5th Annual Summit

November 15th & 16, 2012
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Rural and Remote Memory Clinic Update (March 2004 – March 31, 2012)

L. Holfeld¹, D. Morgan¹, M. O’Connell², M. Crossley³, A. Kirk³, N. Stewart⁴, V. Dal Bello-Haas⁵, L. McBain⁶, A. Cammer¹, D. Minish¹

¹Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; ²Department of Psychology, University of Saskatchewan; ³College of Medicine, University of Saskatchewan; ⁴College of Nursing, University of Saskatchewan; ⁵School of Rehabilitation, McMaster University; ⁶First Nations University of Canada

Background

Introduction:
- Rural and Northern Saskatchewan have 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.

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.

Saskatchewan Telehealth Sites (June 2011)
(Pre-clinic Assessments and Follow-ups)

Comparison of travel time and distance saved:
- Mean distance from home to Telehealth = 35.5 km
- Mean distance from home to Saskatoon = 264.6 km
- Distance saved by Telehealth = 229.1 km (one-way)

Telehealth: 148 videoconferencing endpoints located on the Telehealth network in 76 different communities and in 100 facilities.

RRMC Demographics
n = 363 (March 31, 2012)

Mean Age = 71.8 yrs
Range Age = 33 - 97 yrs
Gender: 42% Males, 58% Females

Pre-clinic 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 tests, and gather information to assist with planning the one-day assessment.

All follow-up appointments are now via telehealth.
- This process was implemented in December 2008 based on research showing high patient and family satisfaction with telehealth.

Clinical Diagnoses to Date
n = 339 (March 31, 2012)

- Alzheimer Disease - 37%
- Other dementias:
  - Vascular Dementia – 5%
  - Dementia with Lewy Bodies – 4%
  - Frontal Temporal – 7%
  - Dementia due to Medical Condition - 1%

- Dementia due to Multiple Etiologies – 4%
- Sub-cortical Dementia - 1%
- No Dementia – 18%
- Mild Cognitive Impairment – 15%

Funding and in-kind support is generously provided by:
The Anticipated and Experienced Benefits of Early Diagnosis According to Informal Caregivers of Memory Clinic Patients

Debra Morgan¹, Sheena Walls-Ingram¹, Allison Cammer¹, Margaret Crossley¹, Vanina Dal Bello-Haas², Dorothy Forbes², Anthea Innes³, Andrew Kirk¹, Megan E. O’Connell¹, Norma Stewart¹

¹University of Saskatchewan ²McMaster University ³University of Western Ontario ⁴Bournemouth University

The 5th Annual Summit of the Knowledge Network in Rural and Remote Dementia Care, November 15-16, Saskatoon.

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<th>Setting</th>
<th>Study Design</th>
<th>Demographics</th>
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<tr>
<td>The Rural &amp; Remote Memory Clinic (RRMC), located in Saskatoon combines interprofessional clinical practice, research and training to provide convenient “one day” access to diagnostic assessment for patients with memory problems living in remote or rural regions of Saskatchewan. RRMC patients are referred by their family doctor, and are followed up by the Clinic team via Telehealth and in-person visits. The RRMC operates under a family-centred model of care, involving the patient’s family and/or caregivers at all points.</td>
<td>Informal caregivers who accompanied the patient to the initial full-day diagnostic assessment at the RRMC were invited to participate in interviews at 3 points over the year following their first visit to the RRMC.</td>
<td>30 Initial Clinic Day interviews 44 caregivers (16 spouses; 24 adult children; 6 other) ** 32 and 16 of the original 44 caregivers participated in the 6 Month and 1-Year interviews via telephone, representing a remaining 26 and 14 cases, respectively. ** Diagnoses of Patients: 15 Alzheimer Disease; 4 Mild Cognitive Impairment; 3 Frontal Temporal Dementia; 1 Vascular Cognitive Impairment; 5 No Dementia; 2 Inconclusive</td>
</tr>
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### Anticipated Benefits

On the day of their family member’s assessment at the RRMC, we asked caregivers about their expectations of the day and the importance of a diagnosis. Caregivers said it would help them deal with the illness by ‘putting a name to it’.

“You know when it comes back to a diagnosis, a definite diagnosis, I mean it’s the same thing as if a kid isn’t diagnosed with ADHD ... they don’t do anything about it. But once they have a title to their problem then they can... deal with it. And it’s just the same kind of thing.”

Daughter of Patient

They also expected a diagnosis to bring about treatment, prognosis and guidance.

“... more understanding of what we’re... to expect and who we can sort of depend on if we have questions.”

Daughter of Patient

Some caregivers expected an assessment to offer an explanation of the patient’s symptoms,

“...just to have a reason for his change... you have a person go from day to night... just to know... what caused it would help... it doesn’t change the outcome at all but... it would be a help I think.”

Wife of Patient

...or rule out any other potential causes of symptoms:

“To rule out any possible brain tumors or to just maybe find out that some of this is normal in aging or normal because of diabetes...”

Wife of Patient

### Experienced Benefits

6 Months after the initial assessment, we asked caregivers about the impact of receiving a diagnosis. Their responses are categorized as:

- **Relief**

“...We were happy...he was really quite concerned and he was happy that his diagnosis wasn’t... they didn’t diagnose him with Alzheimer’s at this time... you know they found a few things that... they were going to watch but he wasn’t actually diagnosed with it.”

Daughter of Patient

- **Acceptance**

“...after years of feeling how I was feeling...[the diagnosis] helped me move on, this is the new normal.”

Wife of Patient

- **Opened doors to services**

“...before we went to [RRMC] we didn’t know that [home community] Home Care would assist us, that they were there...available to assist families in that kind of situation.”

Niece of Patient

- **Validation**

“I guess maybe unless you live with a person day in day out... other people, they wouldn’t see it like I would see it. And I guess just having you guys [RRMC Care team] say... you’re not alone in that, and what you are saying is correct... it made a difference. Then you can carry on without being frustrated.”

Wife of Patient

### Conclusions

The data indicate that just receiving a diagnosis contributed to the well-being of caregivers in several ways. These benefits may not always be obvious to care practitioners. Physicians and other primary healthcare providers need to be aware of the psychosocial benefits of receiving a diagnosis for family caregivers, who provide the majority of unpaid care for persons with dementia. It is hoped that the findings of this study heighten awareness of primary healthcare providers about caregiver-reported benefits of a timely diagnosis.

### One-Year Interview Findings to Date

The data from interviews with the caregivers one year after receiving a diagnosis are currently being analyzed. Initial findings point to themes relating to:

- Planning and decision-making processes for future care of patients
- How past experiences can shape the way caregivers respond to their role and circumstances
- How caregivers’ understanding of the diagnosis impacts coping.
Less formal education predicts cholinesterase inhibitor discontinuation in rural and remote patients with dementia

Solin Saleh¹, Andrew Kirk² MD FRCP, Debra Morgan¹ PhD RN, Chandra Karunanayake³ PhD

¹College of Medicine, University of Saskatchewan, Saskatoon, Saskatchewan, Canada. ²Division of Neurology, University of Saskatchewan, Saskatoon, Saskatchewan, Canada. ³Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, Saskatoon, Saskatchewan, Canada

Introduction

• Dementia currently affects 500,000 Canadians with an economic burden expected to reach $153 billion within the next 30 years.¹
• Patients with dementia who are placed on cholinesterase inhibitors may symptomatically improve, remain the same, or become symptomatically worse.
• A study assessing health data from Saskatchewan, Canada, found that over 40 months, 84% of patients discontinued therapy with the one-year risk of discontinuation being 66.4%.²
• Such high rates underscore the importance of research examining predictors of cholinesterase inhibitor discontinuation to identify patients who are likely to respond to and continue on treatment and those who are less likely to respond or to have adverse effects.

