Summit 6
2013

Knowledge Network in Rural and Remote Dementia Care

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

Scientific Poster Session

6th Annual Summit

October 24th & 25th, 2013

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

SHRF
SASKATCHEWAN HEALTH RESEARCH FOUNDATION

CCHSA / CCSSMA

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

UNIVERSITY OF SASKATCHEWAN

Thursday October 24th, 2013
Wine and Cheese Scientific Poster Program
7:00 PM – 10:00 PM at the Sheraton Hotel (South West Room)

Poster Presenter	Authors & Poster Titles
Mark Barnes & Pat Kessler	Barnes M, Kessler P Dementia Hoshin: How it started and where we are
Carrie Bourassa	Understanding from Within Project/Native Women's Association of Canada Series of 4 Posters: Aboriginal Patient Advocate; It's all in her head; Who is this woman?; In case of a seizure
Camille Branger	Branger C, O'Connell M, Morgan D Factor Analysis of the 12-item Zarit Burden Interview in Caregivers of Persons Diagnosed with Dementia
Allison Cammer	Morgan D, Cammer A, Crossley M, Stewart N, D'Arcy C, Dal Bello-Haas V, McBain L, O'Connell M, Bracken J, Kosteniuk J Evolution of a Community-Based Participatory Approach in a Rural and Remote Dementia Care Research Program
Allison Cammer	Cammer A, O'Connell M, Morgan D, Whiting S Functional Ability to Eat and Drink in Persons with Alzheimer versus non-Alzheimer Dementia
Tracy Danylyshen-Laycock	Danylyshen-Laycock T Factors Leading to the Utilization of a Dementia Specific Training Program in Rural Long-Term Care Homes
Joe Enright	Enright J, O'Connell M An Evaluation of a Reminiscence Intervention for Caregivers of Persons with Dementia via Telehealth Videoconferencing
Joe Enright	O'Connell M, Enright J, Crossley M, Morgan D Differential Caregiver Distress and Burden Associated with Diagnoses of Types of Dementia

Poster Presenter	Authors & Poster Titles
Drew Hager	Hager D, Kirk A, Morgan D, Karunanayake C, O'Connell M Predictors of rapid cognitive decline in rural patients with Alzheimer's disease.
Paulette Hunter	Hunter P Human Exploratory Factor Analysis of the Personhood in Dementia Questionnaire
Julie Kosteniuk	Morgan D, Kosteniuk J, Stewart N, Karunanayake C, Beever R, O'Connell M Psychometric Evaluation of the Telehealth Satisfaction Scale (TeSS)
Xiangfei Meng	Meng X, D'Arcy C APOE gene, environmental risk factors and their interactions in dementia among seniors
Joanne Michael	McAiney C, Harvey D, Hillier L, Stolee P, Schultz M, Michael J Early Referral for Support of Dementia Caregivers: Evaluation of the First Link Demonstration Project
Darrell Mousseau	Chaharyn B, Fehr K, Pennington P, Wei Z, Mousseau D Is Alzheimer disease-related pathology different in males and females?
Norma Stewart	Stewart N, Minish D, Cammer A, Morgan D The Experience of Sons as Carers for a Parent Diagnosed with Dementia at the Rural and Remote Memory Clinic (RRMC)

DEMENTIA PROJECT HOSHIN

- Has been put under the Better Health area as the aim of this area is to "improve access and connectivity in Primary Health Care innovation sites and use early learnings to build foundational components for spread across the province"

OUR BEGINNING

- In 2011 the Saskatchewan Ministry of Health started down the path of Strategic Deployment, based on the Toyota model, known by the Japanese word Hoshin Kanri.

- Hoshin is translated into a "breakthrough activity to be completed within one year with the goal to move the system closer to an improvement target". It also refers to a compass, direction, or shining needle. (SCHR website)

- Kanri means policy

- In 2012/2013 SCHR selected Dementia care as a hoshin

It's all in her head

You look fine.

Get over it.

Just deal with it.

I am different now.

I forget things.

I get confused a lot.

**I suffered a traumatic brain injury.
You can't see it. But it's real.
I'd like to tell you more.
Just follow the steps below.**

To make the poster come alive:

**Step 1: Download the free Layar App for iPhone or Android.
www.layar.com/download**

Step 2: Open App. Point phone at poster. Tap Scan. Enjoy!

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Native Women's Association of Canada

NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH
CENTRE DE COLLABORATION NATIONALE DE LA SANTÉ AUTOCHTONE

NWAC

For more information see
www.nwac.ca

Aboriginal Patient Advocate

Ask your health care provider to recommend an advocate.

Bring a friend or family member to your doctor appointments.

Write down your doctor's instructions.

Always carry a list of your prescriptions so your doctor and pharmacist can check for side effects.

Patient advocates help you navigate the health care system and find the answers you need.

**I have a neurological condition.
I didn't know what to do about it.
I'd like to tell you more.
Just follow the steps below.**

To make the poster come alive:

**Step 1: Download the free Layar App for iPhone or Android.
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In case of a seizure:

DO
move my head to the side and place something soft under it.

DO
move sharp objects out of my way.

Don't
place anything in my mouth.

Don't
try to restrain me.

**I have epilepsy.
I'm not an epileptic.
I'd like to tell you more.
Just follow the steps below.**

To make the poster come alive:

Step 1: Download the free Layar App for iPhone or Android.
www.layar.com/download

Step 2: Open App. Point phone at poster. Tap Scan. Enjoy!

Who is this woman?

"She took care of me when I was sick."

"She stood by me."

"She taught me respect."

"She loved me unconditionally."

"Then she forgot our traditional medicines."

"Then she frustrated me."
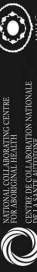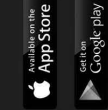
"Then she turned her back on me."

"Now it's too late."

**This is my Auntie.
Her dementia made me forget that.
I'd like to tell you more.
Just follow the steps below.**

To make the poster come alive:

Step 1: Download the free Layar App for iPhone or Android.
www.layar.com/download

Step 2: Open App. Point phone at poster. Tap Scan. Enjoy!

Factor Analysis of the 12-item Zarit Burden Interview in Caregivers of Persons Diagnosed with Dementia

C. Branger[1], M. E. O'Connell[1], & D. Morgan[2]

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

INTRODUCTION

Purpose

→The purpose of the current study was to identify the factor structure of the 12-item ZBI in a sample of 197 rural caregivers of persons with dementia.

Background

→Relatively little data on the ZBI factor structure, despite its popular use.

→A two factor structure is most commonly found for the 12-item ZBI.[1]

→Emerging data indicate, an additional ZBI third factor of 'guilt' is embedded in the items that typically load on personal strain. [2,3,4] The 12-item ZBI includes these same 'guilt' items.

→Guilt is an important predictor of psychological strain, and both guilt and psychological strain appear more acute in caregivers of persons with dementia. [5,6]

PARTICIPANTS

→ This study analyzed archival data from **197** caregivers of persons diagnosed with dementia after an interdisciplinary assessment at the Rural and Remote Memory Clinic in Saskatoon.

Diagnosis	f
Alzheimer's disease	108
Vascular dementia	9
Diffuse Lewy body disease	14
Parkinson's disease	2
Huntington's disease	1
FTD, frontal variant	13
FTD, semantic variant	10
FTD, progressive non-fluent aphasias	5
Normal pressure hydrocephalus	2
Dementia due to medical condition	4
Dementia due to multiple Etiologies (mixed)	23
Dementia not otherwise specified	6
Total	197

Caregivers

M age 61.55, SD = 14.78

	N	%
Male	65	33
Female	132	67
Spouse	105	53
Child	79	40
Sibling	6	3
Extended family	5	3
Other (e.g, friend, neighbour)	2	1

How frequently does each caregiver see the person with dementia

	N	%
Everyday	138	70
A couple of times a week	20	10
Once a week	7	4
A couple of times a month	8	4
Once a month	5	2
Several times a year	15	8
Missing data	4	

Important – the frequency reported here is for in-person contact and does not capture telephone contact, etc.

