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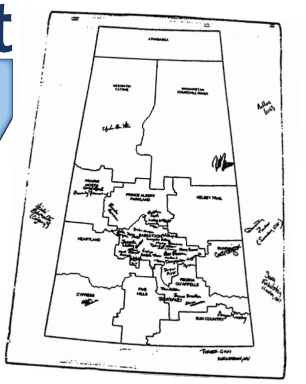

Knowledge Network in Rural and Remote Dementia Care

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

Scientific Poster Session

7th Annual Summit

October 21st & 22nd, 2014

CIHR IRSC
Canadian Institutes of Health Research
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Rural Dementia Care
UNIVERSITY OF SASKATCHEWAN
Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas

UNIVERSITY OF SASKATCHEWAN

Tuesday October 21st, 2014
Scientific Poster Program
5:00 PM – 8:30 PM at the Delta Bessbourough (Battleford Room)

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Rural Older Adults' Perceptions of Cognitive Health

Juanita Bacsu,[123] Marc Viger,[1] Sylvia Abonyi,[123] Bonnie Jeffery,[145]
1Saskatchewan Population Health & Evaluation Research Unit, 2Community Health & Epidemiology, 3University of Saskatchewan, 4Faculty of Social Work, 5University of Regina

Significance

- In 2010, approximately 4.4 million North Americans had dementia and this number is projected to increase significantly (World Health Organization, 2012). Existing literature on cognitive health focuses primarily on three groups of people, including older adults diagnosed with dementia, 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 impairment, especially within rural areas. Several rural barriers may impede early dementia diagnosis related to lack of education, limited health services, cultural obstacles and financial challenges. Research on rural seniors' perceptions of cognitive health is important to inform the development of effective prevention and dementia awareness strategies.

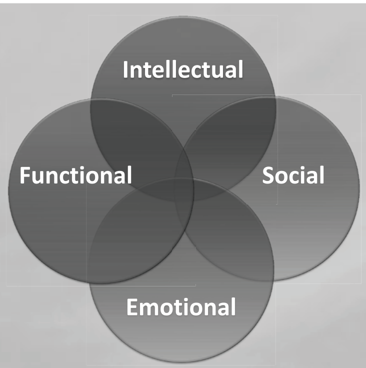
Objectives

- The purpose of this study was two-fold:
    1) To examine rural older adults' perceptions, beliefs and meanings of cognitive health in the cultural context of rural Saskatchewan, Canada;
    2) To identify how healthy rural older adults without impairment maintain and support their cognitive health.

Methods

- Part of a larger Healthy Aging in Place Study at the Saskatchewan Population Health and Evaluation Research Unit (Jeffery et al., 2014).
- Using an ethnographic methodological approach, data was collected through 2 waves of semi-structured interviews with adults aged 60 and over in the rural communities of Young, Watrous and Manitou Beach, Saskatchewan, Canada.
    - 1st wave with 42 participants, February to May, 2014.
    - 2nd wave with 37 participants, July to August, 2014.
- Participant observation was conducted by spending time with 5 older adults to observe day-to-day activities related to memory and cognitive health.
- Guided by lay theory (Furnham, 1988) and cultural schema theory (Quinn, 2005), thematic analysis was performed using the qualitative software Atlas.ti-7 to identify patterns, themes and relationships in the data.

Findings



Key Domains

- ***Intellectual health*** **-** defined as the importance of comprehension, awareness, mental stimulation and continuous learning.
    - ➢ *Supportive activities*: reading, puzzles, crosswords, Sudoku, cards, traveling, learning (i.e., jokes, birds, current events), needle work and wood work.
- ***Social health*** **-** discussed as being active, involved in the community and communicating with others.
    - ➢ *Supportive activities:* coffee row, events, telephone, technology (i.e., Facebook, Skype), pets, volunteering and visiting at lodge and hospital.
- ***Emotional health*** –expressed in terms of mental well-being, balanced lifestyle and spirituality.
    - ➢ *Supportive activities:* meditation, yoga, painting, photography, scrap-booking, gardening, music, church, smiling, exercise and journaling.
- ***Functional health***– described in relation to physical health, activities of daily living and independence.
    - ➢ *Supportive activities:* healthy eating, sleep, exercise (pickle-ball, walk, bowl, golf, curl, swim, tai chi, dance), hearing aids, eye glasses and walking aids.

Conclusions

- Understanding the perceptions of cognitive health among specific cultural groups such as rural older adults supports the development of targeted interventions aimed at awareness, education and early dementia diagnosis.

References
Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18(2), 143-55.
Furnham, A. (1988). *Lay theories: Everyday understanding of problems in the social sciences.* Oxford, England: Pergamon Press.
Jeffery, B., Bacsu, J., Abonyi, S., Novik, N., Martz, D., Johnson, S., & Oosman, S. (2014). *Healthy aging in place: Action plan summary.*. Available from, http://spheru.ca/research_projects/projects/Project.pdf/Healthy%20Aging%20Action%20Plan%202014-2017.pdf.
Quinn, N. (2005). *Finding culture in talk: A collection of methods.* New York, NY: Palgrave Macmillan.
World Health Organization. (2012). *Dementia: A public health priority.* Available from, http://www.who/dementia.html

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UNIVERSITY OF SASKATCHEWAN

Saskatoon Health Region
Seniors' Health and Continuing Care

Accurate assessment, effective care planning and quality improvement for better resident outcomes

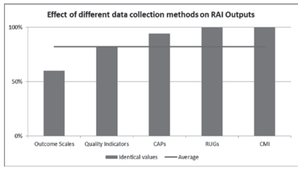
Laureen Nein, BSN RN
Anita Bergen BN, MSc
Tara Evjen, BSN RN

Background

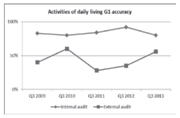
- RAI-MDS assessments are completed quarterly for 2200 people in Saskatoon Health Region
- RAI-MDS outputs are used for care planning, quality improvement, strategic planning and funding
- Internal and external RAI-MDS audit process implemented in 2005
- Lean methodology as part of the Saskatchewan Health-Care Management System increased the focus on health indicators and put more emphasis on performance
- Saskatchewan Ministry of Health implemented a Quality Indicator Improvement initiative in 2013 focusing on seven of the RAI-MDS quality indicators and including improvement plans submitted to the Ministry on a quarterly basis from each home where the target has not been met

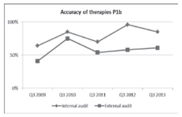
Analysis of current processes

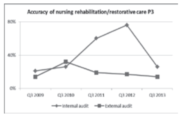
1. Daily data collection by Continuing Care Assistants required knowledge of RAI-MDS coding standards; however a training program to apply the coding accurately was not consistently available. Assessors lacked confidence in the data collected. Was the current method of data collection necessary for accurate assessment? Two assessors simultaneously assessed a resident to answer this question. One assessor used the data collection tools in use, and the other used alternate sources of information from the health record. Test results showed that collecting data in alternative ways had only a small to moderate impact on RAI outputs.


Effect of different data collection methods on RAI Outputs

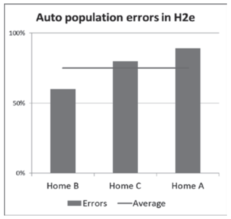
2. RAI-MDS audits and action plans failed to yield consistent improvement in assessment accuracy over a long period of time. Internal audit results varied from external audit results:


Activities of daily living G1 accuracy


Accuracy of therapies P1b


Accuracy of nursing rehabilitation/restorative care P3

3. Information (Hirdes, Poss, Calderelli, Fries, Morris, Teare, Jutan *An evaluation of data quality in Canada's Continuing Care Reporting System*, 2013; and Pringle, Orlikow *An Inconvenient Truth* presentation 2012 interRAI conference) became available about assessment errors caused by auto population (all fields in the assessment are automatically populated with data from the last assessment and assessor changes the data where needed). Auto population of RAI assessments in Saskatoon Health Region caused a high error rate in assessment of elimination patterns in section H2e


Auto population errors in H2e

An accurate response to the assessment of the bowel elimination pattern (item H2e) of the RAI-MDS quarterly assessment is almost always *none of the above*. Auto-population of assessments automatically puts this response into an annual assessment where it is almost always inaccurate; consequently, where *none of the above* is the response to H2e it was considered an error due to auto population. An audit of H2e responses on annual assessments at three homes in Saskatoon Health Region showed that auto population caused an average error rate of 75%.

4. Use of CAPs for care planning was progressing very slowly and CAPs were not supported in the paper-based care planning template.

Objective

Care teams will improve resident outcomes by increasing both the accuracy of RAI-MDS assessments and the use of CAPs for care planning.

Strategies

Create and implement a new RAI data collection tool that:
- Provides accurate data for RAI assessment that cannot be found elsewhere on the health record
- Can be completed accurately without additional training
- Can be completed in a shorter amount of time than the current tools

Replace internal audit process with AIS competency evaluations:
- Activate/reactivate RAI-MDS user accounts only after passing competency evaluations
- Divert RAI-MDS audit funding to paid time for assessors to complete competency evaluations annually

Shut off auto population of RAI-MDS assessments in June of 2014

Implement a care planning tool that:
- Integrates resident preferences, care needs, goals, and outcomes
- Includes planning for nursing rehabilitation/restorative care
- Incorporates Clinical Assessment Protocols (CAPs)

Evaluation of Strategies

Measures of the effectiveness of new data collection process:
- Feedback from a pilot at four homes (to revise tools and processes)
- Pre and post implementation time study
- RUGs accuracy (overall and specific sections) in one year

Measures of the effectiveness of the use of AIS competency evaluations:
- Overall RUGs accuracy (improve by 20% in one year)
- Accuracy of the Physical Functioning RUG (improve by 30% in one year)
- Accuracy of assessment of Nursing Rehabilitation/Restorative care (improve by 30% in one year)
- Accuracy of the assessment of falls (improve by 15% in one year)
- Accuracy of assessment of therapies provided (improve by 20% in one year
- Assessment completion rate (maintain)

Measures of the effectiveness of shutting off auto population:
- Rate of auto population errors (decrease by 70%)
- Assessment completion rate (maintain)

A two year evaluation of the new care plan is currently underway through collaboration with a research team from the University of Saskatchewan led by Dr. Paulette Hunter.

Conclusion

- Changing the data collection process prompted a positive response from staff and managers.
- Managers were receptive to making a decision about activating lapsed RAI-MDS user accounts based on AIS competency evaluations.
- Shutting off auto population of RAI-MDS elicited little feedback.
- The new care plan is fully implemented in 50% of the homes in the Region, 6% of the homes have not yet begun implementation and the remaining 44% are in various stages of implementation.

Acknowledgements

Residents, care teams, and management teams at Saskatoon Health Region special care homes have enthusiastically participated in the implementation of new processes and tools, and provided feedback for the purpose of evaluation. They play the most important role in the success of these strategies and their dedication to improving the service provided in long term care homes is significant.

Coping with Cognitive Impairment and Dementia: Rural caregivers' Perspectives

C. Branger[1], R. Burton[1], M. E. O'Connell[1], N. Stewart[2], & D. Morgan[3]

[1] Department of Psychology, University of Saskatchewan, [2] College of Nursing, University of Saskatchewan, [3]Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

INTRODUCTION

Purpose

- The purpose of the current study is to describe how rural caregivers cope with caring for a loved one with cognitive impairment or dementia.

Rationale

- Canadian informal caregivers provide care with a yearly estimated value of $26 billion[1]
- Incidence of dementia expected to increase 250% by 2038, with this the number of informal caregivers will increase[2,3]
- Caregiving in a rural context is unique, but the experiences of rural caregivers have not been well studied[4]

Method

- This study used qualitative description to analyze responses to the open ended question : **" What helps you cope on a day- to day basis with the demands experienced as a caregiver to someone with memory difficulties?"**
- This methodology allowed us to take an explorative approach to this understudied area and generate a description of the most salient themes brought forth by the research participants.

PARTICIPANTS

- This study is based on 166 caregivers of persons diagnosed with mild cognitive impairment (MCI) or dementia, living in rural Saskatchewan.

Table 1: Frequency of Caregiver/ Care recipient Relationship

Relationship to care- recipient	Wife	Husband	Daughter	Son	Other	Total
Number	59	30	51	16	10	166

Table 2: Frequency of Care- recipient Diagnosis

Care- recipient	AD	FTD	LBD	VD	DME	Other	MCI
Number	64	16	9	3	15	30	31

AD: Dementia due to Alzheimer's Disease; FTD: Frontotemporal Dementia; LBD: Lewy Body Dementia; DME: Dementia due to multiple etiologies; Other: Other Dementias; MCI: Mild cognitive impairment

Findings: Coping Themes

Six themes of coping:

- Social Support *
  "I have good friends I can phone when the pressure is too much"
- Making time for Self *
  "*Doing an activity that is just for me"*
- Adaptation through behavioral and cognitive changes
  "I write in a diary of the day's activities and if I've reacted to/on an issue that arose."

  "I am learning to reduce my expectations of myself and my loved one"
- Reliance on faith and god
  "In the morning I give myself over to God."
- Checking in
  "I usually just call every day or two to see how she is and to remind her of what needs to be done or suggestions as to what to have for supper that day."
- Engaging in joint activity with care recipient.
  "I try to keep her occupied with different things to do."

*Most common themes: *Social Support* and *Making Time for Self*

[1] Hollander, M. J., Liu, G., & Chappell, N. L. (2009). Who cares and how much? The imputed economic contribution to the Canadian. healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. Healthcare Quarterly, 12(2), 42-49.
[2] Dupuis, S. L., Epp, T., & Smale, B. J. A. (2004, March). Caregivers of persons with dementia: Roles, experiences, supports, and coping. Literature review prepared for the Ministry of Health and Long-Term Care and the Ontario Senior's Secretariat as part of Ontario's Alzheimer Stratety (Initiative #6 Research on Caregiver Needs). Waterloo, ON: Murray Alzheimer Research and Education Program. 111 pp.
[3] Smetanin, P., Koback, P., Briante, C., Stiff, D., Sherman, G., & Ahmad, S. (2010). Rising Tide: The impact of Dementia on Canadian Society 2008 to 2038. Alzheimer Society. Retrieved from www.alzheimer.ca
[4] Morgan, D., Innes, A., & Kosteniuk, J(2011). Dementia care in rural and remote settings: A systematic review of formal or paid care. Maturitas, 68(1), 17–33.

RRMC Funding and in-kind support is generously provided by:

RESULTS

Many caregivers reported use of more than one theme of coping, and the frequencies of co-occurring themes are presented.

Table 3: Frequency of Co- occurring Coping Themes

Co-Occurrence of Coping	Frequency
Social Support/Time for Self	20
Social Support/Restructuring	11
Social Support/Time for Self/Spirituality	8
Social Support/Spirituality	8
Social Support/Time for Self/Restructuring	4
Social Support/Time for Self/Restructuring/Joint Activity	3
Social Support/Restructuring/Spirituality	3
Social Support/Check-in	3
Social Support/Restructuring/Joint Activity	2
Social Support/Time for Self Self/Restructuring/ Spirituality	1
Social Support/Joint Activity/Restructuring	1
Social Support/Joint Activity/Check-in	1
Social Support/Time for Self/Spirituality	1
Time for Self/Restructuring/Joint Activity	1
Time for Self/Spirituality	1

DISCUSSION

- 'Social Support' and' Time for Self' emerged as most common forms of coping.
- Predominantly, the methods of coping revealed in this study reflect approach-based coping strategies. Such strategies have been shown to be particularly effective.
- These data suggest these caregivers adopt adaptive coping strategies to meet the demands of the caregiving role

Recruiting individuals diagnosed with dementia due to Alzheimer's disease for cognitive rehabilitation: Ethical tension between the clinician and investigator roles

Rachel L. Burton & Megan E. O'Connell
Department of Psychology, University of Saskatchewan
rachel.burton@usask.ca, megan.oconnell@usask.ca

Introduction

Cognitive rehabilitation is a promising, non-pharmacological intervention for individuals diagnosed with dementia due to Alzheimer's disease (AD) or mixed AD and vascular dementia (VaD; i.e., Clare et al., 2010). While recruiting research participants for a study seeking to replicate and extend previous work in this area, we encountered an ethical dilemma when our role as treating psychologists conflicted with our role as researchers.

The Dilemma

We struggled with how to provide the best possible service to all persons who attended our intake assessment (clinician role), while adhering to exclusion criteria in order to maximize the internal validity of the study (investigator role). Individuals attending the intake assessment had concerns that could be addressed through cognitive rehabilitation, but their eligibility for the study was unclear.

Objectives of the Current Project:

1. Draw attention to the ethical tension between the role of clinician and the role of investigator in the context of recruiting and excluding individuals for a study on cognitive rehabilitation for early stage AD or mixed AD/VaD.
2. Offer an example of ethical decision making using the Canadian Code of Ethics for Psychologists.
3. Provide suggestions for how to best manage the tension between the clinician and investigator roles when recruiting and excluding individuals with a dementia diagnosis for an intervention study.

Ethical Guidelines for the Clinician and the Investigator

Brody and Miller (2003) have argued that the goals of research and the goals of clinical practice are logically inconsistent.

"Difference" position: Research is directed toward providing generalized knowledge and clinical practice is directed toward providing the best possible care to an individual (Brody & Miller, 2003).

- This argument has been fiercely criticized.

"Similarity" position: Clinical investigators ought to be bound by the same principles that govern therapeutic medicine (Brody & Miller, 2003).

Most ethical guidelines treat the two activities as similar. For example: Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

How can the same individual be guided by different moral obligations at different times? "Jekyll-And- Hyde approach". (Miller, 2002)

Additional considerations in dementia:

- Respect for the autonomy of persons and the protection of vulnerable persons (Fisk, 2007).
- Capacity to consent and distributive justice.

Application of the Canadian Code of Ethics for Psychologists

- A unique strength of the Canadian Code of Ethics is that it provides specific guidelines for action when ethical principles are in conflict, and a 10 step approach to addressing ethical dilemmas (Canadian Psychological Association, 2001).

Step 1: Who is involved?

- Individual with cognitive complaints; family members; graduate student; supervising psychologist; individuals who stand to benefit from the research; other researchers.

Step 2: Relevant standards	
I. Respect for the dignity of persons	• Non-discrimination • Informed consent • Freedom of consent • Protection of vulnerable persons
II. Responsible caring	• Maximize benefit • Minimize harm • Risk/benefit analysis
III. Integrity in relationships	• Avoidance of conflict of interest
IV. Responsibility to society	• Development of society

Also relevant: Tri-council Policy Statement, Section 5 on inclusion in research.