Methods

• Data Collection began in March 2004 at the Rural and Remote Memory Clinic in Saskatoon, SK where family physicians referred their non-institutionalized patients.
• Patient and caregiver questionnaires and assessments administered during the in-clinic appointment provided the socio-demographic, clinical and functional variables.
• 63 participants started on a cholinesterase inhibitor at clinic day who also attended a 6-month follow up appointment were included.
• The dependent variable was discontinuation of cholinesterase inhibitor by 6 months.
• Multivariable analysis was done to examine the association between each independent variable and the dependent variable.
• Variables significantly correlated with discontinuation of cholinesterase inhibitor therapy (p<0.05), and important individual factors (age and sex) were retained in final multivariable model

Results

Table 1: Socio-demographic, functional and clinical characteristics of patients at clinic day (baseline)

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<thead>
<tr>
<th>Variable</th>
<th>Mean ± SD</th>
<th>Range</th>
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<tr>
<td>Age (in years)</td>
<td>74.56 ± 7.79</td>
<td>69-89</td>
</tr>
<tr>
<td>Years of Formal Education</td>
<td>13.36 ± 7.37</td>
<td>40-17.10</td>
</tr>
<tr>
<td>MMSE-Mini Mental State Exam</td>
<td>22.81 ± 2.68</td>
<td>0-29</td>
</tr>
<tr>
<td>FAQ Functional Assessment Questionnaire</td>
<td>1.19 ± 1.31</td>
<td>0-2</td>
</tr>
<tr>
<td>FAQ Instrumental Activities of Daily Living, patient rated</td>
<td>22.81 ± 2.44</td>
<td>0-27</td>
</tr>
<tr>
<td>BABA Dressel Activities of Daily Living</td>
<td>7.01 ± 1.59</td>
<td>0-17.5</td>
</tr>
<tr>
<td>NYHA-Quality of Life, patient rated</td>
<td>38.42 ± 5.51</td>
<td>35-45</td>
</tr>
<tr>
<td>28-item CES-D Center for Epidemiological Studies-Depressed Mood Scale, patient rated</td>
<td>13.35 ± 1.52</td>
<td>5-40</td>
</tr>
<tr>
<td>LCS-Life Concerns Scale</td>
<td>4.66 ± 5.21</td>
<td>0-31</td>
</tr>
<tr>
<td>MMSE Self-Rating of Memory Scale</td>
<td>31.9 ± 4.56</td>
<td>17-56</td>
</tr>
<tr>
<td>CES-D Centre for Epidemiological Studies-Depressed Mood Scale, patients rated</td>
<td>22.81 ± 3.37</td>
<td>0-44</td>
</tr>
<tr>
<td>NPI-Neuropsychiatry/Institute Severity</td>
<td>7.91 ± 1.56</td>
<td>5-20</td>
</tr>
<tr>
<td>Weight/Chlorides Per Week</td>
<td>1.32 ± 0.47</td>
<td>0.99-1.98</td>
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Table 2: Multiple logistic regression analysis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate ± SE</th>
<th>Odds Ratio (95% CI)</th>
<th>p value</th>
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<tbody>
<tr>
<td>Age (in years)</td>
<td>-0.03 ± 0.04</td>
<td>0.97 (0.90-1.05)</td>
<td>0.42</td>
</tr>
<tr>
<td>Gender (referent male)</td>
<td>0.07 ± 0.61</td>
<td>1.07 (0.32-3.53)</td>
<td>0.91</td>
</tr>
<tr>
<td>Education (in years)</td>
<td>-0.28 ± 0.12</td>
<td>0.76 (0.59-0.96)</td>
<td>0.02</td>
</tr>
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Figure 1: Reasons for cholinesterase inhibitor discontinuation

Population:
• Total number of patients seen: 318
• Final study sample: 63
• Mean age (clinic day): 74.56 yr (SD:7.78 yr)
• Started on: Donepezil: 61  Galantamine: 2
• Switched from: Donepezil to Galantamine: 1  Donepezil to Rivastigmine: 1
• Discontinuation by 6 months: 19 (30.2%)

Multivariable analyses:
• Years of formal education was the only significant predictor of cholinesterase inhibitor discontinuation
• Patients with fewer years of formal education were more likely to continue by 6 months

Conclusion

• Formal education was the only significant predictor of drug discontinuation.
• We found an inverse correlation between years of formal education and discontinuation by 6 months.
• Patients with more years of formal education may better understand and appreciate the importance of continuing therapy.
• Negative side effects may be dealt with more patiently for this reason, resulting in higher continuation rates among those with higher education.
• Patients with fewer years of formal education should receive counseling about the possible positive and negative effects of treatment as well as the effects of the illness in comparison to negative side effects of treatment.
• Ability to perform activities of daily living, patient quality of life, self-rated memory, mood, and behavioral symptoms did not have a major impact on discontinuation.

References

Effects of the Familial Alzheimer’s Disease-Associated Presenilin-1 M146V Mutation on Hippocampal Morphology and Microvessel Structure in Mice

David Woloschuk1, Taylor Duda1, Beth Blakley2, Brad Chaharyn4, Lane Bekar3, Zelan Wei4, Ric Devon2, Jen Chlan2, Darrell Mousseau4

1College of Medicine, 2Dept. of Anatomy & Cell Biology, 3Dept. of Physiology and Pharmacology, and 4Cell Signalling Laboratory (Dept. of Psychiatry), University of Saskatchewan

Introduction:
Current theories regarding the pathophysiology of Alzheimer’s Disease (AD) suggest that AD is caused by accumulation of toxic amyloid plaques within the brain. However, therapies which effectively eliminate or reduce amyloid plaques have yielded ineffective symptom relief. Additionally, disruptions in neuronal architecture are present at the earliest stages of AD, long before the appearance of amyloid plaques. This suggests that amyloid plaque deposition alone cannot account for the pathogenesis of the disease. The PS-1(M146V) mouse model incorporates a human mutation known to cause early onset AD. While these animals demonstrate learning and memory impairments which mimic AD, as well as AD-related neuropathology, they do not develop amyloid plaques. Recent studies suggest that disruptions of the cerebral vasculature also accompany the disease, but whether this underlies the early progression of AD or simply reflects a long-term epiphenomenon of the disease is unknown. Therefore, we have used the PS-1(M146V) model of AD to determine if vascular-related pathology is present before, during, and/or after AD-related behavioural abnormalities have been observed in these animals.

