Knowledge Network in Rural and Remote Dementia Care

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

Scientific Poster Session
8th Annual Summit

October 27th & 28th, 2015
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Cognitive Health: Rural Older Adults’ Perspectives

Juanita Bacsu, Sylvia Abonyi, Marc Viger, Bonnie Jeffery, Shanthi Johnson, Nuelle Novik

OBJECTIVE

Objective
- To examine older adults’ perceptions of cognitive health within the cultural context of rural Saskatchewan, Canada.

Rationale
- Growing recognition that cognitive health should not be defined merely as the absence of dementia and related diseases.
- Existing literature on cognitive health perceptions focuses predominately on dementia care and health service delivery for those with dementia.
- With the exception of Wu and colleagues, there is limited research on cognitive health perceptions among healthy rural seniors without dementia.
- Rural barriers to early dementia diagnosis may include lack of education, stigma, financial challenges, transportation issues and limited health and support services.
- Research on rural seniors’ perceptions of cognitive health is critical to supporting dementia awareness and early diagnosis in rural areas.

DATA ANALYSIS

- Following informed consent, interviews were audio-recorded and transcribed verbatim.
- Guided by lay theory and cultural schema theory, thematic analysis was performed to identify key patterns, themes and relationships within the data.
- Concept maps were analyzed by focusing on the concepts and relationships identified by rural seniors within the maps.

FINDINGS

Four themes of cognitive health:

1) Intellectual health – defined as the importance of mental stimulation, comprehension and continuous learning.
   - “It means getting out of your comfort zone and learning something different.”

2) Social health – described as social interaction and community engagement.
   - “If you’re just going to sit in your own little space and not communicate with other people, then I think you’re going to go bonkers.”

3) Emotional health – expressed in terms of mental well-being, balanced lifestyle and spirituality.
   - “I think one of the most important things is having a positive attitude and whether you’re a glass half full type of person.”

4) Functional health – discussed in relation to physical health, activities of daily living, decision-making and independence.
   - “It’s about looking after your own affairs and day to day decisions… being able to manage on your own without being dependent on others.”

METHODS

Using an ethnographic approach, data was collected through 2 waves of semi-structured interviews with rural seniors aged 60+ in Young and Watrous, SK.

- 1st wave - 42 participants, February to May, 2014.
- 2nd wave - 37 participants, July to August, 2014.
- Participant observation conducted with 5 seniors to observe day-to-day activities related to cognitive health.
- Using 1st wave findings, a concept map was developed to summarize rural seniors’ conceptual themes of cognitive health into a visually accessible framework (Figure 1).
- During 2nd wave interviews, participants were given the concept map to provide feedback on the framework through in-depth discussion and drawing on the map.

DISCUSSION

- In contrast to current literature which understands cognitive health in terms of pathology, rural older adults described cognitive health within a more holistic and multidimensional context, ranging from intellectual to emotional health.
- Understanding rural seniors’ perspectives of cognitive health provides critical information to inform dementia awareness, education and early diagnosis in rural communities.
- If policy makers and researchers are to develop more effective strategies to support rural cognitive health, older adults’ perspectives must be recognized.
**Study 1 INTRODUCTION**

**Purpose**
The purpose of the proposed research is to gain a better understanding of current conceptualizations and measurement of positive aspects of caring for persons with dementia.

**Rationale**
- Canadian informal caregivers provide care with a yearly estimated value of $26 billion.\(^1\)
- Caregiver research provides better understanding of the caregiver experience and informs on interventions aimed to support and sustain caregivers in their role.
- Extant literature reveals an emphasis on negative aspects of caregiving (i.e., caregiver burden and strain), with a smaller number of studies investigating positive aspects (i.e., caregiver satisfaction and personal gain).
- By synthesizing extant literature on positive aspects of caregiving, this research aims to:
  1. Understand how positive aspects of caregiving are commonly conceptualized,
  2. How these are measured,
  3. If/how positive aspects relate to other commonly measured aspects of caregiving (e.g., burden, well-being, severity of dementia),
  4. Identify what is known and what is missing.

---

**Methods: Mixed Meta Synthesis**

**Meta-Analysis**
Based on Quantitative research this meta analysis will provide information on:
- Current conceptualizations of positive aspects
- Tools of measurement
- Effect sizes indicating how positive aspects relate to other variables

**Meta-Synthesis**
Based on Qualitative research, this meta-synthesis will provide information on:
- Commonalities in caregiver experience
- Summarizing and combining qualitative evidence surrounding positive aspects of caregiving.

**Synthesis**
Findings from the meta-synthesis inform on effect sizes revealed by meta-analysis.
- The findings from this study are expected to expand the current understanding of the positive aspects of caregiving by synthesizing extant literature from both quantitative and qualitative directions.
- This research is expected to give a clear account of how the positive aspects of caregiving are currently conceptualized,
- How we are measuring these aspects
- What may be missing from current conceptualization and measures.
- These findings will indicate important areas for future research.

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**Case Study**

By means of open ended interview with two Aboriginal caregivers, this study aims to:
- Provide insight into this understudied population of caregivers.
- Prompt future research into this important and growing population.
BEST PRACTICES REGARDING NUTRITIONAL CARE OF URBAN AND RURAL LONG-TERM CARE RESIDENTS WITH DEMENTIA

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Background

- Dementia is recognized as a public health priority; worldwide prevalence of dementia is projected to double to 65.7 million by 2030.
- Dementia is the top chronic condition prompting relocation to long-term care (LTC).
- Nutritional health of LTC residents is central to quality of care.
- 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.
- LTC staff are responsible for developing and executing resident nutritional care plans, monitoring residents’ food and fluid intake, encouraging independence and promoting social well-being as it pertains to eating and nourishment. The majority of direct resident care in LTC is performed by care aides.