Step 3: Factors that might influence the development of or choice between courses of action

- Personal biases: Need to recruit participants, need for a 'clean' sample.
- Personal/professional stressors: Shortage of time and resources.
- Self-interest: Dissertation research.

Steps 4 and 5: Alternative course of action, and risks/benefits of action.

Action	Benefits	Risks
Include in the study	Consistent with non-discrimination. Maximizes the potential benefit of cognitive rehabilitation for this individual.	Challenging to interpret data without clear diagnosis. Other services may be more appropriate for the family.
Exclude from the study	Ensures the results of the study contribute to the development of society as much as possible. Make more appropriate referral as guided by responsible caring.	Family does not receive a potentially beneficial intervention.

Step 6: Choice.

- Chose to exclude from the study.

Step 7: Action.

- Provided one session of psychoeducation about cognitive rehabilitation, and information about alternate resources in the city.

Step 8: Evaluate and follow-up.
Step 9: Assumption of responsibility of any consequences.
Step 10: Future prevention.

- Implemented more thorough telephone pre-screening. Clinic-based rather than community recruitment focus.

Suggestions

- When studying interventions it is critical to be aware of the potential for conflict between the clinician and investigator roles regardless of whether one adopts the similarity or the difference position.
- In order to maximize distributive justice, make the inclusion criteria of intervention studies as broad as possible in order to make the research treatment available to as many interested individuals as possible, and the results applicable to as many people as possible.
  - Consider non-traditional research designs such as multiple baseline, single-case experimental designs.
- Consistent with 'responsible caring', when the intervention being studied cannot be offered make referrals to appropriate resources.
- To avoid conflicts of interest, avoid recruiting participants from one's own practice as much as possible.
  - If this is unavoidable, clearly separate the research consent from consent to treatment as usual.
- Recruit participants from clinic-based settings rather than community-based settings in order to minimize difficulties related to diagnosis and inclusion criteria.

References and Acknowledgements

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. (2005). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa, Ontario: Interagency Secretariat on Research Ethics.

Canadian Psychological Association. (2001). *Companion Manual to the Canadian Code of Ethics for Psychologists, Third Edition*. Ottawa, Ontario: Canadian Psychological Association.

Clare, L., Linden, D. E. J., Woods, R. T., Whitaker, R., Evans, S. J., Parkinson, C. H., … Rugg, M. D. (2010). Goal-Oriented Cognitive Rehabilitation for People With Early-Stage Alzheimer Disease: A Single-Blind Randomized Control Trial of Clinical Efficacy. *American Journal of Geriatric Psychiatry, 18*, 928-939. doi:10.1097/JGP 0b013e3181d5792a.

Brody, H. & Miller, F. G. (2002). The clinician-investigator: Unavoidable but manageable tension. *Kennedy Institute of Ethics Journal*, *13*(4), 329-346.

Fisk, J. (2007). Ethical considerations for the conduct of antidementia trials in Canada. *The Canadian Journal of Neurological Sciences, 34*(1), S32-36.

Miller, P. B. (2002). Avoiding a Jekyll-and-Hyde approach to the ethics of clinical research and practice. *The American Journal of Bioethics*, *2*(2), 14 – 17.

R. Burton's Work Supported by a Doctoral Award from: Alzheimer Society CANADA

Contact:

Poster Presented at the 43rd Annual Scientific and Educational Meeting of the Canadian Association on Gerontology

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The Intersection of Resident-Centered Care and Best Practices for Nutrition Care in Long-term Care

A. Cammer[1,2], S. Whiting[2], D. Morgan[1]

[1]Canadian Centre for Health and Safety in Agriculture, College of Medicine, University of Saskatchewan, [2] College of Pharmacy and Nutrition, University of Saskatchewan

Background

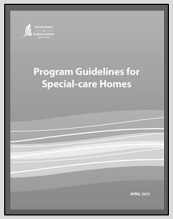
- Care Aides perform the majority of direct resident care in long-term care (LTC) with little training in nutrition
- Policies and standardized care procedures aim to eliminate guesswork but can create routinized, task-based care focus regarding nutrition care
- Person-centered care respects the resident as an individual with unique needs and the right to dignity, respect, and full participation in their own care
- The structured work environment of LTC lends itself to scheduled and standardized care practices, yet:
- Highly defined LTC protocols often oppose the central tenets of person-centered care

Objective

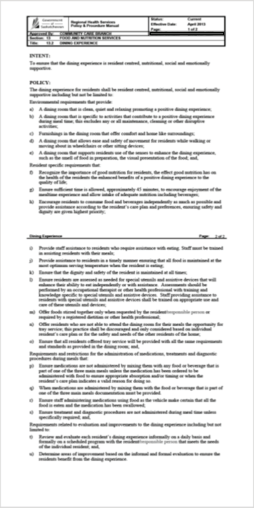
- To examine the intersection of person-centered care philosophy with nutrition care dining best practices in LTC in order to understand where nutrition policy initiatives could enhance quality of care for LTC residents, especially those with dementia

Methods

- In April, 2013 Saskatchewan Health mandated program guidelines for special-care homes (LTC)
- Section 13.2 encompass the Food and Nutrition Dining Experience components of the program guidelines, with a total of 21 policy indications contained within
- The VIPS framework for person-centered care (Brooker, 2007) and Reimer and Keller's (2009) model of 4 elements of person-centered mealtime care for LTC were used to compare person centeredness with the nutrition guidelines
- Four elements of person-centered care:
  - Providing Choices and Preferences
  - Supporting Independence
  - Showing Respect
  - Promoting Social Interaction
- Each guideline was contrasted with elements to determine the *fit* of the legally mandated guidelines with person-centered care philosophy


Program Guidelines for Special-care Homes

APRIL 2013



Comparison of Guidelines to Reimer and Keller's model of person-centered care:

	Choice and Preference	Supporting Independence	Promoting Social Side of Eating	Showing Respect
Environmental (13.a – 13.e)		✓	✓	✓
Resident Specific (13.f – 13.o)	✓	✓	✓	✓
Medication, Treatment, Diagnostic Procedures (13.p – 13.s)			✓	✓
Evaluation and Improvement (13.t – 13.u)	✓			✓

Fit with Brooker's VIPS framework :

Value – states a resident-centered approach

Individualized – review of resident needs, evaluation

Perspective – not explicit within guideline; calls for resident respect and dignity

Social – prescribes a socially supportive environment

Findings

- Structured guidelines for nutrition care serve as an important starting point for ensuring competent nutrition care, but are not comprehensive
- Non-prescriptive style of these guidelines does not force routinized care; allows for tailoring of internal policies and practices to fit each particular LTC in their capacity and style to adopt a person-centered care philosophy of care
- A gap exists between policy and 'how to' practice recommendations to achieve person-centered care in food and nutrition; training efforts should focus on operationalizing person-centered care philosophy in each LTC
- Tools to assist in implementing person-centered nutrition care could help to translate standards and guidelines into effective practice
- Guidelines are a useful first-step; evaluation efforts must examine the ability of the LTC to enable person-centered care in everyday practice

Next Steps

- Comparison with other sections of the guidelines is needed to identify potential supports that enable or discords that create a barrier to achieving person-centered care
- Comparison with other jurisdictions could identify potential 'missing pieces' not outlined within these
- Study of the uptake and application of the guidelines, with specific attention to how each is interpreted and applied, could generate understanding of gaps
- Examination of the balance between person-centered approach and the function of the organization and between person-centered approach and ensuring adequate nutritional intake could reveal systemic challenges within LTC practice

Acknowledgements

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Alzheimer Society CANADA

Characteristics of Falls in Community Dwelling Older Adults with Early Memory Problems

Dal Bello-Haas V[1], Crossley M[2], O'Connell ME[2], Morgan D[3], Kirk A[4]
[1]School of Rehabilitation Science, McMaster University;
[2]Department of Psychology, [3] Canadian Centre for Health and Safety in Agriculture, [4]Neurology, University of Saskatchewan

INTRODUCTION

- The annual incidence of falls in persons with moderate to severe dementia has been reported to be 40% to 60% (Shaw , 2003)
- Limited number of longitudinal, prospective study has examined fall-related injuries in community dwelling older adults with dementia (Allen 2009)
- No studies have prospectively tracked people with early memory problems

PURPOSE

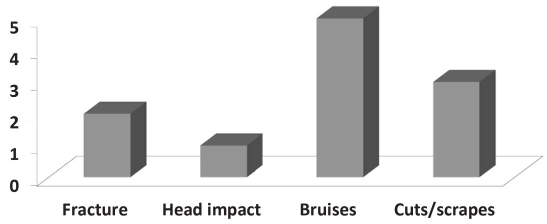
To describe the profile of fall events in people with early memory problems.

METHODS

- Fifty-nine Rural and Remote Memory Clinic patients (Saskatoon, Saskatchewan, Canada)
- Age = 72 ± 10 years; 55.9% female
- Prospective study over six months
- Patient caregivers (PC) completed a monthly fall diary
- Research assistant telephoned PC every two weeks to increase accuracy of the collected data and to increase adherence

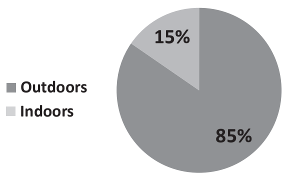
RESULTS

INJURIES RESULTING FROM FALLS

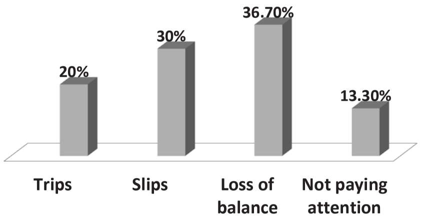


		%
INCIDENCE OF FALLS	Total falls	35.6%
	Single falls	16.9%
	Multiple falls	18.5%
TIME OF FALL	Afternoon or evening	53.8%
SAFETY ISSUE	No footwear/barefoot	41.7%

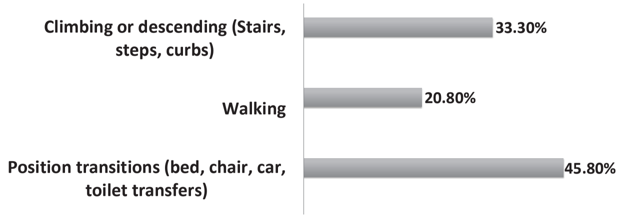
Where the falls occurred



REASON FOR FALLS



Activities at time of fall



DISCUSSION

- Overall fall incidence was similar to what has been reported in community-dwelling older adults without cognitive impairments
- About 1 in 3 community-dwelling older adults fall (Tromp 2001)
- Falls in people with early memory problems occurred mainly during position transitions or while negotiating stairs/steps/curb
- This differs to what has been reported in community-dwelling older adults without cognitive impairments – 55% of falls occurred during ambulation (Talbot 2005)
- The findings have implications for patient and caregiver training and safety in home & community environments to target fall risk for those with early memory problems

Acknowledgements: We thank the participants. Funded by the Saskatchewan Health Research Foundation

Fitness and Physical Activity Levels of Individuals Attending a Rural and Remote Memory Clinic

Dal Bello-Haas V[1], Megan E. O'Connell[2], Debra G. Morgan[3]
[1]School of Rehabilitation Science, McMaster University, Hamilton, Ontario;
[2]Department of Psychology, [3] Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, Saskatoon, Saskatchewan

INTRODUCTION

• There has been growing interest in physical activity as a potential disease-modifying therapeutic intervention for people with dementia.
• Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure; broadly encompasses exercise, sports, physical activities done as part of daily living, occupation, leisure, active transportation [Caspersen 1985]
• Physical activity has been shown to improve cognition [Hokkanen 2008], activities of daily living [Arcoverde 2008], and functional ability and mental health [Teri 2008] in people with dementia

OBJECTIVE

To examine 'fitness' and physical activity levels in community dwelling people with early stage memory problems living in rural and remote areas.

***Physical fitness* - ''[a set of] measurable health and skill-related attributes'' that include cardiorespiratory fitness, muscular strength and endurance, body composition and flexibility, balance, agility, reaction time, power [Caspersen 1985]**
***Functional fitness* - having the physical capacity to perform everyday activities safely and independently without undue fatigue**

METHODS

Fifty-nine Rural and Remote Memory Clinic (Saskatoon, SK) patients participated.

Measures completed:
- **A baseline demographic questionnaire**
- **Neuropsychological tests**

- Mini-mental Status Exam (MMSE), 3MS
- **Senior Fitness Test (SFT) components**

- Sit-to-Stand, Arm Curls, 2-minute step test
- **Physical Activity Scale for the Elderly (PASE; with the assistance of caregivers)**

Neuropsychological Screens

- **MMSE**
  - brief, cognitive screen
  - score ranges from 0 to 30
  - score of 24 indicates further testing is required
- **3MS**
  - brief screening test for dementia
  - score ranges from 0 to 100
  - score < 79 suggests further testing required

PASE (Washburn 1993)

- Measure of physical activity levels of older adults
- Household, occupational, and leisure time activity
- Each activity is given a weight; total score is recorded as the sum of the amount of time in each activity multiplied by the weight of the activity.

Senior Fitness Test (Rikli & Jones 1999)

Lower Body Strength

- Major factor in mobility and disability prevention
- Correlates with stair-climbing ability, walking speed, fall risk
- # of full stands from a seated position in 30 seconds

Upper Body Strength

- Important for normal daily activities, e.g, household chores,
carrying groceries, personal care
- # of arm-curls in 30 seconds (5 lbs for females, 8 lbs for males)

Aerobic Test

- A (alternative) measure of aerobic endurance
- Correlates with common measures of endurance
- Necessary to perform many daily activities e.g., walking,
shopping, recreational activities
- # of times individual can step in place in 2 minutes

RESULTS

STUDY PARTICIPANTS

- Mean age = 72, *SD* = 10.0
- 56% female
- Mean MMSE score = 25 (*SD* = 4)
- Mean 3MS score = 82 (*SD* = 13)

	Males, *n* = 23 Mean (*SD*)	**Females, *n* = 32** Mean (*SD*)	***p***
Sit-to-stand	10.39 (4.46)	8.94 (4.12)	.192
Arm curl	12.00 (4.20)	11.09 (4.51)	.414
Step test	62.15 (25.86)	55.13 (28.72)	.336
PASE	112.73 (63.86)	68.45 (48.11)	.008

Participant Comparison to Age-related Norms

	Males (n = 23)		**Females (n = 32)**	
	Norm Range	Percentile Rank	Norm Range	Percentile Rank
Sit-to-stand	6 to 23	15th	4 to 21	10th to 15th
Arm curl	9 to 27	15th	6 to 24	15th
2-minute step test	48 to 135	5th to 10th	37 to 130	10th to 15th
PASE	102.4	n/a	89.1	n/a

CONCLUSION

• Male participants had more acceptable levels of physical activity , as measured by the PASE, compared to female participants.
• As measured by SFT components, 'fitness' of males and females with early memory problems living in rural and remote areas were not optimal.
• People with early memory problems may require education about the benefits of physical activity and maintaining fitness.

Bibliography:
- Arcoverde C, Deslandes A, Rangel A, Rangel A, Pavao R, Nigri F, et al. Role of physical activity on the maintenance of cognition and activities of daily living in elderly with Alzheimer's disease. Arq Neuro-Psiquiat. 2008;66:323-27.
- Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Rep. 1985;100(2):126–31.
- Hokkanen L, Rantala L, Remes AM, Harkonen B, Viramo P, Winblad I. Dance and movement therapeutic methods in management of dementia: a randomized, controlled study. J Am Geriatr Soc. 2008;56:771-72.
- Rikli RE, Jones JC. Development and validation of a functional fitness test for community-residing older adults.
- J Aging Phys Act. 1999;7:129-61
- Teri L, Logsdon RG, McCurry SM: Exercise interventions for dementia and cognitive impairment: the Seattle Protocols. J Nutr Health Aging. 2008; 12:391394.
- Washburn RA, Smith KW, Jette AM, Janney CA. The Physical Activity Scale for the Elderly (PASE): development and valuation. J Clin Epidemiol. 1993;46(2):153-62

Acknowledgements: We thank the participants. This research was supported by the Saskatchewan Health Research Foundation (*V. Dal Bello-Haas),* and an Applied Chair in Health Services and Policy Research from the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation (*D. Morgan*)

Examining the Relationship Between Leadership and Sustainability of a Dementia Training Program in Long-Term Care

Tracy Danylyshen-Laycock, Ph.D. Candidate, University of Saskatchewan and Dr. Debra Morgan, University of Saskatchewan

UNIVERSITY OF SASKATCHEWAN

CCHSA / CCSSMA

Introduction

Within health care, there is an assumption that once staff receive training they will automatically implement those skills in their daily practice. Unfortunately, simple dissemination of knowledge is not effective in creating and sustaining behavioural change (Nutley, Walter, & Davies, 2003). A key factor that contributes to sustainability of educational programs in long-term care (LTC) is the role of leadership (Wallin et al., 2002). For example, strong leadership is required to "champion" the new program or initiative within the organization (Evashwick & Ory, 2003). In long-term care, the role of leadership has not been examined as extensively as in other health care settings.

Objectives

As part of a larger study of the GPA program, the purpose of this research was to explore the role of leadership in the sustainability of a dementia specific training program for staff in rural long-term care homes.

Gentle Persuasive Approaches Program

The overall goal of the GPA program is to educate staff how to:

- Use a person-centred, compassionate approach with individuals with dementia.
- Respond respectfully, with confidence and skill, to responsive behaviours associated with dementia.

Methods

Two complementary studies were conducted to examine the relationship between sustainability and leadership in rural long-term care homes.

Study One (Retrospective)
Design: cross-sectional, retrospective qualitative research design.
Site Selection: five rural LTC homes in Western Canada where the GPA Program was implemented between May and December 2010.
Participants: this study focused on the experiences of the Administrators, Directors of Care, Managers, GPA Coaches, Nurses, and Nursing Aides.
Data Collection: four focus groups with Nursing Aides and 14 semi-structured interviews with Administrators, Directors of Care, Nurses, and GPA Program Coaches were completed.

Study Two (Prospective)
Design: longitudinal, multi-site, comparative case study design.
Site Selection: two rural LTC homes were purposefully selected to provide maximum variation on organizational factors that may influence sustainability.
Participants: all staff within the two LTC homes were eligible.
Data Collection: interviews were conducted with 18 staff from all departments in both homes. In addition, 85 hours of direction observation and 25 hours of shadowing staff were conducted over 14 months. Resident charts, incident reports, and communication logs were reviewed.