Hypotheses:
1. There will be an increased number of vasculature-associated hemosiderin deposits in the CNS of 6 month PS-1(M146V) HO animals in comparison to their wild-type (WT) littermates.
2. The increased hemosiderin deposits in PS-1(M146V) HO animal brains will be concentrated in regions historically associated with AD-related neuropathology.
3. These vascular defects will increase with age in PS-1(M146V) HO animals.
4. The vasculature in PS-1(M146V) HO animals will demonstrate blood brain barrier (BBB) disruption with a similar distribution that parallels hemosiderin deposition.
5. Electron microscopic analysis of cerebral capillary walls will reveal age-related pathology (such as basement membrane thickening, perivascular fibrosis, and/or pericyte degeneration) in 1, 3, and 6 month old PS-1(M146V) HO animals.

Methodology:
Transgenic Mice: Knock-in mice were originally generated by substitution of exons of the murine PS1 gene for the homologous exon from human PS1, containing the 145V substitution to ‘humanize’ the gene and M146V AD-related substitutions. These animals are routinely used to study aspects of PS-1-dependent dysfunction in the context of AD-related research. Mice were treated in accordance with the University/Comprehensive Animal Care and Safety Committee/Animal Care guidelines.

Figure 1. MAO immunoreactivity (A, D) and Nissl staining (B, C, E, F) of sensorimotor cortex. In the 6 month-old M146V mutant, “patches” were observed in the cortex (D-F) and cortical thickness appeared reduced (E, F).

Figure 2. Nissl stain of V1/V2: primary and secondary visual cortices. The disruption of normal cortical architecture is not limited to limbic cortex.

Figure 3. Perls’ Prussian Blue staining for hemosiderin in the brainstem and cerebellum (A) and primary/secondary visual cortex (B) in 6 month old WT and PS-1(M146V) HO mice. Staining was clearly detected in HO animals and again was not limited to the limbic cortex.

Figure 4. (A) Quantification of hemosiderin staining in WT and PS-1(M146V) HO mice of increasing age. (B) GFAP (red; astrocytes) Aquaporin-4 (green; astrocytic end feet); (C) Tol Blue (0.5 um sections), (D) Sample blood vessel by electron microscopy.

Figure 4. (A) Quantification of hemosiderin staining in WT and PS-1(M146V) HO mice of increasing age. (B) GFAP (red; astrocytes) Aquaporin-4 (green; astrocytic end feet); (C) Tol Blue (0.5 um sections), (D) Sample blood vessel by electron microscopy.

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Future Work:
1. Thee Evan’s Blue staining procedure will be used to determine whether BBB disruption is present in M146V HO animals and parallels hemosiderin deposition.
2. Capillary wall structure will be examined by electron microscopy in 1, 3, and 6 month old PS-1(M146V) HO animals.

Future Work:
1. Thee Evan’s Blue staining procedure will be used to determine whether BBB disruption is present in M146V HO animals and parallels hemosiderin deposition.
2. Capillary wall structure will be examined by electron microscopy in 1, 3, and 6 month old PS-1(M146V) HO animals.

Literature Cited:

Acknowledgments:
ICM is the Saskatchewan Research Chair in Alzheimer’s disease and related disorders that is co-funded by the Alzheimer Society of Saskatchewan and the Saskatchewan Health Research Foundation.
The Northern Cultural Assessment of Memory (N-CAM): Normative Data from an Inner-city Clinic Supports Efficacy and Validity of a Screen for Aboriginal Adults

M. Crossley, S. Lanting, H. St. Denis-Katz, M. E. O’Connell, N. Haugrud, & D. Morgan

Introduction

• Culture, language, and education influence performance on mental status screening tests (e.g., MMSE, 3MS, MoCA, etc.)

• Culturally appropriate assessment protocols will advance knowledge about normal aging and the prevalence of dementia among Aboriginal and other non-majority seniors.

• The Northern Cultural Assessment of Memory (N-CAM) was developed through community-based participatory research (e.g., key informant interviews, case studies, consultation and workshops with Aboriginal front-line health care providers, travel to northern Saskatchewan).

• The current study provides indicators of validity and efficacy for the N-CAM cognitive screen using normative data from adult Aboriginal volunteers attending an inner-city primary healthcare clinic in Saskatoon, SK.

Qualities of the N-CAM

• Created and modified through community-based collaborative research and clinical studies in the U of S Rural and Remote Memory Clinic

• Designed to accommodate low literacy levels and to be administered through translation in the preferred or first language of the patient or research participant

• Includes functional and cognitive components, completed during 1 hr home-based interviews by front-line health workers with patients and family caregivers

• Designed to incorporate colour, humour, and familiar objects and materials to enhance external validity and engagement

• N-CAM cognitive component measures attention, memory, language, executive function and praxis and is scored on 100-point and 30-point scales to facilitate comparison with the MMSE, 3MS, and other cognitive screens

Participants: Volunteers (N=81; 41 males, 92% Aboriginal, age range 19-81 yrs) were recruited from a primary health care clinic serving inner-city, high-risk families.

Materials & Procedures

Participants completed a health and culture interview, standardized cross-cultural measures of memory and language (Grasshoppers and Geese Test, Lanting et al., 2011), and the N-CAM cognitive component in one-hour assessments conducted in an inner-city primary health care clinic in Saskatoon. A fruit basket was provided to all volunteers.

Participants endorsed high levels of chronic health and social problems, including 70% with addiction problems, 48% with hepatitis C, 38% with a history of head injury, and 68% with less than high school education.

N-CAM scores ranged from 73 to 99 (M = 93.4) on a scale from 1 to 100, and had statistically non-significant and small associations with age (r = -.165) and education (r = .20). Importantly, 95% of participants were rated as fully cooperative and only 16% as test-anxious.

Associations were highly significant with standardized tests of memory (r = .513), confrontational naming (r = .508), and semantic associations (r = .601), demonstrating good construct validity.

Participants with scores below 80 (N=5) on the N-CAM performed in the impaired range on one or more of the standardized tests.

Conclusion: The N-CAM, developed through community-based partnerships, is a brief and well-tolerated cognitive screening protocol that demonstrates sensitivity to differences in higher brain functions and impairment, but not to age- or education-effects in Aboriginal adults and high-risk inner city residents.

Results and Discussion

Figures: N-CAM instruments were designed to reflect the culture and environment of Aboriginal seniors living in urban, rural, and remote Northern communities.

Methods

Participants: Volunteers (N=81; 41 males, 92% Aboriginal, age range 19-81 yrs) were recruited from a primary health care clinic serving inner-city, high-risk families.

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Figures: N-CAM instruments were designed to reflect the culture and environment of Aboriginal seniors living in urban, rural, and remote Northern communities.
Perceptions of cognitive health: An ethnographic inquiry of rural older adults

Juanita Bacsu
PhD student, Community Health & Epidemiology, University of Saskatchewan

Introduction

“Edna” is a 75 year old woman who lives alone with her husband on a farm. Last fall, she received a call from the bank informing her that there was no money in her account. Her husband told her that the government had quit sending pension cheques. Three months later and barely surviving on no pension, she discovers the cheques in a bathroom drawer. She is hesitant to discuss her husband’s health and when asked, she quietly whispers, “I think he has the Alzheimer’s.” Despite her reluctance, the news has slowly spread across town, and Edna now finds herself as the local town expert with others coming to her for advice.

• Edna shared her story with me in an interview on rural aging (Jeffery et al., 2011). Although cognitive health is not the study’s focus, it clearly emerges as an area of concern for healthy rural seniors.