PhD research

Using an evidence-based practice framework and integrated knowledge translation approach, what are best practices regarding nutritional care of LTC residents with dementia, and does practice vary according to rural or urban LTC location?

Evidence-Based Practice (EBP) Framework

- EBP involves the integration of evidence, clinical expertise, and patient/resident values to create most appropriate care processes

Research Evidence

- Systematic review of peer-reviewed, published research
- Search strategy and keyword terms determined a priori
- Exclusion criteria developed; articles reviewed by 2 researchers to determine final inclusion
- Appraisal of research using VIA statements
- Review Process (Khan et al., 2011)

Registered Dietitians (RDs)

- In-depth interviews
- Participants recruited from list of RDs practicing in LTC across Saskatchewan
- RDs contacted via email/phone, invited to participate in 1-2 hour in-person interviews
- Mix of both rural and urban practicing RDs
- Mix of full-time, part-time and consultant RDs
- Grounded Theory Analysis (Charmaz, 2014)

Care Aides

- Focus Group Discussions
- Four LTC homes, 2 focus group discussions per home
- Two urban LTC homes and two rural LTC homes included
- Care aides invited to participate via research posters distributed at each LTC home
- Comparison of rural – urban practice setting
- Framework Analysis (Rabiee, 2004)

Knowledge Translation and Exchange (KTE)

- KTE committee of the researcher and decision-makers formed prior to developing research questions
- KTE decision-makers include health region administrators, quality improvement manager, LTC nurse, and LTC RDs
- Research has been developed in partnership, ensuring that findings will be useful and will inform planning processes in the future
- Uptake of research findings will occur at various levels including informing EBP within the province, peer-reviewed publications, presentations

Acknowledgements

Alzheimer Society

PHARE

WRTC

University of Saskatchewan
The Impact of Thinking and Speaking in the Third Person on Interpersonal Processing

Jessica Campoli, B.A. (Hons.) and Dr. David Reid, PhD, C. Psych
Department of Psychology, York University

Abstract
This study isolated a technique used in Systemic-Constructivist Couple Therapy (SCCT) called Thinking and Speaking in the Third Person (TSTP). The effects of TSTP on Interpersonal Processing (IPP), dyadic perspective taking, and negative affect were explored. Sixty-three female participants were randomly assigned to one of three groups. The experimental group who practiced TSTP significantly decreased in their ability to think reciprocally about their relationship and to take their partner's perspective. Additionally, there were higher absolute difference scores in the experimental group, which indicate that the participants practicing TSTP decreased in negative affect from pre-test to post-test. These findings might be related to the 'realism effect.'

Introduction
SCCT uses empirically-derived techniques, such as Interpersonal Processing (IPP), to enhance partner's identity within relationships to increase marital satisfaction. A technique used in SCCT to increase reflexive thinking is Thinking and Speaking in the Third Person (TSTP), where the third person narrative is used to converse with one's partner and write about those interactions. TSTP may increase a central mechanism of change in SCCT: Interpersonal processing, which involves thinking reciprocally about one's self and one's partner. Since higher Interpersonal Processing scores predict couple satisfaction, negative affect (negative emotions) in regards to one's relationship may decrease.

Hypothesis
• Using the third person narrative while thinking and speaking about one's relationship will significantly increase the ability to think reciprocally about the relationship and to engage in dyadic perspective taking, and will decrease negative emotions toward the relationship.

Method
• 63 females recruited from the Undergraduate Research Participant Pool (URPP) and flyers at York University
• In a committed, heterosexual relationship for a minimum of 6 months
• Completed the Interpersonal Processing Scale, Dyadic Perspective Taking Scale, and Positive and Negative Affect Scale prior to and directly after the 2 week duration of the study.

Results
• Absolute difference scores- significant differences in Interpersonal Processing change scores between groups [F (2, 54) = 4.60, p = .014]
• The experimental group decreased in IPP while the comparison group increased in IPP, p = .03 (contrary to hypothesis; see Table 2)
• Significant negative relationship between experimental group’s post-test negative affect and Interpersonal Processing scores
  \[ r = -.68, p < .01 \]
• Absolute difference scores calculated separately for each participant showed the experimental group had the highest absolute difference score from pre- to post-test (M = 8.77), in that their negative affect decreased.

Conclusions
• These results are useful for understanding negative emotions pertaining to relationships and the change processes involved in SCCT
• Unanticipated results highlight the importance of relationship knowledge
• TSTP should be implemented in the middle of therapy, once the couple has learned about each other
• The 'Realism effect' might explain the finding: Taking an objective perspective may have brought subjects to a more realistic view of their relationship

Table 1

<table>
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<th>Control Group (n = 21)</th>
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<td>Pre/post test questionnaires</td>
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<td>-10 journal entries and 10 conversations with partner using the Prf. person narrative</td>
<td>-10 journal entries and 10 conversations with partner using the 3rd. person narrative</td>
<td>-Rule out relationship awareness + reflexive thinking</td>
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Table 2
The experimental group significantly decreased from pre- to post-intervention on dyadic perspective taking, \( p = 0.009 \) (see Table 3)

Table 3

References
The Role of Facilitation in Sustainability of a Dementia Training Program in Long-Term Care

Tracy Cassidy Layton, PhD. Candidate, Health Sciences, College of Medicine, University of Saskatchewan; Debra Morgan, PhD, College of Medicine, University of Saskatchewan; and Norma Stewart, PhD, College of Nursing, University of Saskatchewan

BACKGROUND

Dementia robs individuals of their physical, mental, and emotional functioning. It can cause confusion, memory loss, personality changes, and response behaviours (Torpy, Lynn, & Glaz, 2008). Responsive behaviours may include yelling, swearing or hitting out during care. Nursing aides (NAs) are the most frequent recipients of these behaviours (Gates, Fitzwater & Sucup, 2003).