Results

- In homes where the GPA program was sustained, the leadership team (Administrator and Director of Care) created a culture that was based on the philosphy of person-centred care. For example, the leadership team supported staff in honoring the values, beliefs, and choices of the residents.

- Behaviours required by leadership included role-modelling the skills that were taught in the program and coaching staff who were struggling to manage responsive behaviours.

- Other leadership behaviours that helped to sustain the GPA program included: being visible in the LTC home, spending time in the LTC home to assess/observe and support staff to use the GPA skills, holding staff accountable when they were not using the GPA skills, and meeting regularly with staff to review/brainstorm how the GPA skills could help them manage responsive behaviours.

Results Con't

In homes where the GPA program was not sustained, the leadership team:

- Failed to support the program. It was viewed as "just another program."
- Created a culture of "institutionalization" where residents did not have choice, care was forced on residents, and tasks were completed on staffs' time schedule.
- Disciplined staff who were practicing GPA.
- Allowed bullying of staff who were practicing GPA.
- Spoke negatively about the GPA program in front of their staff.

Conclusion

- In order for the GPA program to be sustained in LTC, the leadership team must fully support the program, model the GPA skills, and coach those individuals who are struggling to change their practice.
- To support the program, leaders must promote person-centred care by creating a culture that allows for resident choice, adherence to resident routine, and life choices.

Reliable Change (RCI) on Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) in a Dementia Sample

Benjamin Gould[1], Joe Enright[1], M. E. O'Connell[1], & Debra Morgan[2]
[1] Department of Psychology, University of Saskatchewan, [2]Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

INTRODUCTION

Purpose

→ Examining reliable change in RBANS scores for persons with dementia at a one year interval using predetermined regression formulas from a normative sample

Background

→ Past literature suggests RCI incorporates reliability in calculation of small but meaningful change in health status over time[1,2,3,5]

→ RCI offers more insightful clinical interpretations than group-level statistics[3,5]

→ RBANS has level of difficulty appropriate for normal older adults through individuals with moderately severe dementia[1,4]

→ Development of "normal" regression-based change algorithms allow for broader application[2,5]

→ Initial performance on test found to be best predictor of retest performance[2]

PARTICIPANTS

→ **53** participants (57% female) at the Rural and Remote Memory Clinic who were diagnosed with dementia based on interview with patient and families in addition to:

- → Recent blood work
- → CT head scan
- → Neurological assessment
- → Neuropsychological assessment
- → Physical therapy assessment

The sample only included patients who completed all neuropsychological variables at clinic day and 1 year later

	Min	Max	*M*	*SD*
Patient age at clinic day	44	92	70.79	10.91
Formal Education	4	16	11.45	2.67

METHOD

→ Each of the 53 persons received an interdisciplinary diagnosis of dementia

Diagnosis	*f*
Alzheimer's disease	28
Vascular dementia	4
Frontotemporal dementia (FTD)	
FTD, frontal variant	7
FTD, semantic variant	1
FTD, progressive non-fluent	1
Dementia multiple aetiologies	6
Dementia medical condition	3
Dementia with Lewy bodies	3
Total	***53***

→ Predetermined regression formulas developed from a normative population[5] were used to ***determine predicted re-test scores*** for persons with dementia

→ ***Predicted re-test*** scores on RBANS indexes were compared to ***actual re-test scores***

→ Correlation between RBANS Index scores and Clinical Dementia Rating – sum of box scores – severity measure

RESULTS

RBANS Test Re-test Means	*Inital M (SD)*	*1 yr M (SD)*
RBANS- Immediate Memory	69.15 (14.09)	65.57 (15.91)*
RBANS- Visuospatial/Construct	80.47 (16.68)	80.55 (15.35)
RBANS- Language Index	84.94 (11.95)	80.02 (16.13)**
RBANS- Attention Index	79.49 (16.04)	75.36 (15.09)*
RBANS- Delayed Memory	60.09 (17.25)	57.40 (16.82)
RBANS- Total Scale	68.13 (10.47)	64.96 (11.99)*

RBANS Index	*Range of Predicted - Actual Scores*	*Predicted-Actual Mean Scores*	*# where Actual Re-scores higher than Predicted*
Imm Memory	2.01 – 79.57	35.11	0
Visuospatial	-1.77 – 75.74	33.39	1
Language	-18.98 – 37.65	8.78	12
Attention	-23.72 – 50.76	12.35	7
Del Memory	-17.64 – 47.21	15.87	6

RESULTS

RBANS Index	*Correlation with CDR r (p)*
RBANS- Immediate Memory	.129 ($p > 0.05$)
RBANS- Visuospatial/Construct	.013 ($p > 0.05$)
RBANS- Language Index	.056 ($p > 0.05$)
RBANS- Attention Index	.206 ($p > 0.05$)
RBANS- Delayed Memory	.094 ($p > 0.05$)
RBANS- Total Scale	.147 ($p > 0.05$)

DISCUSSION

Persons with dementia from this sample demonstrated a decline beyond that expected based on a cognitively healthy older adult sample on all RBANS indices (Mean), but individual variability regarding decline vs stability vs improvement was seen most often on the Language Index. No person with dementia improved on Immediate Memory.

Associations between persons with dementia's RBANS Predicted-Actual RBANS scores with dementia severity) (Clinical Dementia Rating-Sum of box scores scores) were trivial or small in magnitude and statistically non-significant.

Future Directions

- ➢ Future research will aim to determine if a relationship exists between this cognitive battery demonstrative of meaningful change and some form of functional assessment scale.

[1] Attix, D. K., Story, T. J., Chelune, G. J., Ball, J. D., Stutts, M. L., Hart R. P., & Barth J. T. (2009). The prediction of Change: Normative neuropsychological trajectories, *The Clinical Neuropsychologist,* 23(1), 21-38.
[2] Duff, K., Schoenberg, M. R., Patton, D., Paulsen, J. S., Bayless, J. D., Mold, J., Scott, J. G., & Adams, R. L. (2005). Regression-based formulas for predicting change in RBANS subtests with older adults, *Archives of Clinical Neuropsychology*, 20, 281-290.
[3] Schmitt, J. S., & Di Fabio, P. D. (2004). Reliable change and minimum important difference (MID) proportions facilitated group responsiveness comparisons using individual threshold criteria, *Journal of Clinical Epidemiology,* 57, 1008-1018.
[4] Hobson, V. L., Hall, J. R., Humphreys-Clark, J. D., Schrimsher, G. W., & O'Bryant, S. E. (2010). Identifying functional impairment with scores from the repeatable battery for the assessment of neuropsychological status (RBANS), *International Journal of Geriatric Psychiatry,* 25, 525-530.
[5] Duff, K., Schoenberg, M. R., Patton, D., Mold, J., Scott, J. G., & Adams, R. L. (2004). Predicting change with the RBANS in a community dwelling elderly sample, *Journal of the International Neuropsychological Society,* 10, 828-834.

RRMC Funding and in-kind support is generously provided by:
CIHR IRSC
Saskatchewan Health Research Foundation
University of Saskatchewan
HEALTH Healthy People, A Healthy Province.
Alzheimer Society Saskatchewan

Contact

Care farming: providing brighter futures for young and old

Sarah Hambidge
Working in collaboration with Future Roots, Bournemouth University Dementia Institute and the Faculty of Science and Technology

Aims:

To explore the benefits of a care farm in rural Dorset on improving physical and mental health outcomes for older people with mild cognitive impairment/dementia and behaviourally-challenged young people by building individual's resilience, and improving intergenerational interaction.

Research Question:

What are the benefits of a care farm model for people with dementia and troubled youth?

Specific questions to be explored in order to address the overall research question will investigate:

How the care farm environment has an impact (for both groups) in respect of: Behaviour and emotion; Physical activity; Social isolation and interaction; Mental health and quality of life

How does the care farm environment have an impact for both parties (jointly), in respect of: Interaction between both groups; Awareness and respect of other group

Background

This care farm model is innovative in that it uses intergenerational working between older people with a diagnosis of mild cognitive impairment or dementia, and youth with behavioural problems, to help individuals respond resiliently to life's challenges. The current body of research is limited, and very few if any studies focus on how a care farm uses resilient interventions, as a strategic approach, to help people living in constellated disadvantage to sustain or improve their mental and physical health and well-being. Initial observations of three service user group sessions revealed that the farm facilitates productive engagement between older people and youth, and there was a sense of empowerment, inclusion and less dependency.

Research Design:

A mixed methods approach will be adopted with quantitative questionnaires and qualitative interviews and unstructured observations. The questionnaires and interviews will explore how engagement with the activities at the farm improves factors in the aforementioned measures. Unstructured observations will be used to gain a direct understanding of the activities and processes at play during the care farm work. It would also compare outcomes against other models of intervention, and against no intervention.

Data will be analysed qualitatively and quantitatively with triangulation employed to maximise the different data collection methods, sources and analysis techniques enabling a systematic process and outcome analysis to enable a thorough exploration of the benefits of the care farm approach.

Bournemouth University

Dementia Institute (BUDI)

Dorchester age UK

An exploration of commercial gaming technology as a leisure activity for older men with dementia in rural Dorset

LEVEL 1: PROJECT INTRODUCTION

This project aims to address a real world issue for Age UK Dorchester and engage older men with dementia in rural areas of Dorset who are at risk of social exclusion and poor well-being. A technological initiative using commercial gaming systems (Nintendo DS, Wii, Microsoft Kinect and iPads) has been chosen to accomplish this. The research splits into two empirical phases. The first, a consultation phase to develop the initiative. The second (main Doctoral study) is an exploration of the impact of the technological initiative for older men with dementia in rural areas of Dorset.

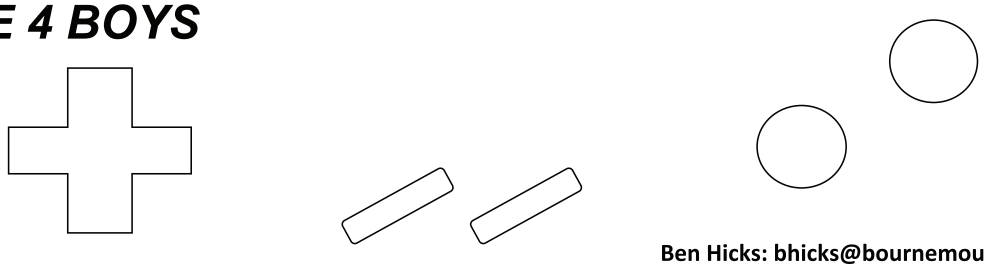
LEVEL 2: CONSULTATION PHASE

The consultation phase was undertaken in the latter part of 2013. It was designed to explore the feasibility of engaging older men with dementia with commercial computer game technology. A user-focussed approach was adopted which enabled the participants to work as active collaborators in the design of the technological initiative. Four one-off consultation sessions using commercial gaming systems were undertaken with older men with dementia in various rural areas of Dorset. Their experiences of engaging with the technology and participating in the groups were elicited through discussions with the men as well as observations and reflective field-notes. The data ascertained from the consultation phase fed into the research design for the main doctoral study.

LEVEL 3: MAIN DOCTORAL STUDY

The main study will implement three technological initiatives each lasting eight weeks (one per week) in three rural communities of Dorset. The groups will adopt a Participatory Action Research approach, working with older men (65+) with dementia to explore their experiences of engaging in the groups and monitor the outcomes to their well-being. Two innovative methods will be used to collect the data; ‘Photovoice’ and ‘Walking interviews.’ It is envisaged that the research design will lead to longer term beneficial effects for the well-being of the participants. The technological initiatives will conclude in early 2015 and a final report alongside guidance documentation (produced in collaboration with the participants) will be published later that year.

GAME 4 BOYS



Ben Hicks: bhicks@bournemouth.ac.uk

RURAL AND REMOTE MEMORY CLINIC – UPDATE (March 2004 – June 2014)

L. Holfeld[1], D. Morgan[1], M. O'Connell[2], M. Crossley[2], A. Kirk[3], N. Stewart[4], V. Dal Bello-Haas[5], L. McBain[6], A. Cammer[1], D. Minish[1], R. Beever[1], J. Kosteniuk[1]

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

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Background

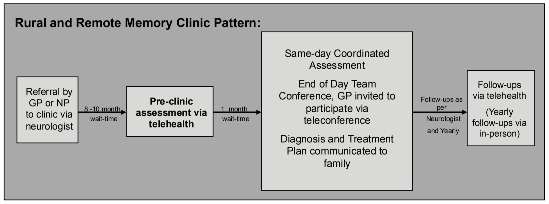
Introduction:

- Rural and Northern Saskatchewan have 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

Rural and Remote Memory Clinic

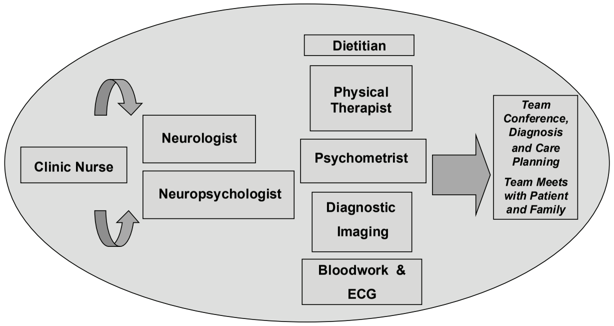
Clinic Goal:

- *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*


Rural and Remote Memory Clinic Pattern:

- **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
- **Coordinated assessment** takes place in Saskatoon, is approximately 8 hours, and involves the patient and their informal caregivers

Full-Day Coordinated Assessment



Saskatchewan Telehealth Sites (2014)
(Pre-clinic Assessments and Follow-ups)

Comparison of travel time and distance saved:

- *Mean distance from home to Telehealth = 32.7 km*
- *Mean distance from home to Saskatoon = 267.5 km*

Distance saved by Telehealth = 234.7 km (one-way)

Teleheath: In 2014 there are over 235 Telehealth sites currently operating in provincial, regional and northern hospitals in Saskatchewan. Telehealth can also link with other select sites provincially, nationally and internationally.

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 = 411 (June 2014)

***Alzheimer Disease* - 162**

Other dementias:

- *Vascular Dementia – 10*
- *Dementia with Lewy Bodies – 17*
- *Frontal Temporal – 34*
- *Dementia due to Medical Condition - 5*
- *Cognitive Impairment Not Otherwise Specified - 13*
- *Dementia due to Multiple Etiologies – 16*
- *Sub-cortical Dementia - 3*

Other diagnoses:

- *No Cognitive Impairment – 81*
- *Mild Cognitive Impairment – 70*

RRMC Demographics
n = 461 (June 2014)

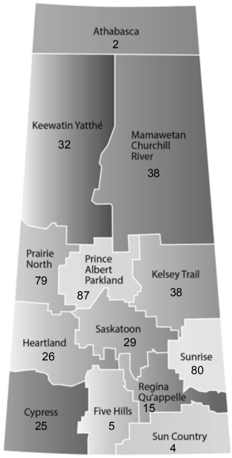
Mean Age = 70.71 yrs

Range Age = 22 - 97 yrs

Gender: 43% Males

58% Females

Patient Referrals per Rural Health Authority
n = 460 (June 2014)



Rural Dementia Care

UNIVERSITY OF SASKATCHEWAN

Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas

www.cchsa-ccssma.usask.ca/ruraldementiacare

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Saskatchewan Health Research FOUNDATION

Alzheimer Society SASKATCHEWAN

Ministry of Health

UNIVERSITY OF SASKATCHEWAN

The Influence of Individual and Organizational Factors on Person-Centred Approaches to Dementia Care

Paulette Hunter, Ph.D., St. Thomas More College, University of Saskatchewan; Thomas Hadjistavropoulos, PhD., University of Regina and Centre for Aging and Health
Lilian Thorpe, MD, PhD, FRCPC, University of Saskatchewan; David Malloy, Faculty of Kinesiology & Health Studies, PhD University of Regina; Fiona Fick, University of Saskatchewan

Background

A person-centred approach toward long-term care residents with dementia promotes quality of life (Kitwood, 1997). Most interventions to promote person-centred residential dementia care (PCRDC) call for attention to the attitudes and actions of individual care providers toward long-term care residents and place less emphasis on organizational contexts. There is little evidence to suggest which theme deserves greater attention. To summarize briefly:

- Previous work suggests that structural empowerment (e.g., power, information, support, and resources) explains approximately half the variance in self-reported individualised care (Caspar & O'Rourke, 2008). ***Hypothesis: Organisational characteristics influence PCRDC.***
- Several studies suggest that higher levels of education and/or qualifications are associated with more positive, person-centred, or hopeful attitudes toward long-term care residents with dementia (e.g., Normann, Asplund, & Norberg, 1999) although such findings are not universal (e.g., MacDonald & Woods, 2005). Few studies have examined the role of age and gender in determining attitudes and there is a dearth of evidence about employee factors associated with person-centred behaviour. ***Hypothesis: Age, gender, years of education, and occupation influence PCRDC.***
- Beliefs about personhood in dementia account for a small but significant amount of variance in intended approaches to pain management for persons with dementia (Hunter et al., 2013). A moderate association between beliefs about personhood and beliefs about the importance of person-centred care has also been documented (Hunter et al., 2013). ***Hypothesis: Employee beliefs about personhood influence PCRDC.***
- Burnout is associated with less positive attitudes and lower empathy toward people with dementia (e.g., Astrom, Nilsson, Norberg, Sandman, & Winblad, 1991), as well as a decreased willing ness to help, low optimism, and negative emotional responses (Todd & Watts, 2005). ***Hypothesis: Employee burnout influences PCRDC.***

The purpose of this study was to investigate the contributions of organizational factors and care providers' personal qualities to self-reported PCRDC.

Method

Design:

- A correlational descriptive survey

Participants:

- 109 staff members from two large rural long-term care homes
- 10% male and 90% female; 25% nurses, 41% care aides, and 34% other; average age 43 (*SD* = 12.71)

Measures:

- The Person-Directed Care scale (PDC; White, Newton-Curtis, & Lyons, 2008) measured self-reported person-centred care across these subscales: Autonomy, Personhood, Knowing the Person, Comfort Care, and Supporting Relationships.
- The Environmental Support for Person-Directed Care scale (White et al., 2008) measured organisational-environmental supports for person-centred care.
- The Personhood in Dementia Questionnaire (Hunter et al., 2013) assessed beliefs about personhood in dementia.
- The Maslach Burnout Inventory – Human Services Scale (Maslach & Jackson, 1996) assessed burnout.
- A demographic form documented age, gender, years of education, and occupation.