ZBI M score= 14.26, SD = 8.71

[1] O'Rourke, N., & Tuokko, H.A. (2003). Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample. The Gerontologist, 43, 121-127.
[2] Flynn Longmire, C.V., & Knight, B.G. Confirmatory factor analysis of a brief version of the Zarit Burden Interview: useful dimensions for clinicians. The Gerontologist, 51, 453-462.
[3] Ankri, J., Andrieu, S., Bauffis, B., Grand, A., & Henrard, J.C. (2005). Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. International Journal of Geriatric Psychiatry, 20, 254-260.
[4] Kight, B.G., Fox, L.S., & Chou, C. (2000). Factor structure of the Burden Interview. Journal of Clinical Geropsychology, 6, 249-258.
[5] Losada A., Marquez- González, M., Penacoba, C., & Romero- Moreno, R. (2010). Development and validation of the Caregiver Guilt Questionnaire. International Psychogeriatrics, 22, 650-660.
[6] Brodaty, H (2007). Meaning and measurement of caregiver outcomes. International Psychogeriatrics, 19, 363-381.

RESULTS

Exploratory factor analysis revealed 2 factors[*].
Factor 1 accounted for 49.5% of the variance and Factor 2 accounted for 14.1% of the variance.

Item	*Factor 1*	*Factor 2*
1. Feel you do not have time for yourself	0.806	
2. Feel you do not have time for other responsibilities	0.713	
3. Feel anger around care recipient	0.641	0.535
4. Feel dependent affects other relationships in a negative way	0.786	
5. Feel strained around your care recipient	0.739	
6. Feel your health has suffered	0.803	
7. Feel you do not have privacy	0.752	
8. Feel your social life has suffered	0.835	
9. Feel you have lost control of your life	0.849	
10. Feel uncertain about the future	0.553	0.557
11. Feel you should be doing more		0.890
12. Feel you could be doing a better job		0.874

Factor loadings above .45 are only displayed
[*]factor structure invariant to caregiver subgroups.

DISCUSSION

We did not find support for recent data suggesting the ZBI may measure a 3rd factor of guilt.

'Personal Strain' factor predicted caregiver psychological distress. 'Role strain' comprised of 'guilt' items did not predict caregiver distress.

Although guilt and burden appear to share a unique relationship, these data suggest guilt is not adequately measured by the 12-item ZBI in caregivers of persons diagnosed with dementia.

Evolution of a Community-Based Participatory Approach in a Rural and Remote Dementia Care Research Program

D. Morgan[1] A. Cammer[1], M. Crossley[2], N. Stewart[3], A. Kirk[4], C. D'Arcy[5], V. dal Bello-Haas[6], L. McBain[7],
M.E. O'Connell[2], J. Bracken[8], J. Kosteniuk[1]

[1]Canadian Centre for Health and Safety in Agriculture, College of Medicine, University of Saskatchewan, [2]Department of Psychology, College of Arts and Science, University of Saskatchewan, [3]College of Nursing, University of Saskatchewan, [4]Department of Neurology, College of Medicine, University of Saskatchewan, [5]Applied Research, University of Saskatchewan, [6]School of Rehabilitation Sciences, McMaster University, [7]First Nations University of Canada, [8]Alzheimer Society of Saskatchewan

Core Principles of Community-Based Participatory Research (CBPR):

1. Recognizes community as unit of identity
2. Builds on community strengths and resources
3. Facilitates collaborative partnerships in all phases
4. Integrates knowledge and action for mutual benefit of all partners
5. Promotes co-learning and empowerment
6. Involves a cyclical and iterative process
7. Addresses health from positive and ecological perspectives
8. Disseminates findings to all partners
9. Involves a long-term commitment by all partners

(Israel et al., 1998, 2001)

Background on Rural and Remote Dementia Care Program of Research:

• Worldwide prevalence of dementia estimated at 35.6 million and expected to double every 20 years (WHO, 2012); Canadian prevalence forecasted to double by 2038 (Rising Tide, 2010)
• Rural and remote areas disproportionately affected due to higher proportion of older adults and specific challenges in informal and formal care (time, travel, cost, lack of access)
• Program of research initiated in Saskatchewan in 1997; began due to shared interests of small group of researchers partnering with community members and developed into a more relational, process-oriented CBPR initiative as the program developed over three key phases

Phase 1: Launching Research

Primary Funding: HSURC (SHRF) grant

Community Engagement: meetings with 30 health districts; full-day consultation with representatives from 27 districts to identify research priorities

Priorities: Examination of challenges in dementia care across the continuum; comparison of long-term care (LTC) facilities with and without special care units; investigation of front-line care providers' conceptions of acts of aggression in LTC

Outcomes: Changes made at regional level in aggressive event reporting and investigation; curriculum changes to continuing care assistant program made; adoption of new training programs to address LTC acts of aggression by residents with dementia

Phase 2: Setting Sail as a Team

Primary Funding: CIHR and SHRF New Emerging Team grant

Community Engagement: meetings with broad range of stakeholders to design projects; relationships built with key people in 14 rural and remote communities; partnership with Aboriginal Grandmothers group and northern healthcare providers

Priorities: development and evaluation of Rural and Remote Memory Clinic (RRMC) with longitudinal database; development and validation of culturally sensitive diagnostic testing materials; evaluation of Enhancing Care program

Outcomes: RRMC model validated, continued operation via funding from Ministry of Health; culturally sensitive testing materials in use; use of telehealth for MMSE delivery validated; use of

Phase 3: Anchoring with Partners

Primary Funding: CIHR Applied Chair funds

Community Engagement: formal partnership created with stakeholders from various levels across spectrum of care, including family and policy makers (Decision Maker Advisory Council); yearly dementia care Summit held

Priorities: Analysis of RRMC database; education of trainees, and partners; examination of pre-diagnosis caregiving needs; investigation of improved supports for caregivers via telehealth support group intervention; evaluation of Summit; determination of next 'big steps' in the research

Outcomes: Capacity building of partners in council; adoption of telehealth support group by ASOS after lobbying by caregiver partners; knowledge translation videos developed by team; research projects developed to engage in Primary

Functional Ability to Eat and Drink in Persons with Alzheimer versus non-Alzheimer Dementia

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

[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. Little is known about differences in ability for Alzheimer Disease dementia and non-Alzheimer Disease dementia (e.g., Vascular, Fronto-temporal, Subcortical, LewyBody).

- An interdisciplinary Rural and Remote Memory Clinic (RRMC) in Saskatchewan was established in 2004 to diagnose 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?
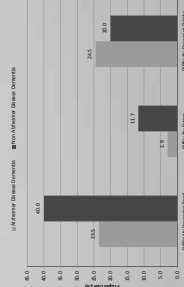
Methods

- Data were collected from 337 RRMC patients and their care partners

- 201 patients were diagnosed with dementia; 164 cases with complete data were included in the analysis

- Cases were grouped according to dementia diagnosis: Alzheimer Disease dementia (AD) versus non-Alzheimer dementia (non-AD)

- 4 items from the Bristol Activities of Daily Living (B-ADL) 20 item scale were 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 'change in functional ability'

- Multiple logistic regression 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 sum of boxes), age, and sex

Findings

Characteristics of the Study Population

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

Proportion of Persons with Difficulty in Functional Ability

Associations with Difficulty Preparing Food

	Crude Association Odds Ratio (95%CI)	Adjusted Association Odds Ratio (95% CI)
Dementia Type		
Alzheimer Disease Dementia (AD)	1.00	1.00
Non-Alzheimer Disease Dementia (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 Association Odds Ratio (95%CI)	Adjusted Association Odds Ratio (95% CI)
Dementia Type		
Alzheimer Disease Dementia (AD)	1.0	1.0
Non-Alzheimer Disease Dementia (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 Association Odds Ratio (95%CI)	Adjusted Association Odds Ratio (95% CI)
Dementia Type		
Alzheimer Disease Dementia (AD)	1.0	1.0
Non-Alzheimer Disease Dementia (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)

Implications

- Monitoring of ability to prepare food and ability to 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.