Staff managers and researchers working in long-term care homes have recommended training programs specifically designed to manage responsive behaviours (Morgan et al., 2007); however, residents diagnosed with dementia unfortunately, there is a gap in knowledge dissemination in long-term care homes (Bostrom, Slaughter, Chojecki, & Stalbrooks, 2013). Implementing evidence-based practices, such as a dementia specific training program in long-term care, is a complex process that requires multiple interventions beyond simple dissemination to sustain practice change (Leiken, Hendk, McCallan, & White, 2010).

THE GENTLE PERSUASIVE

- The implementation of the Gentle Persuasive Approaches (GPA) program in Saskatoon Health Region (SRH) in 2009 created an opportunity to study facilitation within the context of rural long-term care homes (LTC). The main goal of the GPA program is to provide staff who work in LTC homes the skills to prevent and manage responsive behaviours displayed by residents with dementia (Schinold, Martin & Dupuis, 2009).
- GPA Master Coaches are responsible for training GPA Coaches. The GPA Coaches then return to their own home to train staff in all departments.
- The GPA Program consists of four modules:
  - Module 1: encourages staff to move away from a task-oriented to an enabling approach
  - Module 2: teaches staff how the brain is affected by dementia and creates responsive behaviours
  - Module 3: teaches reflective communication skills to reduce responsive behaviours and enables staff to deal with difficult situations
  - Module 4: teaches staff how to physically protect themselves in a way that is respectful and safe for the residents

I-PARIHS FRAMEWORK AND FACILITATION

Within the Integrated Promoting Action on Research Implementation in Health Services framework (I-PARIHS), successful implementation results from the facilitation of an innovation, with the recipients (individual & collective) in their inner & outer context (Harvey & Kitsch, 2015).

This research examined the concept of facilitation within the I-PARIHS framework. Within this framework, facilitation triggers the implementation process. It involves thinking about what to be implemented, who, when, where etc. Facilitation provides the how component of implementation (Harvey & Kitsch, 2015).

Successful implementation is defined by:
- Achievement of agreed implementation/project goals
- The uptake and embedding of the innovation in practice
- Individual, teams, and stakeholders are engaged, motivated and own the innovation
- Variation related to context is minimized and across implementation settings

RESEARCH QUESTIONS AND THEORETICAL PROPOSAL

Research Questions:
- What is the relationship between facilitation and sustainability of training programs in rural LTC homes?
- What type of facilitation (roles, skills, attributes) are associated with sustainability?
- In what ways do the GPA Coaches act as facilitators during and after program implementation? How do these activities compare to others who may play a facilitation role internally and externally?

Theoretical Proposition:
- Appropriate facilitation leads to sustainability of evidence based practice

METHODS

Two studies were conducted simultaneously to examine the relationship between facilitation and sustainability.

Study 1 (Retrospective):
- Design: exploratory, retrospective, qualitative research design
- Site selection: 5 homes were purposely selected from rural LTC homes with similar characteristics and where GPA had been implemented in 2009
- Participants: administrators, Directors of Care, Managers, nurses, RNs, RPNs, LPNs, Clinical Nurse Leaders and NAs
- Data collection: semi-structured interviews (n=14) and focus groups (n=4)
- Data analysis: data were analyzed using a qualitative, inductive approach, using the constant comparative method (Straus &4 Strauss, 1997, Charmaz, 2006)

Study 2 (Prospective):
- Design: prospective longitudinal, multi-site, comparative case study design
- Site selection: 2 homes were purposely selected based on "comparison of difference" design logic (Wright & Dopson, 2009) that maximized variation on organizational factors that may influence implementation and sustainability of the GPA program:
  - Affiliate vs. owned and operated by the health region
  - Management and reporting structure
  - Position of GPA Coach
  - Presence/Absence of Clinical Nurse Leader
- Similar number of residents living in the 2 homes
- Data collection: direct observations (24 months), shadowing, and informal interviews (6-months), semi-structured interviews with staff in all departments (n=15), and document review (i.e., nursing progress notes, communication logs, incident reports) beginning three months prior to GPA implementation

FINDINGS

- In the retrospective study, a continuum of low, medium, and high sustainability homes emerged.
- In the prospective study, data confirmed a low sustainability home and a high sustainability home and supported the theoretical proposition that appropriate facilitation leads to sustainability.

Informed Facilitators:
- All homes had informal facilitators who role modeled and provided support. These facilitators were mostly NAs but were also in other departments (i.e., recreation and dietary). They were primarily younger staff members with formal dementia training.
- Informal facilitation was necessary but not sufficient to sustain the GPA program.

GPA Coaches:
- All GPA Coaches problem solved, coached, and role modeled in all of the homes. GPA Coaches in the medium and high sustainability homes provided support, evaluation, and monitoring of staff using GPA but not in the low sustainability homes.
- The GPA Coaches in the low and medium sustainability homes did not feel they had power or authority in their position to do more facilitation and they were limited to making suggestions.
- In the high sustainability home, in the prospective study, the GPA Coaches were a Clinical Nurse Leader (CNL) and an LPN with authority and power to do more than just making suggestions.
- The GPA Coach Role as currently defined was not sufficient to sustain the GPA program.
- Facilitation after the program was implemented was not an expectation of this role.

Clinical Nurse Leader (CNL):
- Skills of the CNL in the high sustainability home included working with the residents, mentoring daily staff, building relationships, setting expectations for GPA program performance, teaching in the moment, and using critical reflection to change practice.
- Attributes of the CNL in the high sustainability home included being patient, non-judgmental, knowledgeable, and dependable.