Background

• Approximately 500,000 Canadians suffer from cognitive decline and this number is projected to increase to 1,125,200 by 2038 (Alzheimer Society of Canada, 2010).

• Existing literature on rural cognitive health focuses primarily on three groups of people, including older adults already diagnosed with cognitive impairment, family caregivers, and healthcare providers.

• With the exception of Corner and Bond (2004), there is a paucity of research on the perceptions of cognitive health among healthy older adults without cognitive impairment, especially within a rural context.

Significance

• There may be several rural barriers to cognitive health service utilization and early diagnosis related to limited awareness and knowledge, inadequate local health services, limited education, insufficient public transportation, lack of understanding, perceived stigma, cultural obstacles, and financial challenges (WHO, 2012).

• Research on rural seniors’ perceptions of cognitive health is important to inform the development of effective prevention and awareness strategies.

Research objective

• To examine healthy older adults’ perceptions and beliefs of cognitive health within the cultural context of rural Saskatchewan.

Research questions

• How do rural seniors’ cultural beliefs and practices influence their understandings of cognitive health in relation to the Determinants of Active Aging model (WHO, 2002)?

• How do rural seniors’ maintain and support cognitive health?

• What supports, prevention and promotion strategies do rural older adults find most relevant in regards to cognitive health?

Discussion

• This research will improve our understanding of how cognitive health is perceived among rural older adults in Saskatchewan.

• Exploring the values, meanings, and perceptions of cognitive health among specific cultural groups such as rural older adults facilitates the development of appropriate programs and strategies aimed at awareness, prevention, and early diagnosis.

References


Responsive behaviours such as yelling or hitting are often observed in residents with dementia who live in long-term care (LTC) homes (Alzheimer Society of Canada, 2010). Staff who work in these homes often feel as if they do not have the skills to manage these behaviours (Gates, Fitzwater, & Succop, 2005). As a result, researchers, managers, and individuals who work in LTC recommend that additional training in managing behaviours be provided to staff. To meet this need, Saskatoon Health Region (SHR) implemented the Gentle Persuasive Approaches (GPA) Training Program in stages in all 29 LTC homes between 2009 and 2011.

The GPA Program

The GPA curriculum (Schindel Martin, Montemuro, Dempsey & Crane, 2004) is designed for all staff in LTC homes. The overall goal of the GPA program is to educate staff on how to use a person-centred, compassionate and gentle persuasive approach and to respond respectfully, with confidence and skill, to responsive behaviours associated with dementia. The GPA program:

- Is person-centered.
- Teaches that behaviours from someone diagnosed with dementia are brain based and that these behaviours happen for a reason.
- Relies strongly on communication skills (e.g. non-verbal and validation techniques).
- Gives staff permission to “leave the resident be” if they are agitated.
- Moves away from “task focused” care.
- Puts staff “in the shoes” of someone who lives in LTC.
- Teaches that the hands on gentle re-direction techniques are a last resort.

The GPA program consists of four modules delivered over 7.5 hours.

Module 1: Principles of person-centred care, and the meaning behind the self-protective behaviour.

Module 2: Impact of dementia on the brain and the relationship to responsive behaviours.

Module 3: Emotional, environmental, and interpersonal communication strategies that assist care staff to respond to escalating behaviours.

Module 4: Physical intervention strategies that are gentle and respectful yet allow care staff to remain safe.

GPA Website

For further information about the GPA Program, please see their website on the internet at:

http://www.ageinc.ca/

Results

The effectiveness of the GPA program was measured using the Perceived Competency Scale (44 questions) and the Behavioural Agitation Attitudes and Values Clarification Scale (12 questions) in 12 LTC Homes.

For the Perceived Competency Scale, participants were asked to select an answer on a five point Likert Scale (1 = mostly disagree to 5 = mostly agree) that assessed their attitudes and values related to residents with dementia who display responsive behaviours.

- Participants were asked to complete each scale at three points in time (pre-training, post-training and six weeks post training).

A total of 2070 surveys were completed. Surveys were randomly sampled (n = 999) from each time period (pre, post and six weeks after training).

Nineteen questions (n = 19) were selected from the Perceived Competency Scale and the Behavioural Agitation Attitudes and Values Clarification Scale to be analyzed. The questions that were selected were those that assessed the main GPA curriculum content related to understanding and managing responsive behaviours.

Method

The GPA Program

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Discussion

- Staff reported an improvement on all questions in both scales immediately after they received the GPA training.
- At six weeks post-training, staff ratings remained above pre-test scores on all 19 questions.
- Staff ratings decreased from post-training to six weeks after training on twelve of the nineteen questions and increased or remained the same on seven of the nineteen questions.
- To improve the uptake of knowledge, the health care system needs to move beyond simple dissemination of knowledge (Kitson, 2008).
- The health care system is a dynamic, chaotic, and ever changing system where many factors play a role in how knowledge is transferred and disseminated (Davies et al., 2003).
- It would be most effective for the health care system to utilize a knowledge transition model that recognizes the complexities involved in implementing and sustaining training programs (Poeg et al., 2007).
- Literature suggests that facilitation (Fyrcroft-Malone, 2010), change agents (Harvey, 2002), and leadership (Wallen et al., 2002) have an impact on the implementation and sustainability of evidence-based knowledge.
- Further research needs to be conducted on these factors (i.e. facilitation, change agents and leadership) so that there is a better understanding of each of these factors contributes to the sustainability of training programs in LTC.
### Clinical Assessment Protocols (CAPs)

- Undertake a comprehensive, standardized tool for evaluating needs, strengths, and preferences of individuals
- Conducts an MDS (Minimum Data Set) assessment to determine care needs
- Provides a standardized approach to assessing health, functional, and psychosocial needs and strengths of individuals

### Outcome Measurement Scales (OMS)

- Series of scales embedded in the MDS to evaluate clinical status
- Requires us to evaluate changes in resident/client status
- Allows care providers to track functional improvements or deterioration
- Measures effectiveness of interventions and service plans
- Some of the scales include Pain, Depression, Cognitive Performance (CPS), and Activities of Daily Living (Personal hygiene, toileting, locomotion etc.)

### Countries Using the RAI

**Americas**
- Canada, USA, Mexico

**Europe**
- Iceland, Norway, Sweden, Denmark, Netherlands, Germany, Switzerland, France, UK, Ireland, Belgium, Luxembourg, Austria, Portugal

**Central/South America**
- Chile, Brazil, Argentina, Peru, Bolivia, Paraguay, Middle East/South Asia
- India, China, Japan, South Korea, Taiwan, Hong Kong, Australia, New Zealand, Sri Lanka

**Africa**
- South Africa, Egypt, Morocco

**Resource Utilization Groupings (RUGs)**

- RUGs consist of 7 categories used to classify clients based on resources required and clinical characteristics
- Client classified into sub-categories
- Primarily a management planning tool
- Eventually replace current levels of care

### Benefits of the RAI

- Identifies functional problems
- Evaluates the effectiveness of interventions and service plans
- Supports care planning
- Enables best practice
- Calculates the RUG-III/HG grouper
- Identifies those persons that may benefit from care and support in the problem areas identified
- Goals of care may vary from one RUG to the next and from one person to the next (ex. Is the goal to eliminate the problem, reduce the risk of decline or increasing potential for improvement?)
- CAPs are divided into four domains including Function Performance, Cognition and Mental Health, Social Life and Clinical Issues