Analysis:

- Hierarchical regression: Workplace factors, demographic factors, beliefs about personhood, and burnout, were regressed, in that order, on each PDC subscale.

Results

In a series of hierarchical regression models examining five aspects of PCRDC (see Tables), we found that organizational factors were robust predictors of PCRDC, explaining 17 to 34 percent of score variance on the PDC in each of the five models, after controlling for employee demographic factors. Personal variables were also important for some types of PCRDC: gender for comfort care, beliefs about personhood for empathic responses to residents' disabilities (i.e., personhood subscale of PDC), and burnout for comfort care and support for relationships. Beliefs about personhood and burnout were assessed as later steps in the regression models, meaning that they remained important for some types of PCRDC after controlling for other factors.

Discussion

This study contributes to emerging evidence suggesting that organizational factors (e.g., collaboration in care and the built and social environment of care) are very important to PCRDC. PCRDC is a multi-dimensional construct, and personal variables including gender, beliefs about personhood in dementia, and burnout also appear to be important for some of its dimensions. Although each of these observations requires further study, this research invites further consideration of organizational and personal factors when designing and implementing interventions to enhance person-centred residential dementia care.

Tables

Autonomy

		R^2	R^2
Step	Variable set	Total	Δ
1	Demographic	0.08	0.08
2	Organizational	.36***	.28***
3	Beliefs about personhood	.36***	0
4	Burnout	.36***	0.04

Note. N= 100; *p < .05 **p < .01. ***p < .001

Personhood

		R^2	R^2
Step	Variable set	Total	Δ
1	Demographic	0.03	0.03
2	Organizational	.20**	.17**
3	Beliefs about personhood	.28***	0.08**
4	Burnout	.36***	0.08**

Note. N= 101; *p < .05 **p < .01. ***p < .001

Knowing the Person

		R^2	R^2
Step	Variable set	Total	Δ
1	Demographic	0.07	0.07
2	Organizational	.26***	.19***
3	Beliefs about personhood	.27***	0.01
4	Burnout	.28**	0.01

Note. N= 101; *p < .05 **p < .01. ***p < .001

Comfort Care

		R^2	R^2
Step	Variable set	Total	Δ
1	Demographic	0.16**	.16**
2	Organizational	.35***	.19***
3	Beliefs about personhood	.36***	0.01
4	Burnout	.41***	.05*

Note. N= 99; *p < .05 **p < .01. ***p < .001

Supporting Relationships

		R^2	R^2
Step	Variable set	Total	Δ
1	Demographic	0.08	0.08
2	Organizational	.42***	.34***
3	Beliefs about personhood	.42***	0
4	Burnout	.46***	0.04

Note. N= 98; *p < .05 **p < .01. ***p < .001

The Saskatchewan Health Research Foundation provided support for this work.

myPLAN 1.0: Resident Centred Care Planning In Long Term Care

Jan Berger, BSN RN - Lynda Blevins BSN RN - Tara Evjen, BSN RN -
Karen Gelowitz, MSN RN - Laureen Nein, BSN RN - Diane Nowlan, BSN RN -
Alicia Tiedjens, BSN RN - Jill Werle, BSN RN

Background

The Saskatoon Health Region has over 2200 residents who reside in 30 long term care homes. Each resident is assessed quarterly using the Resident Assessment Instrument - Minimum data set 2.0 (RAI-MDS 2.0). Analysis of the assessment data triggers the interRAI Clinical Assessment Protocols (CAPs).

Prior to the development of myPLAN 1.0, existing care plans:
- were not consistently reviewed and updated by care teams
- did not include measurable goals
- did not align with the new RAI-MDS CAPs

We needed a tool that addressed these issues and:
- created a strong link between residents' preferences and their care plans
- captured changes in residents' preferences, health, and care over time
- engaged care teams, including the resident and family, to regularly review and update the goal-directed plan

myPLAN 1.0 Development

Our development process included:
- looking at care planning tools from other sources
- consulting with residents, families, long term care home staff and other consultants (speech language pathologists, dietitians, behaviour management specialists).
- piloting and revising the myPLAN

As a result, myPLAN 1.0 is a resident-centred, interdisciplinary tool that coordinates resident preferences, care needs, goals, and outcomes. MyPLAN 1.0 is organized using RAI-MDS 2.0 assessment sections such as bed mobility, transfer, personal hygiene, cognitive patterns/decision making, continence & dealing with pain. Also, there are four different categories of information in the myPLAN 1.0: All About Me, All About My Care, Nursing Rehabilitation and CAPs. These are described to the right.

Current state

In June 2013, the myPLAN 1.0 was introduced in all long term care homes in the Saskatoon Health Region. Implementation strategies are in place, with homes at various stages of completion.

Next steps

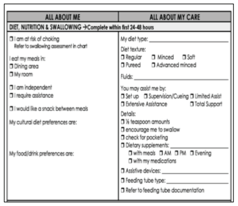
We received feedback initially about the length of the myPLAN 1.0 and the potential time to complete it. We acknowledged these concerns and put in place a comprehensive evaluation process.

Evaluation began in 2013 in partnership with the University of Saskatchewan. The evaluation will identify whether the myPLAN 1.0:
- has better completion rates than past tools
- facilitates the use of RAI-MDS 2.0 data to enhance resident care
- leads to better resident outcomes
- facilitates communication among the care team, including the resident/family

Any necessary revisions are planned for 2015. These will be based on feedback and the evaluation findings.

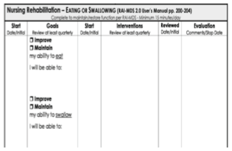
myPLAN 1.0 Details

The **All About Me** contains information and preferences from the resident. The **All About My Care** connects the All About Me and other health information to specific details about the resident's care.



ALL ABOUT ME	ALL ABOUT MY CARE
DIET, NUTRITION & SWALLOWING →Complete within first 24-48 hours	
☐ I am at risk of choking Refer to swallowing assessment in chart I eat my meals in: ☐ Dining area ☐ My room ☐ I am independent ☐ I require assistance ☐ I would like a snack between meals My cultural diet preferences are: My food/drink preferences are:	My diet type: ______ Diet texture: ☐ Regular ☐ Minced ☐ Soft ☐ Pureed ☐ Advanced minced Fluids: ______ You may assist me by: ☐ Set up ☐ Supervision/Cueing ☐ Limited Assist ☐ Extensive Assistance ☐ Total Support Details: ☐ ½ teaspoon amounts ☐ encourage me to swallow ☐ check for pocketing ☐ Dietary supplements: ______ ☐ with meals ☐ AM ☐ PM ☐ Evening ☐ with my medications ☐ Assistive devices: ______ ☐ Feeding tube type: ______ ☐ Refer to feeding tube documentation

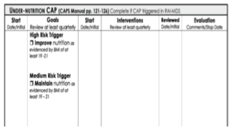
Nursing Rehabilitation is used by the care team, including the resident, when there is a goal to maintain or improve the resident's abilities. The plan must meet RAI-MDS 2.0 requirements for nursing rehabilitation such as taking at least 15 minutes each day. Examples are: walking, transferring, moving in bed, eating and others. The plan must be reviewed, evaluated and revised at least every 90 days.



Nursing Rehabilitation – EATING OR SWALLOWING (RAI-MDS 2.0 User's Manual pp. 200-204)
Complete to maintain/restore function per RAI-MDS - Minimum 15 minutes/day

Start Date/Initial	Goals Review at least quarterly	Start Date/Initial	Interventions Review at least quarterly	Reviewed Date/Initial	Evaluation Comments/Stop Date
	☐ Improve ☐ Maintain my ability to eat I will be able to:				
	☐ Improve ☐ Maintain my ability to swallow I will be able to:				

Clinical Assessment Protocols are triggered through analysis of assessment data within RAI—MDS 2.0. The CAPs fall into four broad categories: functional performance, cognitive and mental health, social life and clinical issues.



UNDER-NUTRITION CAP (CAPS Manual pp. 121-126) Complete if CAP triggered in RAI-MDS

Start Date/Initial	Goals Review at least quarterly	Start Date/Initial	Interventions Review at least quarterly	Reviewed Date/Initial	Evaluation Comments/Stop Date
	High Risk Trigger ☐ Improve nutrition as evidenced by BMI of at least 19-21				
	Medium Risk Trigger ☐ Maintain nutrition as evidenced by BMI of at least 19 – 21				

The purpose of CAPs for the resident is to resolve problems, reduce the risk of decline or increase the potential for improvement. Care teams may develop their own goals or use those provided on the myPLAN. Examples are:

Urinary Incontinence CAP with possible goals of:
- **Improve** bladder function as evidenced by reduced number of episodes of incontinence OR
- **Prevent** decline in bladder function as evidenced by maintained or reduced number of episodes of incontinence

Behaviour CAP with possible goals of:
- **Reduce** daily responsive behaviors as evidenced by responsive behaviours occurring less than daily OR
- **Prevent** increase in responsive behaviors as evidenced by responsive behaviours occurring less than daily OR
- **Minimize** responsive behaviors from occurring as evidenced by Behavior CAP not being triggered

---

myPLAN 1.0: Evaluation Framework

Paulette Hunter, Ph.D., St. Thomas More College, University of Saskatchewan
Anita Bergen, BN, MSc, Saskatoon Health Region
Jan Berger, BSN RN - Lynda Blevins BSN RN - Tara Evjen, BSN RN - Karen Gelowitz, MSN RN –
Laureen Nein, BSN RN - Diane Nowlan, BSN RN - Alicia Tiedjens, BSN RN - Jill Werle, BSN RN

In July, 2013, Seniors' Health and Continuing Care (Saskatoon Health Region) established a two-year partnership with a research group called the Community and Research Alliance for Quality of Life in Older Adults to evaluate a new resident-directed care plan entitled myPLAN 1.0. The first evaluation phase, which focused on Director of Care, Clinical Leader, care provider, resident, and designate perceptions of the plan, was planned to extend from July 1, 2013 to June 30, 2014. The second phase, which focused on the quality of care planning and on resident outcomes, was planned to extend from July 1, 2014 to June 30, 2015.

Phase 1

Four projects were included in Phase 1:
❑ Understanding the Rollout Process
❑ User Responses to myPLAN 1.0
❑ Resident and Family Responses to myPLAN 1.0
❑ Utilisation of myPLAN

Understanding the Rollout Process

Interviews were planned to assess indicators of a smooth rollout, including the ability of homes to articulate the rollout process, rationale for deviations from the chosen process and timeline, rationale for early or late adoption, and factors influencing the success of the rollout.

User Responses

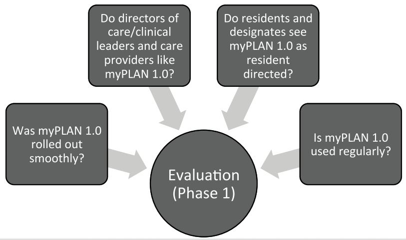
Semi-structured interviews were planned to assess care providers' responses to myPLAN 1.0. In addition, 5 structured questions requiring a Likert-type response assessed the degree to which care providers find the new plan to be concise, relevant, and easy to follow; better integrated with RAI-MDS 2.0; and useful for communication.

Resident and Family Responses

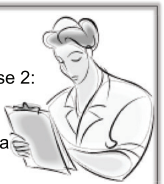
Interviews were planned to assess the degree to which residents or their designates believe that myPLAN 1.0 is resident-directed.

Utilisation of myPLAN 1.0

An experiment involving the retrieval of a note placed on an several old and new care plans was planned to assess whether care providers consult myPLAN 1.0 more frequently than the previous care plan.



Phase 2



Three projects were included in Phase 2:
❑ Qualitative "Spot Check"
❑ Retrospective Chart Review
❑ Pre-Post Comparison of MDS Data

Qualitative "Spot Check"

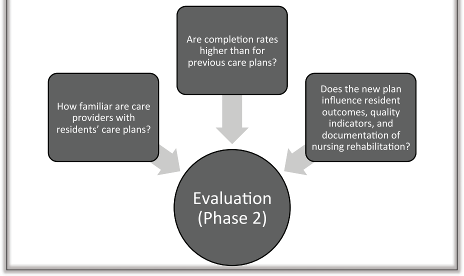
A series of rapid "spot check" interviews was planned to assess care providers' knowledge about residents' care plans. The goal of the interviews was to determine the extent to which care providers are aware of CAPs and Nursing Rehabilitation interventions currently listed in the care plans.

Chart Review

A chart review was planned to assess whether care planning has improved in quality since the implementation of myPLAN 1.0.

Pre-Post Comparison of RAI-MDS Data

A comparison of RAI-MDS outcomes and indicators was planned to assess whether the introduction of myPLAN 1.0 led to any of the following:
- ✓ Quality indicators related to falls, medications, pressure ulcers, restraints, infections, and pain show improvement.
- ✓ Resident outcomes (including depression, pain, activities of daily living performance, social engagement, aggression, pressure ulcers, and delirium) show average improvement.
- ✓ There is an increase in documentation of nursing rehabilitation.



The Saskatchewan Health Research Foundation provided support for this work.

Saskatoon Health Region | Seniors' Health and Continuing Care

University of Saskatchewan

myPLAN 1.0: Evaluation Results (Phase 1)

Paulette Hunter, Ph.D., St. Thomas More College, University of Saskatchewan
& Fiona Fick, University of Saskatchewan

In July, 2013, Seniors' Health and Continuing Care (Saskatoon Health Region) established a two-year partnership with a research group called the Community and Research Alliance for Quality of Life in Older Adults to evaluate a new resident-directed care plan entitled myPLAN 1.0. The first evaluation phase focused on Director of Care, Clinical Leader, care provider, resident, and designate perceptions of the plan, and extended from July 1, 2013 to June 30, 2014.

Methods

We report here on a series of interviews with 9 Directors of Care or Clinical Leaders (DOCs/CLs), 23 care providers (RNs, LPNs, and CCAs), and 4 residents or designates[1]. All participants were asked open-ended questions about their experience of myPLAN 1.0. Interview transcripts were analysed using thematic content analysis. Care provider interviews contained five additional structured interview questions, in which respondents were asked to rate attributes of myPLAN 1.0 and the previous care plan on a 10 point scale ranging from 1 (not at all) to 10 (extremely). These responses were compared using a dependent measures t-test.

Care Provider Perceptions

Care providers saw the plan as comprehensive and well-integrated with the RAI-MDS. However, the length of the document and time needed to complete and/or review each plan was a concern. It was thought to be a good source of comprehensive information for occasional reference, but impractical for day-to-day use. Still, as Table 1 illustrates, myPLAN 1.0 was perceived as more concise, more relevant, better integrated with the RAI-MDS, and more useful for communicating about resident care than the previous care plan.

Table 1: Means, standard deviations, degrees of freedom, t values, and effect sizes for two care plans

Question	MyPLAN 1.0		Previous Plan		*df*		Effect size
	Mean	*(SD)*	*Mean*	*(SD)*	(*N*-1)	*t* value	d_z
QI:	7.14	(2.48)	5.00	(2.42)	13	3.20**	.85
Q2:	7.79	(3.02)	5.71	(2.95)	13	3.94**	1.05
Q3:	6.67	(2.77)	5.03	(2.70)	13	1.77^a	.47
Q4:	8.13	(3.27)	3.33	(1.87)	7^b	5.80**	2.05
Q5:	7.47	(2.88)	5.67	(2.69)	13	2.54*	.68

Note: All questions were answered on a 1-10 rating scale, with higher values more positive than lower values. Q1 = How concise is the plan? Q2 = How relevant is the plan? Q3 = How good is the flow of the plan? Q4 = How well is the plan integrated with MDS? Q5 = How useful is it in helping to communicate with others?

[a] Here, the ability to observe statistical significance was limited by sample size. An adequate sample size for this smaller but meaningful difference would have been 30 (versus the obtained size of 14).

[b] Fewer users expressed responses to this question, reducing the sample size and degrees of freedom for the analysis.

* Statistically significant, $p < .05$

** Statistically significant, $p < .01$

DOC/CL Perceptions

DOCs/CLs indicated that the workload to roll out myPLAN 1.0 was daunting because of the time required to learn the new format and complete each plan. DOC/CLs saw myPLAN 1.0 as comprehensive and well-integrated with the RAI-MDS, but lengthy and time-consuming to complete. They noted that for most residents, some portions of the plan would not be applicable. They were concerned that staff members may become accustomed to blank sections and neglect to re-evaluate those portions of the plan.

Conclusions

Although many users expressed appreciation for the comprehensiveness of myPLAN 1.0 relative to the previous plan, its length was consistently flagged as a factor that may impede reference to the document, including necessary updates. An ongoing challenge will be reconciling DOC/CL and care provider support for a comprehensive care planning tool with their interest in having a day-to-day reference document that is convenient to search and update.

Care Plan Consultation Experiment

The first phase of the myPLAN 1.0 evaluation focused mainly on perceptions of the new plan. However, we also conducted an experiment to assess whether myPLAN 1.0 was being consulted more often than the previous plan. During the experiment, sticky notes were placed in a comparable location on at least one old and one new care plan within the same neighbourhood. The notes contained a message requesting that the care provider who found the note return it to the DOC and claim a prize. Missing data prevented a statistically reliable comparison of return times for old versus new care plans. On average, it took 18.45 days for the notes to be returned (including both old and new plans), suggesting an overall low rate of care plan consultation. This result aligns well with the information care providers gave in interviews. Encouragingly, care providers from diverse occupations (e.g., care aides, nurses, and physiotherapists) retrieved the notes.

---

[1] Residents and designates had experienced myPlan 1.0 in the context of a recent care planning meeting in which they participated in completing the plan. Resident and designate interviews carried over into Phase 2 of the evaluation; therefore, results are not reported here.

SHRF
SASKATCHEWAN HEALTH RESEARCH FOUNDATION

The Saskatchewan Health Research Foundation provided support for this work.

Bournemouth University

Dementia Institute (BUDI)

TECH CLUB

WHAT ARE THE BENEFITS OF A TECHNOLOGY GROUP ON THE QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA LIVING WITHIN THE COMMUNITY?

