Poster Session and Spotlight on Research Evening

Summit 12

12th Annual Summit of the Knowledge Network in Rural and Remote Dementia Care

November 5 & 6
Western Development Museum
Saskatoon, SK

RaDAR
RURAL DEMENTIA ACTION RESEARCH

UNIVERSITY OF SASKATCHEWAN

Alzheimer Society
SASKATCHEWAN

CIHR IRSC
Canadian Institutes of Health Research
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Fondation Brain Canada Foundation

Tuesday November 5th, 2019
Poster Program & Spotlight on Research Evening
6:30 PM – 9:00 pm at the Western Development Museum (Butler Byers Hall)

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Interventions to Reduce Stigma of Dementia: Findings from a Scoping Review

Juanita Bacsu[1,2], Shanthi Johnson[1,3], Marc Viger[1,4],Tom McIntosh[1,2], Bonnie Jeffery[1,2], Nuelle Novik[1,2], & Paul Hackett[1,4]

1Saskatchewan Population Health & Evaluation Research Unit, 2University of Regina, 3University of Alberta, 4University of Saskatchewan

Introduction

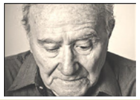
- Age is the greatest risk factor for dementia, and the number of adults aged 65+ is rising.
- Research suggests that there is prevalent stigma attached to dementia and poor cognitive health in older adults (Alzheimer's Disease International, 2012).
- Stigma can be harmful and self-fulfilling for older adults by promoting stereotypes of dementia, and may lead to social isolation, lack of physical mobility, and financial burden (World Health Organization, 2012).
- Dementia-related stigma may detrimentally impact relationships, interactions with health providers, attitudes about service utilization, and lead to social isolation, feelings of shame, loss of status, and a decreased quality of life (Riley, Burgener, & Buckwalter, 2014).
- Stigma of dementia is a well-documented issue among different groups of people such as students, family members, dementia care workers, and health professionals (ADI, 2012).
- Research on interventions to reduce dementia-related stigma are a relatively new and emerging field.

Objectives

1. To explore the literature on interventions to reduce dementia-related stigma; and
2. To identify strength-based components of interventions to reduce stigma of dementia.

Methods

- ➢ Guided by Arksey and O'Malley's (2005) five-stage framework, a scoping review was conducted to explore peer-reviewed literature on anti-stigma interventions of dementia.
- ➢ Electronic databases searched included: PubMed, Medline, CINAHL, Web of Science, PsycINFO, Google Scholar, and Social Services Abstracts.
- ➢ Stigma Reduction Theory (Corrigan & Penn, 2005) used to classify interventions: *education* (to dispel myths with facts and accurate information); *contact* (to provide interaction with persons with dementia); *mixed* (combination of education and contact interventions); and *protest* (to suppress negative attitudes and challenge stereotypes of dementia).



Findings

- From the initial 744 records, 21 articles were included in the review.
- A variety of education, contact, and mixed interventions were identified.
- *Education interventions* (11 studies) included: presentations, films, theatre, and curriculums.
- Strength-based components of education interventions included:
  - ➢ Using multiple mediums to improve dementia-related knowledge and information;
  - ➢ Teaching that dementia is more than memory loss;
  - ➢ Developing culturally and context-informed strategies tailored towards specific audiences;
  - ➢ Providing key facts to challenge myths.
- *Contact interventions* (8 studies) identified: intergenerational storytelling, performing arts groups (e.g., intergenerational choir, ballet, and orchestra), and visual arts programs.
- Strength-based components of contact interventions included:
  - ➢ Highlighting the achievements of people with dementia;
  - ➢ Showing that it is possible to lead an active life with dementia and that there are different stages;
  - ➢ Working as a team and engaging in purposeful learning with a shared objective.
- *Mixed interventions* (2 studies) included: an educational event with the involvement of people with dementia as speakers; and educational modules and clinical rotations with people with dementia and nursing students.
- Strength-based components of mixed interventions included:
  - ➢ Involving people with dementia as educators, spokespersons, and champions to reduce stigma;
  - ➢ Using experiential learning/clinical placements with nursing students and people with dementia.

Discussion

- Addressing dementia-related stigma is necessary to optimize geriatric health services, facilitate preventative interventions, and support the uptake of early dementia diagnosis.
- Findings from this research can help to inform the development of anti-stigma interventions and improve the quality of care for people with dementia. within the community.

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Evaluation of Interprofessional, Team-based Dementia Assessment and Diagnosis in Rural Primary Health Care:

Patient and Family Perspectives

Melanie Bayly, Debra Morgan, Julie Kosteniuk, Amanda Froehlich Chow, & Valerie Elliot

Centre for Health and Safety in Agriculture, University of Saskatchewan

Background & Methods

- Diagnosis and management of dementia is ideally situated within primary health care (PHC)[1], especially in rural communities with limited resources[2,3]
- In partnership with 3 rural PHC teams in Saskatchewan, the RaDAR team has developed team-based rural memory clinics
- The goal of the current work was to explore the assessment and diagnosis experiences of clinic patients and families
- Data were collected via phone interviews and mail-in surveys

Rural PHC Memory Clinics

- Interprofessional team (Physician/NP, OT, PT, Home Care Nurse. Social Worker, Alzheimer Society First Link Coordinator) assess the patient and speak with family members
- Half-day assessments end with discussion of diagnosis/findings and next steps
- Located in 3 rural communities of pop <11,000

Preliminary Findings

Participants

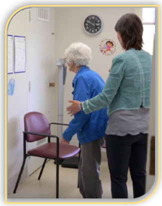
6 Phone interviews

Female patient and husband
Daughter
Daughter
Daughter & Son-in-law
Wife
Male patient and wife

12 Surveys

Patient=1
Family=6
Together=5

Males=6
Females=11



26 Total participants to-date

Qualitative interview and survey data suggest main aspects of positive patient and family clinic experiences:

Local, rural-based care *(comfort and convenience)*

> ***"It is wonderful to see this clinic in a small town. It is so important to the elderly to have local health care and not have to travel many miles or come to a big city to get help."***

Being heard *(positive interactions & clinic duration)*

> ***"You got to have input, and feedback... And you never felt rushed. And they were very open to any kind of questions, you really felt like you had a lot of hope."***

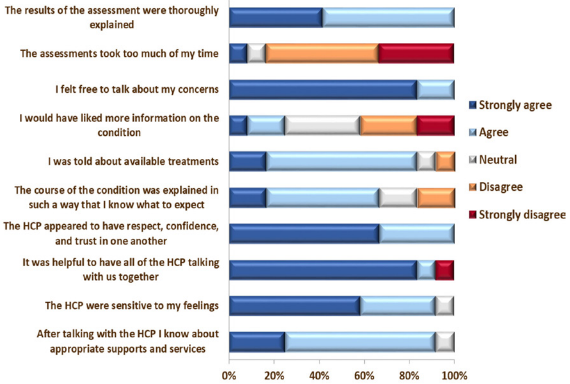
Everyone in the same room and on the same page *(team-based model of care, end of clinic discussion)*

> ***"All of those folks as well as my mom, my dad, my brother and I, hearing the same message... it's so helpful in trying to determine what do we need to do, how do we need to help this person, how do we need to help the family."***

Information communication *(clinic processes, timely follow-up, dementia information)* could be improved.

Quantitative data also illustrated the value of a half-day, team-based memory clinic approach (Figure 1).

Figure 1. Preliminary feedback from the memory clinic survey



Conclusions

- Patient and family experiences with the rural memory clinics have been very positive; attendees felt at ease during the clinics and appreciated the team's professionalism, expertise, openness to questions, sensitivity, and understanding. An area for improvement is communication, especially about the clinic.

- Key elements to the success of the rural memory clinics appear to be their locality, the multi-disciplinary team format, positive team functioning, a patient/family centered approach, and informative communication. Findings are informing further refinement of the rural memory clinics.

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2. Dal Bello-Haas VP, Cammer A, Morgan D, Stewart N, and Kosteniuk J. Rural and remote dementia care challenges and needs: Perspectives of formal and informal care providers residing in Saskatchewan, Canada. Rural Remote Health. 2014;14(3):2747.

3. Morgan D, Innes A, and Kosteniuk J. Dementia care in rural and remote settings: A systematic review of formal or paid care. Maturitas. 2011 Jan;68(1):17-33. doi:10.1016/j.maturitas.2010.09.008

Mobile Recreation Therapy Services; Private Practice, In Rural Saskatchewan and Surrounding Area.

Donna BoserKelly, Recreation Therapist

Developing Strengths and Resources in planning goals, dreams and aspirations, Therapeutic Recreation Practice: A Strengths Approach. (Anderson and L.Heyne, 2012 pg.66).

Recreation Therapy Designed Referral form used by Physicians.

Set up appointment, meet with client and family using the Leisure Diagnostic Battery assessment and the results will identify what the strengths are and or areas to work on in the various domains.

A Recreation Treatment plan is developed and designed with the clients interests, medical information and abilities.

Set goals and Dare to Dream.

Documentation of assessment summary, progress notes and plan updates.

Work closely with family, health professionals in the community along with volunteers, friends and organizations.

Visit one time per week for 8 weeks.

Reassess, results show any changes to be made or maintained.

The client is discharged or continues with the Mobile Recreation Therapy Services

Recreation Therapists assess, plan, implement and evaluate and coordinate recreation based treatment plans for people of all ages and abilities.

The Mobile Recreation Therapy service is delivered on site and offered in clinical, residential and community settings.

An insurance is purchased yearly

Town Business Licence is purchased yearly

Organizations: CTRA and SARP membership renewal annually

Own vehicle

Equipment and supplies

<u>Quality Assurance checklist:</u>

Qualifications – Proof of Training

Ongoing education is offered with the organizations

Documentation, Physicians orders for Leisure modifications

Physical environment, calendar for each month

Program evaluation.

Activity Analysis form completed for all activities offered

Activity program review

Programs offered that meet the diversity of clients needs and abilities.

Advocate and recommendations on a continual basis (Martini, Weeks and Wirth 2011,p.303).

Leisure Ability Model:

Functional intervention – Improve functional ability

Leisure Education– Acquire Leisure Knowledge and skills

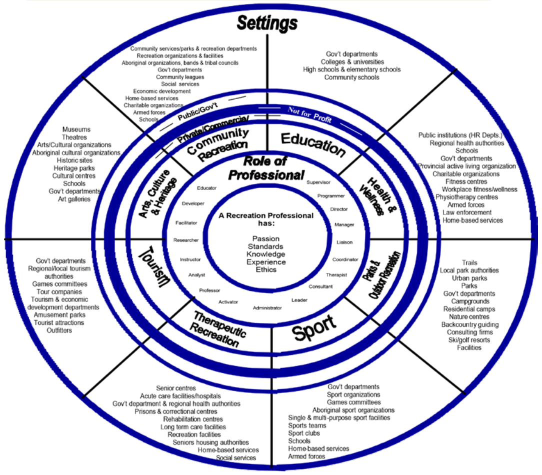
Recreation Participation – Engage in organized participation opportunities.(Stumbo, Peterson, 2000, p.15).

Codes of Ethics, Values and Standard of Practice, Recreation Therapists, as members of Saskatchewan Association of Recreation Professionals and Canadian Therapeutic Recreation Association.

We value professional leadership in the leisure service field.

Saskatchewan Association of Recreation Professionals

Model of the Recreation Profession in Saskatchewan



© S.A.R.P., 2004 *Based on a model developed by the Alberta Recreation & Parks Association, with permission.*

This is my friend and client Betty she has advanced dementia. She was referred by her Doctor. We work closely with her family and her friends in the community. Her assessment showed strength in music, sport and walking. An intervention and program began weekly. Her abilities have been improving her sessions have been documented and assessment results available using The Leisure Diagnostic Battery Assessment, Activity Type, Preference Inventory (permission by signing a waiver and also with family). Betty is becoming more social and she is now playing the piano, before she was sleeping a lot, now she enjoys the lifestyle she used to have which provides her with an improved quality of life.

Physical, Social, Emotional

Quality Of Life Domains

Spiritual and Cognitive

Therapeutic Program Design, (Peterson, Stumbo, 2000, p.79)

Nutrition Care for Residents with Dementia in Long-Term Care Homes: Umbrella Review of Care Aide and Registered Dietitian Services

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

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

Background

Dementia is the top chronic condition prompting relocation to long-term care (LTC) (ADI, 2013) and 60% of Canadian LTC residents have a diagnosis of dementia (CIHI, 2016). Persons with dementia are at higher risk for malnutrition due to both 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, pressure ulcer formation), and negatively impact quality of life.

Recent attention has highlighted the distinct food and nutrition needs of LTC residents with dementia living in LTC. Nutrition care involves assessment of nutritional need, development of an individualized resident nutrition care plan, and provision of safe and appropriate food that fulfills nutritional requirements. Nutrition care is crucial in preventing/addressing malnutrition and enhancing resident quality of life.

Within LTC, much of the direct care responsibilities lies with Care Aides who provide the day-to-day assistance including at mealtimes while registered dietitians (RDs) provide specialized nutrition care.

Many systematic reviews addressing nutrition care for residents with dementia have been published over the last 20 years. Thorough examination of the peer-reviewed, published literature on the best practices regarding nutrition care for persons with dementia living within LTC is a crucial to understanding the state of the evidence that informs practice.

Research Objectives

- **What is reported in peer-reviewed systematic reviews regarding nutrition care for residents with dementia in the LTC setting?**
- **Is consistency observed in nutrition care interventions and outcomes considered?**
- **What does the evidence suggest in terms of roles of RDs and care aides in provision of nutrition care for LTC residents with dementia?**

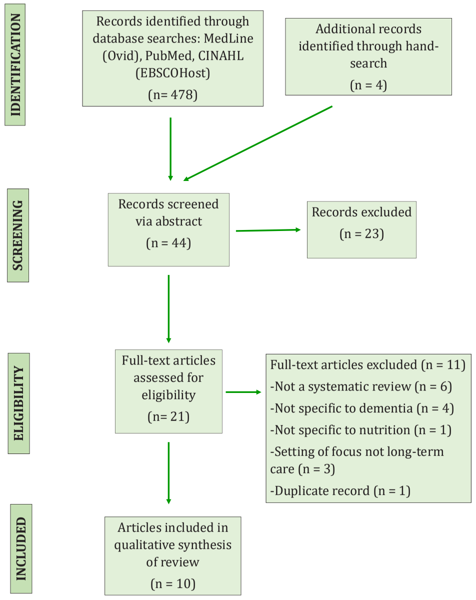
Methods

- Umbrella Review protocol → Systematic Reviews
- Databases: MedLine (Ovid MEDLINE), PubMed, and CINAHL (EBSCo Host)
- Combination of MeSH terms and keyword search terms addressed four categories: dementia, long-term care, nutrition, and reviews

Inclusion Criteria: peer-reviewed systematic reviews, written in English, published from 2000 to November 2017, including all search terms

Exclusion Criteria: non-English, non-systematic review method (e.g., narrative review), published prior to 2000, main setting not specific to LTC, study not focused on residents who have dementia, or study not focused on dementia as a condition

Figure 1: PRISMA Flow Diagram



Records identified through database searches: MedLine (Ovid), PubMed, CINAHL (EBSCOHost)
(n= 478)

Additional records identified through hand-search
(n = 4)

Records screened via abstract
(n = 44)

Records excluded
(n = 23)

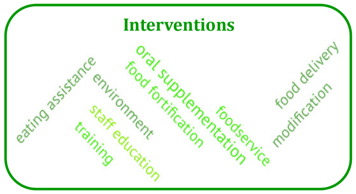
Full-text articles assessed for eligibility
(n= 21)

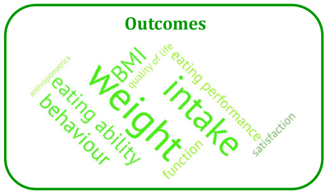
Full-text articles excluded (n = 11)
-Not a systematic review (n = 6)
-Not specific to dementia (n = 4)
-Not specific to nutrition (n = 1)
-Setting of focus not long-term care (n = 3)
-Duplicate record (n = 1)

Articles included in qualitative synthesis of review
(n = 10)

Findings

- Nutrition care for LTC residents with dementia is an important area of interest, as evidenced by the number of studies and systematic reviews on the topic
- Wide variety of nutrition care areas addressed by research
- Quality of evidence rated low to moderate
- Wide variety in types of interventions and little consistency in outcomes measured/reported
- Many recommendations made; in general a high proportion focused on staff education and training





Someone's Missing?