### RAI Suite of Assessments

- **Home Care**
  - Contact Assessment/Emergency Department Screener
  - Palliative Care
  - Complex Continuing Care, Long Term Care
  - Mental Health
  - Inpatient, Community Intellectual Disability
  - Intellectual Disability
- **Community Health**
  - Assessment with supplements for
  - Alzheimer’s/Dementia
  - Alzheimer’s/Dementia
  - Intellectual Disability
  - Intellectual Disability
- **Assisted Living**
  - Functional
  - Functional
  - Visual Impairment
  - Visual Impairment
- **Intellectual Disability**
  - Intellectual Disability
  - Intellectual Disability
  - Intellectual Disability
  - Intellectual Disability

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### MDS Assessment

**MAPLe** (Methods of Assigning Priority)

- Effectiveness of interventions and service plans
- Provides a standardized approach to assessing health, functional, and psychosocial needs and strengths of individuals

### RAI Research/Pilots

- Quality data for evidence-based decision making
- Evaluate the results of quality initiatives
- Support organizational and system-wide planning, identifying system pressures
- Inform policy development on the diverse and challenging issues

---

### Resource Utilization Groupings (RUGs)

- RUGs consist of 7 categories used to classify clients based on resources required and clinical characteristics
- Client classified into sub-categories
- Primarily a management planning tool
- Eventually replace current levels of care

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### Client and Family

- Individual needs are identified, along with strengths and preferences
- Immediate outcomes empower residents and family in the goal setting process
- Evidence for building best practice

### Clinicians

- Improved interdisciplinary communication
- Real-time outputs support care planning and monitoring
- Evidence for building best practice

### Managers and Administrators

- Understand population profiles
- Monitor quality of care provided
- Quality data for evidence-based decision making
- Evaluate the results of quality initiatives

### System Planners

- Support operational and system-wide planning
- Identify system pressures and accountability
- Inform policy development on the diverse and challenging issues
The Hidden Complexity of Long-Term Care: A Case Study of Contextual Factors that Mediate Knowledge Translation and Best Practice


1Canadian Centre for Health and Safety in Agriculture, College of Medicine, University of Saskatchewan, Canada, 2College of Nursing, University of Saskatchewan, Canada, 3School of Health Sciences, Berger, University, Wales, 4Graduate School, University of Oxford, United Kingdom, 5Toronto Rehabilitation Institute, Canada, 6Faculty of Nursing, University of Alberta, Canada

Abstract

As one component of a program of research entitled, Translating Research in Elder Care, an in-depth qualitative case study was conducted to examine the research question "How does organizational context mediate the use of knowledge in practice in long-term care facilities?" A representative long-term care facility was chosen from the province of Saskatchewan, Canada. Data were collected in the form of document review, fieldnotes from direct observation of daily care practices and operations, and interviews with staff at the direct care, allied provider, and administrative levels. Through constant comparative analysis, a theory of the contextual factors that influence knowledge use and best practice was developed. This theory, The Hidden Complexity of Long-Term Care, encompasses eight salient categories that emerged to create a backdrop of context within which knowledge exchange and best practice are executed. These categories range from the more apparent and obvious (Physical environment, Resources) to intrinsic but more obscure (Ambiguity, Flux) to implicitly nearly invisible (Relationships, Philosophies). Two last two categories (Experience & Confidence and Leadership & Mentoring) mediate the impact of the other contextual factors. Decisions regarding care are imbued with nuance; each of the categories identified as central to the context coalesce to demonstrate the truly intricate context of care provision. Navigating the challenges of inappropriate physical environments, inadequate resources, ambiguous situations, continual change, multiple relationships, and often contradictory philosophies makes for an extremely complicated context in which to provide care. This complexity is mediated through tacit knowledge gained through experience and development of confidence and through solid empowering leadership and supportive mentoring. Without attention to the complexity of the context in which care decisions are made, improvement in knowledge exchange mechanisms and best practice uptake cannot be successful.

Research Question

How does organizational context mediate the use of knowledge in practice in long-term care facilities and what are the key factors that constitute organizational context as it affects knowledge use in practice?

Case Study

A modal or ‘typical’ LTC facility purposefully selected based on list of common traits. The case facility had 100 beds and approximately 100 staff.

Methods

Three data sources: observation, documents, interviews
Observations: took place over 5 months and were recorded as fieldnotes
Documents: relevant documents were reviewed
Interviews: semi-structured interviews were conducted with 21 staff, audio-recorded, and transcribed (3 Administrators, 2 Allied providers, 5 nurse or LPN, and 11 care aides)

Analysis

Data were analyzed using constructivist grounded theory technique. A conceptual model and integrated theory called The Hidden Complexity of LTC was developed. The categories of this model are described below.

Physical Environment: The physical environment is the location of the LTC, layout of the building, placement of rooms, storage, and setting. Physical environment can facilitate a home-like setting and increase quality of care, but often care could be limited due to non-modifiable features of the physical environment.

Resources: Resources can be tangible objects such as equipment or supplies used in care, or intangible, such as information, time, or personnel. There are two distinct and opposing aspects: resources can enhance best practice use, and shortage of resources can limit care and impede knowledge use.

Flux: Flux speaks to the changes in healthcare and LTC organization, the multiple changes that happen on a day to day basis in LTC, and the moment to moment changes in a resident’s health, mood, or behaviour. Flux can enhance responsiveness and flexibility, but the unpredictability can also foster resistance to new practices and cause stress.

Ambiguity: Many care practices are not a simple matter of ‘correct’ versus ‘incorrect’. Few care practices are unaffected by multiple factors. Ambiguity refers to the competing needs that must be considered for many care decisions. This can complicate decision-making regarding care.

Discussion

We often think of care as an act between care providers and residents, but it is important that we don’t overlook the importance of the context that surrounds those acts. Context shapes what, why, when, where, and how care is given. Context can be complicated because it continually changes and evolves.

This study illustrates the complexity of LTC context which is, ostensibly, hidden. The complexity of care is not apparent on initial examination; decisions regarding care provision are imbued with nuance, largely due to interconnected contextual influences. Aspects of a LTC’s context will vary; this model can assist with initial examination of a facility’s context, and can be amended to reflect the particular features of the context of that specific facility.

The model we developed is called The Hidden Complexity of Long-Term Care to emphasize that context is complex, and also that much of the complexity in LTC is hidden, or easily overlooked. Knowledge use and care practices are either supported or limited by the context of LTC.

It is critical to understand and account for contextual factors when planning for change in care, knowledge uptake, quality improvement initiatives, or implementation of best care practices.

Acknowledgements
Do beliefs about personhood in dementia influence health providers’ approaches to care?

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McMaster University

Background:
Over the last two decades, there has been substantial interest in fostering more humanistic approaches to dementia care.
• Psychologist Tom Kitwood (1997) emphasized that personhood, a status extended by others, is vital to person-centred dementia care.
• This perspective has become very popular.
• Although development and adoption of person-centred approaches to dementia care continues, important questions remain.
• For instance, no one has demonstrated empirically that beliefs about personhood-as-status influence approaches to dementia care.