The CNL was a key reason for the sustainability of the GPA program in the prospective study.
- The CNL position with appropriate facilitation skills and attributes was related to sustainability.
- The CNL role was a hybrid role of leader (in a position of authority) and facilitator (i.e., facilitation skills such as shaping behaviours, relationship building, problem solving, fostering team work). Strong leadership from those in formal leadership roles such as Director of Care or Manager was needed in conjunction with the CNL role to sustain the GPA program.

CONCLUSIONS

- To sustain the GPA program, the informal facilitators and the GPA Coaches need to be supported to practice the GPA skills by the formal leaders within the home.
- Support from the formal leaders includes: supporting and practicing the GPA program, advocating and creating an environment where staff are not punished when they practice GPA, and coaching or disciplining staff who are not practicing GPA. When staff members observe these leaders practicing and supporting GPA, the program is more likely to be sustained.
- Facilitation needs to be an official part of the GPA Coach role after the initial training program has been delivered. GPA Coaches need to be financially compensated and they need to be freed up from their own duties to work with staff to change their practice.
- When homes are selecting staff members for the GPA Coach role, they should consider staff members who are in a position of authority with credibility and respect from staff (e.g., CNL, RN Manager, or Assistant Manager)

LIMITATIONS AND FURTHER STUDY

- Due to ethical and privacy constraints, observations and shadowing in the prospective study were only conducted within public areas. This decreased the number of times that the researcher could observe staff interacting with residents and utilizing the GPA skills during times of care, bathing, or assisting the residents to bed or getting up in the morning.
# Identity Change as a Predictor of Caregiver Burden in Dementia: A Proposed Model.

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

## Background

- Informal caregivers of persons with dementia experience significant difficulties or “caregiver burden”, which has been associated with caregiver and care-recipient relationship quality.\(^1\)
- Anecdotal evidence suggests that perceived changes in identity of the person with dementia, subsequent to dementia onset, may also impact the caregiver/care-recipient relationship.
- Reminiscence Therapy (RT) is an intervention that may help improve the quality of this relationship and mitigate caregiver difficulties. In rural and remote communities, the high proportion of older-adults with limited access to health services makes dementia care a challenge.\(^2,3\)
- This project explored the role of perceived identity change in burden (Study 1) and evaluated the effectiveness of an RT activity for caregivers (Study 2). The use of videoconferencing as an accessible method of service delivery was also assessed (Study 3).\(^4,5\)
- This following reports preliminary results of Study 1, the objective of which was to investigate the relationships between identity, relationship quality, and burden with the aim of providing evidence for a proposed model of burden.

## Method

- **METHOD**: 99 informal caregivers of persons with dementia who attended a memory clinic were administered measures of perceived change in identity of their care-partner, relationship satisfaction, and burden. It was hypothesized that change in identity would correlate negatively with relationship satisfaction and positively with burden. We further hypothesized that identity and relationship satisfaction would be significant predictors of burden.

## Results

### Perceived change in patient identity

- Positively correlated with relationship satisfaction (\(p < .01\)) and negatively with dementia severity (\(p < .01\)) and burden (\(p < .001\)). Notably, 96.4% of dementia caregivers (\(n=56\)) vs. 65% of non-dementia caregivers (\(n=20\)), endorsed a change in their care-partner’s identity post onset of difficulties. The results of the hierarchical regression revealed a significant change at \(p < .01\), accounting for 10% greater variance than step one. Only relationship satisfaction and identity change were significant predictors of burden (\(p < .05, p < .01\)).

## Relevance

- The present study is one of the first empirical investigations of perceived identity change in dementia. The results demonstrate that a large number of caregivers perceive a change in the identity of their care-partner due to dementia, with a greater level of perceived change associated with increased dementia severity. A significant role for identity in the prediction of caregiver burden was also shown, providing support for a proposed model of identity, relationship quality, and burden.

## Diagram

![Diagram illustrating the relationships between identity, intimacy, quality of relationship, and caregiver burden](image)

## References

1. Alzheimer’s Society of Canada’s (2011). Rising Tide: The Impact of Dementia on Canadian Families.\(^6\)
Sexuality and intimacy in long-term care (LTC): considering the needs of LGBT residents with dementia.

Kathy Kortes-Miller, PhD. Centre for Education and Research on Aging and Health, Lakehead University
Joe Enright, PhD Candidate. Department of Psychology, University of Saskatchewan
Ame Stinchcombe, PhD. Department of Health Sciences, Lakehead University
Kimberley Wilson, PhD. Department of Family Relations & Applied Nutrition, University of Guelph

Background:
- Despite being recognized as an important part of human development throughout the aging process, sex and sexual expression are not often considered when evaluating the needs of older adults entering long term care (Elias & Ryan, 2011).
- Stigma and misconceptions regarding sexuality amongst the elderly, are a major obstacle to ensuring that the sexual rights of long-term care (LTC) residents are protected, respected, and facilitated.
- The concept of sexual rights when applied to older adults with cognitive impairment, such as dementia, becomes particularly complex given the added stigma that comes with the diagnosis and the potential for symptomatology to manifest as perceived sexually inappropriate behaviours (Dhikav, Anand, & Aggarwal, 2007).
- At particular risk of having their sexual rights overlooked and/or discriminated against are older adults of the LGBT community.

Rationale:
- According to estimates, by the year 2030 there will be an estimated two to seven million older adults who identify as Lesbian, Gay, Bisexual or Transgender (LGBT) in Canada. (Fredriksen-Goldsen & Muraco, 2010).
- Many of Canada’s LGBT elderly at some point have experienced systemic and open discrimination, homophobia, and even criminalization, to the detriment of their psychosocial well-being (Haber, 2009).
- The lack of attention to sexual identity among older adults, and by extension LGBT older adults, is a further example of this discrimination and has been labeled a form of "ageism" in the literature (Ford, 1998 as cited in Ward et al., 2009).