- These findings demonstrate the need for tailoring clinical interventions according to the 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

Factors Leading to the Utilization of a Dementia Specific Training Program in Rural Long-Term Care Homes

Tracy Danylyshen-Laycock, B.S.P.E, M.S.W., R.S.W (SK)
Doctoral Student, Health Sciences,
University of Saskatchewan

BACKGROUND

- Individuals with dementia who live in long-term care homes may exhibit responsive behaviours (e.g. yelling, hitting and swearing) (Alzheimer Society of BC, 2010).
- Nursing aides are the most frequent recipients of the responsive behaviours (Gates et al., 2003).
- Staff who work in long–term care homes often feel as if they do not have the skills to manage responsive behaviours. As a result, managers and researchers have recommended that staff be provided with training in managing responsive behaviours.

THE GENTLE PERSUASIVE APPROACHES PROGRAM

- The Gentle Persuasive Approaches Program (GPA) is a dementia specific training program designed for staff in long-term care homes identify, manage and de-escalate responsive behaviours. **Four modules are delivered over 7.5 hours.**

PARIHS FRAMEWORK

- The assumption behind the PARIHS Framework is that the likelihood of research evidence being translated into practice will be more successful when **evidence, context, and facilitation** are high (Rycroft-Malone, 2010).
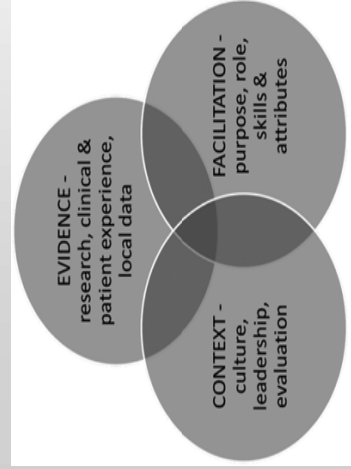
PURPOSE

- The purpose of this research is to examine the relationship between the element of Facilitation in the PARIHS framework and the sustainability of best practice guidelines in care homes, in particular the GPA Program. The general proposition guiding this research was that facilitation plays an important role in the sustainability of best practice interventions such as the GPA Program.
- Data analysis for the full study are in progress. This poster reports on three specific questions related to the implementation and sustainability of the GPA program, from the perspective of staff, GPA Coaches, and long-term care home leaders.

METHODS

- A cross-sectional retrospective qualitative research designed was used for this study.
- **Site selection:** purposeful sampling was used to select five rural long-term care homes in Saskatoon Health Region.
- **Participants:** this study focused on the experiences of the Administrators, Directors of Care (DOC's), GPA Coaches, registered nurses, licensed practical nurses and nursing aides during and after implementation of the GPA program in their care homes.
- **Data collection:** 14 semi-structured interviews and 4 focus groups were conducted between February 1, 2012 and January 21, 2013.
- **Data Analysis:** data were analyzed using a qualitative, inductive approach using the constant comparative method (Glaser & Strauss, 1967; Charmaz, 2006).

RESULTS

Question 1 (from interview with DOC's, nurses, and GPA Coaches and from focus groups with nursing aides)

"How was the GPA program used by staff in your long-term care home?"

Staff reported that they used the following skills from GPA:
- remaining calm and patient
- using the Stop and Go technique
- assessing resident moods
- pacing care,
- redirecting residents
- knowing the resident
- explaining the task
- communicating with staff about triggers & interventions
- understanding the disease process.

RESULTS CON'T

Question 2 (from interviews with GPA coaches)

What skills did you, as the GPA Coach, use to help the staff utilize the skills and interventions taught in the GPA program?
- modeled GPA behaviours (e.g. patience, calmness, pacing care, learning about the resident)
- indirectly provided staff with feedback when they did not utilize GPA skills
- relieve staff when they were struggling with a resident
- taught staff to redirect and de-escalate responsive behaviours.

Question 3 (from interviews with DOCs and Administrators)

What did you as a leader to sustain the GPA Program in your home?
- freed up resources (e.g. financial and staffing) to implement the program
- modeled GPA behaviours (e.g. patience, calmness, and knowing the residents)
- promoted problem solving surrounding responsive behaviours
- ensured they were always available for staff to consult with about behaviours.

CONCLUSIONS

- Many of the GPA skills are being utilized by staff in long-term care homes to varying degrees. The most consistently identified skills that staff use are redirection, remaining calm, and using the Stop and Go technique.
- Leaders play an important role in the implementation and sustainability of a dementia specific training program. When leaders promoted the program and modeled the behaviours, staff were more likely to report using the GPA skills.
- Although the GPA Coaches played a role in the sustainability of the GPA program, they defined their role as "assisting staff behind the scenes."
- GPA Coaches did not provide direct feedback to staff who struggled with managing behaviours. Rather than confronting or directly approaching their co-workers, they modeled the GPA behaviors or coached staff in using the GPA skills.

EVIDENCE - research, clinical & patient experience, local data

FACILITATION - purpose, role, skills & attributes

CONTEXT - culture, leadership, evaluation

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

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

BACKGROUND

- Informal caregivers of persons with dementia experience significant difficulties or "*caregiver burden*", which has been linked to the quality of the caregiver and care-recipient relationship[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 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].

PHASE 1: In-Person Trial

Objective:

- The first objective is to investigate the benefits of a RT activity for caregivers of persons with dementia

Method:

- Sixty-four caregiver/person with dementia dyads will be recruited from the University of Saskatchewan Rural and Remote Memory Clinic and randomly assigned to either an in-person RT intervention group or to a wait-list control group receiving treatment as usual.

- The RT intervention will be based on an empirically supported autobiographical memory activity.

- Relationship quality, caregiver burden, and other outcome measures will be administered at pre, post, and follow-up.

PHASE 2: Telehealth Delivery

Objective:

- A second objective is to assess the efficacy of the RT intervention delivered via videoconferencing.

Method:

- Dyads in the wait-list control group will receive the same RT intervention and measures, but the intervention will be delivered via videoconferencing over Telehealth Saskatchewan.

Project Relevance:

- This project will potentially provide evidence of RT efficacy for improving caregiver/care-recipient relationships and reducing perceived burden 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.

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Differential Caregiver Distress and Burden Associated with Diagnoses of Types of Dementia

M. E. O'Connell[1], J. Enright[1], M. Crossley[1] & D. Morgan[2]

[1]Department of Psychology, University of Saskatchewan, [2]Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan
Presentation at the 74TH Annual Canadian Psychological Association Conference, Quebec City, QB

INTRODUCTION

Purpose

➤ The purpose of the current study was to identify the association between diagnosis and caregivers' report of burden and distress

Background

➤ Dementia due to Alzheimer disease (AD) is most commonly diagnosed, but is only one type of dementia

➤ Each type of dementia is associated with unique behavioural, cognitive, and functional impairments[1]

➤ Early stage impairments differ for the dementia types, which may have implications for care needs
→ Dementia due to AD – early memory loss[2,3,4,5]
→ Behavioural variant FTD – loss of social propriety and executive function[6,7,8]
→ Semantic variant FTD – loss of language comprehension and object knowlege[7,9,10]
→ Progressive non-fluent FTD – loss of language fluency[6,7,8,11]
→ Diffuse Lewy Body Dementia – alertness and visuospatial[12]
→ Vascular/mixed dementia – varied[13], but commonly processing speed/attention, executive function

➤ Caring for persons diagnosed with dementia due to frontotemporal degeneration (FTD) has been shown to be related to greater caregiver distress and burden when compared with caregivers of persons with dementia due to AD[14,15]

SETTING

➤ Rural and Remote Memory Clinic – neuropsychology, neurology (including recent blood work and CT head scan), nursing, and physical therapy assessment
→ Team interview of patient and family
→ Discipline specific assessments
→ Standardized questionnaires
→ Diagnoses after interprofessional team meeting

MEASURES

Caregiver Self-Report

➤ Zarit Burden Interview[16] – caregiver self-report of burden

➤ Brief Symptom Inventory[17] – caregiver self-report of general psychological distress

Patient Variables

➤ Severity of impairment with the Clinical Dementia Rating Scale[18] – sum of box score – less specific to memory changes[19]

