected 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
- Analysis will be conducted within and across sites

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 response to feedback reports
- Interrupted time series analysis to assess impact of feedback reports and educational outreach sessions

PILOTS

- 1. Storytelling**
 - Step 1:** Discovery of stories currently in use
 - Step 2:** Develop a feasible methodology for development of stories
 - Step 3:** Implementation of a storytelling intervention trial (with healthcare aides)
- 2. Supportive Supervision**
 - Step 1:** Develop a supportive supervision intervention to be implemented with supervisors
 - Step 2:** Pilot test the supportive supervision intervention in a quasi-experimental form (with LPNs and RNs)
- 3. Leadership Development**
 - Step 1:** Review content and presentation of Coaching for CARE program
 - Step 2:** Pilot test Coaching for CARE workshop (with managers and directors)
 - Step 3:** Evaluate the workshop

THE TREC RESEARCH TEAM

Principle Investigator: Carole Estabrooks

Co-Investigators: Greta Cummings, Lesley Dejnozka, Sue Dorson, Heather Leschinger, Kathy McGillion, Debra Morgan, Peter Norton, Jeanne Profetto-Gratch, Jo Ryncoft-Malone, Verina Menec, Anne Sales, Malcolm Smith, Norma Stewart, Gary Teare

Collaborators: David Hogan, Chuck Humphrey, Michael Lelzer, Charles Mather

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Scientific Advisory Committee Chair: Dorothy Pringle

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knowledge in practice...

TIMELINE OF QUESTIONNAIRE COMPLETION

RURAL AND REMOTE MEMORY CLINIC

Julie Kosteniuk, Debra Morgan & Freda Elash



If in nursing home or not retestable at 1 year etc., the neuropsychologist decides ahead of time if they will see the patient; sometimes only the neurologist will see them.

Note: Color coded highlighting matches color of paper used for respective questionnaire.



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

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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 ...

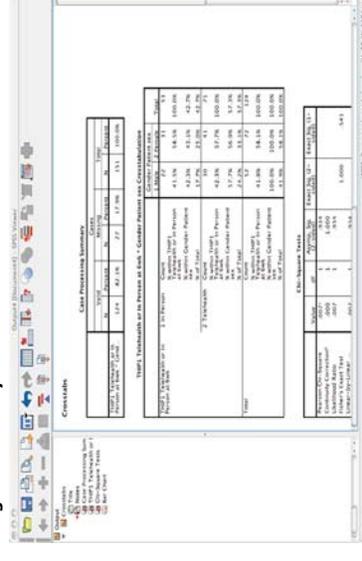
1. Ensuring that there is no missing data, outliers, and data entry errors in the database before any analysis takes place.
2. Researchers need to describe and explain various characteristics of the sample that makes them unique for a particular study.
3. The analysis needs to be conducted and reporting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

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Fig 2: Data is moved from Filemaker to SPSS for analysis



Fig 3: Data analysis derived from SPSS



Once the data has been analyzed, a statistician can be valuable in checking that the conclusions fit the results, suggesting the best way to describe and display the data, and assuring that you have not made erroneous or incomplete statements about the findings.

Acknowledgments



Reference: American Statistical Association (2003). When you consult a statistician ... what to expect. Section on Statistical Consulting. Retrieved November 10th, 2008 from: <http://boostat.mc.vanderbilt.edu/wiki/pub/Main/ConsultingProcedures/SCSbrochure.pdf>.

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



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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 archival collected clinical data.

Relevant Literature

- * Demographic variables - advanced age or few years of formal education - are related to older adults' performance on neuropsychological tests (e.g., Bank et al., 2000; Brevo & Hebert, 1997; Brown et al., 2003; Marcopulos et al., 1997; Marcopulos et al., 1999; Nabors et al., 1997; Youngghin et al., 1995).
- * Due to the demographic variable/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., Feinstein et al., 1975; Mengiere et al., 1995; Marcopulos et al., 1997; Tombaugh, McDowell, Kristjansson, & Hudley, 1998).
- * 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 (Beile et al., 1996; Sliwinski et al., 1997) and dementia screening accuracy (Kraemer et al., 1998; O'Connell et al., 2004).
- * 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 (Faslineau & Adams, 1996; O'Connell et al., 2004).

Data Simulation Method

Overview of simulated data

- * Random numbers to simulate 'test' scores
- * 'age' and 'education' based on r with 'test' scores
- * 'dementia' or 'no dementia' based on 'test' score accuracy

Manipulations in simulated data generation

- Hypothesis re: use of demographic corrections when these demographic variables are also risk factors for dementia
- * kept test score r with age and education constant
 - * varied r_{pb} between demographic variables and dementia
 - ▶ trivial magnitude r_{pb}
 - ▶ small magnitude r_{pb}
 - ▶ medium magnitude r_{pb}

- Hypothesis re: skew of test scores
- * varied skewness of 'test' scores
 - ▶ no skew
 - ▶ slight skew
 - ▶ moderate skew
 - ▶ severe skew
 - * kept all other factors constant

Statistical Comparisons

- For the 100 iterations of each experimental condition;
 - * Diff = AUC for raw - demographically corrected 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;
- * with complete demographic data &
 - * with interdisciplinary consensus diagnoses based on:
 - ◊ physician's assessment
 - ◊ nurse's assessment
 - ◊ neuropsychologist's assessment

Procedure

Participants were grouped based on diagnosis:

- 1) **No dementia** ($n = 1,039$)
 - = diagnoses of no cognitive impairment & cognitive impairment but no dementia
 - or 2) **Dementia** ($n = 213$)
 - = diagnosis of any subtype of dementia
- For 20 test scores, difference in AUCs were compared for:
- * raw scores vs
 - * demographically corrected scores
 - ◊ regression based demographically corrected
 - ◊ demographically stratified from published normative data

Results

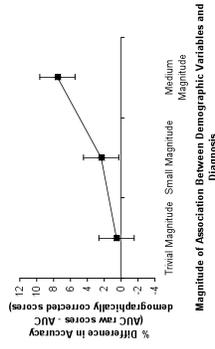


Figure 1. % difference in AUCs of raw minus demographically corrected scores plotted by demographic variable/diagnosis association.

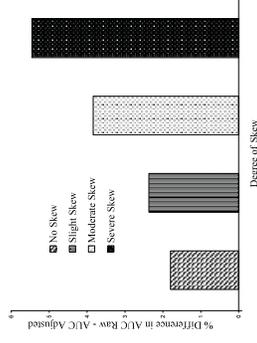


Figure 2. % difference in AUCs of raw minus demographically corrected scores plotted by degree of skew simulated in 'test' scores.

Clinical Data Results

In these clinical data there was a small magnitude of association between age and dementia, trivial for education and dementia

- * **age corrected = raw scores in overall accuracy**
- ◊? due to trade-off between sensitivity and specificity
- ◊ cutoff analyses suggests
 - ▶ **sensitivity ↑ for raw scores, but**
 - ▶ **specificity ↑ for demographically corrected scores**

scores

For tests with extreme skew, AUC of demographically corrected scores appeared ↓ than raw score AUC

Conclusions

- * Use of demographic corrections for test scores is cautioned when these test scores are very skewed
- * 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.

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