State of the Literature:
- Current evidence suggests that:
  - Sexual intimacy is highly valued in older gay men’s lives (Berger, 1982; Gray and Dressel, 1985; Pope and Schulz, 1990). Other research Kehoe (1986; 1988) confirms that older lesbians continue to value sexual expression and sexual intimacy in later life, and where sexual intimacy is absent it is mostly due to lack of opportunity rather than choice.
  - Older LGBT individuals have concerns about how their sexuality/lifestyle may be perceived and interpreted if they are being diagnosed with dementia as they age (Price, 2012).
  - LTC tends to have a medical focus which is not conducive to supporting residents’ sexual expression (Elias & Ryan, 2011) and the majority of staff report never having encountered gay, lesbian, bisexual, or transgendered older clients (Age Concern, 2006). Carers express anxiety related to how to address sexual orientation and uncertainty over what language to use when discussing homosexuality with residents.

Implications & Recommendations:
- Experts suggest that:
  - “Health care providers should be trained on the identities, needs, rights and health disparities of transgender people, including transgender older adults, and clinical guidelines for caring for transgender people” (SAGE & NCTE, 2012, p.33).

“...To support freedom in decision-making for residents with dementia, nursing homes can adopt a more person-centered approach by which the nursing home works to advocate for the personal needs of the resident as opposed to gate-keeping resident’s decision” (Wilkes, 2015, para 7). Additional research is required to fill the gaps in knowledge around transgender older adults particularly within the context of institutional care and for those living with dementia (Alzheimer’s Australia, 2014).

Long-term care homes should strive to:
- Create an inclusive culture that recognizes and responds to intersecting diversities and differences; and
- Value and promote sexuality and intimacy among all residents.

Create a culture where residents feel safe to disclose gender identity/sexual orientation; and
- Educate staff about the complexity of sexuality and sexual expression among LGBT populations.

Conclusion:
- Sexuality of older LGBT adults with dementia in LTC is an issue of growing importance. Despite a paucity of literature on the topic it is clear that older LGBT adults, with or without dementia, face numerous forms of discrimination and obstacles to quality care from multiple fronts.

Although there is a notable shift in understanding and acceptance of sexuality and gender identity this has not yet translated into LTC. As noted in the evidence, this becomes further complicated in cases of dementia and cognitive impairment. Given the aging population and the anticipated increase in LGBT residents, targeted research and knowledge translation is required to ensure person-centred policy and practice.

References:
Are Care Plans Utilised by Long-Term Care Employees? An Assessment of the Degree of Concordance between Care Plans and Actual Care Given to Residents

Fiona E. Fick, Department of Psychology, University of Saskatchewan
Paulette V. Hunter, Ph.D., St. Thomas More College, University of Saskatchewan

The Saskatchewan Health Research Foundation provided support for this work.

Background

By using written care plans, health providers strive to address all aspects of resident care through identification of needs, goals, interventions, and evaluation of outcomes. Despite the anticipated benefits of using care plans, previous research from several geographic regions suggests they are not maximally used by nurses and nursing assistants (NAs) working in long-term care. The following reasons for underuse have been documented:

- Lack of time
- Lack of individualised background information
- Inaccurate information
- Lack of ownership of the plan
- Perceived lack of value of the plan
- Reliance on other (e.g., informal) sources of information

We were interested in discovering whether underuse of care plans was present in a sample of nurses and NAs in a Canadian health region. We were also interested in assessing the degree of congruence between the care provided and the content of care plans.

Hypothesis: Although it was not expected that all participants would know the contents of the written care plan, it was expected that descriptions of the care required by each resident would correspond to the written goals and interventions in the care plan.

Method

A research assistant documented the interventions listed in specific sections of 68 resident's care plan (i.e., sections corresponding to MDS Clinical Assessment Protocol [CAP] triggers and nursing rehabilitation plans).

Twenty-three nurses and 45 nursing assistants (NAs) from nine long-term residential care homes in a small Canadian city were then asked to describe the care required by one resident from the sample with whom they worked regularly. They were asked to describe the care as written in the care plan and, if unknown, they were asked to describe required care based on their personal knowledge of that resident.

A subsample of 18 nurses and 38 NAs were further asked if they were familiar with the terms “CAPs” and “nursing rehabilitations”. They were also asked to describe how they learned about required changes in a resident’s care.

Results

| Respondent is using the care plan information in day-to-day care | 0% |
| Respondent knows there is a written intervention but does not know details | 0% |
| Respondent is unaware of interventions but care corresponds to care plan | 53% |

Fifteen of the 18 nurses who responded to additional questions expressed that they understood the terms “CAPs” and “nursing rehabilitations”; however, of these 15, three were unable to articulate the meaning. Just 3 of the 38 NA interviewees recognised the terms.

The three top methods of learning about changes in care were: consulting communication books, listening to verbal reports at meetings, and consulting a shared whiteboard.

Interpretation

Within the sample of LTC employees we surveyed, none could speak to the specific contents of the care plan without consulting it. In 53% of the cases, care corresponded to the written interventions, and in 47% of the cases, care did not correspond to the care plan. It is important to note that we did not assess whether the care plan or the care the employee was offering corresponded best to the resident’s care needs.

Underuse of nursing care plans has been a concern for decades. Among the most promising directions for enhancing use of care plans documented in health literature are the following:

- Addressing barriers such as lack of time
- Increasing NAs’ ownership and engagement in the care planning process
- Documenting details from the resident’s life in the care plan, to increase a sense of relationship and provide a context for some interventions
- Supporting a workplace culture that includes care planning
Research Protocol:
Evaluation of Alzheimer Organizations’ Websites With Eye Tracking

T. E. Friedrich¹, J. Seaton², P. V. Hunter³, L. J. Elias¹, M. E. O’Connell³, M. Delbaere³ & A. Cammer⁴
University of Saskatchewan

Introduction

Two thirds of Canadians use the internet to search for health information
However
1) The quality of content varies
2) Design features and human factors may limit accessibility to information
As Canadians become more concerned about public health information to prevent cognitive losses associated with pathological aging, development of appropriate websites is warranted.