➤ Diagnosis – based on interprofessional assessment

PARTICIPANTS

Patients

Diagnosis	f	Age
Mild Cognitive Impairment (amnestic non-amnestic, single domain, etc)	46	69.63 (11.81)
Dementia due to Alzheimer's disease (AD)	100	75.56 (7.44)
Vascular dementia or mixed vascular dementia	30	74.27 (9.37)
Subcortical dementias*	17	75.12 (10.61)
FTD variants	26	70.27 (11.50)
Dementia NOS or due to medical condition	10	72.90 (10.94)
Total	229	73.44 (9.82)

*Heterogeneous category, Diffuse Lewy Body Disease, Dementia due to Parkinson's disease or Huntington's

Caregivers

Age 18-93 years old (M = 60.29; SD = 14.69)
Relationship to patient - 51% spouses; 40% children
Frequency of in-person contact with patient - 64% report everyday; 15% report weekly

RESULTS

Descriptive Statistics M (SD)

Diagnosis	CDR-SOB*	ZBI**	BSI***
MCI	2.45 (1.70)	13.65 (10.80)	16.52 (14.31)
AD dementia	6.96 (3.50)	13.63 (9.27)	15.76 (19.32)
Mixed or VaD	7.29 (3.68)	13.33 (5.71)	14.53 (14.38)
Subcortical dementias	6.41 (3.15)	16.13 (8.86)	14.53 (12.44)
FTD variants	5.70 (3.20)	13.88 (8.89)	16.65 (15.08)
Dementia other	4.39 (3.13)	12.80 (10.23)	25.80 (21.53)
Total	5.77 (3.61)	13.77 (9.14)	16.20 (16.96)

*CDR-SOB scores range from 0-18, with higher scores demonstrating more cognitive and functional impairment
**ZBI scores range from 0-36 with higher scores demonstrating more caregiver burden
***BSI scores range from 0-212 with higher scores demonstrating more psychological distress

After controlling for severity (CDR-SOB), no statistically significant differences in burden (ZBI; $F_{5,213} = 1.62$; $p > 0.05$; partial $\eta^2 = 0.04$) or distress (BSI; $F_{5,213} = 1.00$; $p > 0.05$; partial $\eta^2 = 0.02$)

Apparent similarity in burden and distress for MCI and subtypes of dementia, but effect size estimates are small suggesting caution regarding assumption of equivalence. These diagnostic groupings may be too gross to demonstrate differential distress/burden, or these measures may not be sufficiently sensitive.

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Predictors of rapid cognitive decline in rural patients with Alzheimer's disease.

Drew Hager, Andrew Kirk, Debra Morgan, Chandima Karunanayake, Megan O'Connell

Introduction

- There is considerable variation in the rate of cognitive decline in patients diagnosed with Mild Cognitive Impairment (MCI) or Dementia.[1]

- Rapidly deteriorating scores on the Mini Mental State Examination in patients with dementia have been shown to predict a poor prognosis.[2]

- Predictors of rapid cognitive decline would have great clinical utility.

- Previous predictors have been suggested, including younger age, higher education, less cognitive and functional abilities at baseline, family history of dementia, less anxiety, depression, falls, and higher caregiver burden. Predictors of decline may vary between different populations/settings.

- This study aims to determine predictors of decline by assessing clinical data from a rural population in the mid-western Canadian province of Saskatchewan.

- Clear predictors of rapid decline could help physicians navigate appropriate treatment scenarios and allow for time-sensitive discussions with patients and their families.

Methods

- Data Collection began in March 2004 at the Rural and Remote Memory Clinic (RRMC) in Saskatoon, Saskatchewan.

- Non-institutionalized patients were referred to the clinic by their family physicians where they were assessed by a neurologist, neuropsychology team and a physical therapist.

- Sociodemographic and clinical information, as well as functional and lifestyle status, were the independent variables in this study. These were assessed on clinic day by administering patient and caregiver questionnaires.

- The MMSE score at the one year follow up visit subtracted from the MMSE score at the initial clinic day represented cognitive change and was the dependant variable.

- The participants included in this study were the first 72 patients who were diagnosed with AD on clinic day and who were followed up with an MMSE one year later.

Analysis

- A bivariate linear regression analysis was carried out in order to examine the association between each potential independent variable and the dependant variable of change in MMSE over one year.

- Based on bi-variable analysis, independent variables associated with the dependent variable with a $p<0.20$ became candidates for a multivariate linear regression model.

Analysis

- All variables that were significantly correlated with a decline in MMSE over one year ($p<0.05$), as well as important individual factors (age and gender), were retained in the final multivariate model.

- The coefficient of determination, or total variance explained by the regression (R^2 value) was 27.2%.

Results

Population: (mean ± SD)

Population Total	Age	Female Gender	Marital status	European Ethnicity	MMSE- clinic day	MMSE- one year	Days b/w MMSE's
72	75.3 ±7.44	48	48	57	22.1 ± 3.69	20.2 ± 5.41	396 ± 44.8

Bivariate and multivariate analyses:

- Gender, history of hypertension, and BADL score remained significant ($p<0.05$) in the final multivariate model.

Table 1: Bivariate regression analysis

Variables	Estimate ± SE	p value
Age (years)	-0.03 ± 0.06	**0.61**
Gender[a] - male patient	1.10 ± 1.00	**0.28**
Marital status[b]		
Married or Common Law	1.27 ± 1.00	0.28
Formal Education (years)	0.06 ± 0.19	0.76
Family history of dementia[c]	-1.37 ± 0.98	**0.17**
Ethnicity[d] - European	0.39 ± 1.26	0.76
Alcoholic Beverages/week	0.02 ± 0.19	0.925
Diabetes	0.70 ± 1.45	0.63
Heart Disease/Attack	-0.33 ± 1.21	0.79
Hypertension	-2.48 ± 0.98	**0.01**
Psychiatric Disorder	0.06 ± 1.26	0.96
Chronic conditions[e] - 5+	-3.09 ± 0.88	**0.00**
Number of falls in the past year[f]		
1	0.80 ± 1.15	0.49
2	2.63 ± 1.73	**0.13**
Worry of Falls[g]	-0.29 ± 1.26	0.82
FAQ	-0.12 ± 0.06	**0.062**
BADL	-0.22 ± 0.08	**0.005**
QOL-CG	0.04 ± 0.09	0.64
QOL-PT	0.137 ± 0.099	**0.168**
IADL1	0.16 ± 0.11	**0.134**
MEM	0.047 ± 0.075	0.53
CES-D	-0.07 ± 0.04	**0.14**

a. Gender (patient): reference is female. b. Marital status: reference is single/divorced/widowed
c. Family history of dementia: reference is none d. Ethnicity: reference is Other
e. Chronic conditions: reference is 0-4 chronic conditions f. Falls per year: reference is none
g. Worry of Falls: reference is no worry of falls   Notes: $p < 0.2$

Table 2: Multiple regression analysis

Variable	Estimate ± SE	95% CI for Estimate	p value
Age	0.08 ± 0.07	(-0.59, 0.22)	0.25
Gender: Male	2.00 ± 0.99	(-0.10, 3.95)	**0.05**
Hypertension	-2.50 ± 0.93	(-4.36, -0.63)	**0.01**
BADL	-0.28 ± 0.08	(-0.42, -0.12)	**0.00**

Discussion

- Reduced capacity to complete activities of daily living as a predictor of greater cognitive decline is both expected and consistent with other results in the literature. For every one point decrease in BADL score (range= 0-60), there is a predicted average greater decline of 0.281 points on the MMSE over one year.

- Self-rating of independence in activities of daily living (IADL1) was not found to be significant. This suggests the importance of a caregiver's presence on the initial clinic day.

- Females lost a mean of 1.97 more MMSE points within a year than their male counterparts. Results concerning gender as a predictor vary. This suggests the need for continued research in many populations and settings.

- Patients with a history of hypertension lost an average of 2.50 points more on the MMSE within a year compared to those without.