CLARE CUTLER (PART TIME PHD STUDENT), PROF. ANTHEA INNES
CCUTLER@BOURNEMOUTH.AC.UK

BACKGROUND

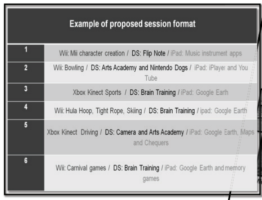
- Within the UK there is a push towards active and healthy ageing with the aim of enabling people living with dementia to remain independent and as a part of their society and community for as long as possible. There is a huge body of literature around the benefits of maintaining and enhancing wellbeing and the importance of physical, social and mental activity (Hall et al 2009; Hill et al 2010; Wang et al 2012; Swan 2012). With approximately two thirds of people with dementia living within the community (Alzheimer's Society 2013) there is now a national drive towards maintaining a good quality of life in older age and when living with dementia (Harley et al 2010).
- Limited research has been conducted into the role of gaming technology in dementia care and has neglected the potential Quality of Life (QoL) benefits arising from the use of such equipment. To date, gaming technology research has traditionally looked at its role in rehabilitation for people affected by strokes, cancer, asthma and autism (Rahmani and Boren 2012), and as a preventative measure against cognitive decline (Wang et al 2012). From this we know that gaming technology, particularly the Nintendo Wii, has the potential to enhance and support health care. What we don't know is the potential when used in dementia care, especially its potential to enhance QoL and to support active and healthy ageing.
- This poster will report on two Technology Club's, looking specifically at QoL benefits.

METHODS

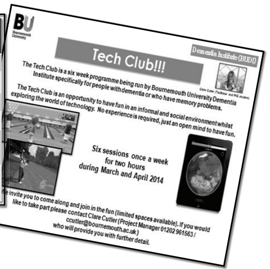
Using the Nintendo Wii, Nintendo DS, Xbox Kinect and Apple iPad, two sets of Technology sessions (called the Tech Club) were provided for people living with dementia within the Bournemouth area (Dorset). The aim of the Tech Club was to establish and explore the quality of life benefits of a technology group for people living with dementia.

A total of 12 sessions were delivered between two groups of people living with dementia, the first at a local day centre and the second at a community venue. The sessions (each two hours long) aimed to use all aspects (games, apps, software) of each piece of equipment throughout the duration of the Tech Club.

Quality of life interviews were conducted with the person with dementia and a QoL questionnaire was completed by the professional or family carer prior to the start of the sessions. This QoL process will be repeated following the final session and at a three month follow up stage. In addition to QoL data, the sessions used qualitative data collection methods to capture the participants thoughts, comments, opinions, likes and dislikes about the technologies and the sessions as a whole.



Example of proposed session format	
1	Wii: Mii character creation / DS: Flip Note / iPad: Music instrument apps
2	Wii: Bowling / DS: Arts Academy and Nintendo Dogs / iPad: iPlayer and You Tube
3	Xbox Kinect Sports / DS: Brain Training / iPad: Google Earth
4	Wii: Hula Hoop, Tight Rope, Skiing / DS: Brain Training / ipad: Google Earth
5	Xbox Kinect Driving / DS: Camera and Arts Academy / iPad: Google Earth, Maps and Chequers
6	Wii: Carnival games / DS: Brain Training / iPad: Google Earth and memory games



Bournemouth University

Dementia Institute (BUDI)

Tech Club!!!

The Tech Club is a six week programme being run by Bournemouth University Dementia Institute specifically for people with dementia or who have memory problems.

The Tech Club is an opportunity to have fun in an informal and social environment whilst exploring the world of technology. No experience is required, just an open mind to have fun.

Six sessions once a week
for two hours
during March and April 2014

We invite you to come along and join in the fun (limited spaces available). If you would like to take part please contact Clare Cutler (Project Manager 01202 961563 / ccutler@bournemouth.ac.uk) who will provide you with further detail.

NEXT STEPS

Completion of field work and QoL interviews. The data will then be thematically analysed and will inform the main body of discussion for this thesis.

Service evaluation funded by Bournemouth Borough Council

www.bournemouth.ac.uk/dementia-institute

Bournemouth University

Dementia Institute (BUDI)

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
BUDI, BOURNEMOUTH UNIVERSITY

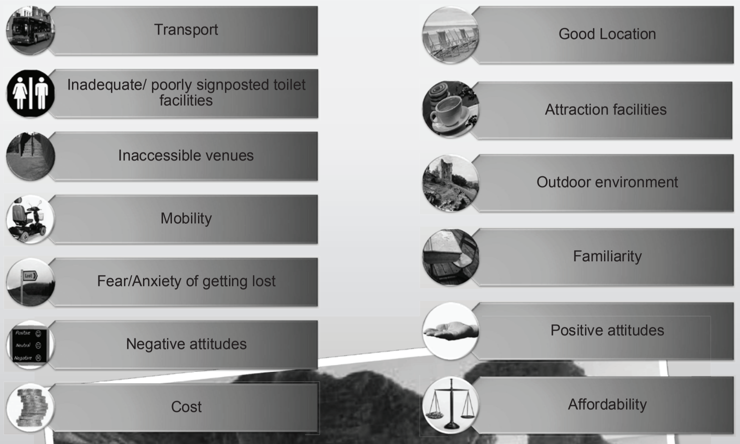
BACKGROUND

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 :

Barriers	Enablers
Transport	Good Location
Inadequate/ poorly signposted toilet facilities	Attraction facilities
Inaccessible venues	Outdoor environment
Mobility	Familiarity
Fear/Anxiety of getting lost	Positive attitudes
Negative attitudes	Affordability
Cost	

PRELIMINARY CONCLUSIONS

- •Leisure and tourism is under used 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

Dementia Institute (BUDI)

Introducing the

BUDI Orchestra

> *I can honestly say that the orchestra has been the **best experience**… since [person with dementia] was diagnosed … quite honestly this was so different… and **it does lift the spirits**.*
>
> Participant.

A Musical Ensemble

- The intervention consisted of 10 weekly music sessions facilitated by members of the Bournemouth Symphony Orchestra (BSO), BU Music scholars, and students .
- The BUDI Orchestra members (people with dementia and their carers) were invited to use instruments and sing in order to create an integrated musical ensemble with the BSO and BU Music students.
- Each session built upon previous weeks; increasing the number of musical pieces and their complexity.
- The BUDI Orchestra were invited to showcase their talents in a performance at the end of the 10 weeks.

> *It's not about kudos… It's about what we can **achieve** with these people. **I'm learning just as much from them** as they are, hopefully, from us.*
>
> BSO Facilitator.

Our Objectives

1. To identify any impact on quality of life for people with dementia as a result of the intervention.
2. To identify any impact on quality of life for carers as a result of the intervention.
3. To evaluate the intervention process for potential future groups via feedback from participants.
4. To refine the intervention process, if necessary, for any future groups based on the evaluative feedback.

Our Evaluation

Our evaluation has consisted of a variety of measures in order to gain a holistic overview of the intervention. We have collected:

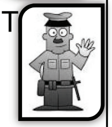
- Weekly observations of each session
- Weekly evaluation sheets completed by facilitators and BUDI Orchestra members
- Quality of life questionnaires completed by people with dementia and their carers pre- and post-intervention.
- Interviews before the intervention to discover musical preferences and experiences so that the intervention could be tailored to the participants
- Interviews after the intervention with facilitators and BUDI orchestra members to find out what they thought worked well, if they had any challenges and if they have any thoughts about how we may improve the sessions.

For more information, please visit: http://www.bournemouth.ac.uk/dementia-institute/

Dementia Institute (BUDI)

DEMENTIA FRIENDLY COMMUNITIES: DORSET

CUTLER, C., HEWARD, M., HAMBIDGE, S. AND INNES, A



BACKGROUND

The number of people aged 65 or over living with dementia in Dorset, England, will increase from 7,796 in 2010 to 11,734 by 2025 (Dorset Health Scrutiny Committee, 2010)(1). This increase in the number of people who will be living with dementia in the next few years has resulted in significant public and political commitment to drive improvement and change for those affected by dementia (Alzheimer Society, 2013)(2). Whilst many initiatives are progressing under the agenda of age friendly communities (WHO 2007)(3), in the UK the Prime Minister launched a specific Dementia Challenge (Department of Health, 2012)(4). The aim of the Dementia Challenge is to improve the lives of people with dementia and their families through three areas of action: driving improvements in health and care, creating dementia friendly communities and improving dementia research (Department of Health, 2012) (4).

METHODS

In response to the Prime Ministers Dementia Challenge and the national Dementia Friendly Community (DFC) initiative (Department of Health, 2012)(4), 10 partners from across Dorset developed the Dorset DFC (DDFC) project. The overall aim of the DDFC project was:

> *'To create dementia friendly communities and local Dementia Action Alliances involving local businesses, charities, independent, voluntary and community services, and independent providers as well as the statutory sector'.*

Work was undertaken in seven localities in the Dorset region (Blandford Forum, Christchurch, Dorchester, Poole, Southbourne, Weymouth and Portland, and Wimborne Minster). This evaluation focuses on the first year of activity of the Dorset DFC project between March 2013 and March 2014. The evaluation used the Alzheimer's Society (2013) framework, which provides ten areas of focus for a DFC. The progress of each locality was measured against this framework.

KEY FINDINGS

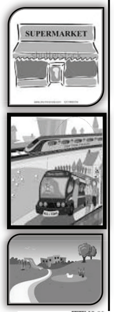
Dementia Friendly Community
10 key focus areas

1. Involvement of people with dementia
2. Challenge stigma and build understanding
3. Accessible community activities
4. Acknowledge potential
5. Ensure an early diagnosis
6. Practical support to enable engagement in community life
7. Community-based solutions
8. Consistent and reliable travel options
9. Easy-to-navigate environments
10. Respectful and responsive businesses and services

- *599 people attended awareness raising sessions in Dorset.*
- *Steering groups have been established.*
- *Communities have committed to local and national Dementia Action Alliance's.*

- *Businesses were positive about the DFC initiatives.*
- *Dementia awareness raising and the number of organisations joining local DAA's or Memory Aware Scheme's increased over time.*

CONCLUSION



- Establishing networks and connections within a community takes time and ultimately is an on-going responsibility of each locality.
- Every community is different. Lessons learnt and examples of good practice from each of the seven localities could be developed and shared with others developing DFC's regionally and nationally.
- The DDFC project achievement has been to create the circumstances to enable progress towards developing these fully in all seven localities in the future.

(1) Dorset Health Scrutiny Committee, Scrutiny Review Panel. 2010. Dementia Services Dorset. Dorset County Council. Improving the quality of life for people in Dorset, now and for the future.
(2) Alzheimer's Society. 2013. 'Building dementia friendly communities: A priority for everyone'.
(3) World Health Organisation. 2007. 'Global age-friendly cities: A Guide'.
(4) Department of Health. 2012. *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015.* London: DH Publications.

www.bournemouth.ac.uk/dementia-institute

Dementia Institute (BUDI)

The School of Applied Sciences (ApSci)

TALES FROM THE SEA

ENGAGING PEOPLE WITH DEMENTIA IN MARITIME ARCHAEOLOGY

CUTLER,C (BUDI) AND PALMA, P (APSC)

BACKGROUND

Maritime archaeology is a vital part of the UK's national heritage that people with dementia are often excluded from accessing. The Tales From the Sea project therefore delivered a series of interactive, educational and stimulating maritime archaeological sessions for people with dementia. The aim of the sessions was to provide an opportunity for access and learning around the history, discovery and recovery of the UK's maritime archaeological heritage. This poster reports on a pilot study that has evaluated the above initiative and discusses how to engage people with dementia with non-conventional topics such as maritime archaeology. This novel intervention is an innovative demonstration of the ways in which people with dementia can be stimulated and engaged in culture and history in a way that is meaningful to their locality. It is hoped that the findings will provide inspiration to others to try 'new' activities that are stimulating.

METHODS

The aim of the project was to evaluate the impact of interactive maritime archaeological sessions (as an activity) with people with dementia living within the community. Sessions were delivered to 87 individuals with dementia in five Dorset community day centres over a consecutive three week period. The sessions were evaluated using qualitative methods which included ethnographic field notes, end of session discussions and evaluation forms.

The sessions replicated archaeological processes which are followed by field archaeologists and included activities such as:

- Reconstructing artefacts (putting excavated artefacts back to their original state)
- Processing of artefacts (collecting and ordering artefacts found from the excavation)
- Conducting a maritime archaeological excavation
- Photographing artefacts in situ
- Interacting with archaeological artefacts (for example pottery and wood)

RESULTS

Analysis of the sessions indicated four recurrent themes:

Access to information

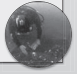
- The sessions enabled people to ask **questions** and learn
- Personal **interests**, hobbies and experiences were prompted by the sessions and were explored and discussed
- Providing **information** directly about the regional locality was of interest as it had relevance to many of the participants which made contributing to discussions easier

Access to learning

- Completion and engagement in the activities provided **a sense of achievement**
- **Progression** of building confidence was achieved throughout the sessions
- **Concentration** was promoted during the sessions. It gave participants time to think about the activity and explore at their own pace

Access to activities

- There was a general **excitement** to take part
- The sessions enabled **reminiscence** and the sharing of stories
- The sessions were suggested to be **intergenerational** as they can be replicated with grandchildren
- There was **an eagerness to take part**
- Sessions provided **stimulation**



Access to support

- A good **atmosphere** was integral to the success of the sessions as a 'fun' element was promoted
- **Support** enabled and encouraged participation without fear of 'doing something wrong'
- **Encouragement** prompted participants to participate and 'have a go'

CONCLUSION

Many participants enjoyed the maritime archaeological sessions and found these interesting. The importance of the sessions was that they allowed the participants to be apart of:

- Social interaction
- Stimulation
- Reminiscence
- Engagement in a 'different activity'
- Learning about an interesting topic

Dementia Friendly Architecture

Reducing spatial-disorientation for people with Alzheimer's disease (AD)

Mary O'Malley
mary.omalley@bournemouth.ac.uk
Supervisors: Jan Wiener, Anthea Innes, Mariela Gaete-Reyes
Bournemouth University Dementia Institute (BUDI), UK Psychology Research Centre, Bournemouth University, UK Wayfinding Research Centre, Bournemouth University, UK

Overall aim: To identify the environmental features that can alleviate disorientation for people with AD.

Objectives:

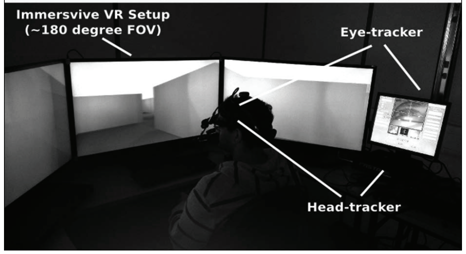
- Understanding how interior design facilitates or impedes orientation in people with AD.
- Developing an in-depth understanding of the specific impairments in landmark based navigation in people with AD.
- Constructing empirically validated dementia design guidelines.

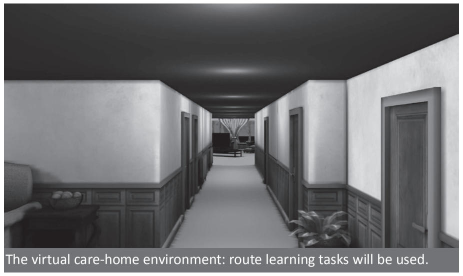
Background:

- One of the **early** effects of **AD** is a marked **difficulty** to orient and 'wayfind' around **unfamiliar**/recently learned environments, which as the disease progresses, starts to affect familiar environments as well (Cushman et al, 2008).
- The areas **first affected** in AD are those associated with navigation; the **hippocampus** (**spatial** memories), the parahippocampal gyrus (landmark encoding) and surrounding regions.
- Very **few** dementia-friendly environment **guidelines** addressing orientation skills exist; these are often based on custom and practice rather than on empirical data.
- It is **unclear** which **navigation strategies** and landmark characteristics (e.g. positioning, uniqueness, saliency, stability) are most important in **alleviating spatial disorientation** for people with AD. **Striatal** function has been said to remain relatively **intact** in **early AD**; this region is implicated in **egocentric,** person-centred navigation.

ViRtUOS

(**Vi**rtual **R**eali**t**y **U**ser **O**rientation **S**ystem)





The virtual care-home environment: route learning tasks will be used.

My Approach:

- Virtual Reality (**VR**) will allow to systematically **manipulate** the **environment** i.e. structural layout and landmarks.
- Manipulating landmark characteristics will highlight **which** features are more **beneficial** for people with AD as well as the navigation strategies that have been adopted.
- Navigation performance will be **measured** by assessing reaction time, error rate and eye gaze performance.
- **Results** will be related to **psychological** and **neuropsychological** research.

Applications:

- Translate findings from the empirical experiments into dementia friendly design guidelines.
- Use the findings from the VR experiments in real care-home settings. Potential improvements could then be mapped onto other spaces e.g. shops and leisure centres.
- Such applications would further well-being and independence for people with AD.