Objectives:
• Determine the usability of Alzheimer organizations’ websites that contain brain health/prevention information
• Examine how the websites usability affects users’ ability to locate and evaluate information about preventing cognitive decline
• Examine the relationship between participants’ performance in completing the task, eye movement patterns, and usability ratings

Eye tracking:
1) Informs researchers of problematic features and where users have difficulty with the website
2) Can be used to understand how users view, search, and process interface information
• Duration of fixations and pattern of saccades are dependent on how easy or difficult the display is to process
• Difficult to process websites = longer fixations, more fixations closer together, shorter saccades and an overall longer scan path

Methods

Participants: 50 University of Saskatchewan undergraduate students
Materials: Sensomotoric Instruments (SMI) Remote Eye-Tracking Device (RED 4) at 60 Hz

Presentation: Experiment Center (C.9) on a 1280 x 1024 resolution monitor
Tasks completed using 4 websites (counterbalanced):
• Tasks were worded in the 2nd person to encourage participants to think of the task as their own
• Pages presented in Internet Explorer
1) “You want to know about strategies to prevent dementia”
2) “You want to know what Alzheimer’s Disease is”
3) Completed task by finding the webpage where the task information could be found and pressing F11 to move to the next task (whether it was the correct page or not)

Measures:
• E-health literacy scale (8 questions)
• Usability questions (19 questions)

Eye tracking data variables:
Quantitative: Success rates of completing task
• Completion time
• Total fixation duration
• Average fixation duration
• Number of backtracking saccades
• Total scan path duration

Qualitative: Heat maps
• Gaze plots

Predicted Results

Hypotheses:
1) The four webpages will not differ in their support of the participants’ task
2) Task 1 (finding prevention strategies) will be more difficult than Task 2 (finding the definition of Alzheimer’s Disease)
3) Eye movement patterns (total fixation duration, average number of fixations, number of backtracking saccades, and total scan path duration) will be closely correlated with the participants’ performance (success rates and completion time for Task 1 and 2) and usability ratings

Analysis:
Success rates: Logistic Regression to examine if Website and Task are predictive of task completion
Quantitative variables (except success rates): examined using ANOVA
Website [A,B,C,D] x Task [Task 1, Task 2]

Future Research

The team aims to use information gathered from this study to generate ideas on how to make brain health/prevention information more accessible on the Internet
To contribute to the growing need for accurate information about cognitive health, our team is presently completing:
• A qualitative study of the usability of two cognitive health websites
• A review of the nature and quality of Internet resources on the topic of lifestyle and cognitive health

Interdisciplinary collaboration: Department of Psychology, Interdisciplinary Studies in Education and Computer Science, Edwards School of Business, and the College of Pharmacy and Nutrition
Exploring Indigenous Community Needs and Fostering Community Involvement

Gould, B.1, O’Connell, M. E.1, Morgan, D.1, Bourassa, C.2,3, Jacklin, K.4, Warry, W.5, & Carter, J.1

**PURPOSE**
To explore user needs and acceptability for Indigenous older adults, in an attempt to increase accessibility of the technologies developed in AGE-WELL. Also, to explore needs for older adults through community involvement to promote and to build on the cultural value of group approaches.

**OBJECTIVES**
- Discover the communities’ perceived needs of their aging adults.
- Identify needs related to geographic isolation.
- Describe findings in cultural diversity that may impact user needs.
- Discover personally relevant end-user needs in the target communities.
- Use a community-based participatory approach to explore cultural relevance of AGE-WELL technologies.

**MAIN ACTIVITIES**
- Qualitative interviews and focus groups on needs associated with perceptual and user diversity in indigenous participants.
- Group involvement and communication to promote and foster community awareness and unity.
- Relationship building with the indigenous communities in PEI, in particular, the Abegweit First Nation & Lennox Island Mi’Kmaq First Nation.

**Indigenous older adults** are vulnerable due to restricted access to local supports, services, and potentially conflicting cultural norms/perceptions, and are, therefore, the quintessential end-users for AGE-WELL technologies.

**NEXT STEPS**
- Providing important information about adaptation or modifications to technology developed in WPs 3-6 to increase accessibility and acceptability for Indigenous older adults.
- Exploring projects’ cultural relevance for Indigenous older adults; advocacy for to meet needs identified by Indigenous communities.
- Simulated remote training for indigenous older adults and Indigenous adults with cognitive impairment.
- Establish groundwork with community for perceived needs.

**KEY TAKEAWAY**
This work will inform development and adaptation of technology to aid accessibility for older Canadians who are of Indigenous ancestry.
RURAL AND REMOTE MEMORY CLINIC – UPDATE (Data Release 7 : March 2004 – April 2015)

L. Holfeld¹ (Clinic Nurse), M. E. O'Connell² (Clinical Psychologist, Neuropsychology), D. Morgan¹ (Clinic Director), J. Kosteniuk¹ (Research), A. Kirk³ (Neurologist), N. Stewart⁴ (Research), A. Cammer¹ (Dietitian), K. Stevenson² (Physiotherapist), R. Loeppky² (Physiotherapist), D. Minish¹ (Psychometrist)

¹Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; ²Department of Psychology, University of Saskatchewan; ³College of Medicine, University of Saskatchewan; ⁴College of Nursing, University of Saskatchewan; ⁵School of Physical Therapy, University of Saskatchewan

Background

• Rural and Northern Saskatchewan (SK) have a low population density resulting in large travel burden for medical appointments
• Rural SK has a higher proportion of older adults than urban SK