- It is known that hypertension increases the risk of developing dementia and, in this study, the presence of hypertension accelerates decline.[3] Variables such as young age, years of education, and family history of dementia were not found to be predictive. These have been cited as significant in other papers throughout the literature.

- Although findings from this study will potentially improve clinicians' abilities to navigate their patients' disease, this study also suggests that predictors may vary between populations. Additional research is required in this field in order to identify predictors of decline and the possible interactions between them.

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# EXPLORATORY FACTOR ANALYSIS OF THE PERSONHOOD IN DEMENTIA QUESTIONNAIRE

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INTRODUCTION

- The Personhood in Dementia Questionnaire (PDQ; Hunter et al., 2013) assesses beliefs about the personhood of long-term care residents with advanced dementia.
- During the design of the PDQ, homogeneity of item content was emphasized in order to permit the calculation of a single "beliefs about personhood" score.
- Nonetheless, beliefs about personhood are very likely multi-dimensional. For example, there are biological, psychological, and social aspects of personhood (e.g., life, capacities, and rights, respectively).
- Given that this is a new area of measurement, exploratory factor analysis was employed to better understand the dimensionality of the PDQ.

FIGURE 1: SCREE PLOT

Scree Plot
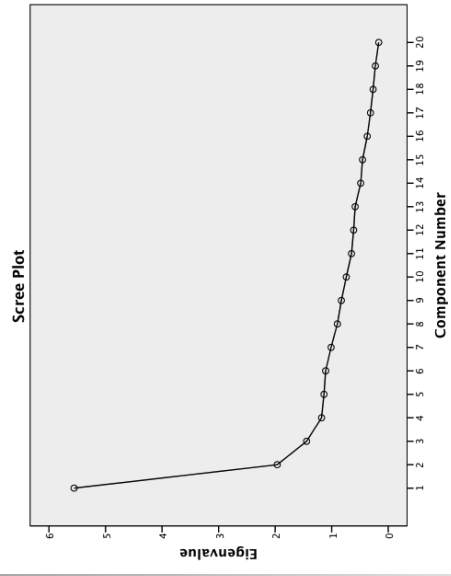
METHOD

- A sample of 109 long-term care staff completed the 20-item PDQ as part of a larger battery of measures.
- Negatively-phrased items were reverse-scored.
- Principal Axis Factoring (PAF) of the PDQ was then completed.

RESULTS

- The Kaiser-Maier-Olkin measure was used to confirm sampling adequacy; KMO = .73 (good; Hutcheson & Sofroniou, 1999).
- Item intercorrelations were sufficiently large for PAF using Bartlett's test of sphericity, χ^2 (190) = 716.36, p <.001.
- Therefore, an initial PAF was run to obtain eigenvalues for each component of the data. Seven components had eigenvalues over Kaiser's criterion of 1.
- However, a scree plot suggested a three-factor solution (**Figure 1**). Parallel analysis confirmed that three factors should be retained for PAF (Osborne, Costello, & Kello, 2008).
- A three-factor solution explained 44.81% of the variance in scores. **Table 1** shows the factor loadings after oblique (direct oblimin) rotation. Factors represented *Basic Respect, Positive Attitudes, and Absence of Negative Attitudes.*
- Reverse-scored items were the only ones to load onto the *Absence of Negative Attitudes* factor. Item 1 did not have a high loading on any factor, and item 6 loaded on two factors.

CONCLUSIONS

- PAF of the PDQ resulted in a three-factor solution.
- One factor was comprised entirely of reverse-scored items, suggesting that a method effect is contributing to the differential functioning of positively and negatively worded items.
- Although it may be helpful to rephrase the reverse-scored items, it is also possible that these factors are theoretically meaningful.
- Method effects (DiStefano & Motl, 2006) can be better evaluated with confirmatory factor analysis of competing factor models, but this requires a larger sample size.
- Given the small size of the current sample, these findings should be considered preliminary.

KEY REFERENCE

Hunter, P.V., Hadjistavropoulos, T., Smythe, W., Malloy, D., Kaasalainen, S., & Williams, J. (2013). The Personhood in Dementia Questionnaire (PDQ): Establishing an association between beliefs about personhood and health providers' approaches to person-centred care. *Journal of Aging Studies, 27(3),* 276–287.

TABLE 1: FACTOR LOADINGS

Factor	1	2	3
11. Residents with dementia can continue to play an important role in their families	.629		
10. Residents with dementia want to socialize with the people around them	.622		
20. Most residents with dementia feel the same range of emotions as I do	.537		
19. Residents with dementia have feelings about their experiences	.518		
13. Providing stimulation such as music is very helpful for a resident with end-stage dementia	.492		
12. Some residents with dementia have had an important role in my life	.457		
9. It is possible for residents with dementia to connect with each other in meaningful ways	.435		
15. Residents with end-stage dementia have some awareness of what is happening around them	.429		
1. Residents with dementia have a sense of purpose			
18. (R) Residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically		.918	
8. (R) Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines		.542	
17. (R) The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness		.526	
5. (R) Residents with end-stage dementia can no longer contribute to the world in any meaningful way		.514	
14. (R) As dementia advances, residents with dementia no longer experience basic feelings such as pleasure		.443	
4. (R) Residents with very advanced dementia are so low-functioning that they are no longer persons		.410	
16. (R) Residents with dementia who whine a lot should be isolated		.363	
6. Residents with dementia contribute to a sense of community within our long-term care facility	.409		.562
7. All residents with dementia should be treated with respect			.555
2. Most residents with dementia are still capable of making some informed choices about their lives			.477
3. Residents with dementia have a basic right to make any choices they can about their care			.411

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Psychometric Evaluation of the Telehealth Satisfaction Scale (TeSS)

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Background

Rural areas are disproportionately affected by the increasing prevalence of dementia globally because of the higher proportion of older adults and the geographic challenges in accessing necessary services. Rural-specific barriers to dementia care access include time, travel, cost, and lack of access to services and educational opportunities.

Telehealth Technology

- Satisfaction with telemedicine is an important research focus because it is a critical aspect of quality of care and health outcomes.[1]

- The most frequently measured dimensions of telehealth satisfaction are professional-patient interaction, patient experience, overall satisfaction, and technical aspects.[2] Reviews of patient satisfaction studies have identified significant methodological weaknesses in much of the research: small sample sizes, convenience samples, absence of a definition of satisfaction, and lack of reliable and valid tools.[1-3]

- Of the few studies that have reported on patient satisfaction with telehealth in programs aimed at individuals with memory problems, none have reported on the psychometric properties of the user satisfaction scales employed.

Objectives

This research is part of a larger on-going research program involving the development and evaluation of a Rural and Remote Clinic (RRMC) that incorporates telehealth video-conferencing with a one-stop interdisciplinary assessment in a tertiary care centre.

The aim of the current study is to evaluate the psychometric properties of the Telehealth Satisfaction Scale (TeSS), adopted for use in a memory clinic serving a rural and remote population.

Methods

- Leveque K. Telehealth provider satisfaction
- A single case design was used to evaluate telehealth (TH):
  - patients randomly assigned to either TH or in-person (IP) appointment for their first follow-up assessment
  - alternated between TH and IP for 6-week, 12-week, and 6-month follow-ups[4]
- Immediately following pre-clinic assessment and each follow-up TH appointment, patients and caregivers completed the TeSS. The psychometric evaluation reported here used data from the pre-clinic assessment to control for potential differences in satisfaction due to familiarity with telehealth over time.
- With data from 223 patients, factor analysis was conducted using principal components analysis (PCA) extraction method with varimax rotation on the 10-item TeSS, 5-item telehealth system satisfaction subscale, 5-item team satisfaction subscale.

Telehealth Satisfaction Scale (TeSS)

Satisfaction with telehealth was assessed with a 12-item scale used in previous TH studies in Saskatchewan, including First Nations communities,[5] pediatric surgery clinic,[6] and amputee clinic.[7] "Specialist" was replaced with "Memory Clinic Team."