Participants:
• 178 health care providers participated in this study.
• There were 41 nurses and 137 SCAs.
• Ninety-three percent of the participants were female.
• On average, participants were 45 years old.
• On average, participants had worked in long-term care for 13 years.

Method:
• We gave each respondent these items to complete:
  1. Three vignettes*
  2. The Personhood in Dementia Questionnaire*
  3. Three other questionnaires (not discussed in this poster)
• The vignettes were about patients with a history of pain, showing agitation (see Figure 1).
• Half of the vignettes were about patients with dementia.
• The other half were about patients with no dementia.
• We shuffled the questionnaire packages to ensure that we had no other influence over which respondent would receive vignettes about patients with dementia.
• We used a statistical procedure called linear regression to see whether beliefs about personhood influence intended approaches to dementia care.
• This procedure involved testing how much of the final score on the vignettes was explained by the patient’s diagnosis and the respondents’ beliefs about personhood.

Results:
• Two variables, beliefs about personhood in dementia and dementia diagnosis, accounted for a small but significant proportion of variability in the likelihood of responding to the vignette by choosing pain medication (Table 1).
• These two variables also accounted for a small proportion of variability in the likelihood of responding to the vignette with alternative (non-pharmacological) approaches to pain management (see Table 2).
• The probability that we obtained these results by chance is less than 1%.

What the Results Mean:
• These results may be the first objective evidence that beliefs about personhood influence health providers’ care decisions.
• Specifically, these results suggest that beliefs about personhood have potential to influence pain management practices.
• We have not shown that the same results would apply in an actual practice setting (but many studies do show a connection between vignette responses and actual practice).
• We could not explain all of the variability in health care decisions by knowing the patients’ diagnosis and the care providers’ beliefs about personhood. This tells us that other factors are involved in making care decisions, too.

Table 1. Moderated multiple regression analysis summary: Beliefs about personhood and cognitive status as predictors of the likelihood of considering additional pain medication.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>B</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs about Personhood</td>
<td>0.091</td>
<td>0.35</td>
<td>0.196</td>
<td>0.09</td>
<td>0.197</td>
</tr>
<tr>
<td>Cognitive Status</td>
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<td>0.906</td>
<td>-0.168</td>
<td>0.026</td>
<td>-0.169</td>
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Table 2. Moderated multiple regression analysis summary: Beliefs about personhood and cognitive status as predictors of the likelihood of considering non-pharmacological pain management techniques.

<table>
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<th>SEB</th>
<th>B</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs about Personhood</td>
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<td>0.105</td>
<td>0.314</td>
<td>0.001</td>
<td>0.314</td>
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<tr>
<td>Cognitive Status</td>
<td>-1.108</td>
<td>2.760</td>
<td>-0.029</td>
<td>0.689</td>
<td>-0.031</td>
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</tbody>
</table>

Funding for this project was provided by a CIHR Doctoral Research Award to P.H. and a Saskatchewan Health Research Foundation grant to T.H. We are also grateful for the support of Regina Qu’Appelle Health Region.
Human Beings not Human Doings....

Vanessa Heaslip & Michele Board – Senior Lecturer : Bournemouth University  vheaslip@bournemouth.ac.uk [Preferred Contact]
Karen Fuggle (HR Mgr) & June Gallagher (Ops Mgr) – Colten Care  operations@coltencare.co.uk

Rationale

Dementia affects 6% of people over the age of 65 years and 30% of people over the age of 90 years. With an increasing ageing population, these rates are set to rise (Department of Health (DoH) 2009). The National Dementia Strategy (Department of Health 2009) set out a clear vision that people with dementia and their carers should be helped to live well with dementia. To meet that objective 13 there needs an effective and informed workforce to care for people with dementia.

“All health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.”(DoH 2009)

Bournemouth University was approached by Colten Care to work collaboratively in developing a dementia care educational programme that would enhance the delivery of Colten Care’s person centered approach to dementia care.

Aims

The aim of the project was to devise and evaluate an educational programme to raise awareness of Dementia within a care home setting. The philosophical premise behind the programme was the valuing of the individual whether they are employees or a resident within one of Colten Care’s homes .

Specific aims included;
1. Staff from BU to devise and facilitate a 5 day programme at the university
2. A formal qualitative evaluation of this programme would be undertaken
3. Staff from BU would then support Colten Care to devise a 2.5 day in house programme that could be delivered to all their staff.
4. Colten Care would seek accreditation of this 2.5 day programme at the university
5. Staff from BU and Colten Care would collaborate to disseminate the findings of the project nationally.

Projects

The inclusion of the projects was fundamental to the programme. Each team had to identify a project they could implement in the care home that would enhance the lives of the residents and support staff to provide high quality care. The group then had to present their ideas to members of the executive board. Thus enabling them to see that they as individuals, have the ability to shape the care within the home in which they worked, as well as getting them to work within a team supporting each other and harnessing each other strengths. Examples of the projects included;

- Sensory Garden
- Sensory cushions
- 10 Golden Rules about me
- Resident collage
- My bedtime routine
- Stimulating Nutrition
- Mentors/Buddy scheme for new staff
- Residents scrapbook
- Use of signage in the home.
- Family information book

Programme

1. Setting the Scene Introduction to dementia
2. Experiences of dementia & Person centred care
3. Assessment & Mental Capacity
4. Personalisation & Management Strategies
5. Quality & service development

“Traditiona l lessons”

“Two things I’ve just thought of. One is this idea of going forward, looking at things through our residents’ eyes, and the one phrase that keeps coming back to me to… is celebrate what we do well.”

(Heaslip and Board 2011)

Feedback from Participants

“They may have dementia, but they are still human beings and still people…”

“Observation insightful …made me feel how it is to be a resident”

“Dementia people have rights like other people their rights should not be undermined/invalidated”

“I liked how we were doing projects to improve our homes”

“Personally I think it’s made me a better carer for this course. It’s made me consider them …as people more”

“I think it’s, personally, I’ve got a wider view now. Instead of thinking I’m doing this, this is the way we do it, ‘I say ‘hang on, is it the best way of doing it?’”

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Conclusions

This paper offers an example of how a university and a care home provider in collaboration can deliver a person centred educational programme. We believe that it is vital that the programme philosophy focuses upon the individual, not only the person with dementia but also their carers and the staff themselves. Looking after a person with dementia demands a great deal from staff both physically and emotionally. As such staff need to feel valued and that their voice and opinions are important within any organisation, so they can feel empowered to make a difference. This process can be facilitated through utilising the skills of higher educational staff whose expertise lie in constructing and delivering educational programmes.
Dementia Friendly Tourism

Exploring how the tourism and leisure industry can respond to the needs of people with dementia and their carers.

Innes, A., Page, S., Cutler, C., Crossen-White, H., Cash, M., McParland, P.
BU, Bournemouth University

There is little research exploring the connection between the experience of people with dementia and their engagement with tourism and leisure. Research on tourism and health has traditionally focused on travel medicine and the connections between tourism and medical issues faced by travellers in destinations. There is a growing body of knowledge emerging from human geography and public health that argues that tourism can be used as a major tool for positive enhancement of the quality of life with such groups as the elderly. The prevalence of dementia among older people and the current emphasis on building dementia friendly communities means that people with dementia must be considered in provision of tourism and leisure. However existing infrastructure and strategies for tourism have largely overlooked the impending demographic time bomb. To date, comparatively little research has examined the implications of tourism and health research in relation to domestic tourism, which is arguably four to six times more important in volume than international tourism for many countries. This highlights the gap in knowledge about the role tourism can play in supporting the well-being of people with dementia and their carers.