- Very often "LTC staff" were referred to as a homogenous group, or "nursing staff"
- Only 1 review addressed Care Aides specifically
- RDs were mentioned in only 3 of the reviews and recommendations re: RD role in resident care in 1 review

Conclusions and Implications for Practice

- Consensus on relevant outcomes pertaining to nutritional health and dementia could enhance applicability of findings
- Despite being specialists in nutrition or responsible for the majority of the direct care related to nutrition, RDs and Care Aides are largely absent from the published literature
- Advocacy for the roles of RDs and Care Aides is needed; interventions aimed at enhancing nutrition care for LTC residents with dementia should include RDs and Care Aides

Acknowledgements

End-of-life care for people living with dementia in rural areas: a scoping review

Valerie Elliot, Debra Morgan, Julie Kosteniuk, Amanda Froehlich Chow, Melanie Bayly, Megan E. O'Connell
Rural Dementia Action Research (RaDAR), University of Saskatchewan

Background

What is end-of-life/palliative care?

- **Specialized care for people facing life-limiting illnesses** like dementia[1]
- **Advanced disease stage services provided by health professionals for added comfort and relief** of patients and support and assistance of families[2]
- Services **can be in-hospital, at an outpatient clinic or at home**[3]

Why is end-of-life care for people with dementia important?

- It can play a **key role in improving and maintaining the best quality of life and death**[1,2]
- **Needs are increasing globally:** an aging population demands more end-of-life care services;[4] early planning should begin soon after diagnosis[5]
- People with dementia often face **gaps in end-of-life care**[6] and living in **rural areas can create additional challenges**[7]

Objectives:

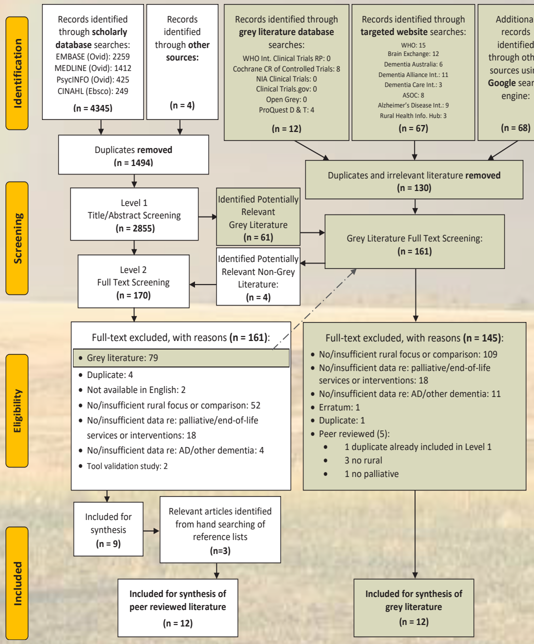
- **To conduct a scoping review of the literature to explore and summarize the evidence** regarding end-of-life care specifically for people with dementia living in rural areas
- **Map the evidence and identify gaps**
- **Help inform future research and efforts to improve quality of life and death** for people with dementia living in rural areas

Methods

Arksey & O'Malley[8] 5-Step Framework:

i) Identification of research questions
ii) Identification of relevant studies
iii) Study selection
iv) Data Charting
v) Collating, summarizing, reporting results

Modified PRISMA[9] Flow Diagram



Identification

Records identified through **scholarly database** searches:
EMBASE (Ovid): 2259
MEDLINE (Ovid): 1412
PsycINFO (Ovid): 425
CINAHL (Ebsco): 249
(n = 4345)

Records identified through **other sources:**
(n = 4)

Records identified through **grey literature database** searches:
WHO Int. Clinical Trials RP: 0
Cochrane CR of Controlled Trials: 8
NIA Clinical Trials: 0
Clinical Trials.gov: 0
Open Grey: 0
ProQuest D & T: 4
(n = 12)

Records identified through **targeted website** searches:
WHO: 15
Brain Exchange: 12
Dementia Australia: 6
Dementia Alliance Int.: 11
Dementia Care Int.: 3
ASOC: 8
Alzheimer's Disease Int.: 9
Rural Health Info. Hub: 3
(n = 67)

Additional records identified through other sources using **Google** search engine:
(n = 68)

Duplicates **removed**
(n = 1494)

Duplicates and irrelevant literature **removed**
(n = 130)

Screening

Level 1
Title/Abstract Screening
(n = 2855)

Identified Potentially Relevant Grey Literature
(n = 61)

Grey Literature Full Text Screening:
(n = 161)

Level 2
Full Text Screening
(n = 170)

Identified Potentially Relevant Non-Grey Literature:
(n = 4)

Eligibility

Full-text excluded, with reasons **(n = 161)**:
- Grey literature: 79
- Duplicate: 4
- Not available in English: 2
- No/insufficient rural focus or comparison: 52
- No/insufficient data re: palliative/end-of-life services or interventions: 18
- No/insufficient data re: AD/other dementia: 4
- Tool validation study: 2

Full-text excluded, with reasons **(n = 145)**:
- No/insufficient rural focus or comparison: 109
- No/insufficient data re: palliative/end-of-life services or interventions: 18
- No/insufficient data re: AD/other dementia: 11
- Erratum: 1
- Duplicate: 1
- Peer reviewed (5):
    - 1 duplicate already included in Level 1
    - 3 no rural
    - 1 no palliative

Included

Included for synthesis
(n = 9)

Relevant articles identified from hand searching of reference lists
(n=3)

Included for synthesis of peer reviewed literature
(n = 12)

Included for synthesis of grey literature
(n = 12)

Inclusion criteria: English language only, relevant to research objectives
- Peer-reviewed literature defined as "peer reviewed, original research"
- Grey literature defined as "Letters to the editor, opinion letters, commentaries, dissertations, study protocols, reviews, policy papers, reports, book chapters, and works published in non-peer-reviewed journals or non-published works such as web pages, news articles"

Results

Overview	
Palliative care services and interventions	. Mainly educational and supportive . In-person and remote delivery . Settings included in-hospital, clinic, long-term care, hospice, and in-home
Gap in evidence	. Only 12 peer-reviewed studies and 12 grey literature included for synthesis . Primary gap: rural-specific literature
Main Findings	
Knowledge about dementia in general and as a terminal illness	. Information and education was important and empowering . Understanding dementia as a terminal disease allowed for early discussions about care/ service options and advance planning
Availability and accessibility of dementia-related end-of-life care, support services, and preferred care settings	. Rural areas, often due to being sparsely populated with low resources, resulted in barriers such as: - travelling long distances for specialized care - inadequate internet coverage/expertise - inability to provide/receive care in-home until death
Care decision-making, value of person-centred approach, collaborative support	. Care services should be interdisciplinary, flexible and individualized . Care decisions should consider needs and desires of patient/family
Perspectives on artificial nutrition and hydration, comfort care	. Care providers expressed families' desire to prolong life, often prolonging suffering . Where rural-urban comparisons were made, desire to delay impending death appeared to be somewhat less in rural settings
Quality of life and quality of death	Improved by: . Early discussion/advance planning . Tailoring care services/interventions to meet individual needs Worsened by: . Family desire to prolong life/suffering . Unpredictable end-of-life trajectory (long stays in specialized care away from home/family)

Conclusions

- **More research is needed on end-of-life care and support for rural people with dementia, families, and providers, to explore the unique experiences/needs of this group**
- **Findings can be used to inform future research, policy, and intervention strategies designed specifically for rural areas aimed at providing best care/support**

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Interdisciplinary Primary Health Care (PHC) Approaches for Dementia and Chronic Conditions: A Case Study

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University of Saskatchewan[1], Canadian Centre For Health and Safety in Agriculture[2], Rural Dementia Action Research Team RaDAR)[3], Department of Psychology[4]

Background

- Rural areas tend to have limited access and availability to health care professionals and services[1]; in turn, impacting the abilities of interdisciplinary PHC teams to work collaboratively. Moreover, minimal literature exists regarding the processes PHC teams employ when delivering care in rural settings.[2,3]
- The Rural Dementia Action Research (RaDAR) Team has developed an interdisciplinary rural PHC memory clinic model of dementia diagnosis and management; the current study assesses how rural PHC teams collaborate to deliver care on a daily basis and in the RaDAR memory clinics.

Objectives

- This study sought to explore:
  - a) interdisciplinary collaborative care approaches employed among rural PHC teams delivering care to those living with dementia and other chronic conditions;
  - b) and PHC team members' perceptions of factors (barriers and facilitators) affecting collaborative care, which may be unique to rural settings.

Methods

- PHC Team established 2013
- Population: 1,140 plus surrounding area
- 7 team members
- Interview participants:
  - 2 occupational therapists
  - 1 nurse
  - 1 dietitian

Team 1

- PHC Team established 2014
- Population: 10,870 plus surrounding area
- 10 team members
- Interview participants:
  - 1 Physician
  - 3 Social Workers
  - 1 Occupational Therapist
  - 1 PHC team Facilitator
  - 1 Physiotherapist
  - 1 Nurse Practitioner
  - 2 Home Care Nurses

Team 2

- PHC Team Established 2010
- Population approximately 2,000 across three communities
- 8 team members
- Interview Participants:
  - PHC Team Facilitator
  - 1 Nurse Practitioner
  - 2 Home Care Nurses

Team 3

Figure 1. Description of PHC teams and participants enrolled in the study

- A case study design was employed and participants included 3 PHC teams (Figure 1) from southern Saskatchewan who are currently working with the RaDAR team.
- Data were collected from the following sources:
  1) One-on-one semi structured interviews with PHC team members
  2) Annual PHC Team Effectiveness Surveys

Results

- Overall PHC teams felt that engaging in team-based collaborative care (as opposed to coordinated and consultative approaches) was the most efficient and effective way to deliver care; however it was not always possible.
- All teams identified benefits to both their own practices and for their patients as a result of participating in the RaDAR memory clinics.
- Key themes and quotes were identified to represent how PHC team members work together (Table 1).

Implications

- This research enhances knowledge about the impacts (positive and negative) of geographic locale (specifically rural settings) on team-based care approaches for dementia and other chronic conditions common among older adults.
- Specific collaborative care strategies can be incorporated and evaluated to enhance the RaDAR teams' model of dementia diagnosis and management.

Corresponding Research Question	Theme	Representative Quote
1. How do PHC team members work together (processes they use) to deliver care?	Degree of collaboration	*“Yeah, we love to do that [collaborate]…… unfortunately, I think just with the patient load that we're experiencing being down a provider [physician] and of course, money, they [the PHC team] haven't been able to make that work[working collaboratively]. “ (PW7)* *“Yeah, very collaborative. We're working very closely with occupational therapy, physiotherapy, nursing, speech language… Pharmacy.” (PW3)*
	Communication strategies and tools	*“Primarily [team engages in face to face communication], but we also do use email and phone if need be.” (PW3)* *“Well yeah when you look at the team format of communication, I'd say your EMR [Electronic Medical Record] is probably your biggest tool.” (PW4)*
	Importance of team leader	*“Teams really need somebody engaged as a leader to lead it, otherwise it tends to be very disorganized and disjointed.” (PW4)*
2. Are there benefits of collaborative team-based care in the RaDAR memory clinics	RaDAR memory clinic reduces pressure on team members	*“ It's [memory clinic] very helpful; it takes a lot of pressure off one team member when you do have those case conferences and opportunities to discuss things with the family.” (PK2)*
	RaDAR memory clinics enhances quality of care for patients and families	*“Oh, for sure. Yeah. It's [memory clinic] amazing. Just the difference and level of support that the patients are feeling. You can see it in that day and you know, they're reassured.” (PW4)*
3. What factors (barriers and facilitators) do PHC team members perceive as affecting team collaborations in rural settings?	Rural areas facilitate personal and professional relationships	*“I think in the rural facility, the nice thing is, is that we do know each other. Not only do we know each other personally but we know them professionally. We see these people in the grocery store, our kids go to daycare together and whatnot. That personal relationship, it's a little easier to get together and make decisions because you're comfortable and you know their face and their name. (PW7)*
	Travel associated with living in rural areas	*“So just physical distance to get here in order to collaborate with us on a client is sometime an impossibility, not that the phone isn't great or email isn't great, and we definitely use those resources because that's what we have. But to actually physically meet and discuss together with the client is always going to be your best solution but it's not always a possibility.” (PRW1)*

Table 1. Key themes and quotes representing collaborative care approaches and factors influencing care delivery in rural settings

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UNIVERSITY OF SASKATCHEWAN

IMPROVING ACCESS TO SUPPORT FOR CAREGIVERS: FOSTERING SELF-COMPASSION USING A MOBILE APP

Jennafer Neiser[1] , Nathan Reis[2], Donna Goodridge[3], Nathaniel Osgood[1], Allison Cammer[3], Jo Storozinski[4], Cesar Gonzales[4], Tim Haubrich[5], Bev Westberg[5], Laura Erickson-Lumb[6]

INTRODUCTION

Our project's goal is to look at whether a self-compassion and resource support program delivered via smartphone app can help to promote well-being and alleviate some of the stresses associated with caring for someone with dementia.

Self-compassion is an approach to dealing with challenging or difficult situations that fosters emotionally positive, understanding and non-judgmental attitudes. Self-compassion is a valuable coping skill and has been shown to reduce stress for various clinical populations.

THE SUPPORT PROGRAM

- The goal of the program is to foster new ways of coping to reduce caregiver stress
- 8-week program
- Designed to teach about self-care
- Provided in the form of podcasts and practice exercises
- Daily and weekly surveys provided to assess mental health: The Burden Scale, WHO-5 Scale, The Brief Cope Scale
- Participants are able to notify us if they have had a major change in routine or disruptive event

PROGRAM CURRICULUM

WEEK 1 - The Foundations

- Podcast 1 : Introduction to practices of Mindfulness and Self-Compassion
- Podcast 2 : Who Should Practice Mindfulness Self-Compassion
- Exercise - Soothing Touch and Self-Compassion

WEEK 2 - Mindfulness

- Podcast 3 : Living Well with Difficult Emotions and Situations
- Exercise - Thought Stopping Activity
- Exercise - Worry and Worry Time
- Meditation Breathing Exercises
- Meditation - For this One Moment

WEEK 3 - Nutrition, Sleep, and Exercise

- Introduction to Exercise
- Giving Physical Activity guidelines
- Exercise Routine Videos
- Introduction to the Importance of Sleep
- The Importance of Nutrition

WEEK 4 - Coping with Stress

- Podcast 4 : Caregiver Stress
- Podcast 5 Self-Reflection Exercise: Unpacking Fierce Compassion
- Podcast 5.5 : Setting Healthy Limits Boundaries
- Meditation – Giving and Receiving
- Meditation – Opening the Heart Space
- Podcast 6 : Equanimity and Compassion Practice
- Meditation – Connecting to Your Faith

WEEK 5 - Forgiveness and Relationships

- Podcast 7 Practice : The Role of Self-Compassion in Relationships and Self-Compassion Break in Relationship
- Podcast 8 Practice : Introduction to Metta Practice and Metta Practice Meditation
- Podcast 8.5: Forgiveness
- Meditation – Forgiveness Practice

WEEK 6 - Coping with Change

- Meditation - Change, Loss , and Transition : When We Find Ourselves Resisting Change
- The parable of the trapeze – Danaan Parry

WEEK 7 - Gratitude

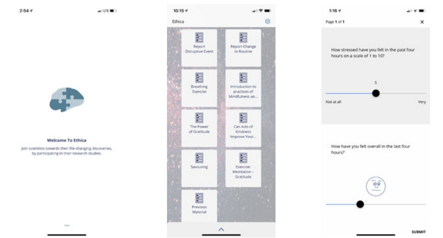
- Podcast 9 : The Power of Gratitude
- Podcast 10 : Can Acts of Kindness Improve Your Well-Being
- Podcast 11: Savouring
- Meditation – Gratitude

WEEK 8 – Deepening your Practice

- Meditation - Walking, Sensing and Savouring
- Meditation - Body Scan Practice

Listening devices are provided next to the poster if you would like to listen to an example of the podcasts and exercises created for this program.

THE APP



NEXT STEPS

- The app is currently being tested with our research team
- Recruit a cohort of 40 caregivers to participate in the study
- Refine the 8-week support program according to the feedback received
- Analyze the effect of self-care on mental health and stress using the measures taken throughout the study

PARTICIPATION AND FEEDBACK

Below are post-it notes and pens, we would love it if you would provide feedback or comments.