Rural and Remote Memory Clinic

Goals

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

Full-Day Coordinated Assessment

<table>
<thead>
<tr>
<th>pre-clinic visit</th>
<th>Referral from rural primary care provider</th>
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<tbody>
<tr>
<td></td>
<td>- Comprehensive blood work - ECG</td>
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<table>
<thead>
<tr>
<th>clinic day</th>
<th>Clinical nurse - medical history</th>
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<tbody>
<tr>
<td>Interprofessional team interview with patient and caregiver</td>
<td></td>
</tr>
<tr>
<td>Neurological exam (Neurologist)</td>
<td></td>
</tr>
</tbody>
</table>

Neuropsychological battery (Psychometrist & Neuropsychologist)

Caregiver completes standardized scales (e.g., FAQ, NPI, Zarit, etc)

Caregiver interviews (Neuropsychologist & Registered Dietitian)

Patient completes physical therapy assessment (Physiotherapist)

Patient completes standardized nutrition assessment

CT head scan

Patient completes standardized scales, including of mood

Interprofessional team meeting regarding patient management and diagnosis

Consensus diagnosis (Neurologist & Neuropsychologist) - reports to primary care provider

Communicate diagnosis and management plan to patient and caregiver(s)

Follow-up by team as necessary

Saskatchewan Telehealth Sites

Comparison of travel time and distance saved:
• Mean distance from home to Telehealth = 32.9 km
• Mean distance from home to Saskatoon = 267.6 km
Distance saved by Telehealth = 234.7 km (one-way)

Telehealth: As of August 11, 2015 there are 265 Telehealth sites currently operating in provincial, regional and northern hospitals in Saskatchewan. Telehealth can also link with other select sites provincially, nationally, and internationally.

All neurologist follow-up appointments are now via telehealth.

• This process was implemented in December 2008 based on research showing equivalency of appointment-type and high patient and family satisfaction with telehealth.

Clinical Diagnoses to Date

Mean Age = 71.4; Range 22-92 years old

Of the 412 patients seen to date:
- 20% (N = 86) displayed no cognitive impairment
- 61% (N = 251) were diagnosed with dementia & of those with dementia 62% were diagnosed with dementia due to Alzheimer Disease (AD)
- 16% were diagnosed with some form of mild cognitive impairment (MCI; amnestic vs non-amnestic; single domain vs multi-domain)
- 3% were diagnosed with cognitive impairment not otherwise specified

- N = 158 dementia due to AD
- N = 18 vascular dementia
- N = 35 frontotemporal dementia
- N = 17 dementia with Lewy Bodies
- N = 15 dementia due to multiple etiologies
- N = 8 dementia – other (general medical condition, NOS)

Patient Referrals per Rural Health Authority

www.ruraldementiacare.usask.ca
Elder Friendly Care in Acute Care

Jayna Holroyd-Leduc, MD FRCP C1,2 & Karen Osiowy, MSc1 for the Calgary Zone Elder Friendly Care Advisory Group1

Alberta Health Services and 2the University of Calgary

BACKGROUND

As the proportion of older people in Alberta continues to increase, the number of individuals seeking acute care services is likely to increase. Hospitals can be a difficult place for frail, older people with functional and/or cognitive impairment. One challenge involves the development of new and functional interventions designed to deal with the illness that caused their hospital admission. Seniors currently account for:

- 63% of acute inpatient days
- 44% of provincial health expenditures
- This changing demographic will require adaptation of current care delivery models.

OBJECTIVES

The goal of the project was to implement and evaluate an elder friendly care initiative (EFCI) at the 4 adult hospitals in Calgary, AB.

The EFC Initiative promotes evidence-informed interventions that include:

- comfort rounds (intentional rounding)
- delirium detection using the Confusion Assessment Measure (CAM) and management
- least restraint use

The initiative focused on a holistic approach to the patient using:

- Comfort Rounds
- Delirium Detection/Management
- Least Restraint Use

The initiative merges overlapping evidence-informed care strategies to help prevent and address the common geriatric issues of delirium, falls/immobility, functional decline and malnutrition.

IMPROVEMENT PLAN AND MEASUREMENT STRATEGY

Education and Implementation:

- A modified Learning Collaborative Model was used to support implementations.
- Developed by the Institute for Healthcare Improvement (IHI), a Collaborative is a short-term (6-15 month) learning system that brings together a number of teams (units) to implement improvement.
- The Collaborative provides the structure for teams to easily learn from each other and from recognized experts in Senior Care

Tracking Measurement:

A Balanced Scorecard was used in this initiative to track progress on identified key measures.

- Key measures were identified in a meeting attended by key stakeholders from across the province.
- Both process and outcome measures were identified and classified based on the Health Quality Council of Alberta’s quality framework in order to cover all aspects of quality (see Table 1 below).
- Two measures were identified as being mandatory, the remaining were optional to allow flexibility amongst units to focus on what makes most sense for them.
- The goal is to improve on the scorecard from the baseline data (8/10 and 10/10) and to maintain improvement.

RESULTS

Participation in Learning Collaboratives:

- Two Collaboratives were held with each of the four Calgary acute sites.
- Turnout ranged from 40-100 participants at each site
- 15 units agreed to participate in data collection.

Key Findings:

- Data are truly unique to each unit, depending on their focus and selection of process and outcomes measures. In addition, each unit has a unique mix of patient demographics.

For an overall picture, the following measures (in which > 10 units measured), can be broadly looked at:

Comfort Rounds correctly documented:
Baseline 76% (range 65%-90%)
Improved an average of 8% in the second data collection period

Observed completion of comfort rounds as prescribed:
Baseline 77% (range 47%-98%)
Improved an average of 5% in the second data collection period

Completion of Whiteboards:
Baseline 66% (range 47%-90%)
Improved an average of 9% in the second data collection period

Call Bell Use:
Amount of call bells decreased 17% on average between the baseline and second data collection period

KEY LESSONS

Key Lessons from participating units in the initiative:

- We are very busy on the front lines, and measurement takes time. But without the measurement, we will never be able to improve and act on time more effectively.