The TeSS was designed to assess patients' satisfaction and comfort with aspects of the telehealth system, ease of accessing the telehealth site, and satisfaction with the Memory Clinic team and telehealth staff. The 12 items were rated on a 4-point Likert scale (1 = poor, 2 = fair, 3 = good, 4 = excellent) with higher scores indicating higher satisfaction. Two items were excluded from factor analysis: satisfaction with length of time to get appointment and overall treatment experience at using Telehealth. Examination of the scale items suggested that **two** dimensions of satisfaction were being evaluated:

- **system factors**, e.g., voice and visual quality
- **team factors**, e.g., skillfulness and respect of privacy

Results and Discussion

Table 1

Characteristics of Rural and Remote Memory Clinic patients (n=223)

Item	N	%
Gender		
Male	128	57.4
Female	95	42.6
Age[a] (Mean, range, SD)	71.5 (41-91, 11.0)	
< 65	52	23.3
65-74	46	20.6
75-84	81	36.3
≥ 85	23	10.3
Missing		
Diagnosis		
Alzheimer's disease	85	38.1
Mild cognitive impairment	25	11.2
Related Dementia[b]	49	22.0
Dementia not diagnosed	40	17.9
Missing	24	10.8
Distance (km) to telehealth site (Mean, range, SD)	33.0 (1-150, 42.1)	
Distance (km) to Memory Clinic site (Mean, range, SD)	260.9 (103-595, 102.3)	
Distance one-way (km) saved by telehealth (Mean, range, SD)	227.9 (34-594, 106.5)	

[a] At Clinic Day
[b] Vascular dementia, Dementia with lewy bodies, Frontotemporal dementia, Dementia multiple etiologies, Vascular cognitive impairment, Parkinson's Disease, IID, NPH, DMC, cognitive impairment not otherwise specified

Table 2

Factor analysis of reduced 10-item Telehealth Satisfaction Scale (TeSS) (n=223)

Item no.	Statement	Factor I
10	How well your privacy was respected	0.79
9	The courtesy, respect, sensitivity, and friendliness of the Memory Clinic team	0.78
8	The thoroughness, carefulness and skillfulness of the Memory Clinic team	0.77
7	The explanation of your treatment by the Memory Clinic team	0.76
11	How well the staff answered your questions about the equipment	0.75
2	The visual quality of the equipment	0.72
6	The length of time with the Memory Clinic team	0.71
1	The voice quality of the equipment	0.70
3	Your personal comfort in using the Telehealth system	0.68
5	The ease of getting to the telehealth department	0.54
	% Variance	54.09
	Eigenvalue	2.7
	Cronbach's α	0.90
	Sum Mean (range, SD)	35.5 (28-40, 3.75)

Table 3

Factor analysis of 5-item *Telehealth System Satisfaction* Subscale of 10-item Telehealth Satisfaction Scale (n=223)

Item no.	Statement	Factor I
2	The visual quality of the equipment	0.82
1	The voice quality of the equipment	0.79
11	How well the staff answered your questions about the equipment	0.74
3	Your personal comfort in using the Telehealth system	0.72
5	The ease of getting to the telehealth department	0.59
	% Variance	54.1
	Eigenvalue	2.70
	Cronbach's α	0.78
	Sum Mean (range, SD)	17.6 (13-20, 2.0)

Table 4

Factor analysis of 5-item *Team Satisfaction* Subscale of 10-item Telehealth Satisfaction Scale (n=223)

Item no.	Statement	Factor I
8	The thoroughness, carefulness and skillfulness of the Memory Clinic team	0.84
9	The courtesy, respect, sensitivity, and friendliness of the Memory Clinic team	0.83
7	The explanation of your treatment by the Memory Clinic team	0.80
10	How well your privacy was respected	0.79
6	The length of time with the Memory Clinic team	0.74
	% Variance	63.9
	Eigenvalue	3.19
	Cronbach's α	0.86
	Sum Mean (range, SD)	17.9 (12-20, 2.0)

Telehealth Satisfaction

Patients and caregivers expressed a high degree of satisfaction with their telehealth preclinic assessment (results not shown). The majority of scores on the scale items averaged higher than 3.5, indicating a rating of 'good' to 'excellent' satisfaction.

Factor Analysis

As demonstrated in Tables 2 through 4, factor loadings for all items in each of the three scales were greater than 0.40 (range 0.54 – 0.84), indicating that the items within each of the three scales loaded onto only one factor per scale and factor structures were strong for each scale.

The items within each of the three scales demonstrated high internal consistency reliability, as indicated by the Cronbach's alpha scores for the 10-item TeSS (0.90), 5-item telehealth system satisfaction subscale (0.78), and 5-item team satisfaction subscale (0.86).

The total variance explained by the 5-item team satisfaction factor (63.9%) is higher than the total variance explained by the 5-item telehealth system factor (54.1%) and the 10-item telehealth satisfaction factor (52.1%).

DISCUSSION

The construct validity and reliability of the 10-item TeSS and the two subscales are supported by the study findings. Factor analysis and Cronbach's alpha confirmed that the composite "system" and "team" subscales measured particular dimensions of satisfaction with telehealth.

The results of the current study support the use of all three scales in future studies, depending on the context of the study or intervention.

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APOE gene, environmental risk factors and their interactions in dementia among seniors

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① Key Points/Conclusions

✓ Seniors with ApoE ε4 alleles or ε3/ε4 genotypes were at risk of dementia.

✓ Those with more education had a reduced risk of dementia and cognitively impaired not demented (CIND). Previous health conditions (e·g· stroke, depression, etc.) increased the risk of dementia and CIND. Regular exercise decreased the risk of CIND.

✓ Seniors with ApoE ε3/ε4 genotype and pre-existing depression had a 7.97-fold greater risk of incident dementia after adjusting for other significant risk factors.

✓ Future studies should be encouraged to replicate these findings in other population settings. Seniors with depression and ApoE ε3/ε4 genotype are at increased risk of dementia and warranted more attention.

② Background

Dementia -Worldwide

❖ Prevalence. 24.2 million people suffering from dementia

❖ Incidence. 4.6 million new dementia cases are diagnosed every year.

❖ Etiology of dementia

❖ Hypothesis - A combination of interacting genetic, social environmental, and biological elements, and there is an emerging emphasis on joint effect of these factors.

❖ Risk factors - Diabetes, apolipoprotein E gene (ApoE) ε4 allele, smoking, and depressio

❖ Protective factors - Cognitive engagement and physical activity.

Comorbidity

❖ Depression. Dementia patients are likely to have depressive behaviors, and those with depression will have an increased risk of dementia and a higher probability of earlier death.

❖ Diabetes. Depression is associated with a 60% increased risk of type 2 diabetes, whereas type 2 diabetes is only modestly associated with the onset of depression.

❖ Cognitively impaired not demented. People who are cognitively impaired not demented (CIND) are at a great risk of having dementia.

Research situation

❖ Trend. A growing interest in comorbidity between depression and dementia has been found.

❖ Gap. There is still a great need for research that includes a life course approach to the comorbidity between depression and dementia.
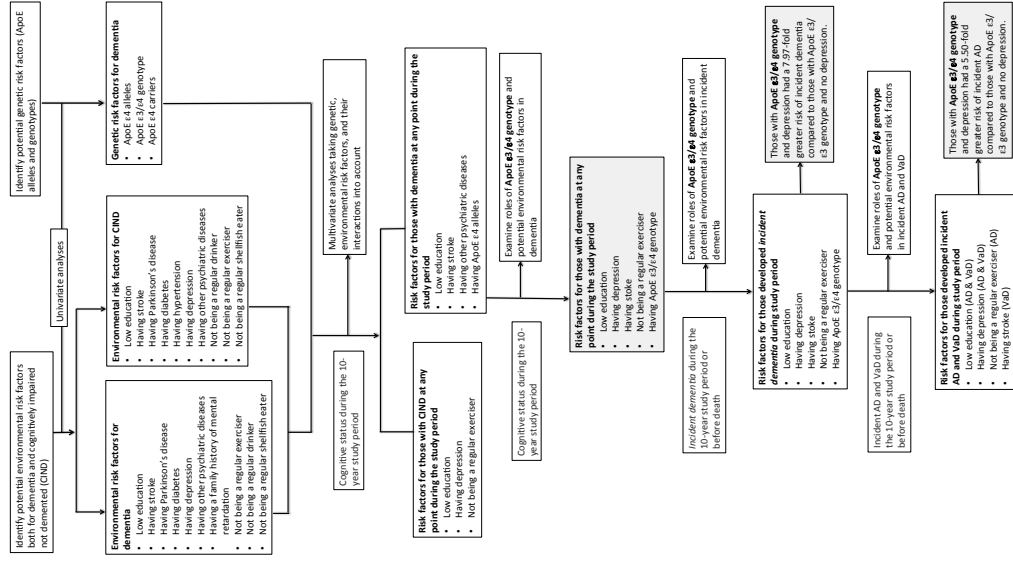
③ Objectives

Using a longitudinal dataset we aimed to:

◇ 1) examine roles of ApoE gene alleles and genotypes in dementia and CIND;

◇ 2) explore roles of environmental risk factors in dementia and CIND including pre-existing health conditions (i.e. depression, diabetes, etc.), family history of diseases, and lifestyle factors; and,

◇ 3) explore interactions between genetic and environmental factors in dementia and CIND.