Methods

Five focus groups with older people, people with dementia, and their carers within the Dorset region.

Emerging Themes from Preliminary Analysis:

Access to tourism and leisure for people with dementia and their carers:

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Enablers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport</td>
<td>Good Location</td>
</tr>
<tr>
<td>Inadequate/ poorly signposted toilet facilities</td>
<td>Attraction facilities</td>
</tr>
<tr>
<td>Inaccessible venues</td>
<td>Outdoor environment</td>
</tr>
<tr>
<td>Mobility</td>
<td>Familiarity</td>
</tr>
<tr>
<td>Fear/Anxiety of getting lost</td>
<td>Positive attitudes</td>
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<tr>
<td>Negative attitudes</td>
<td>Affordability</td>
</tr>
<tr>
<td>Cost</td>
<td></td>
</tr>
</tbody>
</table>

Preliminary Conclusions

- Leisure and tourism is underused by people with dementia and their carers.
- Carers fear the reception from other leisure users and a lack of understanding from staff working in the industry.
- Tourism and leisure providers have very little awareness of dementia.
- Tourism providers have yet to embrace the potential of targeting their ‘product/service’ to those with dementia despite legislation promoting ‘tourism for all’.

www.bournemouth.ac.uk/dementia-institute
Diagnostic Processes and Post Diagnostic Support in the Scottish Highlands
Anthea Innes1, Paulina Szymczynska2, Cameron Stark3

1 Bournemouth University, UK; 2 University of Stirling, UK; 3 NHS Highland, Inverness, UK

Background
In 2008 the Scottish Government introduced a target to increase the number of people diagnosed with dementia1 and a National Dementia Strategy that clearly recognises that dementia is a National public health priority2.

This poster presents findings from a Knowledge Transfer project between NHS Highland and the University of Stirling designed to evaluate and improve the diagnostic processes and post diagnostic support offered to people with dementia and their carers in the largest remote and rural area of Scotland.

Key Findings

1. Best Practice Review
A literature review and a database of international best practice examples was influential in helping to shape the protocols for the different diagnostic service models in place across the region3.

2. Staff consultation
Staff providing community mental health services were consulted via survey. Findings from the survey allowed for the modelling of service delivery, the identification of inefficiencies and service gaps and

3. Preliminary evaluation of a Community Mental Health Team
The evaluation revealed a complex local context with limited resources and a growing population requiring support in a geographically challenging landscape. Findings from the evaluation resulted in the introduction of a service improvement methodology for staff in that team.

4. Consultation with people with dementia and carers
Consultation with memory service users (people with dementia and their carers) revealed mixed views about the dementia services they had experiences, most reported appreciation for the services and support they did receive, but also concerns about the diagnostic process, available care and support, and meeting individual needs.

5. Delivery and evaluation of training events
The training events facilitated by the KTP project team were evaluated positively, but a key finding was the lack of dementia training staff had previously received4.

6. Shadowing and service observation
Day to day practice of four staff members in four Community Health Partnerships were observed through a shadowing exercise. This provided examples of innovation across the region that could be replicated or adapted to meet the needs of other local teams and service users in Highland.

Project Objectives

• Establish best practice in dementia diagnosis and post-diagnostic support
• Identify and compare diagnostic processes in place
• Consult key stakeholders to evaluate services
• Support dementia services to incorporate identified learning and deliver evidence-based services

Methods
The project involved six distinct phases of work:

1. Best practice review
2. Staff consultation with Community Mental Health Teams
   Method: Postal questionnaire (n=10)
3. Preliminary evaluation of a Community Mental Health Team
4. Consultation with people with dementia and carers
   Method: Semi-structured qualitative interviews (n=20)
5. Delivery and evaluation of training events
6. Shadowing and service observation

Project Achievements

• Provided usable evidence about international best practice
• Supported NHS Highland in addressing the Scottish Government Dementia target and Scotland’s National Dementia Strategy
• Facilitated staff and service user engagement
• Provided evidence to NHS about staff and service user experiences, views and needs
• Enabled access to academic expertise through training, advice, and evidence-based recommendations for service development

Conclusion
There are key building blocks in place across NHS Highland region to provide high quality support to those with dementia from diagnosis onwards, achieving this requires the development of local initiatives across a geographical landscape that poses distinct challenges to high quality service delivery.

References
1. Scottish Government. HEAT (Health, Efficiency, Access Treatment) Targets [Internet]. 2008

Acknowledgements
The Knowledge Transfer Partnership project between NHS Highland and the University of Stirling (Dementia Services Development Centre) was funded by the Technology Strategy Board (TSB). Further support with selected project activities was provided by the Highland Region Health Board via the Mental Health Collaborative, part of the Scotland wide National Improvement Programme.
# Early referral for support of dementia caregivers: Evaluation of the First Link demonstration project

**Carrie McAiney¹, David Harvey², Loretta M. Hillier³, Paul Stolee⁴, Mary Schultz⁵, Joanne Michael⁶**

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## Background

- Significant care gaps for persons with dementia living in the community and their caregivers.
- Despite the availability of education and support services, few individuals with dementia or their caregivers access help early in the course of the disease.

## First Link

- Innovative referral program developed and implemented by Alzheimer Society of Ontario.
- Links individuals diagnosed with Alzheimer’s or a related dementia and their families to a community of learning, services and support.
- Utilizes the local Alzheimer Society and other community partners.

## Goal

To link individuals and their family members as early as possible in the disease process.

## Study Objective

- To measure the impact of First Link® in Ontario (4 sites) and Saskatchewan (2 sites) on:
  - Connecting family caregivers to the Alzheimer Society and other services earlier in the disease process
  - Knowledge & awareness among professionals
  - Knowledge & awareness among family caregivers
  - Caregiver coping and burnout

## Methods

### Design

- Mixed method, prospective cohort design

### Data tracking

- Referrals
- Activities undertaken by First Link® Coordinators

### Surveys

- Caregivers
- Primary care providers

### Interviews & focus groups

- Project leaders
- Persons with dementia & family caregivers
- Key stakeholders (e.g., Alzheimer Chapters, physicians, community providers, First Link® Coordinators)

## Project Findings

### Referrals to First Link:

- A significantly higher number of individuals were self-referred (65%) vs. referred via First Link (24%), p=.001.
- Those referred via First Link were referred sooner after diagnosis of ADRD than those who were self-referred (6 vs. 17 months, respectively).
- Those referred via First Link were on average older (67yrs) than those self-referred (59 yrs), p = .001.

### Knowledge & awareness raising with Health Professionals:

- First Link Coordinators provided/ coordinated 444 hours of dementia-related education with a total of 1,250 people in attendance, in addition to 102 volunteers hours to this end.
- Health Professionals were more aware of Alzheimer Society services and supports due to First Link promotional activities.