If you are interested in participating in this project or know any individuals who would please contact Nathan Reis.
Email: nathan.reis@usask.ca
Call/Text at (306)-700-7590

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[5] Family Project Advisors
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Profile Analysis of Dispersion Variability Across Diagnostic Criteria

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Introduction

Purpose

Investigate variability patterns of executive function (EF), immediate memory (IM) and delayed memory (DM) across individuals with differing diagnoses in hopes of finding novel diagnostic information.

Rationale

- 564,000 Canadians live with dementia, with this number expected to double in the next 10-15 years, placing burden on the health care system and caregiver networks[1].
- Timely diagnosis improves patient quality of life[2].
- Memory impairment is a hallmark of Alzheimer's Disease (AD)[3], but the patterns of decline are debated[4,5].
- It appears that decline due to AD generates distinct yet heterogenous profiles of memory dysfunction[6,7].
- There also appears to be patterns of decline in executive functioning[8] which may have diagnostic utility[9].
- Increases in intraindividual variability (IIV) have been linked to deleterious age-related outcomes[10], with dispersion (**within person across tasks**) being correlated to cognitive performance and employed at the level of cognitive domains[12].

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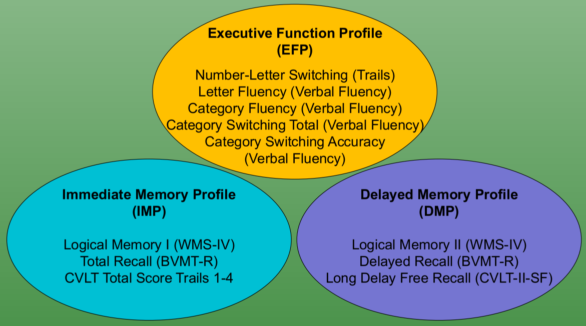
Methods

- Secondary analysis of RRMC clinical data.
- Individuals were classified as Subjective Cognitive Impairment (SCI), amnestic-Mild Cognitive Impairment (a-MCI), and AD.
- Constructed dispersion profiles for EF, IM and DM domains based on available tests in RRMC battery.
- Calculated estimates of dispersion variability for each person in each domain using regression to create a an intraindividual standard deviation (ISD) score.
- Employed tentative profile analysis to compare variability across SCI, a-MCI, and AD individuals.

Table 1. *Descriptives and demographics between groups.*

Characteristic	SCI	a-MCI	AD
n	35	9	27
Sex	20 male; 15 female	5 male; 4 female	11 male; 16 female
Mean Age	61.71 (12.04)	69.67 (10.99)	75.96 (7.03)
Average Highest Degree Achieved	Highschool/ Technical School	Some Highschool/ Technical School	Some Highschool/ Technical School



Executive Function Profile (EFP)
Number-Letter Switching (Trails)
Letter Fluency (Verbal Fluency)
Category Fluency (Verbal Fluency)
Category Switching Total (Verbal Fluency)
Category Switching Accuracy (Verbal Fluency)

Immediate Memory Profile (IMP)
Logical Memory I (WMS-IV)
Total Recall (BVMT-R)
CVLT Total Score Trails 1-4

Delayed Memory Profile (DMP)
Logical Memory II (WMS-IV)
Delayed Recall (BVMT-R)
Long Delay Free Recall (CVLT-II-SF)

Figure 2. Visual representation of the EMP, IMP, and DMP profiles and the test scores comprising them. Tests were selected from the current RRMC neuropsychological battery.

Table 3. Summary of Profile Analysis Hypotheses

Hypothesis	Statistic	Value	Significance (p-value)
Levels (Omnibus)	F-Test	F = 6.421	0.003*
Flatness	Pillai's Trace	F = 2.079	0.133
Parallelism	Pillai's Trace	F = 1.912	0.122

Table 3. Decomposing the Levels Hypothesis using One-Way ANOVAs

Profile	Statistic	Value	Significance (p-value)
EFP	F-Test	F = 0.174	0.840
IMP	F-Test	F = 7.151	0.002*
DMP	F-Test	F = 4.936	0.010*

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

Results

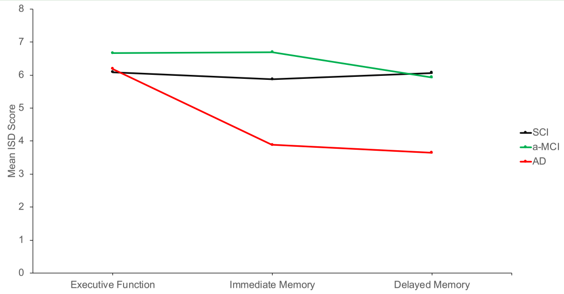


Figure 2. Visual representation of the mean ISD score across each profile (i.e., EFP, IMP, and DMP) indexed for SCI, a-MCI and AD individuals respectively.

- Significant effect of cognitive classification; difference between the IMP and DMP.
- Profiles were found to be flat; no differences in domain of functioning averaged across cognitive classification.
- Parallelism was identified; no interaction between cognitive classification and domain of functioning.

Discussion

- The apparent effect of group membership is consistent with previous theory of memory decline[6,13].
- Flatness and parallelism hypotheses did not return useful information.
- EFP, IMP, & DMP were likely under-representative of target constructs due to battery restrictions[14,15,16].
- Profile analysis may not be appropriate for small clinical samples due to violated statistical assumptions.
- It may also lack the sensitivity to detect IIV unless profiles are extremely well-defined due to collapsing of information.
- Future investigations should consider granular profiles (e.g., EF domains).

Adapting a Carer Co-designed Mental Wellness App for Rural Carers of Persons with Dementia: *RuralCARES*

M. T. Harrison, RN, MN Student; S. Peacock, RN, PhD; M. E. O'Connell, PhD, R.D. Psych;
L. Holtslander, RN, PhD; K. Haase, RN, PhD.; J. Michael; R. Macrae, RMN, MSc, PhD; M. Flath

BACKGROUND

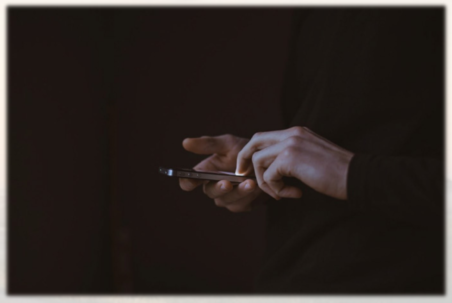
- In Saskatchewan, every 24 hours 10 people will develop dementia – this number will double by 2038[1]
- In Canada, we face (a) a significant shortage of long-term care beds, (b) a higher proportion of people living with dementia in their own home, and (c) an increase in demand for family carers[2]
- Interventions for carers of persons living with dementia are needed to improve mental well-being and social support
- Carers in rural settings and/or who care for someone with a rare-dementia are in greater need of support

OBJECTIVE

The purpose of this project is to adapt a mental wellness app to meet the needs of spousal carers to older adults living with dementia who reside in rural Saskatchewan.

METHODS

- Mixed methods approach, guided by Agile methodology[3] requiring:
  - Continuous teamwork
  - Incremental cycles of development
  - Cooperative relationships
  - An adaptive feedback cycle
- Demographic information and measures for social support and connectedness, depression, and life satisfaction (baseline and throughout) collected
- **Stage 1:** telehealth focus groups to gain information on what carers find helpful in obtaining support
- **Stage 2:** adaptation of app, then deployment for use by carers, use interviews for feedback



The RuralCARES App

- Target: rural carers of persons with rare-dementia across Saskatchewan
- What do carers want?:
  - ✓ Access to information
  - ✓ Live chat support
  - ✓ Notifications for dementia-related information (e.g., articles, television shows, etc.)
  - ✓ Access to emergent support
  - ✓ Potential to track/check-in on their relative

FUTURE STEPS

Family carers are vital to the health care system, supporting an increasing number of persons living with dementia to remain in their own homes. Initially this app will be an adjunct to current support groups offered by the Alzheimer Society of Saskatchewan. When this app proves useful to carers it could change how carers across Saskatchewan connect and obtain much needed support. This work is critical to support rural Saskatchewan residents to age well in place.

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Factors associated with a higher frequency of visits to Canadian long-term care residents

Hunter, P.V., Wickson-Griffiths, A., Myge, I., & Hadjistavropoulos, T.

BACKGROUND & OBJECTIVES

- Many family members visit and provide care to loved ones living in long-term care (LTC) settings.[1]
- Family presence generally contributes to residents' psychosocial and physical wellbeing.[1,2,3, 4]
- Working to promote family involvement may be a way to promote residents' wellbeing without adding to costs. [5]
- Although we know that some family members visit LTC homes more, and others less, the reasons are not clear. [1,6] For example, it is unclear whether these differences are best explained by individual preferences, family relationships, or characteristics of the long-term care home.
- Therefore, the objective of this study was to examine the extent to which a range of personal, resident, family relationship, and facility variables are associated with family member involvement in the province of Saskatchewan, Canada (SK).

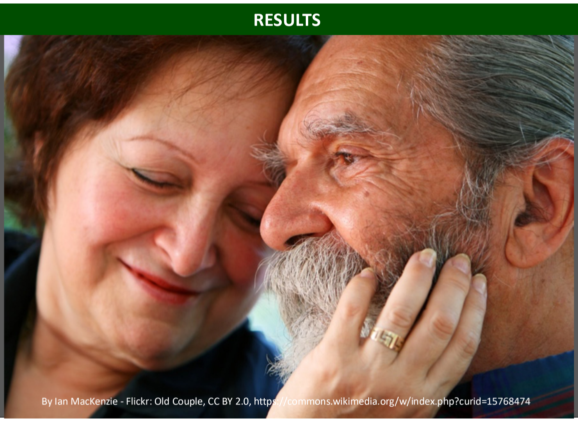
DESIGN & SAMPLING STRATEGY

- This study relied on a cross-sectional survey design. The survey focused on a range of variables potentially associated with family involvement in long-term care.
- We used a multi-stage cluster sampling approach to ensure representation by: geography/population size, LTC home ownership (health region or other), LTC home size, and LTC home values (religious or other).
- In total 1,000 survey packages were mailed by LTC homes. To avoid burden to the homes, no reminders were sent.

MEASURES

- Single item about visiting frequency **(primary outcome)**
- Person-Centred Climate Questionnairee[7]
- Family Involvement Questionnaire[8]
- Single Likert-type item about quality of care
- Selected items from SF-36[9]
  (self-perceived health)
- Marwit-Meuser Caregiver Grief Inventory–Short Form[10]
  (anticipatory grief - worry/loneliness and sadness)
- Death Attitude Profile[11]
  (death avoidance; death acceptance)
- Attitudes to Ageing Questionnaire[12]
  (expectations of loss or growth)
- Modified Personhood in Dementia Questionnaire[13]
  (beliefs about personhood)
- Filial Obligation Scale[14]
  (filial piety with respect to finances, physical support, and psychosocial support)
- Single Likert-type items about relationship quality
  (present vs. past)
- Other: 10-year age band, employment status, highest level of education, sex, respondent's relationship to the LTC resident (e.g., spouse, child), number of months since admission, whether the resident has decision-making capacity, whether the respondent is a substitute decision-maker, whether the respondent is the primary contact, kilometres from LTC

RESULTS



By Ian MacKenzie - Flickr: Old Couple, CC BY 2.0, https://commons.wikimedia.org/w/index.php?curid=15768474

T-tests (or Welch's t as appropriate) comparing higher-frequency (>= 7days/week) and lower-frequency visitors showed that higher-frequency visitors were significantly (p < . 05) more likely to live close to the LTC, report less health interference (p < .10), perceive their relationship with the resident as close, have a strong sense of responsibility for their family member's physical (p < .10) and emotional wellbeing, and feel worried and lonely (see Table). Regression results, omitted for brevity, were similar.

Chi-square tests of independence were performed to examine the relation between high-frequency visiting and the following dichotomous variables: primary contact person, substitute decision maker, immediate family member. Higher-frequency visitors were significantly more likely to be primary contact persons, designated decision makers, and immediate family members, X^2 (2, N = 255) = 15.54, p <.05; X^2 (2, N = 255) = 7.06, p <.05; X^2 (2, N = 254) = 3.72, p <.10; X^2 (2, N = 256) = 2.92; respectively.

Table: Group Means, Standard Deviations, and t values for high- and low-frequency visitors (N=74, 183)

	Maximum	M (SD) Full Sample	M (SD) More Frequent	M (SD) Less Frequent	t[1]
Estimated frequency of visits[c]	6.00	3.94 (1.20)	--	--	--
Total number of visits last 14 days	14.00	5.66 (4.46)	--	--	--
Age[a]	8.00	5.48 (1.05)	5.60 (1.11)	5.43 (1.02)	1.18
Education level[b]	8.00	4.91 (1.03)	4.78 (.94)	4.97 (1.06)	-1.30
Perceived health	5.00	3.52 (.98)	3.39 (1.06)	3.57 (.95)	-1.34
Perceived health interference	5.00	1.94 (1.16)	2.16 (1.23)	1.85 (1.13)	1.94*
Proximity to LTC[b]	**7.00**	**2.51 (1.26)**	**1.97 (.87)**	**2.73 (1.32)**	**-5.43**
Resident's length of stay (months)	--	30.36 (24.09)	26.93 (24.31)	31.75 (23.93)	-.146
Current quality of relationship	**10.00**	**7.04 (2.71)**	**7.72 (2.23)**	**6.77 (2.84)**	**2.85**
Prior quality of relationship	10.00	8.28 (1.77)	8.42 (1.59)	8.22 (1.85)	.80
Filial obligation (physical care)	5.00	3.95 (0.86)	4.10 (0.88)	3.89 (0.84)	1.75*
Filial obligation (emotional care)	**5.00**	**3.97 (0.90)**	**4.23 (0.78)**	**3.87 (0.93)**	**2.95**
Anticipatory grief (sadness)	30.00	16.80 (5.56)	17.54 (5.47)	16.51 (5.59)	1.32
Anticipatory grief (loneliness)	**29.00**	**12.66 (4.88)**	**14.07 (4.99)**	**12.10 (4.74)**	**2.94**
Attitude toward death (approach)	70.00	49.62 (18.66)	49.79 (18.73)	49.56 (18.69)	.09
Attitude toward death (avoidance)	35.00	13.71 (7.09)	13.10 (7.23)	14.01 (7.19)	-.90
Beliefs about personhood	99.00	66.04 (14.83)	68.22 (15.13)	65.91 (14.67)	1.14
Perceived quality of care	10.00	8.12 (1.85)	7.99 (2.02)	8.17 (1.74)	-.73
Family Involvement in LTC	79.00	58.15 (12.72)	58.20 (13.31)	58.21 (12.24)	-.01
Person-centred climate – Safe	18.00	15.84 (3.11)	15.77 (3.59)	15.84 (2.32)	-.17
Person-centred climate 2 – Homelike	24.00	18.83 (4.88)	18.99 (4.42)	18.82 (4.97)	.25
Person-centred climate – Community	18.00	14.20 (3.41)	14.16 (3.50)	14.27 (3.34)	-.25
Person-centred climate – Communication	24.00	19.67 (4.36)	19.20 (4.72)	19.29 (6.73)	-1.33
Attitudes toward aging (negative)	40.00	20.34 (6.96)	19.29 (6.73)	20.80 (6.90)	-1.61
Attitudes toward aging (positive)	40.00	28.25 (5.93)	28.19 (6.05)	28.31 (5.75)	-.15

Notes: *= p<.10; bold = p<.05; a Measured using an interval scale; b Measured using a nominal scale approximating interval characteristics

DISCUSSION & IMPLICATIONS

- Factors related to distance, relationship quality, and role obligations were most strongly associated with visiting frequency.
- We were surprised to find that LTC homes' efforts to create a positive climate or welcome families bore no relationship to visiting frequency.
- We were also surprised to find that beliefs about aging, illness, and dying were not associated with visiting frequency.
- Based on the findings, efforts to promote family involvement in LTC should focus on:
  - LTC placement close to the primary caregiver's home.
  - Affirming family members' sense of responsibility for residents' emotional and physical wellbeing
  - Involving family members in specific caring roles, not necessarily limited to substitute decision making.
  - Responding to signs of worry or loneliness (perhaps, offering reassurance or assisting with initial steps to cultivate a social network within or outside LTC).
  - Recognizing that a change in visiting frequency might be associated with the caregiver's own health interference (e.g., inquiring about health when a change in visiting frequency is noticed).

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SASKATCHEWAN HEALTH RESEARCH FOUNDATION

Social Isolation: Understanding the Experience of Older Adults

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SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

Introduction

The social isolation experienced by older adults has been identified as having negative consequences for overall quality of life and well-being (National Seniors Council, 2014; Nicholson, 2012) and a risk factor for decreased health, including negative effects on psychological and cognitive health. Social isolation can also affect the health of communities when older adults are no longer able to contribute to their communities (National Seniors Council, 2014).