④ Methods

Data

❖ Source. Canadian Study of Health and Aging (CSHA).

❖ Characteristics.
  ○ A national longitudinal study
  ○ N=10,263 people aged 65+
  ○ Assessed at 5-year intervals: beginning at 1991 (Wave I), 1996 (Wave II), and a final time at 2001 (Wave III).
  ○ Used a two-stage screening–clinical diagnostic assessment procedure.

Study cohort

❖ Participants had to:
  1) have ApoE information available;
  2) be of Caucasian origin (97% of those with ApoE information self-identified themselves as Caucasians); and
  3) have a diagnosis of cognitive status at all waves of CSHA or before death.

Measures

❖ Genetic factors – ApoE alleles and genotypes.
❖ Diagnosis of dementia – Neuropsychological testing and clinical workup following the Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R) criteria.
❖ Environmental risk factors
  ○ Socio-demographic factors
  ○ Self-reported previous health status
  ○ Family history of diseases
  ○ Lifestyle factors

Analyses

❖ Comparison tests
❖ Genetic association tests
❖ Multivariate analyses

Acknowledgements

❖ CIHR-Public Health and the Agricultural Rural Ecosystem(PHARE) program
❖ Saskatchewan Health Research Foundation (SHRF)
❖ CFI Leaders Opportunity Foundation Award

⑤ Results

Identify potential environmental risk factors both for dementia and cognitively impaired not demented (CIND)

Identify potential genetic risk factors (ApoE alleles and genotypes)

Univariate analyses

Environmental risk factors for dementia
- Low education
- Having stroke
- Having Parkinson's disease
- Having diabetes
- Having depression
- Having other psychiatric diseases
- Having a family history of mental retardation
- Not being a regular exerciser
- Not being a regular drinker
- Not being a regular shellfish eater

Environmental risk factors for CIND
- Low education
- Having stroke
- Having Parkinson's disease
- Having diabetes
- Having hypertension
- Having depression
- Having other psychiatric diseases
- Not being a regular drinker
- Not being a regular exerciser
- Not being a regular shellfish eater

Genetic risk factors for dementia
- ApoE ε4 alleles
- ApoE ε3/ε4 genotype
- ApoE ε4 carriers

Multivariate analyses taking genetic, environmental risk factors, and their interactions into account

Cognitive status during the 10-year study period

Risk factors for those with CIND at any point during the study period
- Low education
- Having depression
- Not being a regular exerciser

Risk factors for those with dementia at any point during the study period
- Low education
- Having stroke
- Having other psychiatric diseases
- Having ApoE ε4 alleles

Cognitive status during the 10-year study period

Examine roles of **ApoE ε3/ε4 genotype** and potential environmental risk factors in dementia

Risk factors for those with dementia at any point during the study period
- Low education
- Having depression
- Having stroke
- Not being a regular exerciser
- Having ApoE ε3/ε4 genotype

Examine roles of **ApoE ε3/ε4 genotype** and potential environmental risk factors in incident dementia

Incident dementia during the 10-year study period or before death

Risk factors for those developed incident dementia during study period
- Low education
- Having depression
- Having stroke
- Not being a regular exerciser
- Having ApoE ε3/ε4 genotype

Those with **ApoE ε3/ε4 genotype** and depression had a 7.97-fold greater risk of incident dementia compared to those with ApoE ε3/ε3 genotype and no depression.

Examine roles of **ApoE ε3/ε4 genotype** and potential environmental risk factors in incident AD and VaD

Incident AD and VaD during the 10-year study period or before death

Risk factors for those developed incident AD and VaD during study period
- Low education (AD & VaD)
- Having depression (AD & VaD)
- Not being a regular exerciser (AD)
- Having stroke (VaD)

Those with **ApoE ε3/ε4 genotype** and depression had a 5.50-fold greater risk of incident AD compared to those with ApoE ε3/ε3 genotype and no depression.

Figure 1 Summary of analyses and findings

Early referral for support of dementia caregivers: Evaluation of the First Link demonstration project

Carrie McAiney[1], David Harvey[2], Loretta M. Hillier[3], Paul Stolee[4], Mary Schultz[5], Joanne Michael[6]

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[3]Lawson Health Institute, St Joseph's Health Centre London; [4]Health Studies & Gerontology, University of Waterloo; [5]Alzheimer Society of Canada;
[6]Alzheimer Society of Saskatchewan

Objectives and Study

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

First Link
• Innovative referral program developed and implemented by Alzheimer Society of Ontario.
• Links individuals diagnosed with Alzheimer's or a related dementia and their families to a community of learning, services and support.
• Utilizes the local Alzheimer Society and other community partners.
• **Goal**: to link individuals and their family members *as early as possible* in the disease process.

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

Methods

Design
  ~ Mixed method, prospective cohort design

Data tracking
  ~ Referrals
  ~ Activities undertaken by First Link® Coordinators

Surveys
  ~ Caregivers
  ~ Primary care providers

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

Project Findings

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

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

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

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

Conclusions

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

References

McAiney, C.A., Harvey, D. & Schulz, M. (2008). First Link: Strengthening Primary Care Partnerships for Dementia Support. *Canadian Journal of Community Mental Health*, 27(2), 117-127.
Pratt, R., Clare, L., & Kirchner, V. (2006). 'It's like a revolving door syndrome': Professional perspectives on models of access to services for people with early-stage dementia. *Aging and Mental Health, 10*, 55-62.

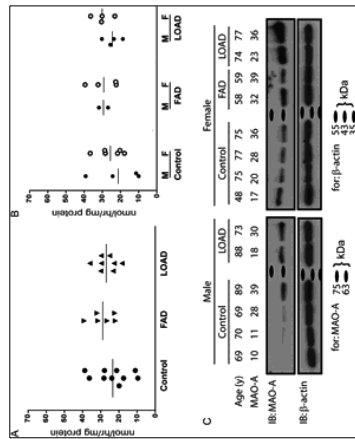# Is Alzheimer disease-related pathology different in males and females?

Bradley M. Chaharyn, Kelsey Fehr, Paul R. Pennington, Zelan Wei and Darrell D. Mousseau.

Cell Signalling Laboratory, Department of Psychiatry, University of Saskatchewan.
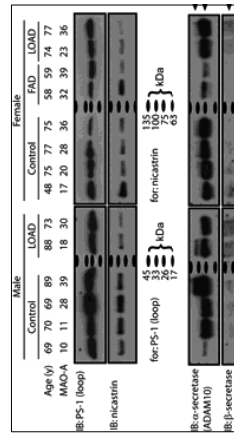
Introduction

A history of depression increases the chance of developing Alzheimer disease (AD) in later life, yet it is still unclear how the one leads to the other. We used human autopsied control and AD cortical samples to examine MAO-A activity and expression. We observed that MAO-A activity and expression correlate in males, but not in females. We also noted similar patterns of expression of some of the major secretases in brain. These changes were not maintained in the AD samples. This suggests both sex-dependent and AD-dependent patterns of expression. A closer look at some of the fragments of the secretase-substrate Amyloid Precursor Protein (APP) reveals unexpected patterns of N-terminal fragments, that, again, differ between males and females. An examination of APP fragmentation patterns in male APP transgenic mice reveals age-dependent and region-specific changes in APP processing that coincide with changes in the level of 'depression' (based on the tail-suspension test) in these mice. We continue to examine the changes in APP processing using autopsied hippocampal samples from the same donors as used in our cortical studies in the hopes of a clearer understanding of two mental health issues with global impact, namely depression and AD. Perhaps our observations could provide for a means of identifying depressed individuals who might be at highest risk of AD in later life.