### Knowledge & awareness among family caregivers:

- More knowledgeable about ADRD and the community resources available to them.
- More confident in taking on the caregiver role.
- Increased access to information and support for caregivers, especially in rural and remote areas of the province.
- Increased access to system navigation support.

### Caregiver coping and burnout:

- Alzheimer Society services and supports improved caregiver’s ability to cope and manage as the disease progressed.
- First Link provided morale support, practical strategies, assistance with decision-making, and reduced caregiver stress.

## Conclusions

- The evaluation has demonstrated that the objectives of First Link have largely been achieved.
- The new model of service access as facilitated by First Link represents a major move towards filling dementia care gaps that are well documented within the literature (Pratt et al., 2006).
- Further development, implementation and expansion of First Link have the potential to significantly impact early detection and quality of dementia care.

## References

Rural Dementia Action Research (RaDAR)
Planning for the Rising Tide: New Models of Rural Community-Based Primary Health Care
for Persons with Mild Cognitive Impairment or Dementia

Background
The RaDAR Team is an interdisciplinary group of researchers, health professionals, decision-makers, and community members from four Canadian provinces and the UK.

The team formed in 2011 in response to an initiative from the Canadian Institutes of Health Research (CIHR) to fund research teams in the area of community-based primary healthcare for a minimum of five years, with the possibility of extension for ten years.

Work to Date

October, 2011 Planning Session

• One-day session held in Saskatoon in October 2011.

• Ethics approval was obtained from the University of Saskatchewan Behavioural Research Ethics Board (BEHA 11-1192) to collect focus group and survey data.

Purpose

• Bring together researchers, health professionals, decision-makers, and family caregivers, to identify important issues in primary healthcare and innovative service delivery models for people with dementia and their caregivers in rural and remote areas.

Participants

• 35 participants, in addition to the RaDAR Team, included family physicians, nurse practitioners, health region directors and staff, family caregivers, Alzheimer Society, RxFiles, and Saskatchewan Health Quality Council.

Proposed Research

RaDAR Innovation Program

The RaDAR Innovation Program consists of four conceptually linked research streams that will be implemented across five years.

Stream 1: develop and evaluate a Dementia Advisor-Working Group model to facilitate innovation at the health region level.

Stream 2: develop, implement, and evaluate a capacity-building and mentoring program in quality improvement and dementia care for rural primary healthcare professionals.

Stream 3: develop and evaluate public awareness programs targeting primary health care for rural primary healthcare professionals.

Stream 4: develop and evaluate chronic disease management strategies targeted to rural primary health care professionals.

June, 2012 Planning Retreat

One-day session held in Saskatoon in June 2012.

Purpose

• Bring together researchers, health professionals, decision-makers, and family caregivers, to further develop the RAH N CIHR team impact proposal.

Participants

• 15 participants in addition to the RaDAR Team, included family physicians, nurse practitioners, health region directors, Alzheimer Society, and Saskatchewan Health Quality Council.

Outcomes of the Planning Retreat

• Participants reported a need for access to expertise on dementia best practices and support to adapt these practices in their regional context.

A Dementia Advisor model proposed by decision-makers at our 1-day retreat will be expanded to include regional or cross regional dementia Working Groups.

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Current Research

RaDAR-HQC Gap Analysis

The RaDAR Team and the Health Quality Council have partnered to conduct the first-ever provincial-level evidence-based analysis of gaps between actual and best dementia care practices.

The purpose of the gap analysis is to highlight priorities for research, policy, and practice and to provide baseline and follow-up outcome data for the RaDAR Innovation Program.

The gap analysis consists of three components:

1. Synthesis of best practices in dementia care

2. Environmental scan/inventory of available dementia-related services along the continuum of care in SK health regions.

3. Analysis of administrative health databases, identified and linked to beneficiaries’ unique health services number, covering the periods 2009 to 2012 (baseline) and 2014 to 2017 (follow-up).

Purpose

To compare outcomes in dementia-related services between baseline and follow-up and between intervention and comparison groups.

Sample

Telephone interviews and focus groups will be conducted with family physicians and health region staff familiar with available dementia-related services.

Outcome

Access, quality, safety, equity, fit with community needs, interprofessional collaboration, and patient/community participation in service planning.

To learn more about the RaDAR Program or to become involved, contact Dr. Delia Morgan at delia.morgan@saskatoon.ca or 966-7000.
Exploring the Natural History of Mild Cognitive Impairment in a Memory Clinic Sample

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1Department of Psychology, University of Saskatchewan; 2Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

Methods

MCI Diagnostic Criteria
• Participants were judged to have either:
  1. amnestic MCI (aMCI) single domain
  2. aMCI multiple domain
  3. non-amnestic MCI (non-aMCI) single domain
  4. non-aMCI multiple domain

Measures
• Immediate memory, delayed memory and attention indices from the Repeatable Battery for the Assessment of Neuropsychological Status (Randolf, 1989).
• Participants rated their performance on the Lawton Instrumental Activities of Daily Living (IADL, Lawton, Mars, Falozier, & Kleban, 1982).

Summary and Conclusions

• When the 8 MCI patients were examined longitudinally, 3 had progressed to dementia by three years.
• All progressors had an initial aMCI diagnosis (2 single domain aMCI and 1 multi-domain aMCI).
• On the self-rating of memory scale, non-progressors reported that their memory was improving over 3 years and progressors self-rating of memory remained stable.
• No one neuropsychological test differentiated those who progressed to dementia from those who did not, with the exception of poor initial episodic memory, a criterion of the aMCI diagnosis.

Conclusion: The differential conversion rates for aMCI versus non-aMCI support conceptualizations of MCI as a separate diagnostic entity (likely preclinical AD) from other forms of MCI.

References and Acknowledgements

# Group Dyadic Reminiscence Therapy: An Evaluation of Efficacy for Caregivers, and Delivery via Telehealth

Joe Enright & Megan E. O’Connell

<table>
<thead>
<tr>
<th>BACKGROUND</th>
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<tr>
<td><strong>Dyadic Reminiscence Therapy is:</strong></td>
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<td>• Structured activities aimed at encouraging the recall of shared positive memories between a Family Caregiver and the Person with Dementia.</td>
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<td>• Thought to improve the quality of relationship between the caregiver and care-recipient, by revitalizing their emotional connection. It has been demonstrated to have a number of benefits to the person with dementia, and is believed to positively affect caregivers as well.</td>
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<th>PHASE 1: In-Person Trial</th>
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<td>• Conduct a trial of group dyadic Reminiscence Therapy for pairs of caregivers and persons with dementia using the <em>Remembering Yesterday, Caring Today</em> program.</td>
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<td>• Evaluate the effects of the therapy for caregivers in comparison to a control group.</td>
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<td>• Investigate the role of identity and emotional intimacy as Reminiscence Therapy’s active agents of change.</td>
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<th>PHASE 2: Telehealth Delivery</th>
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<td>• Modify the Remembering Yesterday Caring Today program for delivery via Telehealth.</td>
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<tr>
<td>• Conduct a trial of group Reminiscence Therapy for pairs of caregivers and persons with dementia over Telehealth videoconferencing.</td>
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<tr>
<td>• Compare the efficacy of in person versus Telehealth delivery of Reminiscence Therapy.</td>
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**Acknowledgements**

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