In June 2016, SPHERU researchers began a 3-year evaluation of a collective impact project titled: *Reducing Isolation of Seniors – Saskatchewan Impact Plan*. The organizational partners on this project include Saskatchewan Seniors Mechanism, Red Cross in Saskatchewan, and the Alzheimer Society of Saskatchewan. Through multiple interventions, at both community and individual levels, the collective effort was intended to reduce social isolation for older adults in central and southern Saskatchewan.

Of the multiple instruments used in the evaluation process, the *Saskatchewan Seniors Impact Survey* was created to gather a baseline of key variables explored in the evaluation in order to understand the social isolation experiences of older adults in the province. Key variables of interest included:

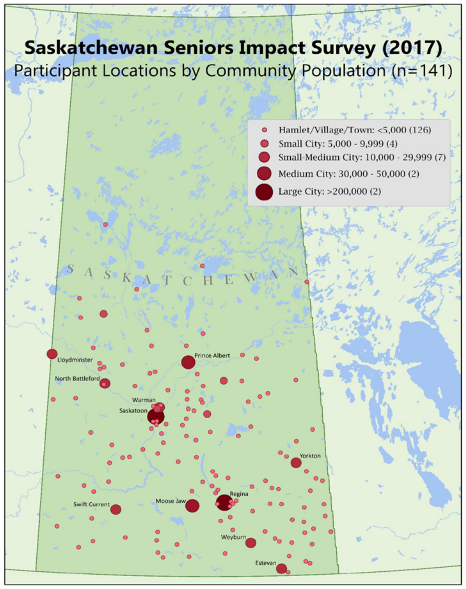
- senior access to services/supports
- participation in activities
- access to support when needed
- feelings of connectedness to family and friends
- feelings of being valued by others
- barriers to services/supports
- overall isolation experienced by seniors
- suggestions for meaningful interventions and supports

Methods

- ➢ Survey instrument was developed through reviewing available literature on measuring social isolation of seniors (Cornwell & Waite, 2009; Dickens, Richards, Greaves, & Campbell, 2011; Medical Advisory Secretariat, 2008; Public Health Agency of Canada, 2015)
- ➢ Additional development included discussion and feedback from the organizational partners regarding the scope, nature, design, and implementation of the survey; survey instrument was piloted and revisions made
- ➢ Survey implementation involved multiple formats: written hard copy, electronic (online using Qualtrics software), and telephone interviews available in both English and French
- ➢ Survey administered to older adults (55 years+) from May-October 2017; partner organizations assisted in distributing the survey through their membership lists
- ➢ 1,719 responses received from 141 communities in Saskatchewan

Findings

- ➢ Who responded?
  - 2/3 were women; 1/3 were men
  - 52% were age 55-69 years; 48% were age 70 to 85+ years
  - 25% lived in rural areas (villages, towns, hamlets, farms)
  - 18% reported that they are a care partner
- ➢ Level of social isolation
  - ▪ Almost one-quarter of respondents (23.4%) were experiencing a high or medium level of social isolation
  - ▪ Comparable to the percentage of Canadians over 65 years who feel socially isolated (National Seniors Council, 2014)
- ➢ Participation in activities
  - About one-quarter participate in activities 1-2 times a week; another one-quarter reported less regular participation in activities
  - Comparable to one-quarter of Canadian adults over 65 years who report they would like to participate in more social activities (Gilmour, 2012)
  - One-third reported experiencing barriers to accessing activities outside of their home
- ➢ Suggestions to promote community engagement
  - Accommodate needs of older adults [ice/snow removal; low cost activities; transportation to activities]
  - Advocate for or provide services [rural bus service; respite; well-being checks; individual support]
  - Change in practices [provide family education on aging; engage younger generations in activities; improved communication about activities]
  - Provide a range of activities throughout the year [visiting circles; summer gatherings; indoor winter activities; technology training]



Saskatchewan Seniors Impact Survey (2017)

Participant Locations by Community Population (n=141)

Discussion

- ➢ The social isolation experienced by older adults in Saskatchewan requires attention to interventions that address individual needs; but also requires attention to community and policy level responses
- ➢ Older adults provided suggestions for low-cost interventions that communities could implement to assist those feeling isolated. An important aspect is creating more awareness of social isolation in their own communities
- ➢ Addressing social isolation requires that we continue to hear from older adults on their experiences. The response rate in the survey was high, but as a non-random sample the results should be interpreted as indicative of needs that are not necessarily generalizable to all older adults in the province
- ➢ Participants at a recent *Policy-Maker Community Summit on the Social Isolation of Older Adults in South and Central Saskatchewan* affirmed the importance of continued advocacy on program and policy issues to address social isolation of older adults in Saskatchewan (McIntosh, Jeffery, Novik, & Nilson, 2019)

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University of Regina

CCNA CCNV 15 Team équipe
University of Saskatchewan

Protocol for a Review of Interventions to Increase Social Inclusion for Caregivers

Kortzman, A., O'Connell, M. E., McWilliams, L. A., Peacock, S., Holtslander, L., & Morgan. D. E.

INTRODUCTION

Social inclusion is important for informal caregivers of persons with dementia[1]

- Reduced levels of stress, depression, anxiety
- Increased subjective contentment

Most research focuses on <u>formal</u> social support interventions (i.e., organizational programs)[2]

- <u>Few informal</u> social support interventions exist

There is an opportunity to improve informal social networks and enhance social inclusion

- Caregivers tend to underestimate the size of their social network[3]
- Mismatch between supply and demand[4]

Rural caregivers experience less formal support and rely more heavily on family and friends than do urban counterparts[5,6,7,8]

Current informal social support interventions not feasible in the rural caregiving context

- Involves mobilizing all network members to attend urban area services (e.g., family interventions)[2]

AIM

To integrate the body of knowledge surrounding informal social inclusion interventions available to other populations in order to inform the design of an effective intervention for rural caregivers of persons with dementia

REGISTRATION

Awaiting PROSPERO registration approval

RESEARCH QUESTION

What empirically-supported interventions are available that target individuals and focus on improving their informal social support network on dimensions of social support and/or well-being?

- How effective are the interventions?
- What is the methodological quality of such interventions?
- Are any of these interventions adaptable to the context of rural caregivers?

METHODOLOGY

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format[9]

Inclusion Criteria:

- General population and any subset therein
- Interventions that target individuals (not groups – e.g., family units) in order to optimize functioning of informal support network

Information Sources include PsycINFO, MedLine, Embase, Cinahl, and Scopus

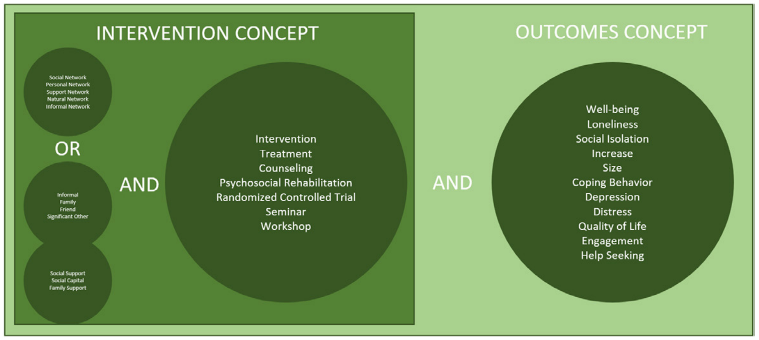
Titles, abstracts, and full text to be screened independently by two researchers via Covidence[10]

- Third reviewer will resolve conflict and review random sample of all studies

Applicable records assessed independently using Cochrane Collaboration's Risk of Bias tool[11]

SEARCH STRATEGY

PICO (Population, Intervention, Comparison, Outcomes) concept strategy employed



INTERVENTION CONCEPT

Social Network
Personal Network
Support Network
Natural Network
Informal Network

OR

Informal
Family
Friend
Significant Other

Social Support
Social Capital
Family Support

AND

Intervention
Treatment
Counseling
Psychosocial Rehabilitation
Randomized Controlled Trial
Seminar
Workshop

AND

OUTCOMES CONCEPT

Well-being
Loneliness
Social Isolation
Increase
Size
Coping Behavior
Depression
Distress
Quality of Life
Engagement
Help Seeking

SYNTHESIS/ANALYSIS

Meta-analyses may be conducted dependent on depth of findings within population subgroups

RevMan software will be used for analyses[12]

Summary of findings table and PRISMA flowchart will be completed

GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) approach will be employed to assess quality of evidence[13]

IMPLICATIONS

Knowledge synthesis in this area is important

- Informal social support networks need to be optimized

Will inform the design of an intervention for rural caregivers of persons with dementia

- Component of **Rural and Remote Memory Clinic-interventions (RRMCi)** initiative

May lay the foundation for further research

- The integration of formal and informal social support interventions
- Can be translated to other populations with service provision gaps

POTENTIAL CHALLENGES

Multicomponent interventions targeting formal and informal social support

- If support sources or systems are not delineated, these studies will be excluded

Missing statistics (e.g., standard deviations)

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Fondation Brain Canada Foundation

RaDAR
RURAL DEMENTIA ACTION RESEARCH

RaDAR Memory Clinics: Update

Kipling | Weyburn | Rural West | Carlyle

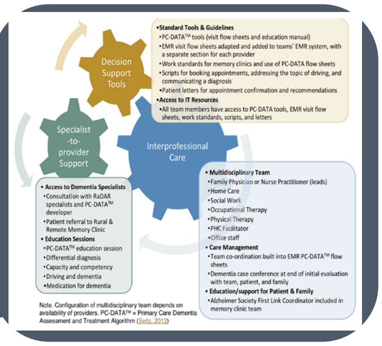
Julie Kosteniuk, Debra Morgan, Megan O'Connell, Andrew Kirk, Norma Stewart,
Dallas Seitz, Melanie Bayly, Amanda Froehlich Chow, and Valerie Elliot

CCNA CCNV 15 Team équipe

UNIVERSITY OF SASKATCHEWAN

Background

- RaDAR memory clinics are offered by primary health care teams in rural Saskatchewan, supported by the RaDAR Team as part of an ongoing research study that began in 2014.
- The goals of local memory clinics are to help make timely connections between patients and community services, and to reduce the need for specialist referrals.
- RaDAR Memory Clinics incorporate *interprofessional care, remote specialist-to-provider support*, and *decision support tools*. These 3 elements are associated with positive outcomes for health care providers, patients, and families (scoping review by Aminzadeh et al. 2012).



- **Standard Tools & Guidelines**
  - PC-DATA^{TM} tools (visit flow sheets and education manual)
  - EMR visit flow sheets adapted and added to teams' EMR system, with a separate section for each provider
  - Work standards for memory clinics and use of PC-DATA flow sheets
  - Scripts for booking appointments, addressing the topic of driving, and communicating a diagnosis
  - Patient letters for appointment confirmation and recommendations
- **Access to IT Resources**
  - All team members have access to PC-DATA tools, EMR visit flow sheets, work standards, scripts, and letters

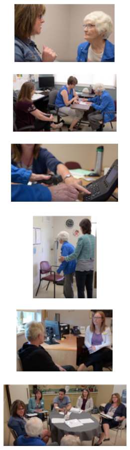
- **Access to Dementia Specialists**
  - Consultation with RaDAR specialists and PC-DATA^{TM} developer
  - Patient referral to Rural & Remote Memory Clinic
- **Education Sessions**
  - PC-DATA^{TM} education session
  - Differential diagnosis
  - Capacity and competency
  - Driving and dementia
  - Medication for dementia

- **Multidisciplinary Team**
  - Family Physician or Nurse Practitioner (leads)
  - Home Care
  - Social Work
  - Occupational Therapy
  - Physical Therapy
  - PHC Facilitator
  - Office staff
- **Care Management**
  - Team co-ordination built into EMR PC-DATA^{TM} flow sheets
  - Dementia case conference at end of initial evaluation with team, patient, and family
- **Education/support for Patient & Family**
  - Alzheimer Society First Link Coordinator included in memory clinic team

Note. Configuration of multidisciplinary team depends on availability of providers. PC-DATA^{TM} = Primary Care Dementia Assessment and Treatment Algorithm (Seitz, 2012)

RaDAR Memory Clinic Model

Memory Clinic Format



Pre-Assessment

- Patients are referred for a memory clinic evaluation by any member of a participating PHC team
- Office staff arrange patient bookings and family member participation
- A CT scan or bloodwork may be ordered in advance for review on clinic day

Initial Evaluation (Clinic Day)

- 2 patients, 3-hr appointment each (am & pm)
- Appointment:
  - Team huddle
  - Team meeting with patient and family to discuss concerns and review appointment plan
  - Individual assessment by each team member in turn, including family consultation with Alzheimer Society First Link Coordinator
  - Team debrief
  - Team case conference with patient and family to discuss results, recommendations, and follow-up plans

Follow-up

- Scheduled as needed
- Patients are also individually followed by members of their PHC team

Photos from the Rural Primary Health Care Memory Clinic Video (Credit: Tara Yolan Productions)

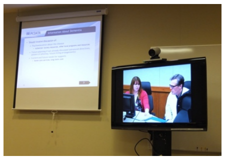
Decision Support Tools

- PC-DATA^{TM} is a point-of-care decision support tool in the Med Access EMR, used in RaDAR memory clinics to guide initial evaluation and ongoing management
- PC-DATA^{TM} is based on Canadian guidelines (Primary Care Dementia Assessment and Treatment Algorithm, Seitz 2012)
- The PC-DATA^{TM} initial evaluation flow sheet includes a section to be completed by each team member
  - Physician/NP
  - Home Care Nurse/Social Worker
  - Occupational Therapist
  - Physical Therapist
  - End-of-day case conference with patient & family

PC-DATA^{TM} education session with Valerie Elliot, Jean Daku, Dr. Morgan, Dr. Seitz, Dr. Nokam

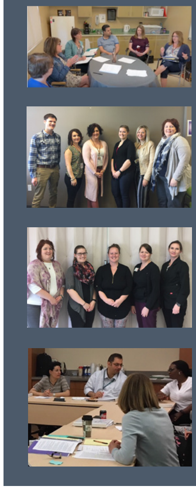
Specialist-to Provider Support

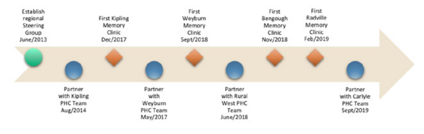
- Memory clinic teams take part in interactive PC-DATA^{TM} education sessions with Dr. Dallas Seitz (geriatric psychiatrist and U of C faculty)
- Other education sessions are tailored to team needs and provided by Dr. Andrew Kirk (neurologist), Dr. Megan O'Connell (neuropsychologist), and guest speakers such as the SGI Medical Review Unit



Education session with Dr. O'Connell and Dr. Kirk

Teams





Timeline of rural PHC memory clinic development

- Multi-year collaboration began in 2014 with the Kipling PHC team, using a 5-step approach (Morgan et al. 2019)
- The Kipling team held the first 1-day RaDAR memory clinic in Saskatchewan in December, 2017
- Memory clinic locations - year established
  - Kipling - 2017
  - Weyburn - 2018
  - Bengough (Rural West) - 2018
  - Radville (Rural West) - 2019
  - Carlyle - in development
- Memory clinics are held monthly or every second month depending on patient need

*Memory Clinic Teams (from top)
Kipling, Weyburn, Bengough, and Radville*

Ongoing Projects

- See poster - *Evaluation of interprofessional, team-based dementia assessment and diagnosis in rural primary health care* (Dr. Melanie Bayly)
- See poster - *Using the Consolidated Framework for Implementation Research to identify barriers and facilitators to implementation of a rural primary health care intervention for dementia* (Dr. Debra Morgan)
- See poster *Interdisciplinary primary health care approaches for dementia and chronic conditions: a case study* (Dr. Amanda Froehlich Chow)

Upcoming Projects

Dr. Julie Kosteniuk and Dr. Debra Morgan (Co-leads)
- Evaluation and management of patients in interprofessional rural PHC memory clinics: a chart review study
- Care partner outcomes after family member evaluation in interprofessional rural primary health care memory clinics
- Interprofessional rural primary health care memory clinics: a multiple case observational study

Dr. Melanie Bayly (Lead)
- Benefits & challenges of the Alzheimer Society First Link Coordinator role in rural primary health care memory clinics

Dr. Megan O'Connell (Lead)
- We thank Jeanie Daku for consulting with PhD student Andrea Scerbe on the format and content for an education app, and Dr. O'Connell is piloting some examples at Summit 12

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RaDAR Memory Clinics: Plans to Sustain and Spread

Julie Kosteniuk, Debra Morgan, Megan O'Connell, Andrew Kirk, Norma Stewart, Dallas Seitz,
Melanie Bayly, Amanda Froehlich Chow, Chelsie Cameron, and Valerie Elliot

About RaDAR Memory Clinics

RaDAR memory clinics are offered by primary health care (PHC) teams in rural Saskatchewan, supported by Team RaDAR as part of an ongoing research program

Memory clinic locations - year established
- Kipling - 2017
- Weyburn - 2018
- Bengough (Rural West) - 2018
- Radville (Rural West) - 2019
- Carlyle - in development

Memory clinics are held monthly or every second month, depending on patient need

Memory Clinic Teams (from top)
Kipling, Weyburn, Bengough, and Radville

Initial steps to establish a RaDAR Memory Clinic

~ 6 months

1. Information session with full PHC team
2. Orientation session with initial memory clinic team
3. Shadowing of RaDAR memory clinic in neighboring community
4. PC-DATA^{TM} initial education session (led by Dr. Dallas Seitz)
5. Half-day memory clinic with one patient and family
6. Workgroup teleconference #1
7. Full-day memory clinic with two patients and families
8. Workgroup teleconference #2
9. PC-DATA^{TM} refresher education session (led by Dr. Dallas Seitz)

The RaDAR Memory Clinic Coordinator assists with sustaining and spreading the memory clinic model to primary health care teams in rural Saskatchewan. Chelsie Cameron is also a PHC Facilitator with the Saskatchewan Health Authority.