Results

1. MAO-A activity corresponds with MAO-A protein expression in males, but not in females.

(A) MAO-A activity was not significantly different in autopsied cortical samples from controls and from patients with Early-Onset/Familial AD (FAD) or Late-Onset AD (LOAD). (B) Subtle differences could be detected if the samples were separated according to the sex of the donour. (C) Male and female samples were selected based on those with the lowest MAO-A activity and those with the highest. In these samples, MAO-A activity appears to correlate with MAO-A protein expression in control males, but not in control females. This difference is lost in the AD tissues. These results suggest the potential for post-translation regulation of MAO-A function.

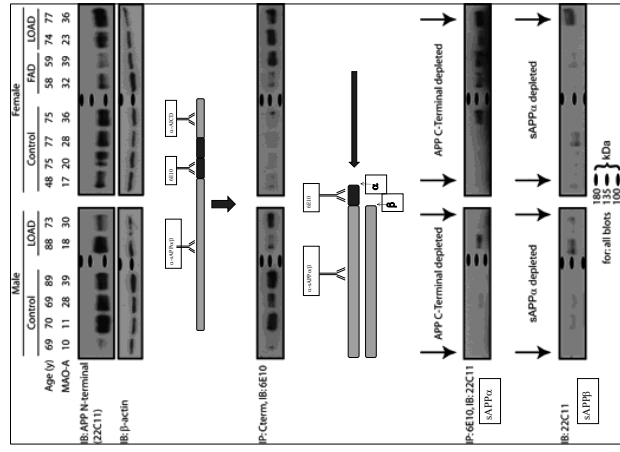### 2. The levels of secretase expression differs in a sex-dependent and AD-dependent manner.

We recently demonstrated that presenilin-1 (PS-1)/γ-secretase can directly regulate MAO-A activity. The same samples as above were analyzed for levels of the primary secretases involved in AD. The levels of PS-1 (γ-secretase) and α-secretase parallel MAO-A activity in males, but not in females. Levels of β-secretase only increase in LOAD samples, suggesting a shift towards amyloidogenic APP processing in these individuals.

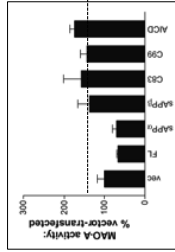### 3. APP is a substrate for α-, β- and γ-secretases.
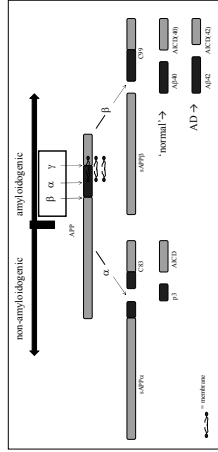
4. The pattern of APP fragments differs between males and females.

5. The different APP fragments exert different influences on MAO-A activity in human neuronal cells.

The overexpression of the major secretase-mediated APP fragments influence MAO-A activity in human SH-Sy5y cell cultures.

6. Young mice that express an AD-related APP are less depressed than older mice expressing the same gene.
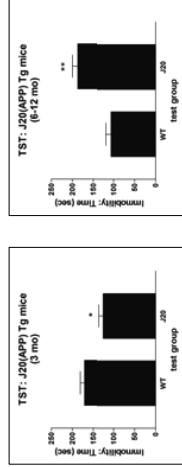
Using the tail suspension (TST) test for behavioural despair, e.g. 'depression', we observed that (left) young (3 month-old) mice expressing the AD-related APP allele (J20) were less depressed than (right) older (6 month-old) mice expressing APP. WT: wildtype (littermates)

7. Immunoprecipitation strategies reveal differences in young and old male J20 mouse cortex and hippocampus.

Cortical and hippocampal extracts from young (3 mo) and old (6 mo) J20 mice were used to examine for levels of expression of the full length APP and sAPPα and sAPPβ fragments. The same extracts were used to determine the levels of expression of the β-secretase-mediated (C99) and α-secretase-mediated (C83) C-terminal fragments.
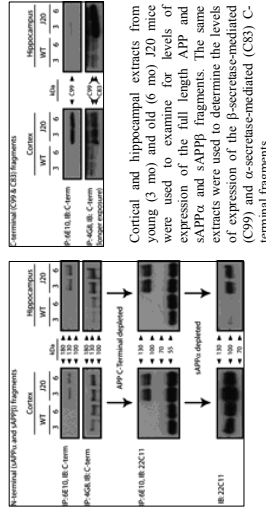
Sequential immunoprecipitation strategies reveal that the expression pattern of APP and its major secretase-mediated fragments differ in males and females. Females clearly have far more detectable APP fragments in AD and the sAPPα is negatively

General conclusions:

- MAO-A expression is different in males and females.
- Secretases and the secretase substrate APP are different in males and females.
- APP could be an endogenous regulator of MAO-A function.

The Experience of Sons as Carers for a Parent Diagnosed with Dementia at the Rural and Remote Memory Clinic (RRMC)

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Aim

To explore the experiences of sons as carers for a parent with dementia and to understand their contributions and challenges in rural settings

Method

- Interpretive Description (Thorne, 2008) approach
- Retrospective interviews conducted in-person and via telephone

  - Semi-structured interview guide adapted from Harris and Bichler's *Men Giving Care: Reflections of Sons and Husbands* (1997)
  - Interviews focused on roles, stress and coping, family relations, motivation, and meaning of experience
  - Constant comparison analysis

Participants

- Study participants were primary carers of parents treated at RRMC

Total RRMC primary caregivers	210 (100%)
Son primary caregivers	19 (9.0%)
Sons who, upon contact, functioned in primary caregiving role for parent	6 (2.9%)
Age range of Sons in primary carer role	32 – 57yr (M=50.7yr)
Parent diagnoses	3 Alzheimer Disease, 1 Vascular Dementia, 1 Mixed Dementia, 1 Frontotemporal Dementia
Parent	5 Mothers, 1 Father

- At the time of interview, 3 parents were deceased, 1 in long-term care, and 1 living independently
- 4 sons lived in same community as parent, 1 lived 24km and 1 lived 227km from parent
- All sons were employed; 1 semi-retired

Findings

Interpretation of the experiences of sons as carers included:

Emotional Engagement: All sons actively engaged in process of caring. Strong emotional reactions to the carer role (anxiety about safety, frustration with health system, anguish over symptoms of decline).

Resilience: Sense of duty permeated role; most were oldest sons. Described as a full-time job but were able to "get the job done and move on." None used language of burden except to negate the idea; "She'll never be a burden no matter what." Managed to find positives in caring.

Gender and Geography: No expression of concern about what might be considered 'women's work'; embraced carer role. None did personal care; one expressed concern that his parent would be embarrassed. Geography appeared to be a key factor in determining who provided care; proximity was mentioned often. Rural context elicited mixed reactions; positive in some cases but disadvantage of "falling through the cracks".

Care for the Caregiver: Little use of formal services; term 'caregiver' rejected as this was family. When support was not found during crisis son felt "hung out to dry".

Meaning of Care Roles: Carer role a source of pride; rewarding in spite of challenges, "a role you grow into" and an opportunity to "give back".

Conclusions

- Though relatively few sons have taken on role of primary carer, the 6 in this study were committed
- Support, when needed, was sourced by partners and siblings rather than through formal services (exception: dangerous behaviour associated with frontotemporal dementia; help sought but turned down by family physician and hospital)

  - More education for families and healthcare workers is needed, and formal support when behaviour is unsafe

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