References:

Braak, H., Braak, E. (1991). Neuropathological stageing of Alzheimer-related changes. *Acta Neuropathologica* **82** (4): 239–59

Cushman L. A., Stein, K., Duffy, C. J. (2008) Detecting navigational deficits in cognitive aging and Alzheimer disease using virtual reality. *Neurology* 71:888 –895

Echavarri, C., Aalten, P., Uylings, H. B., Jacobs, H. I., Visser, P. J., Gronenschild, E. H., . . . Burgmans, S. (2011). Atrophy in the parahippocampal gyrus as an early biomarker of Alzheimer's disease. *Brain Struct Funct, 215*(3-4), 265-271. doi: 10.1007/s00429-010-0283-8

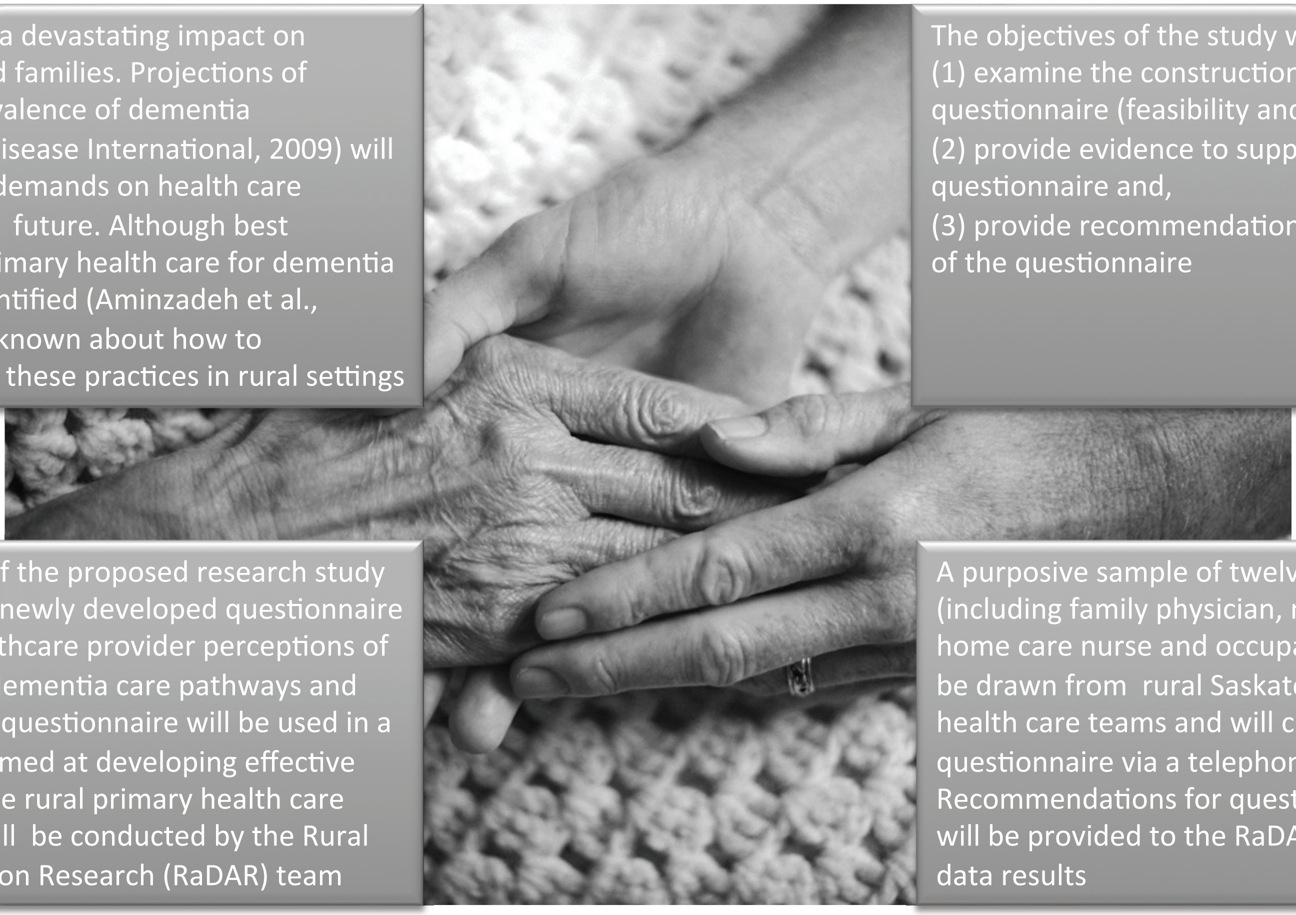
Looi, J. C., Svensson, L., Lindberg, O., Zandbelt, B. B., Ostberg, P., Orndahl, E., Wahlund, L. O. (2009). Putaminal volume in frontotemporal lobar degeneration and Alzheimer disease: differential volumes in dementia subtypes and controls. *AJNR Am J Neuroradiol, 30*(8), 1552-1560. doi: 10.3174/ajnr.A1640

Pengas, G., Patterson, K., Arnold, R. J., Bird, C. M., Burgess, N., Nestor, P. J. (2010) Lost and found: bespoke memory testing for Alzheimer's disease and Semantic Dementia. Journal of Alzheimer's disease. **21**: p. 1347-1365.

Dementia Institute (BUDI)

Evaluating the Construction and Validity of a Questionnaire Assessing Healthcare Provider Perceptions of Rural Dementia Care Pathways

Kathleen Kulyk, BSN; Norma Stewart, PhD, RN; Shelley Peacock, PhD, RN; Debra Morgan, PhD, RN; Megan O’Connell, PhD, RD Psych; Julie Kosteniuk, PhD.



Dementia has a devastating impact on individuals and families. Projections of increased prevalence of dementia (Alzheimer’s Disease International, 2009) will place greater demands on health care systems in the future. Although best practices in primary health care for dementia have been identified (Aminzadeh et al., 2012), little is known about how to operationalize these practices in rural settings

The objectives of the study will be to:
(1) examine the construction of the questionnaire (feasibility and acceptability),
(2) provide evidence to support validity of the questionnaire and,
(3) provide recommendations for the refinement of the questionnaire

The purpose of the proposed research study is to pretest a newly developed questionnaire assessing healthcare provider perceptions of current rural dementia care pathways and practices. The questionnaire will be used in a larger study aimed at developing effective and sustainable rural primary health care models and will be conducted by the Rural Dementia Action Research (RaDAR) team

A purposive sample of twelve participants (including family physician, nurse practitioner, home care nurse and occupational therapist) will be drawn from rural Saskatchewan primary health care teams and will complete the questionnaire via a telephone-based interview. Recommendations for questionnaire refinement will be provided to the RaDAR team based on data results

Alzheimer’s Disease International. (2009). *World Alzheimer Report.* http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf

Aminzadeh, F., Molnar, F., Dalziel, W.B., Mounde, C., & Ayotte, D. (2012). A scoping interpretive review of literature on perspectives and practices of primary care physicians vis-à-vis diagnosis and management of community living older persons with dementia. *Canadian Geriatrics Journal, 15*(3), 1-13 . doi: 10.5770/cgj.15.42

(RaDAR) team: http://www.cchsa-ccssma.usask.ca/ruraldementiacare/

Team 20 of the Canadian Consortium on Neurodegeneration in Aging (CCNA): Rural Dementia Action Research (*RaDAR*)

[1]D. Morgan , [1]J. Kosteniuk, [1]M. Crossley, [1]M.E. O'Connell, [1]A. Kirk, [1]N. Stewart, [2]V. Dal Bello-Haas, [3]D. Forbes, [4]A. Innes, [5]L. McBain, [1]H. Mou, [6]E. Parrott

[1]University of Saskatchewan, [2] McMaster University, [3]University of Alberta, [4]Bournemouth University, [5]First Nations University of Canada, , [6]Family caregiver

Background

Rural and remote individuals with mild cognitive impairment (MCI) and dementia are a highly vulnerable population that faces challenges accessing necessary services. Saskatchewan's geography and sparse population contribute to the challenges in rural health service delivery.

The ***Rural and Remote Memory Clinic (RRMC)**** is located in the city of Saskatoon, Saskatchewan and serves rural and remote individuals living independently in communities that are more than 100 km from Saskatoon or Regina (the two census metropolitan areas in the province of Saskatchewan):

- Patients and families are referred to the family-centred interprofessional *RRMC* by their primary care health provider
- Patients, accompanied by a caregiver, receive a preclinic telehealth-facilitated assessment by a neuropsychologist and nurse
- Four to six weeks later, patients and caregiver(s) attend a 1-day in-person clinic evaluation that involves the full clinical team of a neurologist, physical therapist, dietitian, and neuropsychology team.
- At the end of the 1-day evaluation, patients and caregivers receive information regarding the probable diagnosis, recommendations for management, and service referrals as appropriate.

*Rural Dementia Care website:
http://www.cchsa-ccssma.usask.ca/ruraldementiacare/

The **RaDAR (Rural Dementia Action Research) Team***

- An interdisciplinary group of researchers from three Canadian provinces and the UK. Since 2011, the team has been developing a community-based participatory research program aimed **at improving primary health care (PHC) for people with dementia in rural and remote settings** in response to a call for *Community-Based Primary Health Care Team Grants* by CIHR (Canadian Institutes of Health Research).

*Rural Dementia Action Research website:
http://www.cchsa-ccssma.usask.ca/ruraldementiacare/radar.html

INFORMATION

Dr. Debra Morgan. Canadian Centre for Health & Safety in Agriculture, University of Saskatchewan:
debra.morgan@usask.ca or 306-966-7905

ACKNOWLEDGEMENTS

CCNA Team 20

October 2012
CBPHC Team Grant submitted to CIHR

April 2013
Notification of CIHR review: CBPHC Team grant not funded

May 2013
Invitation to participate in the Canadian Consortium on Neurodegeneration in Aging (CCNA)

June 2013
RaDAR Team and members of the International Indigenous Dementia Research Network form CCNA Team 20

April 2014
CIHR establishes CCNA

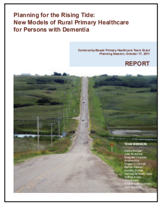
Initial stages – submitting a CBPHC Team Grant

October, 2011 Planning Session* to develop a CBPHC Team Research Program

- The purpose of this planning session was to bring together researchers (15) and Decision Makers (53) **to identify important issues in primary healthcare (PHC) and innovative service delivery models** for people with dementia and their caregivers living in rural/remote areas.

Recommendations from October, 2011 Planning Session

1. Develop dementia care coordinators to provide case management and system navigation
2. Offer education & training to PHC providers
3. Establish guidelines to improve early detection & diagnosis
4. Introduce standardized care pathways for PHC providers
5. Support a provincial and national strategy for dementia, that recognizes dementia as a chronic disease



Planning for the Rising Tide:
New Models of Rural Primary Healthcare for Persons with Dementia

Community-Based Primary Healthcare Team Grant
Planning Session, October 17, 2011

REPORT

TEAM MEMBERS

Debra Morgan
Julie Kosteniuk
Margaret Crossley
Andrew Kirk
Megan O'Connell
Norma Stewart
Dorothy Forbes
Vanina Dal Bello-Haas
Anthea Innes
John Keady
Sridhar Vaitheswaran
Alan Murdoch

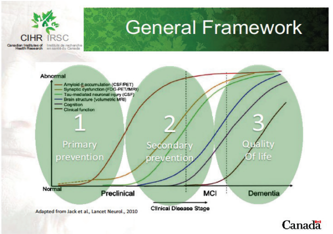
***Full Report of Planning Session (109 pages) available online**
http://www.cchsa-ccssma.usask.ca/ruraldementiacare/radar.html

Invitation to Join CCNA

CCNA – Bringing Together Canadian Expertise

Consortium of expert cores

"The vision of the CCNA is to bring together the best of Canadian research in the field of neurodegernative diseases affecting cognition in a collaborative and synergistic space to work on bold, innovative and transformative research that will ultimately impact the quality of life and quality of services for those having to live with dementia and their carers" (CIHR, 2014)



The Canadian Consortium of Neurodegeneration in Aging brings together 340 researchers across 20 research teams, organized into three Themes (prevention, treatment, care).

CCNA Team 20

CCNA Team 20
July 29, 2013
(University of Saskatchewan)

Team 20 Leads:

- **Rural:** Debra Morgan (University of Saskatchewan)
- **Indigenous:** Kristen Jacklin (Northern Ontario School of Medicine), Carrie Bourassa (First Nations University of Canada)

Team 20 Rural Research Projects:

Working *initially* with 1 health region in Saskatchewan:

1. **Rural PHC Dementia Care Model Development** - longitudinal mix-method multiple case study to identify gaps in dementia care pathways, assist PHC teams to adapt PHC dementia care practices to rural settings (using PDSA cycles), and evaluate the adapted interventions and facilitators/barriers of successful adaptation
2. **Standardized Care Pathways and Tools (RaDAR Toolkit)** - identify and adapt evidence-based clinical support tools to rural PHC settings; evaluate the efficacy of the adapted tools for improving the quality of care provided to individuals with dementia
3. **Capacity-building/Mentoring of PHC Providers** - deliver tailored e-learning models and case-based specialist-to-PHC support using web-based tools for specialist consultation and peer learning, evaluate the effectiveness and acceptability of e-learning models, and determine the impact of specialist-to-PHC support on diagnosis and specialist referral.

RaDAR and SK Health Quality Council will provide the first-ever provincial-level evidence-based analysis (Team 20 baseline data): 1) a synthesis of best practices from international dementia strategies; 2) an environmental scan/inventory of available dementia services and their PHC attributes, by SK health region; and 3) a linked analysis of 10 SK databases (2001-2013) to estimate the prevalence and incidence of dementia among adults 45 years of age and older.

Phosphorylation of the insulin receptor substrate-1 regulates monoamine oxidase-A in primary and immortalized neuronal, but not glial, cultures

Zelan Wei[1], Jennifer N.K. Nyarko[1], Paul R. Pennington[1], Paul Fernyhough[2], Glen B. Baker[3], and Darrell D. Mousseau[1]

1: Cell Signalling Laboratory, Psychiatry, University of Saskatchewan; 2: Division of Neurodegenerative Disorders, St. Boniface Research Centre, University of Manitoba; 3: Neurochemical Research Unit, Psychiatry, University of Alberta

Summary

Introduction: The mechanism underlying the significant comorbidity between diabetes and depression remains unexplained.

Methods: We used tissues from db/db mice, a preclinical model of Type II diabetes, and primary and immortalized neuronal and glial cultures to determine the effect of insulin (INS) receptor signalling on the function of the depression-related enzyme, monoamine oxidase-A (MAO-A).

Results: In db/db mouse, circulating levels of INS are increased, whereas cortical levels of INS are similar to levels in the 'lean' control mice. In db/db mouse cortex, serotonin turnover is decreased and dopamine turnover remains unchanged. An increase in MAO-A activity and protein expression in these same tissues parallels an increase in immunodetection of the INS receptor as well as the phosphorylation of its major effector protein, the INS receptor substrate-1 (IRS-1). Treatment of primary neuronal cultures (C57BL/6 mouse brain) and mouse HT-22 neuronal cells with INS alters MAO-A activity and protein expression. This is positively correlated with the expression of the INS receptor and IRS-1 phosphorylation. In contrast, INS-induced changes in MAO-A activity and protein expression are independent of IRS-1 phosphorylationin in primary astrocytes and in C6 glioblastoma cells. These observations are corroborated by overexpression of IRS-1 variants containing targeted Serine-to-Alanine substitutions in HT-22 and in C6 cell lines.

Conclusion: INS influences cell type-dependent IRS-1 signalling that contributes to regulation of MAO-A function. Given the potential negative health consequences associated with comorbid diabetes and depression, knowledge of this molecular mechanism could benefit patients being treated for either pathology.

Results

1. MAO-A expression/activity was increased in the cerebral cortex of diabetic mice

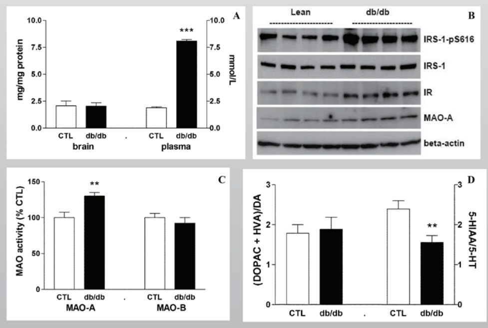


Fig 1. (**A**) The level of insulin (INS) in the cortex of 'lean' controls (CTL) is similar to that in diabetic (db/db) mice, but is significantly higher in db/db mouse plasma (*note*, plasma values are 0.2x for ease of interpretation). (**B**) the expression of the INS receptor (IR) and its major signalling molecule INS receptor substrate-1 (IRS-1) are increased in db/db mouse cortex. (**C**) MAO-A activity is increased in the db/db mouse cortex, but MAO-B activity is not. (**D**) Paradoxically, serotonin (5-HT) turnover is decreased in these same tissues Note that dopamine (DA) turnover is unchanged.. ** p<0.01 *** p<0.001 compared to lean control mice (n = 8 ~ 12, mean ± SEM).

2. IR regulates neuronal MAO-A activity and implicates IRS-1

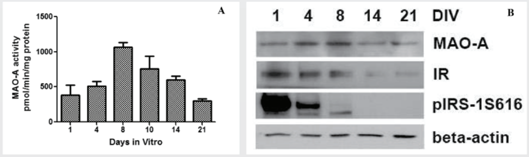


Fig 2. (A) MAO-A activity in primary neuronal cultures peaked at day *in vitro* (DIV) 8. (B) The expression MAO-A protein also peaked on DIV 8 and paralleled the expression of the insulin receptor (IR) and pIRS-1Ser616..

3. Astrocyte MAO-A activity also responds to insulin

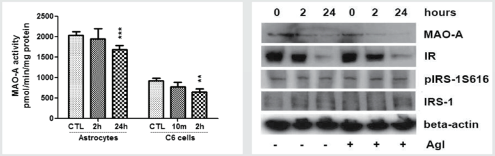


Fig 3. (left) Insulin treatment decreases MAO-A activity in primary astrocyte and in C6 cell cultures; ** p<0.01, *** p<0.001 compared to corresponding control cultures. (n = 3, mean ± SEM). (right) The loss of MAO-A activity in astrocytes is reflected by a loss of MAO-A protein and a concurrent loss of IR expression, while the levels of pIRS-1S616 and IRS-1 remained unchanged. The insulin receptor antagonist AgI does not alter the outcome.

4. The effect of IRS-1 on MAO-A is cell line-dependent.

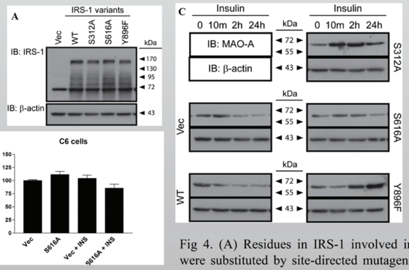


Fig 4. (A) Residues in IRS-1 involved in signalling were substituted by site-directed mutagenesis. (B, C) These non-phosphorylatable variants of IRES-1 affect C6 cell MAO-A expression and activity (only the S616A was tested) in response to insulin treatment.

4⊠. Insulin affects MAO -A expression/activity *via* IR signaling

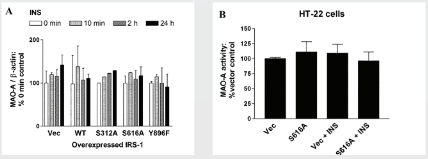


Fig 4⊠ (A) Densitometry demonstrates that the overexpression of the IRS-1 variants (S312A, S616A and Y896F) do not significantly affect MAO-A expression or activity in the immortalized HT-22 neuronal cell line.

5. Is the effect of insulin on MAO-A function due to an aberrant translocation of the MAO-A protein to the nucleus?

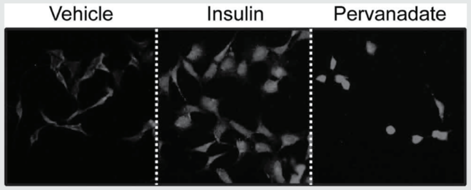


Fig 5. Immunohistochemistry reveals that the MAO-A protein translocates to the nuclear compartment by 30 minutes of insulin treatment. A similar event is observed in cells treated with the insulomimetic pervandate.