Process Evaluation

Objectives
- To examine the sustainability of current RaDAR memory clinics
- To examine the spread of RaDAR memory clinics to other PHC teams in rural Sask

Methods
- Consolidated Framework for Implementation Research (Damschroder et al. 2009)
- Contextual factors will be analysed at 5 levels (innovation, individual, inner setting, outer setting, and process)

Action Plans

Objectives
- To co-develop and evaluate action plans to <u>sustain</u> current RaDAR memory clinics, and to <u>spread</u> the clinics to other rural Saskatchewan communities

Methods
- Team RaDAR will co-develop the action plans with current RaDAR memory clinic teams, managers, and staff
- Nominal group technique approach to develop and evaluate the action plans will be used in a series of WebEx focus groups
- Sustainability constructs will be derived from the Consolidated Framework for Sustainability in Health Care (Lennox et al. 2018)
- Spread constructs will be identified from implementation science literature (CFHI, 2014; Laur et al. 2018; Greenhalgh and Papoutsi, 2019)

Community Programs

Environmental Scan – Objectives and Methods
- To identify community programs providing post-diagnostic services to clients who include RaDAR memory clinic patients and families, at baseline (early 2020), mid-point (2022), and end (2024)
- To create inventories and maps of community programs for each time period and track changes in the availability of post-diagnostic services
- Multi-method qualitative research design, with focus groups and a document review

Formative Evaluation – Objectives and Methods
- To evaluate community programs implemented or adapted to provide post-diagnostic services to clients who include RaDAR memory clinic patients and families, allowing an opportunity to modify programs before implementing fully and spreading to other rural communities
- Focus groups with program staff to examine whether programs are reaching intended clients, achieving promising short-term outcomes, and have the resources necessary to effectively operate
- Questionnaires with program clients to examine whether short-term outcomes are meeting expectations

<u>Potential significance</u>: The goals of this research are to support rural primary health care teams to make timely dementia diagnoses and connections between patients and community services, thereby improving quality of care and reducing referrals to urban specialists

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North SK Dementia Assessment Team: 2019 Program Update

Information assembled by: Lalonde, R., Leclaire, S. & Joanis, L.

What's the need?

- Saskatchewan has an aging population
- ↑ age = ↑ risk for dementia
- Limited resources in rural and acute settings, resulting in a service gap
- With this growing need, there is a resulting increase in the demand for dementia-related services available to the people in Saskatchewan who have been diagnosed with dementia and extends to the caregivers and staff teams who support them. The program aims to provide services to these groups, regardless of setting.

Behavioural and Psychological Symptoms of Dementia (BPSD)

"In dementing illnesses, the central symptom is cognitive impairment and the surrounding symptoms are usually called behavioral and psychological symptoms of dementia (BPSD). These BPSD are the most troublesome for caregivers of demented patients and can be classified into two groups:

(i) symptoms that are disclosed following interviews with patients and/or their caregivers, such as delusions, hallucinations, anxiety and depression; and

(ii)symptoms recognized following observation of patients' behavior, such as wandering, psychomotor excitement, agitation and negativism."

- Kosaka, K. (2008). Behavioral and psychological symptoms of dementia (BPSD) in dementia with Lewy bodies. *Psychogeriatrics*, *8*(3), 134-136

FAQs

What is the Dementia Assessment Team?

We provide support to persons with the diagnosis of dementia who are experiencing highly responsive or protective behaviours. We also provide support and consultation for people who work and live with individuals who have a diagnosis of dementia (e.g., family, staff members, caregivers). This work is done through two connected multidisciplinary teams that work together to support these individuals: the Dementia Assessment Outreach Team & the Dementia Assessment Unit (*Eastview*).

Our beginnings

- The Dementia Assessment Outreach Team and Eastview are located at Parkridge Centre in Saskatoon, SK.
- The Dementia Assessment Outreach Team started taking referrals in March 2017
- The Dementia Assessment Unit (*Eastview*) accepted its first inpatient admission in April 2017

Who do we serve?

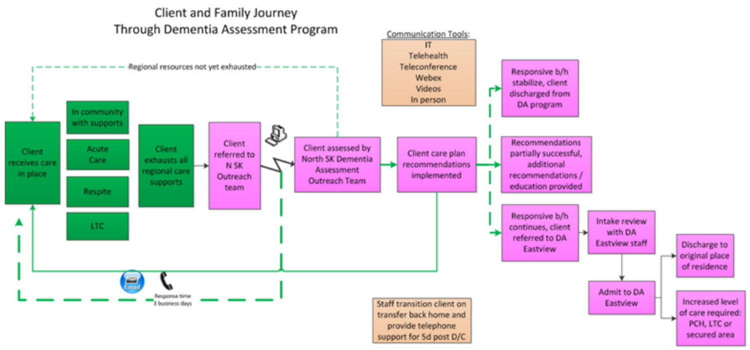
Referral Criteria

- Primary Diagnosis: Age-related degenerative dementia (Neurocognitive Disorder)
- Exhibiting "responsive behaviours"
- Require enhance behavioural support in their current care environment
- All local services have been utilized
- Typically >65 years of age

What does it cost?

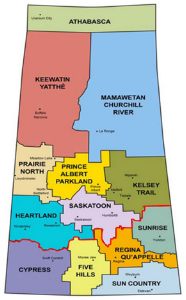
- There is no charge for accessing the Dementia Assessment Outreach Team, or admission to Eastview
- If admitted to Eastview, clients are expected to continue paying "rent" or fees at their home, as the 90 day programming is temporary in nature

Client and Family Journey



Northern Coverage

- 2 Geographical Areas (North/South)
- Diverse referrals: community, long term care, acute hospital care, personal care homes, etc.
- Inpatient units located in Saskatoon and Regina



North: 8 health regions
Age >65: 85,436
489,418 square km

South: 5 health regions
Age >65: 78,667
161,618 square km

Program Stats and Highlights

Since opening in March 2017, the Dementia Assessment Team has supported:

126 total clients

- 26 admissions to Eastview
- 100 Clients stabilized and supported in their home setting

A diverse range of clients, with referrals from:

- Long Term Care
- Community
- Personal Care Homes
- Acute Care Settings
- Transitional Care Settings

6+ rural site visits per year, with education sessions to staff teams in communities such as Hafford, Big River, La Ronge.

Contact Information

Dementia Assessment Team
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Hand Grip Strength as a Functional Measure Related to Malnutrition Risk and Cognitive Decline

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Cognitive Decline and Malnutrition Risk

Nutritional deficiencies can cause individuals to experience an increase in dementia symptoms. People with dementia are at a higher risk for malnutrition or inadequate nutrition. This could in part be explained by the behavioural and psychological symptoms of dementia that then impact nutrition requirements. As dementia progresses individuals may lose the ability to prepare food, to feed themselves, or to recognize food-related objects, such as dishes or cutlery. When people with dementia move into long-term care homes or are cared for by a caregiver, they may not experience the social, cultural or environmental factors that they typically associate with mealtime. Additionally, people with dementia may not be able to recognize hunger cues or lose the ability to swallow. Also, individuals with late-stage dementia are known to resist eating.

Current Methods of Measurement in a Clinical Setting

Current best practice for nutrition assessment in Canada involves a series of tasks including determining the patient's current height and weight, reviewing significant lab values, determining usual nutritional intake, current intake of foods and fluids, as well as socioenvironmental factors that influence nutritional intake. This can be time-consuming and cumbersome for the patient and requires a high level of training for health care professionals.

Objective

To examine how functional measurement is related to malnutrition risk and cognitive decline.

Hand Grip Strength as a Functional Measure

Hand grip strength is the maximum strength of an individual's hand muscles. Hand grip strength can easily be measured with a dynamometer

Benefits of Dynamometer Use

- quick and easy to use
- inexpensive
- portable
- low variability, high reliability
- measures patients against their own baseline rather than population averages
- Relatively little training required for health care professionals

Comments or
feedback
welcome!

Hand Grip Strength and Malnutrition Risk

Previous research indicates that hand grip strength is associated with nutritional measures such as body weight, BMI, and mid-upper arm circumference.

Muscle function reacts rapidly to nutritional deprivation as well as nutritional restoration. Weight loss has a greater impact on muscle mass, and therefore hand grip strength than body mass.

The Academy of Nutrition and Dietetics and the American Society for Parental and Enteral Nutrition recommend reduced hand grip strength as criteria for the identification of malnutrition.

Hand Grip Strength and Cognitive Decline

Reduced handgrip strength has been used as a marker for mild cognitive impairment and Alzheimer's disease. Declines in handgrip strength tend to be associated with cognitive decline. Similarly, higher handgrip strength seems to be protective against cognitive decline. This correlation persists over time.

Stronger hand grip strength may represent the integrity of the neuromuscular system and high resistance to oxidative stress and inflammation, which possibly extends to the preservation of cognitive function.

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The Annual Summit of the Knowledge Network in Rural and Remote Dementia Care: An Example of an Integrated Knowledge Translations (iKT) Approach.

Debra Morgan, Julie Kosteniuk, Megan E. O'Connell, Andrew Kirk, Allison Cammer, Duane Minish, Valerie Elliot.
Rural Dementia Action Research (RaDAR) team, University of Saskatchewan.

Background

- Growing evidence demonstrates the value of stakeholder engagement in Integrated Knowledge Translation (iKT) research throughout the research process.
- The RaDAR team evolved from a group of researchers established in 1997 to improve health service delivery for people with dementia in rural and remote settings.
- Community based participatory research (CBPR) methods have been an integral part of team activities since inception.
- Models and guidelines for stakeholder engagement exist, but few provide examples of strategies and how they are implemented, and fewer still focus on approaches in rural and remote communities.
- We aim to provide an overview of the Annual Summit event and report on participant characteristics, attendance, satisfaction, and perceptions.

Overview of Summit

- Since 2008 the RaDAR team has hosted an Annual Summit meeting as a stakeholder engagement strategy that guides team research.
- Attendance has grown from 32 in 2008 to 110 in 2018.
- With broad geographic and jurisdictional representation from across the province, participants include people with dementia, family carers, health care providers, administrators, Ministry of Health representatives, the Alzheimer Society of Saskatchewan, researchers, and trainees.

Elements of Annual Summit

During both days, ample networking time is allotted

Day 1

Evening Poster Session and networking
↓
Brief Education session
↓
Student poster prize awards

(Posters remain on display in meeting room during day 2)

Day 2

Welcome and overview
↓
Keynote presentation (international researcher or Canadian researcher from other region)
↓
Small group sessions (participants work with a research lead to provide direction to new/ongoing projects)
↓
Panel Discussion – updates on RaDAR team research
↓
Panel Discussion – new dementia initiatives from community
↓
Panel Session – person with dementia and/or family member
↓
Education Session

- There is no cost to attend, RaDAR funding provides for meeting costs, participation is by invitation with attendees referring new potential participants to the RaDAR team.


2010 - telehealth-based caregiver support group project members present at Summit – leads to partnership with Alzheimer Society who now host the support group


2015 Co-Keynote presenters, Drs. Dallas Seitz (l) and Jayna Holroyd-Leduc (r)


2016 – Dr. Mark Rapoport as keynote presenter with Dr. Debra Morgan

Findings

Rating Scale Items

Over time Summit attendance has increased as participant interest and capacity among the research team has grown. The end-of-Summit evaluation form quantitative measures suggest that participants have been very satisfied with: Summit content; opportunities to learn and to connect one-on-one with researchers and others working in rural and remote dementia care; and value provided by their attendance.

Summary of attendees by year, and evaluation completion rates by year

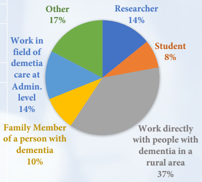
Summit year	Attendees	Evaluations returned	Return rate
S1, 2008	50	32	64%
S2, 2009	61	21	34%
S3, 2010	54	28	52%
S4, 2011	45	30	67%
S5, 2012	52	31	60%
S6, 2013	69	40	58%
S7, 2014	68	38	56%
S8, 2015	73	49	67%
S9, 2016	95	53	56%
S10, 2017	93	53	57%
S11, 2018	110	59	54%

Summary of some Evaluation Form responses from Summits 1 through 10, percentage positive responses†

	S1 2008	S2 2009	S3 2010	S4 2011	S5 2012	S6 2013	S7 2014	S8 2015	S9 2016	S10 2017
Poster Session										
Provided opportunity to learn about rural and remote dementia research*	96	100	100	100	100	100	100	100	100	96
Provides an opportunity to meet researchers*	100	100	100	100	100	100	100	97		
Provides an opportunity to meet others interested in dementia care*				100	100	100	97	97	100	100
Poster session provided good value for your time*	100	100	100	100	100	100	100	100	98	95
Summit Day										
Time allotted for agenda items was sufficient*	100	100	84	97	100	98	98	96		
Time allotted for breaks was sufficient*	97	95	92	100	100	98	98	100		
Enjoyed the meeting room/venue*	94	100	96	100	100	98	97	98	100	100
I was able to share my opinions and ideas today*	100	100	100	100	100	95	100	100	100	98
It was worth my time to attend Summit meeting*	100	95	100	100	100	98	100	100	100	100

†Percentage of respondents who answered either "yes" or gave a positively-valenced response, Ex: strongly agree/agree.

I would best describe my role at summit as:
(Responses summarized from 2011 to 2018)



Scan → Download evaluation form from Summit 11

Themes across open-ended questions – combined across 11 years

Learning (evidence-based research and services)	Networking (building connections /relationships)	Format (inviting and organized)	Representation (interprofessional and multidisciplinary)	Structure (letting voices be heard)	Motivation (inspiring/hopeful)	Impact (for stakeholders)
"Excited to hear about dementia-related, evidence-based programs, initiatives, (what works and what doesn't) research, and educational opportunities going on in the province, around the country, and all over the world"	"particularly important to connect with others when you work in such a remote location" "Great opportunity to network, build relationships for future collaboration"	"I liked the chance to connect the night before. It then lets us "get to work" on the [next day]" "Great job organizing several activities into a small amount of time – Well Done!"	"A wide variety of professionals that are working with and supporting people with dementia" "people who are passionate about dementia from a broad range of perspectives"	"leave with a sense that all contribute and come away with something" "opportunity to review findings and recommend future directions for research [and] provided an excellent mix of stakeholders and experiences"	"this is a priority to attend in my calendar – I always go home eager to find different things to do" "Chance to renew my enthusiasm by connecting with others who are immersed in & passionate about the field"	"not only has [Summit] benefitted me […] it has benefitted our staff and most importantly it's benefitted people living with dementia in our province" "the concrete ideas that you can take away, and revamp to fit your local area. That to me is key."

Discussion

-Participants report impacts beyond the original Summit goals of guiding the RaDAR program. The Summit meets a need for access to education, information about current research and emerging best practices, and connecting with others with similar interests.

- Summit activities have had a profound impact on the direction of the RaDAR research program, and Summit provides a vital connection to dementia care and research initiatives in Saskatchewan, in Canada, and internationally.

-The Summit is an effective strategy for engaging stakeholders in a large ongoing research program (vs. a specific project).

Acknowledgements

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Scan to visit Summit web page

Using the Consolidated Framework for Implementation Research to identify barriers and facilitators to implementation of a rural primary health care intervention for dementia

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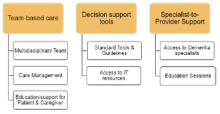
Background

- Higher proportions of seniors live rurally[1]; growing numbers of people with dementia live rurally and remotely[2]
- Primary health care (PHC) plays a critical role in rural settings[1,3] – a model of service delivery for dementia where PHC has a central role is more sustainable and appropriate
- Comprehensive integrated models of PHC for dementia are associated with better outcomes[4], but rural-specific implementation and sustainability strategies and identified barriers and facilitators are lacking[5]
- **This poster reports findings of a process evaluation conducted over 2.5 years to identify barriers and facilitators to developing, implementing, and sustaining the intervention in a rural PHC team[6]**

Methods

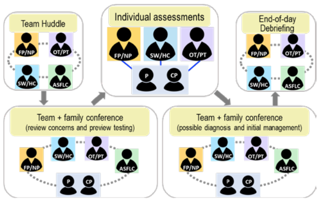
Evidence-based foundation for the intervention:

- Seven strategies associated with better outcomes were identified from an extensive scoping review of international literature[4]
- The **Rural PHC Model of Dementia** was created by incorporating these 7 strategies into 3 domains



The Intervention – 1-day Rural PHC Memory Clinic:

- **The research and PHC team iteratively co-designed** an intervention that operationalizes the model elements
- **The memory clinic is held every 1 to 2 months,** with 2 patients and their families attending for a half-day each
- **Team-based follow-up appointments scheduled at 3 to 6 months.**
- **Evidence-based decision support tools (PC-DATA™)[7]** are used to guide the initial evaluation and follow-up appointments



Patient Care Pathway for 1-day Memory Clinic Appointment

FP/NP = Family Physician/ Nurse Practitioner
OT/PT = Occupational Therapist/ Physical Therapist
SW/HC = Social Worker/ Home Care Nurse
ASFLC = Alzheimer Society First Link Coordinator;
P = Patient
CP = Care Partner

Process Evaluation:

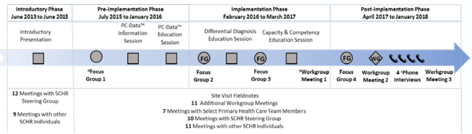
- **A qualitative longitudinal process evaluation** was conducted[6] pre- to post-implementation
- Data collection and analyses guided by the **Consolidated Framework for Implementation Research (CFIR)[8]**
- **Deductive analysis:** CFIR constructs and domains as an apriori coding framework
- **Inductive analysis:** to identify barriers and facilitators

The CFIR is a theoretical framework used to guide the design and/or evaluation of implementation[8]

The CFIR Consists of 5 Major Domains:

1. **Innovation Characteristics:** e.g., Relative Advantage, Adaptability
2. **Outer Setting:** e.g., External Policy & Incentives, Peer Pressure
3. **Inner Setting:** e.g., Cultural, Structural
4. **Characteristics of Individuals:** e.g., Self-efficacy, Individual Stage of Change
5. **Process:** e.g., Planning, Champions

- **Data were collected via** focus groups with PHC team and stakeholders, smaller team workgroup meetings, team member interviews, site visit field notes and meeting minutes



Results

- **14 constructs (across all 5 domains)** influenced development, implementation, and sustainability
- **3 domains were most important:** innovation characteristics, inner setting, process
- **8 key facilitators were identified:**
  - relative advantage of the intervention
  - ability to trial on a small scale
  - tension for change
  - leadership engagement
  - availability of resources, education and support from researchers
  - increased self-efficacy, and engagement of champions
- **9 barriers were identified:**
  - the complexity of multiple intervention components
  - required practice changes
  - lack of formal incentive programs
  - time intensiveness of modifying the EMR during iterative development
  - lack of EMR access by all team members
  - lack of co-location of team members
  - workload and busy clinical schedules
  - inability to justify a designated dementia care manager role
  - turnover of PHC team members

Quotations Exemplifying Constructs

Relative Advantage:
"The providers… didn't feel like it [usual care] was very standardized so they wanted a process for when a patient complains of cognitive difficulties, what exactly do we do, what are the steps that we take."
(PHC Team Member, Post-implementation, Telephone Interview)

Needs and Resources of those served by the Innovation:
"The families were just so appreciative of getting together at the end of our all our testing and talking about it and including their family member… they're going home with something to think about and some ideas."
(PHC Team Member, Post-implementation, Workgroup Meeting 3)

Implementation Climate – Tension for change:
"I was all for it [the intervention] just because I had been seeing lots of people with pre-dementia or dementia and I had seen some less-than-desirable effects from people falling through the cracks because of… practitioners not knowing what to do, or where to go from here."
(PHC Team Member, Pre-implementation, Focus Group 1)

Readiness for Implementation – Leadership Engagement:
"These meetings do take time from the day, so just to have the support from managers and supervisors you know, to attend the meetings, to be part of the team, and to help develop [the intervention] would definitely [help] them to continue."
(Manager, Post-implementation, Telephone Interview)

Self-efficacy:
"I think it's influenced it [care] huge, just to have those tools, and the kind of process by which to follow… we had the misconception that everybody had to have a scan and everybody had to see a neurologist… I think it's accomplished what I think the initial thing was about -- building capacity. It's helped you know give us the tools and give us the confidence that yeah, we can do that."
(PHC Team Member, Post-implementation, Telephone Interview)

Conclusions

- **Key factors** that supported and hindered the development and implementation of a rural-specific strategy for dementia assessment and management in PHC were identified
- **Despite challenges related to the rural context, the researcher-academic partnership was successful** in developing and implementing the intervention

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Champlain BASE eConsult

eConsult: An innovative opportunity to optimize dementia care

Isabella Moroz[1,2], Celeste Fung[3], Mary Helmer-Smith[1,2], Clare Liddy[1,2,3]
[1]C.T. Lamont Primary Health Care Research Centre, Department of Family Medicine, University of Ottawa, Ottawa, Canada, [2]Bruyère Research Institute, Ottawa, Canada, [3]St. Patrick's Home of Ottawa, Ottawa, Canada, [4]Ontario eConsult Centre of Excellence, The Ottawa Hospital, Ottawa, Canada

eConsult is a secure web-based tool that allows primary care providers (PCPs) such as physicians and nurse practitioners timely access to specialist advice for all patients and often eliminates the need for an in-person visit

Case 1: Orthopedics

PCP Question

- Resident is fully dependent for ADLs, non-ambulatory, lift transfer with advanced **dementia**, aphasia, and chronic pain
- Sustained prolonged shoulder dislocation and Hill-Sachs fracture. Mechanism of injury unknown. Remains in sling. Please advise how to reduce this frail resident's risk of re-dislocation

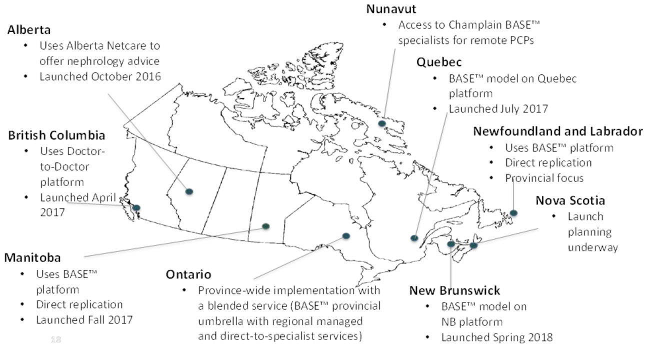
Specialist Response

- Provided recommendation for duration of immobilization and limitations in ROM thereafter. Suggested educating staff/family/visitors about signs of re-dislocation and limited course of action if re-dislocation occurs

Clinical Relevance

✓ Complexity of LTC resident conveyed
✓ Practical, applicable advice that considered limitations of the resident and care context
✓ Advice may empower care staff and reassure family

eConsult National Updates – October 2019



Utility of eConsult for patients in long-term care

- Specific, practical advice
- Appropriate for the complex patient and setting
- Empowers the care team
- Provides alternate management and treatment pathways
- Provides reassurance to family
- Opportunities for continuity of care
- Ability to have continued dialogue
- Supports clinical decision making
- No external appointment or transfer

Case 2: Neurology

PCP Question

- Resident has advanced **dementia**, aphasia, full care, and fluctuating mobility with new seizure activity x3. Please advise on further assessment and management.
- Further investigation is limited d/t dementia. Spouse requests neuro opinion prior to initiating anti-sz

Specialist Response

- Discussed etiology. Advised to avoid further investigation as per resident/SDM goals
- Described considerations of 4 anticonvulsants

Clinical Relevance

✓ Complexity of LTC resident conveyed and considered
✓ Practical, context appropriate advice, with detailed rationale, provided
✓ Information to support clinical decision making and to provide reassurance to family
✓ Resident-specific advise

- **eConsult provides an innovative opportunity to optimize dementia care by connecting family doctors, nurse practitioners, specialists (potentially social workers, personal support workers and therapists) to provide excellent care**

Contact: Dr. Clare Liddy, cliddy@bruyere.org; www.ChamplainBASEeConsult.com

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Bruyère
Winchester District Memorial Hospital
Ontario Champlain Local Health Integration Network

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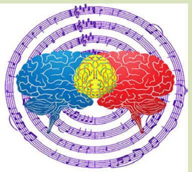
USING THE E-MUSIC BOX IN DEMENTIA CARE
~THE MUSIC MEMORY MAKERS PROJECT~

Jennifer Nicol (PhD, RDPsych, MTA); Justin Christensen (PhD); Janeen Loehr, (PhD);
Jennifer Lang (PhD); Shelley Peacock (PhD, RN)



ABSTRACT

As dementia increases worldwide at dramatic rates, demands on informal caregivers increase. Spouses often have their own needs and health conditions, yet they spend the most time providing care, and compared to adult children caregivers, report more burden. Retaining a sense of relationship continuity and couple identity contributes to adjustment and quality of life.

Shared activities are recommended to support relationship continuity. The newly developed *E-music box* (an electronic version of the mechanical music box that was popular in the 19th century) offers an innovative solution to address caregiver support for couples living with dementia. E-music boxes are simple to use and allow people with no musical training to produce music together. Further, musical behaviors continue even in severe dementia and group music making promotes social bonding. E-music boxes could provide a meaningful way for couples to continue interacting over the disease course.

The Music Memory Makers group is a new interdisciplinary research team able to investigate this possibility. With expertise in psychology (counselling psychology/cognitive neuroscience), music (music therapy/music education), and nursing (dementia care), we are uniquely configured to advance clinical goals (quality of life for those with dementia) and scientific goals (understanding mechanisms by which group music-making promotes social bonding).

Our first undertaking is a feasibility project to investigate the viability of E-music boxes as a means for individuals with dementia and their spousal informal caregivers to make music together. This will lay the groundwork for future research that (a) develops, tests, and assesses the brain basis of a novel intervention that uses E-Music boxes to improve the quality of life of people with dementia and their spousal caregivers, and (b) further develops and commercializes E-music boxes as a tool for group music making in dementia care and other contexts.

SHRF SASKATCHEWAN HEALTH RESEARCH FOUNDATION

CENTRE FOR AGING + BRAIN HEALTH INNOVATION
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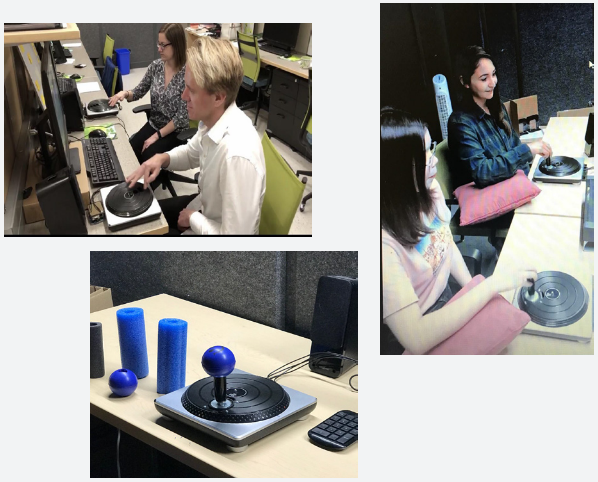
* Thank you to the RA Team: Tania Rediron, Erika Rybinski, Zijun Zhou *

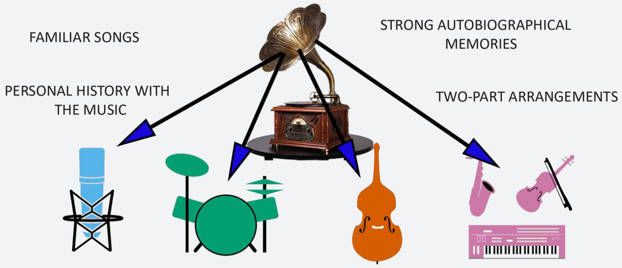
DEVELOPING THE E-MUSIC BOX



DEVELOPING INSTRUCTIONS

"I DO"	RA explains, models, talk-aloud
"WE DO"	RA interacts with, prompts, cues couples
"YOU DO"	Couples play independently

PREPARING E-MUSIC BOX SONGS



METHODOLOGY

Qualitative methodology
Multiple case studies, each case is a couple
Multiple sources of data
  * observation, field notes, video recording, interview
Descriptive and thematic analysis
  * assessing levels of synchrony, perceptions of task difficulty and overall enjoyment
  * opportunities for comparison and progressive opportunities for modification across Study 1 and Study 2

STUDY 1
Recruit 3 older adult couples who are
  * married/in long-term relationships
  * age 55+ years
  * speak English and live in Saskatoon
  * willing to meet in their home with research assistants
Data Collection
  * learn to play songs together using E-music boxes
  * provide feedback and answer questions about the activity

STUDY 2
Recruit 3 older adult couples as per Study 1 plus criteria:
  * one person is diagnosed with early-stage dementia
Data collection
  * learn to play songs together using E-music boxes
  * provide feedback and answer questions about the activity

ANTICIPATED OUTCOMES

1. RESEARCH CONTRIBUTIONS
Advance knowledge in 3 areas: **cognitive neuroscience of music** (social bonding in group music-making and experience of joint agency, and E-music boxes as an empirical method); **dementia care** (relationship continuity for couples living with dementia; and **music therapy** (group music-making in dementia care)

2. PRACTICE CONTRIBUTIONS
Increase awareness about music in dementia care; provide a means to bring music into the lives of couples impacted by dementia; support spousal informal caregivers

CCNA CCNV 15 Team équipe

RRMCi – Rural and Remote Memory Clinic-interventions

UNIVERSITY OF SASKATCHEWAN

O'Connell, M. E. & Teams as Detailed Below

Sleep Treatment

O'Connell, M. E., & Co-Is Rapoport, M., Cammer, A., McWilliams, L., Hunter, P., Kirk. A., Morgan. D., Dal Bello-Haas, V., Hadjistavropoulos, T., & Panyavin, I. (1 March 2019-28 Feb 2020). *RAIIN – Remote Assessment and Interprofessional Intervention with Neuropsychology – Remote Treatment of Sleep Disturbance for Persons with Dementia and their Caregivers,* $50,000. **Saskatchewan Health Research Foundation (SHRF) & Centre for Aging and Brain Health Innovation (CABHI)** Innovative Development grant.