Conclusions

The insulin receptor system and its major signalling molecule IRS-1 affect MAO-A function in a cell line-dependent manner. Some of this might reflect changes in MAO-A protein expression, whereas some of the effect might reflect a novel translocation of the MAO-A protein to the nuclear compartment.

These cell line-dependent events could certainly contribute to the neurochemical changes associated with a depressive phenotype in the human context.

Financial supports:

DDM is a Saskatchewan Research Chair in Alzheimer's disease and related dementias that is co-funded by the Alzheimer Society of Saskatchewan and the Saskatchewan Health Research Foundation.

The project is also supported, in part, by College of Medicine funding and, in part, by funds from the Natural Sciences and Engineering Research Council of Canada

From Research to Practice: Collaboration with the Alzheimer Society of Saskatchewan for a Telehealth Delivered Frontotemporal Dementia Caregiver Support Group

Megan E. O'Connell,[1] Rachel Burton[1] & Joanne Michael[2]

[1] Department of Psychology, University of Saskatchewan, [2]Program Services Manager, Alzheimer Society of Saskatchewan

Presented at the 43rd Annual Scientific and Educational Meeting of the Canadian Association on Gerontology, Niagara Falls, ON

Alzheimer disease is the most common form of dementia

- First impacts the part of the brain responsible for forming new memories, but personality remains the same – at least early on

Frontotemporal dementias

- Impacts circuits of the brain responsible for personality and language

4 variants (first 3 most commonly recognized)

1. Behavioural or frontal variant – personality changes
2. Semantic dementia – loss of understanding of language
3. Non-fluent variant – loss of ability to communicate language
4. Logopenic variant – errors in speaking/repeating

High need for caregiver interventions specific to atypical non-Alzheimer dementias such as frontotemporal dementia (FTD) or other early-onset dementias

- Spousal caregivers of persons diagnosed with atypical dementias (e.g., FTD) experience more psychological distress than spouses of persons diagnosed with Alzheimer disease[1]
- Few specific interventions have been developed to address their needs[2]

Rationale for Specialized Group Intervention

- Spousal carers of individuals diagnosed with atypical dementias can obtain both practical information and support from others who are experiencing similar troubling behaviours in their spouse[2]

Problem – Large Geographic Distances

- In rural and remote regions it is difficult to find many carers of individuals diagnosed with these rare dementias (prevalence estimates of 15 per 100,000[3] age of onset 50-60 years most common, but but range 21 to 85 years old[1]) **– cannot connect in-person**

Solution

- Innovative use **of telehealth videoconferencing** to connect 10 caregivers from 6 regions of the province
- Once monthly group 1½ hr meeting for spouses
- Emotion processing focus of group rather than psycho-education

Evaluation of Effectiveness

Research at the Rural and Remote Memory Clinic, University of Saskatchewan suggests that the telehealth videoconferenced support group was helpful for spousal caregivers of persons diagnosed with FTD

O'Connell, M. E., Crossley, M., Cammer, A., Morgan, D., Allingham, W., Cheavins, B., Dalziel, D., Lemire, M., Mitchell, S., & Morgan, E. (2014). ***Dementia: The International Journal of Social Research and Practice, 13(3),* 382-95.** **DOI:** 10.1177/1471301212474143.

Sustainability of Research Initiative *Dependent* on Community-Based Partnership Building

- Alzheimer Society of SK were asked by caregiver advocates to fill this need
- Alzheimer Society agreed only if researchers co-facilitated to build capacity for FTD specific knowledge
- ***First Link*** to find caregivers from across the province

Unique collaboration – clinical researchers co-facilitating with Alzheimer Society of SK staff to increase capacity for telehealth delivery of a specialized intervention for spouses of persons diagnosed with FTD

- collaboration for 1st new group began February 2012
- discovered complementary skills that enhance the support group intervention
- additional capacity building and a 2nd group began January 2013

Researcher co-facilitation disseminated to community-based staff learning about FTD and its unique challenges for spouses; although initially deferring to the researchers, community-based facilitators are now able to respond to FTD specific questions and validate specific behaviors as typical in this type of dementia.

Co-facilitation of researchers and community-based staff led to dissemination of how to deliver a support group virtually via telehealth versus in-person; learning included awkwardness of maintaining equal eye contact for group members attending in person and those who attend by videoconferencing.

- We acknowledge our caregiver partners without whom we would not have been able to do this work
- We would like to acknowledge our wonderful support from Telehealth Saskatchewan

REFERENCES

[1]de Vugt, M., Riedijk, S. R., Aalten, P., Tibben, A., van Swieten, J. C., & Verhey, F. R. J. (2006). Impact of behavioural problems on spousal caregivers: A comparison between Alzheimer's disease and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders, 22,* 35-41.

[2]Diehl, J., Mayer, T., Forstl, H., & Kurz, A. (2003). A support group for caregivers of patients with frontotemporal dementia. *Dementia, 2,* 151-61.

[3]van Swieten, J. C. & Rosso, S. M. (2006). Review: Epidemiology of frontotemporal dementia. *Advances in Clinical Neuroscience and Rehabilitation, 6(1),* 9-10.

Contact

Nutrition Care Needs of Alzheimer Disease versus non-Alzheimer Disease Dementia Patients

[1]A. Cammer, [2]M.E. O'Connell, [3]D. Morgan, [1]S. Whiting

University of Saskatchewan

[1]College of Pharmacy and Nutrition, University of Saskatchewan, [2]Department of Psychology, College of Arts and Science, University of Saskatchewan, [3]Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

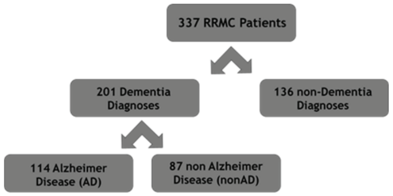
Background

- Persons with dementia are at higher risk for malnutrition due to physiological and behaviour changes. Malnutrition can accelerate cognitive decline, increase risk of negative health outcomes (unwanted weight loss or gain, muscle wasting, infection, poor wound healing), and negatively impact quality of life.
- Ability to eat and drink is critical to maintaining nutritional health and personal independence of persons with dementia, and is strongly related to quality of life.
- Little is known about differences in ability for Alzheimer Disease (AD) dementia and non-Alzheimer Disease (non-AD) dementia (e.g., Vascular, Fronto-temporal, Subcortical, LewyBody).
- An interdisciplinary Rural and Remote Memory Clinic (RRMC) in Saskatchewan was established in 2004 to diagnose and treat early-stage and complex cases of dementia.

Research Question

Is type of dementia associated with differential eating and drinking functional ability in early-stage diagnosed cases of Alzheimer and non-Alzheimer dementia?

Study Sample and Methods



337 RRMC Patients

201 Dementia Diagnoses

136 non-Dementia Diagnoses

114 Alzheimer Disease (AD)

87 non Alzheimer Disease (nonAD)

- Data were collected from 337 RRMC patients and their care partners.
- 201 patients were diagnosed with dementia; 114 AD and 87 non-AD.
- Cases were grouped according to dementia diagnosis: Alzheimer Disease dementia (AD) versus non-Alzheimer dementia (non-AD).

- The validated, dementia-specific Bristol Activities of Daily Living (B-ADL) 20 item scale was used to measure functional ability. At assessment, care partners rated patients' average ability over the past two weeks to prepare food, eat, prepare drinks, and drink.
- B-ADL ratings were dichotomized to 'never did when well and no change in functional ability' versus 'impairment in functional ability'.
- Multiple logistic regression analysis was used to contrast ability to prepare food, eat, and ability to prepare drinks for AD and non-AD after adjusting for severity of dementia (Clinical Dementia Rating Scale), age, and sex.

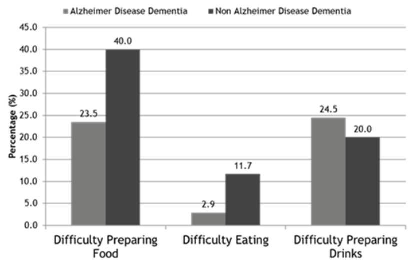
Results

Characteristics of the Study Sample

	Frequency (%) or Mean (SD)
Mean Age, years	74.7 (8.9)
Mean Severity	6.8 (3.5)
Sex:	
Male	77 (38.3)
Female	124 (61.7)
Dementia Type:	
AD	114 (56.7)
NonAD	87 (43.3)

Functional Ability:	Frequency (%)
Difficulty Preparing Food	
No/not applicable	123 (61.2)
Yes	54 (26.9)
Missing	24 (11.9)
Difficulty Eating	
No/not applicable	167 (83.1)
Yes	12 (6.0)
Missing	22 (10.9)
Difficulty Preparing Drinks	
No/not applicable	137 (68.2)
Yes	40 (19.9)
Missing	24 (11.9)
Difficulty Drinking	
No/not applicable	177 (88.1)
Yes	2 (1.0)
Missing	22 (10.9)

Percentage of Persons with Difficulty in Functional Ability



Associations with Difficulty Preparing Food

	Crude Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Dementia Type:		
AD	1.00	1.00
NonAD	2.17 (1.13 - 4.15)	2.35 (1.11 - 4.98)
Sex:		
Male	1.00	1.00
Female	1.26 (0.65 - 2.45)	1.46 (0.67 - 3.19)
Age	1.02 (0.98 - 1.06)	1.02 (0.98 - 1.06)
Severity	1.33 (1.18 - 1.50)	1.34 (1.18 - 1.52)

Associations with Difficulty Eating

	Crude Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Dementia Type:		
AD	1.00	1.00
NonAD	4.37 (1.14 - 16.72)	5.11 (1.11 - 23.49)
Sex:		
Male	1.0	1.0
Female	0.30 (0.09 - 1.02)	0.20 (0.05 - 0.89)
Age	1.04 (0.97 - 1.12)	1.08 (0.99 - 1.19)
Severity	1.27 (1.08 - 1.50)	1.27 (1.05 - 1.54)

Associations with Difficulty Preparing Drinks

	Crude Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Dementia Type:		
AD	1.00	1.00
NonAD	0.77 (0.37 - 1.59)	0.76 (0.31 - 1.83)
Sex:		
Male	1.0	1.0
Female	0.49 (0.24 - 1.00)	0.55 (0.23 - 1.31)
Age	1.05 (1.00 - 1.10)	1.04 (0.98 - 1.09)
Severity	1.55 (1.32 - 1.83)	1.56 (1.31 - 1.84)

Key Findings

- Nutrition related functional ability differs based on type of dementia.
- Persons with non-AD dementia are more likely to experience functional impairment preparing food and eating in early stages of disease compared to those with AD.

Implications

- Monitoring ability to prepare food and eat may be required sooner in the disease trajectory for non-AD dementia.
- Those with non-AD dementia may benefit from increased nutrition support and intervention at an earlier stage of the disease trajectory; clinical support should be tailored to type of dementia.
- Future research is needed on the longitudinal effect of AD and non-AD on functional ability to eat and drink, and the impact of difference on care need and care burden over time.

Acknowledgements

Alzheimer Society CANADA

PHARE Public Health and the Agricultural Rural Ecosystem

wrtc Health Services Research

An Evaluation of a Reminiscence Intervention via Telehealth Videoconferencing for Caregivers of Persons with Dementia

Joe Enright & Megan E. O'Connell - *Department of Psychology, University of Saskatchewan*

BACKGROUND

- Informal caregivers of persons with dementia often experience significant difficulties or "*caregiver burden*", which has been linked to the quality of the caregiver and care-recipient relationship[1]. The negative effects of caring on physical and mental health have a considerable and growing impact on the economy and society[1].
- Reminiscence Therapy (RT) is the facilitated recall of shared positive memories, and may improve the quality of the relationship and mitigate caregiver difficulties[2,3].
- In rural and remote communities there is a high proportion of older-adults and limited access to health services[4]. This makes efficient delivery of dementia-care related services a challenge.
- Videoconferencing over the Telehealth Saskatchewan network offers a secure medium for the delivery of service to rural and remote areas, aimed at improving access to services hindered by geography[5]. Though promising, the potential of this medium for the delivery of psychosocial interventions for caregivers is relatively untested[6].

METHOD

Objectives:

- The first objective is to investigate the benefits of a RT activity for informal caregivers of persons with dementia
- A second objective is to assess the efficacy of the RT intervention delivered via videoconferencing.

Method:

- Sixty-four informal caregivers will be recruited from the University of Saskatchewan Rural and Remote Memory Clinic and randomly assigned to 1 of four conditions: in-person RT / in-person control, Telehealth RT / Telehealth control.
- The RT intervention will be based on an empirically supported autobiographical memory activity[7].
- Relationship quality, caregiver burden, and other outcome measures will be administered at pre, post, and follow-up.

HYPOTHESES & RELEVANCE

Hypotheses:

- It is expected that caregivers in the RT groups will demonstrate an increase in perceived quality of their relationship with the care-recipient and a decrease in perceived burden of caring
- It is also anticipated that there will not be a significant difference in outcomes between the in-person versus Telehealth delivery conditions.

Project Relevance:

- This project will provide evidence of RT efficacy for improving caregiver/care-recipient relationships and reducing the perceived burden and strain of caring for persons with dementia. Further, it will inform the use of videoconferencing technology in the development of accessible services for those with limited access, especially in rural and remote areas.

References

1.Alzheimer Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society.* Toronto: Author **2.** Woods, B., et al. (2005). Reminiscence therapy for people with dementia (review).*Cochrane Database Systematic Review, 2005*, (2); 3. Woods, R.T., et al. (2009)**.** Reminiscence groups for people with dementia and their family carers: pragmatic eight-centre randomised trial of joint reminiscence and maintenance versus usual treatment: a protocol**.** *Trials 2009*, (10),64 **4.** Morgan**,** D.,et al. (2002). Rural families caring for a relative with dementia:Barriers to use of formal services. *Social Science & Medicine, 55*(7), 51-64 **5**. Morgan, D. G., Crossley, M., Kirk, A., McBain, L., Stewart, N. J., D'Arcy, C., ... & Basran, J. (2011). Evaluation of telehealth for preclinic assessment and follow-up in an interprofessional rural and remote memory clinic. *Journal of Applied Gerontology*, *30*(3), 304-331. **6.** O'Connell, M. E., Crossley, M., Cammer, A., Morgan, D., Allingham, W., Cheavins, B., Dalziel, D., Lemire, M., Mitchell, S., & Morgan, E. (in press). Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early- onset dementias. *Dementia: TheInternational Journal of Social Research and Practice*. **7.** Alea, N., & Bluck, S. (2007). I'll keep you in mind: The intimacy function of autobiographical memory. Applied Cognitive Psychology, 21(8), 1091-1111.

Acknowledgements

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Analysis of dementia prevalence, incidence, and care gaps in Saskatchewan: A mixed methods study

J. Kosteniuk[1] D. Morgan[1], J. Quail[2], G. Teare[2], K. Kulyk[1], M. O'Connell[1], A. Kirk[1], M. Crossley[1], N. Stewart[1], V. Dal Bello-Haas[3], L. McBain[4], H. Mou[1], D. Forbes[5], A. Innes[6], J. Bracken[7], E. Parrot[8]

[1]University of Saskatchewan [2]SK Health Quality Council [3]McMaster University [4]First Nations University of Canada [5]University of Alberta [6]Bournemouth University [7]Alzheimer Society of Saskatchewan [8]Family caregiver

Background

Worldwide, it is estimated that there is one new (incident) case of dementia every 4 seconds, or 7.7 million incident cases each year (WHO and ADI 2012). The most recent estimates show that 44 million people now live with dementia (prevalence), projected to increase to 135 million by 2050 (Prince et al. 2013a).

To date, little research has been carried out to examine the scope of dementia and dementia care across the province of Saskatchewan. Epidemiological data that is as current as possible, and that combines both community-based and long-term data, can inform policy decisions that affect individuals with dementia and their families living in every corner of the province.

Study objectives

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

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

Study setting

- The provincial health system has a regional model of governance (see map below), with each of the 13 health regions responsible for providing basic health services to their population.

The Province of Saskatchewan (Canada) covers 651,000 km² and has a population of over 1.08 million (SK Bureau of Statistics, 2014)

Province of Saskatchewan

Best Practice Review

Research Questions

- What are the current international best practices in dementia care in national plans?
- What best practice themes are represented across all national plans?

Search strategy

A total of twelve national plans were identified from the Alzheimer Disease International website.

Inclusion criteria

A national plan was considered for if it met all of the following criteria:

- A national dementia plan listed on the "Government Alzheimer Plans" page on the Alzheimer's Disease International webpage: http://www.alz.co.uk/alzheimer-plans
- Not a *sub-national* Alzheimer plan nor a *non-governmental* dementia strategy
- Available in English
- Published after January 1 2000
- Publically available online

Data charting and extraction

One reviewer extracted the data from each national plan (KK). Common themes in best practices were identified across the plans.

KEY FINDINGS

Nine national dementia plans were included in the review: Australia, England, Finland, France, Norway, Scotland, Northern Ireland, United States, and Wales.

Six best practice themes were identified:

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

**** Supported by all 9 countries
*** Supported by 8 countries
** Supported by 6 countries
* Supported by 5 countries

Administrative Data Analysis

Study objectives

- To determine the 12-month incidence and prevalence of dementia among individuals aged 45 and older* in the province of Saskatchewan by database of identification, demographic characteristics (age group, sex, and **rural/urban**** residence), and health region.

* Age cut-off of 45 years was used to identify the incidence and prevalence of 'early onset dementia' (i.e., dementia in individuals younger than age 65 years).
** Based on postal code, residents of census metropolitan areas (100,000 or over, with a core population of 50,000 or over) and census agglomerations (core population of 10,000 or over) were considered urban, and were otherwise considered rural.

Data sources

- 10 provincial-level databases linked by a unique personal health services number assigned to individuals eligible for health insurance benefits. The databases were accessed, linked, and analysed by researchers at the SK Health Quality Council.