***Cognitive behavioural therapy for insomnia adapted to dementia* (CBTid)** See Dr. Panyavin's poster

- CBTi a well-supported treatment of insomnia & useful for persons with traumatic brain injury
- Sleep disturbance is common in persons with dementia and caregivers
- We are modifying CBTi using cogitive rehab for persons with dementia - CBTid – **currently** conducting a feasibility RCT of CBTid for Telehealth delivery
- RRMCi will deliver a waitlist controlled RCT of CBTid with rural caregivers and persons living with MCI or dementia to improve self-reported sleep, mood, and quality of life
- *Future work*
  - Adapt the dyadic sleep treatment (NITE-AD which is now DREAMSTART) for Telehealth delivery
  - Randomly assign caregiver patient dyads to CBTid vs DREAMSTART

Cognitive Rehabilitation

O'Connell., M.E., Co-Is Bier, N., Couture, M., Giroux, S., Arlene, A., Spiteri, R., Morgan, D., Dal Bello-Haas, V., Kirk, A., & Cammer, A, & Collaborators Stewart, N., & Kosteniuk, J. Remote Assessment and Interprofessional Intervention with Neuropsychology (RAIIN): Remote Cognitive Rehabilitation and Acceptability and Feasibility of Technology Facilitation of Rehabilitation. Applied for funding – not successful

Cognitive rehabilitation (CR) is an individual person-centered intervention that helps persons with MCI and dementia achieve personally meaningful goals and improve everyday function

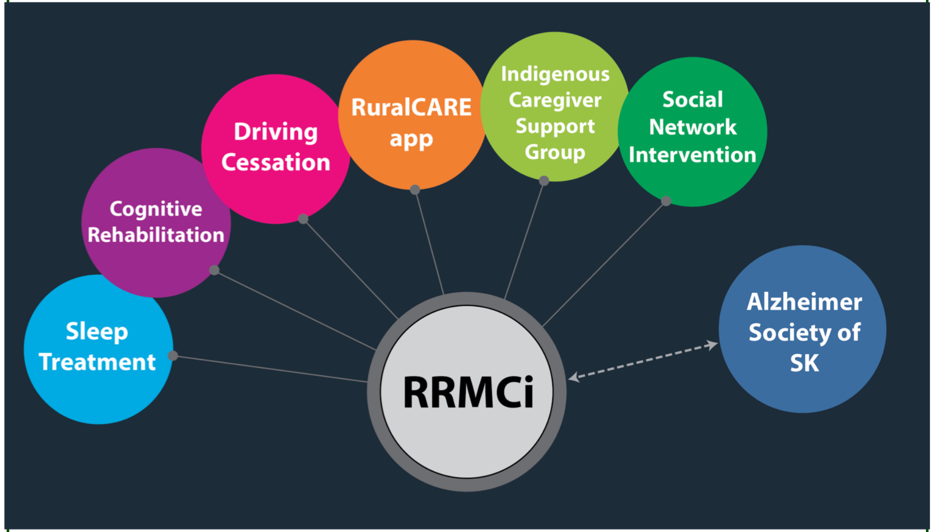
- Burton & O'Connell demonstrated with a RCT that CR can be delivered by Telehealth
- The RRMCi will **soon** deliver a single-case controlled multiple baseline trial of Telehealth CR and measure the impact on mood, quality of life, and satisfaction with goal attainment for persons with MCI or dementia and caregivers
- **Karl Grewal, PhD student**, will be exploring technology + CR for his dissertation. Technology includes in-home sensors to monitor behavior
- *Future work* - add Apple Watches to the CR+technology

NPI O'Connell, M. E., Co-PI Morgan, D. & Co-Is Kosteniuk, J., Kirk, A., Stewart, N., Cammer, A., Dal Bello-Haas, V., D.; Astell, A., Bier, N., Boeheme, G., Bracken, J., Haase, K., Herron, R., Hadjistravopoulos, T., Holroyd-Leduc, J., Holtslander, L., Hunter, P., McWilliams, L., Micheal, J., Naglie, G., Peacock. S., Rapoport, M., Seitz, D., Skinner, M., & Walker, J. (1 April 2019 - 31 March 2024). ***Canadian Consortium on Neurodegeneration in Aging (CCNA)*** *Phase II, Team 15: Issues in Dementia Care for Rural Populations.* $683,300 (from CCNA PHASE II Partners, $333,300 Alzheimer Society of Canada, $50,000 Brain Canada, $100,000 CABHI, & $200,000 SHRF).

Team 15 Includes the RRMCi

The RRMCi includes common intake and outcome measures of cognition, mood, function, and an interview with a collateral informant

- One intake and outcome measure is cognitive assessment with a brief telephone-administered neuropsychological battery
- O'Connell has developed an algorithm for this battery, and **Jake Ursenbach, PhD student,** is adding this telephone-administered battery to the RRMC to gather support for the validity of the algorithm



Driving Cessation

O'Connell, M. E., Rapoport, M., Naglie, G., & Seitz, D.

Driving cessation has psychological consequences that are not well managed

- CCNA Team 16's is creating a driving cessation support group program augmented by problem solving therapy
- We will adapt for Telehealth delivery, deliver from the RRMCi, and evaluate efficacy for rural families.

Indigenous Caregiver Support Group

O'Connell, M. E., Bourassa, C., & Boheme, G.

Indigenous caregivers need a safe space to share and encourage social inclusion

- We will work with the File Hills Qu'Appelle Tribal Council in Southern SK to collaboratively develop Indigenous caregiver support groups that can be offered province-wide and remotely facilitated by the RRMCi

RuralCARE app

Peacock, S., & Co-Is Haase K., Sari, O., Thurmeier, R., Holtslander, L., Michael, J., & Macrae, R. (1 March 2019-28 Feb 2020). *Adapting a ca*O'Connell, M. E., *regiver co- designed mental wellness app for rural caregivers of persons with dementia: RuralCARES*, $45,380. SHRF & CABHI Collaborative Innovative Development grant.

Adapt a smartphone app for rural caregivers to increase their social inclusion – see Dr. Peacock's poster

- O'Connell et al. developed a Telehealth caregiver support group for spouses of persons with atypical dementia such as due to frontotemporal dementia (FTD) and the Alzheimer Society has this as a provincial resource
- We are adapting a co-designed caregiver smartphone app to be an adjunct to the Telehealth support groups
- We will train caregivers how to use this app
- We will trial use of this app and measure impact on mood and social connectedness
- *Future work*
  - Add resource information to the app – collaborate with Australian researchers and researchers at University College London
  - Consider app as a stand-alone caregiver support platform to increase social inclusion

Social Network Intervention

O'Connell, M. E., Panyavin, I., Kortzman, A., Peacock, S., Holtslander, L., McWilliams, L.

Social inclusion for caregivers is critical

- Caregivers might not engage with their social network due to poor identification of social support and thoughts like – "I can't ask for help," etc.
- Systematic review of interventions for informal social supports - See **August Kortzman, PhD student**'s poster
- From this systematic review Kortzman will adapt an intervention for caregivers of persons with dementia and for Telehealth delivery
- An individual social network intervention will become part of the RRMCi
- *Future work*
  - **Meghan Flath, MA-level student**, will explore pet assisted socialization for social inclusion for introverted persons living with cognitive impairment

ACKNOWLEDGEMENTS

CIHR IRSC
Centre for Aging + Brain Health Innovation
SHRF Saskatchewan Health Research Foundation
Alzheimer Society Canada
Brain Canada Foundation

Reclaiming Yourself Tool: A Psycho-social Writing Intervention for Older Adults Bereaved of a Spouse with Dementia

Shelley Peacock; Lorraine Holtslander; Genevieve Thompson; Megan O'Connell; Melanie Bayly; & Kirstian Gibson

Introduction

Bereaved spouses of a person with dementia have been identified as being in need of bereavement interventions. The *Reclaiming Yourself* tool was developed to fill a gap in the current interventions available to bereaved spousal carers.

Phases of tool development

Phase 1

1. Problem defined (need for writing tool)
2. Support from local Alzheimer Society and older adult residences
3. Recruitment through Alzheimer Society advertisements and local social workers
4. Current bereaved dementia caregivers interviewed about their experiences during caregiving and bereavement (audio recorded)
5. Interviews transcribed verbatim, analyzed, and coded into themes by three independent coders (Braun & Clarke, 2013)

⇩

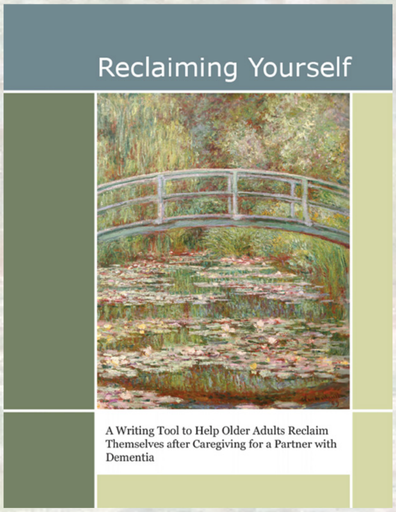
Phase 2

1. Draft tool developed by team from identified themes
2. Experts in the field (current professionals, academics, and bereaved dementia caregivers) asked to review the tool for validity and provide feedback
3. Three rounds of feedback received; adjustments made between each round
4. Acceptance by all experts received after three rounds
5. Final tool professionally printed and bound for use in Phase 3

⇩

Phase 3

1. Recruitment through Alzheimer Societies advertisements and local social workers
2. Current bereaved dementia caregivers take part in three session study over three months (1 month between each approximately 1.5-hour session):
   - *Session 1:* Explanation of study, informed consent received, completion of 3 measures ^{a}
   - *Session 2:* Completion of 3 measures $^{a, b}$
   - *Session 3:* Completion of 3 measures ^{b}
3. Interviews (audio recorded) transcribed verbatim, analyzed, and coded into themes by three independent coders (Braun & Clarke, 2013)
4. Measures statistically described



Reclaiming Yourself

A Writing Tool to Help Older Adults Reclaim Themselves after Caregiving for a Partner with Dementia

Reclaiming Yourself Tool

The tool is intended to encourage reflection, through focused writing, with the overall goal of assisting bereaved spouses to find their own unique way of moving ahead in their grief. There are exercises included in the tool to help spouses to reclaim themselves in life.

Section 1 of Tool: *Deep Grieving*

This section consists of activities that address the process of deep grieving (e.g., feeling empty after a death or feeling overwhelmed / consumed by sadness). Activities include:

- ❖Expressing Your Emotions
- ❖Time Out
- ❖Create a Support System
- ❖Creative Space

Section 2 of Tool: *Embracing Self*

This section consists of activities that address the process of reclaiming who you were before dementia touched your life. Activities include:

- ❖Past Enjoyable Activities
- ❖Recovering Pleasant Activities
- ❖Getting Creative
- ❖Creative Space

Section 3 of Tool: *Moving Forward*

This section consists of activities that address the process of moving forward. Activities include:

- ❖Letting Go of Regrets
- ❖My Story Makes Me Stronger
- ❖Creative Space

Acknowledgements

We would like to thank all the research participants that contributed to this tool. Thanks also to *LutherCare* Communities and the Alzheimer Societies of Saskatchewan and Manitoba for their support.

We gratefully acknowledge the generous funding from the Saskatchewan Health Research Foundation.

Available: https://research-groups.usask.ca/reclaimingyourself/

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Associate Professor
College of Nursing,
University of Saskatchewan
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We are a grassroots group of Canadian care partners and people living with dementia.

We are speaking up.

We want to have an active and respected role in decisions about policies and programs that impact our lives.

Make dementia matter.

Dementia Advocacy Canada

Voices of Lived Experience

Our Priorities & Recommendations:

Reduce stigma.

Development of a national public awareness campaign to raise awareness about dementia.

A single point of contact to mitigate a fragmented system.

Appointment of a dedicated system navigator from diagnosis through to end of life to help with all aspects of care coordination.

Standards of excellence in dementia education.

Regulation of Personal Support Workers, and the establishment of federal regulations for core competencies and standards of excellence in dementia care.

Rehabilitation to live as well as possible with a dementia diagnosis.

Creation of national guidelines for a strengths-based rehabilitation program, activated immediately following a diagnosis of dementia.

Learn more at **www.dementiacanada.com**

Dementia is a health care crisis in Canada.

>419,000
number of Canadians over 65 currently living with diagnosed dementia

937,000
projected number of Canadians living with dementia by 2031

3%
approximate proportion of Canadians with dementia younger than 65

$16.6B
projected total cost of health care and out-of-pocket caregivers costs in Canada by 2031

~9/hr
approximate number of seniors who are diagnosed with dementia every hour in Canada

486,000
number of Canadians that are a family or friend caregiver for someone currently living with dementia

Sources:
https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html
http://www.cihi.ca/en/dementia-in-canada/spotlight-on-dementia-issues/young-onset-dementia

CCNA CCNV 15 Team équipe

Feasibility and Acceptability of Digitally-Delivered Spaced-Education for Dementia

UNIVERSITY OF SASKATCHEWAN

A. Scerbe[1], M. E. O'Connell[1], D. Morgan[2], D. Kosteniuk[2]

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

INTRODUCTION

- Dementia is generally perceived as more complex than other conditions by medical specialists[1, 2].
- Rural healthcare providers report a lack of access to dementia education/training[3], and so are more likely to chose to refer a patient to a specialist.

SPACED EDUCATION

- Derived from spacing and repetition research[4].
- Learning is facilitated by spaced presentation of materials (pre-determined intervals), in a repetitive manner.
- Presentation of correct answer = delivery of an educational piece.
- Spaced education for healthcare professionals is routinely delivered via technology-based mediums such as email, and smart phones[4,5,6], and noted to be as effective as face-to-face education[6].

GAMIFICATION

- Refers to application of game-like elements to non-game settings, to increase enjoyment in participation[6, 7].
- Examples include appointment-based dynamic[6] (automatic loss of questions not answered within a prescribed time period), and anonymous leader board or progress board[7].

FEASIBILITY-PARTICIPATORY STUDIES

- Critical in establishing foundation for pilot studies[8], ensuring that implementation is practical, and minimizing threats to validity[9].
- Inclusion of an intended participant/user can enrich the methodological approach[10] and protect against single-sided conceptualization in pilots[11].

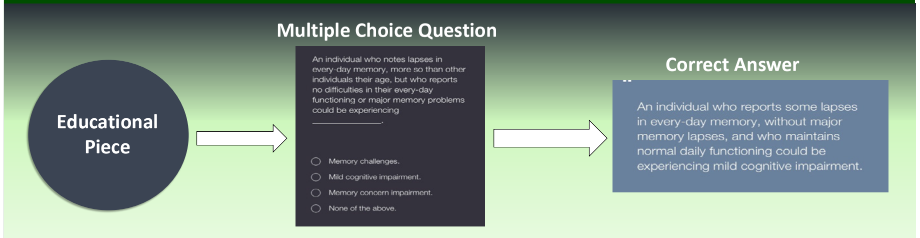
PRESENT STUDY

- A feasibility study was conducted with one rural primary healthcare provider.
- Assumes principles of participatory research to answer questions regarding feasibility and acceptability of digitally-based dementia education.
- Educational content used in proposed intervention was based on the Primary Care Dementia Assessment and Treatment Algorithm Project (PC-DATA) algorithm developed by Dallas Seitz.
- Content was designed to educate on when to refer a patient to a specialist.

METHODOLOGY

- Questions were programmed and presented in Ethica (smart phone application for healthcare research use).
- **Three formats**: case-based vignettes, short white board educational videos, and textual content followed by multiple choice questions.
- Collaborator reviewed a presentation on research regarding digitally-delivered spaced-education for healthcare providers (when to refer to a specialist), and was interviewed regarding the content, presentation/format of questions, and reception of such materials.

SMART PHONE APPLICATION INTERFACE



An individual who notes lapses in every-day memory, more so than other individuals their age, but who reports no difficulties in their every-day functioning or major memory problems could be experiencing ______________.

○ Memory challenges.
○ Mild cognitive impairment.
○ Memory concern impairment.
○ None of the above.

An individual who reports some lapses in every-day memory, without major memory lapses, and who maintains normal daily functioning could be experiencing mild cognitive impairment.

QUALITATIVE ANALYSIS

- Semi-structured interview, was transcribed and analyzed using content analysis.

Visual Presentation of Content	Format of Presentation	Feasibility	Enhancing User Participation
Notification of new content should resemble popular movie streaming services	Support for repetition of educational content	Positive perceived information relevance, ease, applicability of information	Support for including acknowledgment for completion
Enthusiasm regarding visual and auditory content	Suggestion to keep number of questions presented at a time to 2, and provide immediate feedback	Intervention won't incur burden on primary healthcare	Suggestion for researchers to present in person to stimulate initial user buy in
Enthusiasm regarding mobile application format	Enthusiasm regarding information appeal to authority	Importance of continuing dementia education for primary healthcare	Enthusiasm regarding inclusion of case studies
Endorsement for inclusion of varied presentation formats	Endorsement for testing long-term knowledge	Plausible anticipation of involvement of physicians	Endorsement of gamification-stimulating healthy competition
			Endorsement for podcast type education
			Dislike for emailing of educational content

GENERAL FINDINGS

- The interview revealed an overall positive reception and anticipated delivery of digitally-based spaced education for rural primary healthcare.
- Suggested changes included enhancing the mobile application interface to include immediate feedback after a response.
- Most desirable format of presentation included case-based scenarios, and white-board style educational video snippets.
- There was a strong support for development of short podcast style content presentation.