Case definition

- The **cohort** included individuals aged 45 years and older at their first-ever recorded identification of dementia* (i.e., index date) between April 1, 2001 and March 31, 2013 in one of 4 administrative health databases (Hospital Discharge Abstracts, Physician Service Claims, Prescription Drug, and RAI-MDS, i.e., Long-term Care). Incidence and prevalence for the 2012-2013 period *only* were calculated for the present analysis.
- **Case definition algorithm**: ≥ 1 physician visits or ≥ 1 hospitalizations or ≥ 1 prescriptions for a cholinesterase inhibitor or [a RAI-MDS CPS score of ≥ 2 and/or (a disease category of Alzheimer's disease or dementia other than Alzheimer's disease)]

Hospital Discharge Abstracts (ICD-10-CA codes: F00, F01, F02, F03, F04, F05.1, F06.8, F06.9, F09, F10.6, F10.7, F18.6, F18.7, F19.6, F19.7, G30, G31.0, G31.1, G91, R54); ***Physician Services Claims*** (ICD-9-CM codes: 290, 294, 331, 797); ***Prescription Drug*** (Aricept DINs: 02232043, 02232044; Exelon DINs: 02242115-02242118, 02245240; Reminyl DINs: 02244298-02244300, 02266717, 02266725, 02266733)***; Long-term Care, i.e., RAI-MDS*** (Cognitive Performance Scale (CPS) score of 2 and over, indicating mild to very severe impairment) [Morris et al. 1994] and/or a disease category of Alzheimer's disease *or* dementia other than Alzheimer's disease).

KEY FINDINGS

Incidence (2012/2013)

- **3,270 incident (new) cases of dementia** were identified among adults 45 years and older in Saskatchewan during the 2012/13 12-month period **[7.28 per 1,000 population at risk (PAR)]**
- 1,887 incident cases among females (8.25 per 1,000 PAR) vs. 1,383 among males (6.28 per 1,000 PAR) [$p<0.05$]
- Adults aged 45 to 64 contributed 8% of incident cases, aged 65 to 84 contributed 41%, and aged 85 and older accounted for 51%
- Unadjusted incidence rate increased 152 times between the group aged 45 to 54 and those aged 85 years and older (0.46 vs. 69.73 per 1,000 PAR)
- The greatest proportion was first identified in LTC (34.98%, 1,144/3,270), followed by a diagnosis in physician services claims (29.94%), in hospital (28.53%), and by a cholinesterase inhibitor prescription (6.54%)
- Of incident cases that were *first identified in long-term care*, 79.72% (912/1,144) were identified at the point of admission [therefore 27.89% of *all* incident cases (912/1,144) were first identified with dementia at the point of admission to LTC]
- Among aged 85 years and older, the unadjusted incidence rate was 14% higher among rural than urban [$p<0.05$]
- Incidence (and population at risk) was highest in Saskatoon Health Region (880 new cases) and lowest in the Northern Health Regions (32 new cases)
- The age- and sex-adjusted incidence rates were highest in Sun Country Health Region (8.77 per 1,000 PAR) and Heartland Health Region (8.63 per 1,000 PAR) vs. the adjusted rate for all health regions combined (7.51 per 1,000 PAR) [$p<0.05$]
- The age- and sex-adjusted incidence rates were lowest in Prince Albert Parkland (6.59 per 1,000 PAR) and the Northern Health Regions (6.66 per 1,000 PAR) vs. the adjusted rate for all health regions combined (7.51 per 1,000 PAR) [$p<0.05$]

Prevalence (2012/2013)

- **13,012 prevalent (existing) cases** were identified among adults 45 years and older in Saskatchewan during the 2012/13 12-month period [**rate of 28.16 per 1,000 population at risk (PAR**)]
- 8,099 prevalent cases among females (34.19 per 1,000 PAR) vs. 4,913 among males (21,92 per 1,000 PAR) [$p<0.05$]
- Adults aged 45 to 64 accounted for 8% of prevalent cases, aged 65 to 84 accounted for 39%, and those 85 years and older contributed 53%
- Unadjusted prevalence rate was 160 times higher among adults aged 85 and older than among those 45 to 54 years of age (221.30 vs. 1.38 per 1,000 PAR)
- The greatest proportion was first identified by a diagnosis in physician services claims (40.16%), followed by a diagnosis in LTC (24.72%, 3,217/13,012), in hospital (23.84%), and by a cholinesterase inhibitor prescription (11.28%)
- Of prevalent cases *that were first identified in long-term care*, 68.89% (2,216/3,217) were identified at the point of admission to LTC [therefore, 17.03% of *all* prevalent cases (2,216/13,012) were first identified with dementia at the point of admission to long-term care]
- Among those younger than 85, the unadjusted prevalence rates were higher among urban than rural residents [$p<0.05$]; among those aged 85 years and older, the unadjusted prevalence rate was higher among rural than urban [$p<0.05$]. Among all age groups combined, the unadjusted prevalence rate was 6% higher among urban than rural [$p<0.05$]
- Prevalence (and population at risk) was highest in Saskatoon Health Region (3,286 cases) and Regina Qu'Appelle Health Region (3,041 cases). Prevalence (and population at risk) was lowest in the Northern Health Regions (126 cases)
- The age- and sex-adjusted prevalence rate was highest in Prince Albert Parkland Health Region (31.91 per 1,000 PAR) and Sun Country Health Region (30.55 per 1,000 PAR) [*not* significantly higher ($p<0.05$) than all health regions combined (28.16 per 1,000 PAR)]. Two additional health regions had adjusted prevalence rates that were significantly higher ($p<0.05$) than all health regions combined: Sunrise at 29.40 and Regina Qu'Appelle at 28.75 per 1,000 PAR.
- The age- and sex-adjusted prevalence rate was lowest in the Northern Health Regions (25.87 per 1,000 PAR) [*not* significantly lower ($p<0.05$) than all health regions combined (28.16 per 1,000 PAR)]. The adjusted prevalence rate in the Saskatoon Health Region (26.45 per 1,000 PAR) was significantly lower than the adjusted rate for all health regions combined [$p<0.05$].

Environmental Scan

Study objectives

To determine, within each of the 13 health regions of Saskatchewan and for the province as a whole:

- the availability of dementia-related services and resources across the continuum of care, and
- the orientation of dementia-related services toward key dimensions of primary health care

Sample and data collection

- Data collection between June and December, 2013
- Study population consisted of all Home Care Assessors (Client Care Coordinators, Case Managers, or Team Managers) serving Sask.
- **Assessors serving the cities of Saskatoon or Regina were considered 'urban' and Assessors serving outside of Saskatoon and Regina were considered 'rural'**

Environmental Scan instrument

- **Availability of dementia-related services:** Respondents indicated the availability of 43 services in the majority of communities for which they were primarily responsible ('everyday', 'a few times a week', 'once a week', 'once a month', 'less often than once a month', and 'not available')
- **Primary Health Care Orientation of dementia-related services**: Six 5-item scales, each item rated on a 5-point scale from 'no, not at all' (1) to 'yes, to a very great extent' (5); higher scores indicated greater orientation of dementia-related services to key dimensions of primary health care.

Response by health region

- Only the results for health regions with 4+ survey respondents survey were included (the exception was Athabasca Health Authority, which had 1 respondent and was grouped with Keewatin Yatthe into the 'Northern Health Regions')
- Response rate of 45.6% (82 of 180): 68 rural and 14 urban (all urban respondents were from Regina Qu'Appelle Health Region)

KEY FINDINGS

Availability of Dementia-related Services

- **Health Promotion Programs** *related to dementia care were reported to be widely unavailable according to more than half of respondents.*
- **Primary Health Care services** related to dementia care that were available at least weekly according to more than half of respondents, rank ordered, included basic services – pharmacists, family physicians, physical therapists, and occupational therapists. *However, Nurse Practitioners and multidisciplinary team assessment were unavailable in nearly half of the communities served by respondents.*
- **Post-diagnosis Support services** most available weekly included the broad health services of palliative care, adult day programs, case management, and volunteer services/visitors. *More than half of respondents reported that other post-diagnostic support was not available in their communities (private caregiving, caregiver support groups, and counselling for diagnosed individuals)*
- **Home Care services** were widely available weekly (personal care services, meals on wheels and meal preparation, planned respite, and in-home respite). *Home care services that were unavailable according to the majority of respondents included night respite, weekend respite, and transportation to health care.*
- **Long-term Care** counselling for individuals with dementia and caregivers was reported to be widely unavailable. Long-term care housing available in most communities included seniors housing, special care homes, and personal care homes. *Long-term care housing that was more likely to be unavailable included assisted living options and special care units.*

Primary Health Care Orientation of Dementia-related Services

- **Information and Education.** Community-level dementia-related information and education were perceived as inadequate, ranging from strongly negative (public education to reduce stigma) to somewhat positive (dementia awareness among local health care professional).
- **Accessibility.** Respondents held overall somewhat negative perceptions, particularly regarding the influence of geographic location on accessibility and availability of subsidized/free transportation services.
- **Population Orientation (community fit).** Respondents held somewhat negative views overall, specifically on level of caregiver support and level of primary health care services.
- **Coordinated Care**. Perceptions were neutral on the seamlessness of transition from community to long-term care as well as ease of access to patient health history, and somewhat positive on coordination of patient care and service delivery.
- **Comprehensiveness of Care.** Of the 6 dimensions considered, *Comprehensiveness of Care* fared the most favorably with somewhat positive views overall. Perceptions ranged from neutral regarding timely referral to appropriate services to somewhat positive with respect to one or more health care professional being able to provide on-going management.
- **Quality of Care.** This dimension was viewed neutrally overall, ranging from somewhat negative (timely diagnosis) to somewhat positive (effectiveness of screening tools).
- According to **a single summary item**, the amount of supportive resources and services available in the community was somewhat *inadequate* overall.

Item statistics of Primary Health Care Orientation of Dementia-related Services, Saskatchewan (N = 83)

Attribute	N	Mean (max. 25)	SD (range)
Information and Education	81	13.0	3.9 (6-23)
Adequate awareness about 'what to do' or 'where to go'	81	2.7	1.1 (1-5)
Adequate information for caregivers	81	2.4	1.1 (1-4)
Adequate awareness of dementia among health care professionals in the community	81	3.5	1.2 (1-5)
Adequate dementia-specific continuing education for health care professionals	81	2.5	1.1 (1-5)
Adequate public education to reduce stigma of dementia	81	1.8	0.8 (1-4)
Accessibility	80	12.4	3.8 (5-22)
Appropriate frequency of services	81	2.4	1.1 (1-5)
Appropriate wait time for services	80	2.7	1.3 (1-5)
Available public transportation to services (for older adults)	81	3.1	1.5 (1-5)
Available subsidized/free transportation to services (for older adults)	81	1.9	1.3 (1-5)
Equally accessible services, regardless of geographic location	80	2.2	1.2 (1-5)
Population Orientation	81	11.9	3.8 (5-21)
Appropriate level of PHC services	81	2.2	1.0 (1-5)
Appropriate level of Home Care services	81	2.7	1.2 (1-5)
Appropriate number of LTC beds	81	2.3	1.3 (1-5)
Appropriate telehealth services	81	2.7	1.1 (1-5)
Appropriate level of support for caregivers	81	2.0	0.9 (1-4)
Co-ordinated Care	81	15.6	3.6 (8-24)
Service delivery by different health care professionals in the community is co-ordinated	81	3.3	1.1 (1-5)
All health care professionals in the community have easy access to patient health history	81	2.8	1.3 (1-5)
Health care professionals co-ordinate well with each other to manage [patient care (within and outside community)	81	3.4	1.0 (1-5)
Health care professionals co-ordinate well with community agencies to manage patient care (within and outside community)	81	3.3	1.0 (1-5)
Seamless transition from community to LTC	81	2.8	1.2 (1-5)
Comprehensiveness of Care	81	17.1	3.9 (7-25)
One or more health care professional is able to diagnose	81	3.3	1.4 (1-5)
One or more health care professional is able to provide on-going management	81	3.8	0.9 (2-5)
There is timely referral to appropriate health and social services	81	3.0	1.0 (1-5)
Multidisciplinary care is available	81	3.6	1.1 (1-5)
Health care professionals consider dementia a chronic disease	81	3.4	1.1 (1-5)
Quality of care	81	14.3	3.2 (8-21)
Timely diagnosis occurs	81	2.5	0.9 (1-5)
Health care professionals use standardized diagnostic criteria	81	3.1	1.0 (1-5)
Current screening tools are effective	81	3.3	0.9 (1-5)
Care and management are guided by standardized care pathways	81	2.4	1.0 (1-5)
Health care professionals adequately monitor safety of individuals with dementia living at home	81	2.9	1.1 (1-5)
Adequate amount of supportive resources and services	80	2.4	1.1 (1-4)

Do you have *recommendations for action on dementia?* Please share ➡

Conclusions

- When compared to *Rising Tide* projections for Sask (Smetanin et al., 2009), our findings suggest that only 79% of incident cases (3,270/4,154) and 71% of prevalent cases (13,012/18,332) were diagnosed or otherwise identified; i.e., an estimated 21% of incident cases and 29% of prevalent cases were not diagnosed or otherwise identified.
- This study highlights significant gaps between best practices in dementia care (Best Practice Review) and actual practices (Environmental Scan):

Best Practice (Best Practice Review)	Actual Practice (Environmental Scan)
Expanding Dementia Research	Not examined
Quality Improvement in Care Services	Across Sask: Low accessibility to dementia-related services, poor fit between community needs and services, and room for improvement in coordinated care
Raising Public Awareness	Inadequate dementia-related info and education
Early Diagnosis and Treatment	Room for improvement in timely diagnosis and use of standardized diagnostic criteria and care pathways
Staff Training	Dementia-specific continuing education for health care professionals is currently inadequate
Family Support	Numerous services need to be offered more frequently: post-diagnostic care (counselling, support groups, private caregiving), home care (transportation, respite) and long-term care (counselling, assisted living, special care units)

References

Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri C. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's and Dementia* 2013;9:63-75.

Saskatchewan Bureau of Statistics. *Saskatchewan Population by 5 Year Age Groups, 2003 to 2013.* 2014. [http://www.stats.gov.sk.ca/pop/]

Smetanin P, Kobak P, Briante C, Stiff D, Sharman G, Ahmad S. *Rising Tide: The Impact of Dementia in Saskatchewan 2008 to 2038.* 2009. RiskAnalytica and Alzheimer Society of Saskatchewan, Canada.

World Health Organization and Alzheimer's Disease International. *Dementia: A Public Health Priority.* 2012. [http://www.who.int/mental_health/publications/dementia_report_2012/en/]

*Rural Dementia Action Research website: http://www.cchsa-ccssma.usask.ca/ruraldementiacare/radar.html

INQUIRIES:

Dr. Debra Morgan. Canadian Centre for Health & Safety in Agriculture, University of Saskatchewan: debra.morgan@usask.ca or 306-966-7905

ACKNOWLEDGEMENTS

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

RaDAR's recommendations

These recommendations address the challenges raised in this mixed-methods study: that our provincial health care system currently underdiagnoses dementia and underserves individuals with dementia and their families – challenges that will intensify over the coming years as our population ages if we do not develop long-term plans.

Policy

1. **Revisit and update** *the Provincial Strategy for Alzheimer Disease and Related Dementias in Saskatchewan*, **released in 2004**
   - collaborate with individuals with dementia and families, experts in dementia and dementia care, health care professionals, health region representatives, the Alzheimer Society of Saskatchewan, and other partners
   - focus on best practices in dementia care, as put forth in national dementia plans from other countries: expanding dementia research, quality improvement in care services, raising public awareness, early diagnosis, family support, and staff training.
   - builds on recommendations put forth in the Alzheimer Society of Canada *Rising Tide Report*
2. **Improve access to a timely diagnosis** by identifying and addressing potential barriers to a diagnosis, including patient and caregiver factors (e.g., lack of symptom awareness), health care professional factors (e.g., diagnostic uncertainty), and health system factors (lack of access to standardized care pathways, dementia-specific continuing education, and multidisciplinary team assessment).
3. **Increase access to health and community services for individuals living in rural communities** by:
   - increasing investments in subsidized and free transportation for older adults living outside of Saskatoon and Regina (specialist services) and outside of communities with the desired services
   - increasing the capacity of local resources, in order to reduce the need for travel and institutionalization earlier than necessary among older adults (e.g., primary health care, home care, and other support services)
4. **Ensure that family caregivers are adequately supported** by increasing investments to improve the availability and frequency of home-based and community-based respite care, including evening, weekend, and emergency care.
5. **Include dementia in the provincial Chronic Disease Management Quality Improvement Program**, thereby establishing a patient registry and decision support tools (standardized care) for health care professionals similar to other chronic conditions (e.g., diabetes, health disease).

Research

6. **Track quality indicators of dementia care provincially and by health region**, to ensure that individuals are properly assessed, diagnosed, and managed within the health care system. The following principles provide guidance:
   - quality indicators should be developed in partnership with experts in dementia, health care professionals, health region representatives (e.g., Population and Public Health, Primary Health Care, Acute Care, Home Care, and Long-term Care), eHealth, and Health Quality Council.
   - quality indicators should be reported annually, with improvements and declines noted, and health regions' comments on findings included.
7. **Increase investment in the First Link referral program provided by the Alzheimer Society of Saskatchewan**, to ensure that links are made among individuals with dementia, their families, local health services, and Alzheimer Society programs. Additional staff should be hired in health regions that currently have the First Link program in operation (Saskatoon, Regina Qu'Appelle, Cypress, Prairie North, Prince Albert Parkland, Sun Country) and expanded to those health regions without First Link (Cypress, Five Hills, Heartland, Kelsey Trail, Sunrise, and the Northern health regions).

Knowledge Translation and Exchange

8. **Partner with television and newspaper media to raise public awareness** of risk reduction, warning signs, and the importance of timely diagnosis, e.g., contribute a regular twice-monthly column to the Saskatoon Star Phoenix and Regina Leader Post and contribute regular items to Saskatoon and Regina news programs.
9. **Establish and maintain continuing education programs** for health care professionals to improve skills in assessment, diagnosis, and management. Partners may include experts in dementia and dementia care, University of Saskatchewan, Telehealth Saskatchewan, Saskatchewan Medical Association, nursing associations, Alzheimer Society of Saskatchewan, health region representatives, and others.
10. **Increase awareness of early onset dementia (younger than 65 years)** among the public as well as health care professionals. Establish services that are designed for adults with early onset dementia, who may have unique needs (e.g., in the workforce, with children).

For additional information contact:
Debra Morgan, PhD, RN
Professor
CIHR-SHRF Applied Chair in Health Services and Policy Research
College of Medicine Chair, Rural Health Delivery
Canadian Centre for Health & Safety in Agriculture (CCHSA)
University of Saskatchewan
104 Clinic Pl, PO Box 23
Saskatoon, SK S7N 2Z4

Telephone: (306) 966-7905
Facsimilie: (306) 966-8799
Email: debra.morgan@usask.ca
http://cchsa-ccssma.usask.ca