LIMITATIONS AND FUTURE DIRECTIONS

- A limitation included involvement of a single respondent, however the respondent has been employed in healthcare field for over 33 years and has worked in the context of a "closely knit" rural primary healthcare team during this time.
- Moving forward, researchers will consider a strategy for gaining healthcare participant buy in (e.g., intermittent check-ins, presentations, team champions).

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SHRF SASKATCHEWAN HEALTH RESEARCH FOUNDATION
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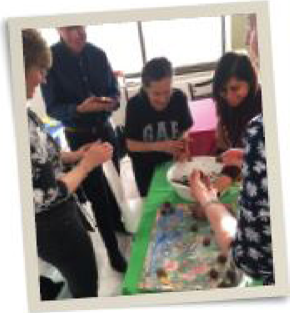
Fondation Brain Canada Foundation

Facilitating Clubs for People with Young Onset Dementia: A User-Friendly Resource Manual

"The most important part of a young onset dementia club is the community it offers - a place to feel like you belong."

Young onset dementia (YOD) is defined as dementia diagnosed before the age of 65. YOD accounts for 2-8% of all dementia cases (World Alzheimer Report, 2015).



What is the problem?

People with YOD often experience personal and social challenges that are different than those of people with dementia who are diagnosed later in life. These may include trouble getting a diagnosis, employment or financial struggles and changing family roles, among others. A lack of knowledge about YOD among health and social care providers further contributes to these challenges.

What did the Alzheimer Society of Canada do?

The Society conducted a YOD Gap Analysis survey in 2016 that included people with YOD, their families and the providers who support them. People with YOD and their caregivers said they needed:

- Separate support groups for people with YOD and their caregivers
- Activities and social programs that are meaningful, fulfilling and suitable to their unique needs

In response, the Society worked with people with lived experience and clinicians to create a user-friendly resource manual on facilitating clubs for people with young onset dementia.

> **"My YOD group reminds me that I have some strengths to offer, qualities I can share, experiences that others find interesting. It reminds me that I am still me."**
>
> – Person with dementia

What was the result?

A "Young Onset Dementia Facilitator's Resource Manual" was developed based on best practices and available research. The manual provides practical, user-friendly strategies to help community organizations create, implement and evaluate clubs for people with YOD and their families. It is available in English in French.

The Resource Manual's Practical Tips and Tools

Tips for assessing needs and what to offer
- Determining eligibility
- Considering the type of dementia
- Goals of the program
- Transitioning out of the group
- Meeting the needs of youth/children

Special considerations for planning and implementing online/web-based groups
- Determining the "hub" site or platform
- Training facilitators
- Assessing technology level of participants
- Facilitation and follow-up
- Collaboration with the community

Program planning
- Identifying participants
- Recruitment
- Intake interviews
- Location and frequency of meetings

Program implementation
- Choosing activities
- Facilitation/leadership style
- Staff and volunteers
- Leadership training
- Budgeting

Strategies for success
- Marketing/outreach
- Branding
- Funding
- Community partnerships
- Program evaluation

Self-care tips for facilitators
- Importance of self-care
- Individual self-care
- Peer and organizational support

Resources

In the manual, you will find:
- Checklist for implementing a YOD group
- Recruitment flyers
- YOD "Strengths and Strategies" Interview Form
- Participant interview questions
- Introductory letter for online/web-based groups
- Referral form
- Evaluation forms

A webinar on the importance of social programs for people with YOD is available for viewing at: www.alzheimer.ca/youngonset

The manual is available in English at: www.alzheimer.ca/youngonset

The manual is available in French at: www.alzheimer.ca/debutprecoce

Alzheimer *Society*

Registered Dietitians Current Practice in End-of-Life Care in Long-Term Care Homes

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Canadian Frailty Network

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Background

- In long-term care (LTC), Registered Dietitians (RD) are the health care professionals specialized in food and nutrition care.
- Many LTC residents are frail older adults that will experience end of life in their LTC home[1,2].
- End of life (EoL) refers to the days to months prior to death. Residents' quality of life should be the priority at this time[3].
- Body functions like digestive processes slow considerably at EoL. Minimal hunger and thirst is normal at this time[4].
- Families may experience distress when their loved one's food and fluid intake declines.
- Comfort feeding only, first proposed for individuals with late stage dementia, is recommended as a best practice at EoL[5,6].

> ***Comfort Feeding:*** *Careful hand feeding in the least invasive and most enjoyable way possible. Mouth care, gentle touch and conversation when oral feeding is no longer appropriate[5].*

Research Objective: Examine the current state of practice of RDs working in LTC regarding EoL care.

- What are the demographic and occupational characteristics of RDs?
- What is the current state of RD practice competence (knowledge, confidence, & application) related to EoL nutrition care?
- What is the relationship between practice competence, RD demographics, and occupational characteristics?

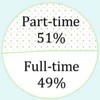
Methods

- A 32-item online survey was developed and distributed to RDs practicing in LTC via Dietitians of Canada's Gerontology Network.
- Inclusion criteria: currently practicing as a RD and currently working in LTC.
- Qualitative data was analyzed thematically.
- Quantitative data was analyzed using SPSS.

Results

- Of the 130 respondents who attempted the survey, 114 complete and valid responses were received.
- The average age of participants was 42.69 years (*SD* = 13.55), with 16.12 years (*SD* = 12.57) experience as a RD and 11.66 years (*SD* = 9.41) working in LTC. Most (97.32%) respondents were female and 59.30% practice in Ontario.

RD hours



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Mean number of LTC homes RDs provide care.

166

Median resident case load (range: 1-549).

15%

Mean % of residents at EoL.

RD Role in End-of-Life Care

RDs described the role as twofold:

Educate family & staff: *"Helping the family understand and accept changes to intake, mood, [and] desire to eat at end of life".*

Therapeutic Modifications to Nutrition Care: *"Helping the team in providing [the] resident with foods and fluids that are accepted, tolerated and provide comfort".*

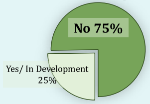
Is your role being used to its fullest capacity?

Yes	No	Unsure
24%	**45%**	31%

Lack of Involvement: Not receiving referrals & not made aware resident is at EoL

Time Constraints: Limited hours & servicing multiple LTC homes

Does your home have a Comfort Feeding Policy?

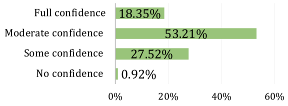


86% Percentage of RDs with ≥ 1 resident currently prescribed comfort feeding.

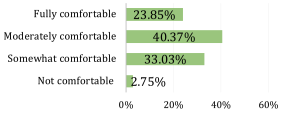
10% Average percentage of resident caseload currently prescribed comfort feeding.

	Confidence in providing nutrition care to residents at EoL	Comfort in having discussions about EoL nutrition care with residents' family	Knowledge of applying comfort feeding principles to residents at EoL	Confidence in applying comfort feeding principles at EoL
	M ± *SD*	*M* ± *SD*	*M* ± *SD*	*M* ± *SD*
Policy				
Yes	3.15 ± .61	3.12 ± .65	3.19 ± .57	3.19 ± .63
No	2.82 ± .69	2.77 ± .85	2.67 ± .65	2.67 ± .71
p value	.032*	.058	.001*	.001*

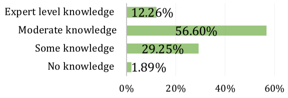
What is your level of **confidence** about providing nutrition care to residents at EoL ?



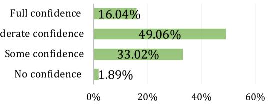
How **comfortable** are you having **discussions** about EoL nutrition care with family of residents?



What is your current level of **knowledge** of applying comfort feeding principles to residents at EoL?



What is your current level of **confidence** in applying comfort feeding principles at EoL?



Conclusions

- Overall, most RDs endorse moderate or full practice competence in EoL nutrition care and comfort feeding.
- RDs reports of moderate or full confidence in providing nutrition care at EoL and moderate or full knowledge and confidence in applying comfort feeding principles at EoL in LTC were positively associated with having a formal Comfort Feeding policy.
- Nearly half of RDs felt their role in EoL care was not being used fully.

Implications for Practice

- EoL care is an important practice area for RDs; more should be done to involve RDS in the EoL care team, and to improve practice competence for RDs in EoL care and comfort feeding at EoL.

Limitations

- Participants were recruited via the Gerontology Network; not all RDs practicing in LTC are members of this network.
- We do not know how many RDs received the survey link and therefore cannot calculate a response rate.

Next Steps

- Complete an adjusted analysis of survey data.
- Conduct in-depth interviews with RDs working in LTC to gain a deeper understanding of their experience with EoL care and comfort feeding in the LTC context.

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Short Form Scoring Algorithm for a Computer-based Cognitive Screening Tool

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INTRODUCTION

- Half of mild to moderate dementia cases are undiagnosed[1,2] and many primary care providers (PCP) lack training and time to administer necessary cognitive tests.
- Mild cognitive impairment (MCI) is important to diagnose.[3]
- Computer Assessment of Memory and Cognition – Research (CAMCI-R)[8] a computer-based cognitive test with evidence for reliability and validity in detection of MCI [4,5] - is easily administered and influences PCPs' care decisions.[6]
- **The CAMCI-R requires about 25 minutes to administer which is considered to be too long for some busy PCPs.[7]**

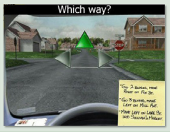
OBJECTIVE

Develop a short form version of the CAMCI-R that approximates the classification accuracy of the full test.

CAMCI-R Overview

CAMCI assesses 5 cognitive domains in 7 tasks.

- **Attention.** Digit span forward; star selection task.
- **Verbal memory**. Verbal recall (immediate, delayed, recognition).
- **Visual memory.** Picture repetition task.
- **Executive function.** Go-no-go task.
- **Working memory.** Digit span backward.
- **'Virtual environment' task.** Shopping trip that assesses following instructions, recognition, incidental memory, prospective memory.

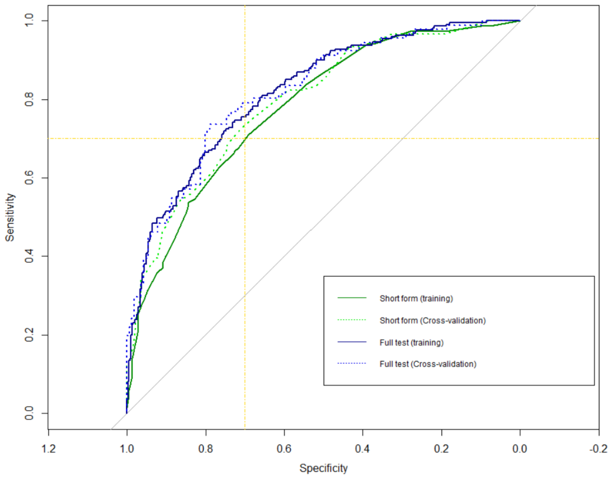


METHODS

- Secondary analysis – 887 community dwelling adults with independent classification of MCI or no cognitive impairment.
- Dataset/2 = training and cross-validation.
- Estimated logistic regression model with principal components of all CAMCI-R raw scores in training dataset ('full test model').[8]
- Backwards stepwise logistic regression of the estimated log odds of MCI regressed on the principal components of the CAMCI-R scores, stopped when the 'short-form model' accounted for 95% of the variance of the 'full test model.'
- Receiver Operator Characteristic (ROC) curves of principal component scores from 'full test model' and 'short form model' with independent dx as criterion

RESULTS

Full and Short Form Median AUC model performance on training and cross-validation data



- **Full CAMCI-R** classification accuracy within the cross-validation sample area under curve (AUC) = **0.82** [95% confidence interval 0.77 – 0.87]).
- Youden's optimal threshold cut off, sensitivity 0.74 [0.64 – 0.82] and specificity 0.79 [0.72 – 0.85].
- In cross-validation sample, **short-form** AUC = **0.80** [0.74 – 0.85], at Youden's cut off sensitivity = 0.74 [0.64 – 0.82] and specificity = 0.70 [0.63 – 0.77]).
- **Completion time for the full CAMCI-R is 24.0 minutes. Short form is 9.3 minutes.**

CONCLUSIONS

- Long- and short-form interpretive algorithms for CAMCI-R performance estimate probability that patient presenting to primary care would be classified as MCI or not by independent neuropsychological evaluation.
- CAMCI-R short-form less than half the duration of the long form without substantial loss to classification accuracy.
- If the CAMCI-R short-form were used to screen 1000 older adults in a population with an 8.4% baserate of MCI, predictive values are:
  - Of 84 older adults with MCI
    - 62 classified correctly (true positives)
    - 22 not identified (false negatives)
  - Of 916 older adults without MCI,
    - 274 incorrectly classified with MCI (false positives)
    - 641 correctly classified with no cognitive impairment (true negatives)

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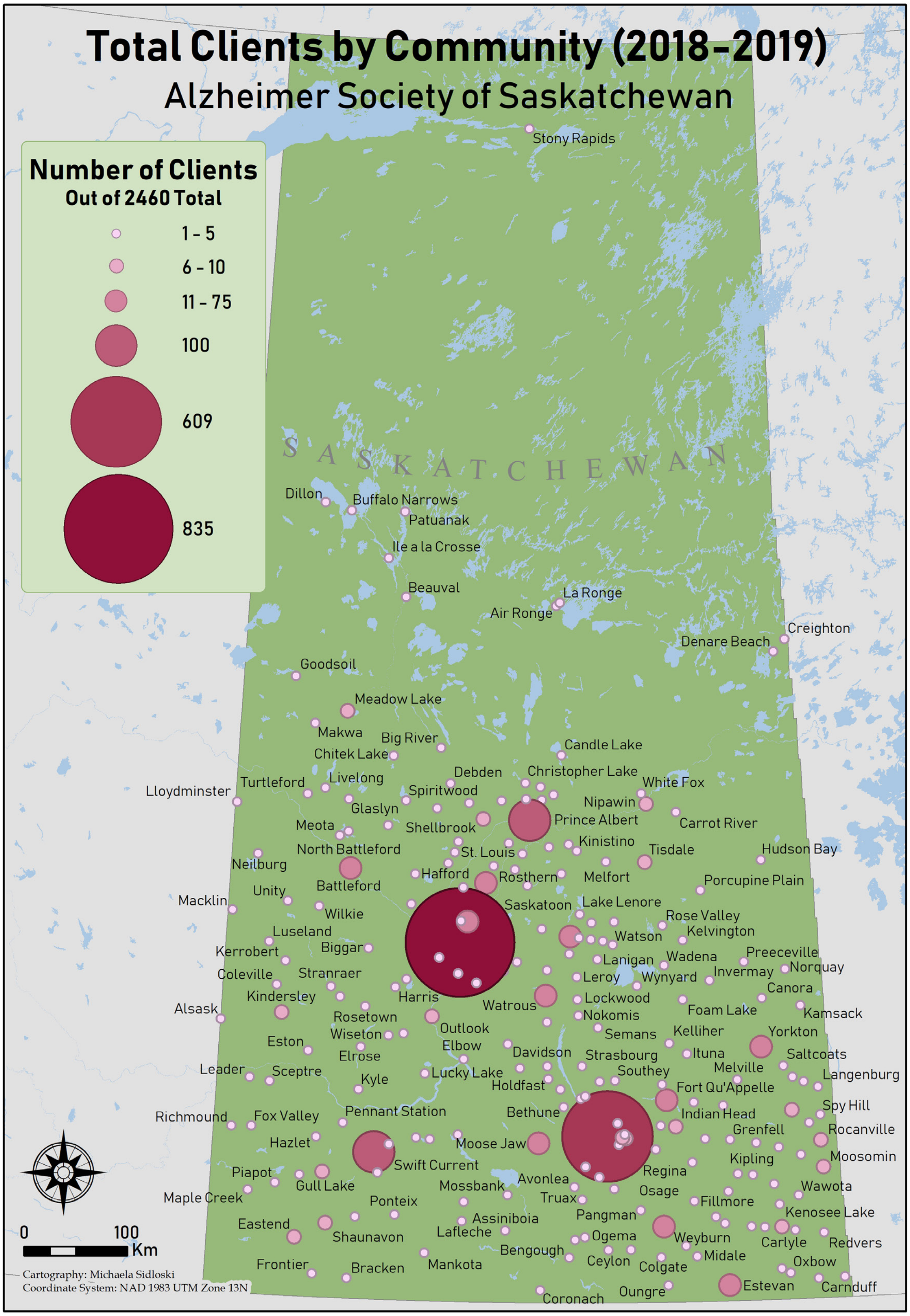

In 2018-2019 the Alzheimer Society supported over 2,400 individuals from 297 communities.

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