- It is common practice nursing that keeps the patient as a person, we just sometimes have to be reminded of common sense.

ACKNOWLEDGMENTS

This project was co-led by the AHS Calgary zone Elder Friendly Advisory group and the AHS Seniors Health Strategy. Clinical Network, both of which are multi-stakeholder groups that included patient/caregiver members. This project was funded by a Calgary zone Quality Improvement grant. This project ACRECCI score = 1.
Development and Psychometric Testing of the Effects of Exercise Questionnaire

Paulette Hunter*, Marjorie Delbaere, Megan E. O’Connell, Allison Cammer

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INTRODUCTION

• Health organizations are working to raise awareness of exercise and other lifestyle factors as modifiable risk factors for cognitive impairment. It is anticipated that these efforts will delay the personal and social costs associated with dementia diagnosis.
• As these efforts are scaled up, it is important to identify suitable outcome measures to assess their impact.
• To address the unavailability of measures of expectations about the effects of exercise on cognition, we developed the Effects of Exercise Questionnaire (EEQ).
• This questionnaire contains four five-item subscales measuring expectations about the effect of exercise on cognition, health, quality of life, and physical functioning.

QUESTIONNAIRE ITEMS

The following items are rated on a 5-point Likert scale, with responses ranging from “strongly disagree” to “strongly agree”:

A. Cardiovascular and endocrine benefits scale
1. Exercise prevents heart attacks
5. Exercise prevents stroke
9. Exercise helps control blood sugar
13. Exercise makes people less likely to get diabetes
17. Exercise lowers “bad” cholesterol

B. Musculoskeletal and dermatological benefits scale
2. Exercise builds muscle
6. Exercise strengthens bones
10. Exercise prevents accidental falls
14. Exercise prevents broken bones
18. Exercise is good for your skin

C. Psychological benefits scale
3. Exercise reduces anxiety and stress
7. Exercise puts people in a better mood
11. Exercise gives people a better quality of life
15. Exercise increases energy
20. Exercise helps people sleep better

D. Cognitive benefits scale
4. Exercise prevents dementia
8. Exercise improves memory
12. Exercise improves decision-making
16. Exercise improves thinking speed
19. Exercise improves attention

RESULTS

• The EEQ (shown at right) demonstrated excellent internal consistency reliability (α = 0.92).
• At the 5-item subscale level, internal consistency was adequate to good (A: .87; B: .73; C: .78; D: .85).
• Convergent validity was supported by a moderate correlation between EEQ scores and attitudes toward exercise as measured by the Outcome Expectations of Exercise Scale (Resnick et al., 2000) (r = 0.58, p < .01).
• Divergent validity was supported by a small correlation between EEQ scores and amount of exercise as measured by the Rapid Assessment of Physical Activity scale (Topolski et al., 2006) (r = 0.16, p > .05).

METHOD

• Items were generated through literature review and vetted by members of an interdisciplinary research team.
• The EEQ was administered, along with three additional measures, to a sample of 87 undergraduate students.
• Internal consistency reliability was estimated using Cronbach’s alpha. Convergent and divergent validity were assessed by examining correlations between the EEQ and measures of similar and distinct constructs.

CONCLUSIONS

• The EEQ may have promise as an outcome measure for campaigns to promote cognitive health.
A Volunteer-Delivered Montessori Program for Long-Term Care Residents with Dementia

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Murray Tempel, Luther Special Care Home, Saskatoon, Saskatchewan
Darla Bolin, Luther Special Care Home, Saskatoon, Saskatchewan
Celine Hounjet, University of British Columbia
Leticia Pickard, University of Saskatchewan

The Saskatchewan Health Research Foundation provided support for this work.

What is Montessori?

The Montessori approach is among several emerging models of care tailored specifically for long-term care residents with dementia. It emphasizes the opportunity to participate in personally meaningful activities and roles at a level that respects current cognitive, sensory, and motor abilities. Initial research suggests the method has potential to improve mood, reduce agitated behaviour, and foster the maintenance or enhancement of certain abilities. The approach is drawn from educational practices first promoted by Italian physician and educator Maria Montessori (1870–1952; shown below).

Why Montessori?

Residents living in long-term care often do not have adequate access to personally meaningful activities and roles, and this has a negative effect on their quality of life. A lack of supported involvement in personally meaningful activities and roles also contributes to excess disability. The individually tailored and appropriately challenging nature of Montessori activities provides a means to increase residents’ engagement in meaningful activity.

The Problem

What is personally meaningful and suited to one resident’s needs does not always meet the needs of others. Given the finite resources available for recreational programming in long-term care, recreation teams are not always able to accommodate each resident’s individual interests. Most resources are devoted to group programming that is likely to interest many, though not all, residents.

Partnering Toward a Solution

A community-research partnership was initiated in May through July 2015 to support the work of a recreation teams at Luther Special Care Home (LSCH).

LSCH, the community partner, recruited volunteers to learn about visiting “the Montessori way”. Eighteen volunteers committed to a minimum of 20 one-to-one visits with LSCH residents.

The research team created and tested 40 activity kits. Kits were designed to complement resident’s interests and abilities. For example, some residents enjoyed reviewing a map of Canada and discussing where they had traveled. Others enjoyed organizing electrical couplers, making a flashlight work, playing a simple dice game, or working with textiles.

Before the visits began, LSCH and the research team partnered to provide each volunteer with two training sessions. Training included an overview of possible symptoms of dementia, experience on a locked dementia care neighbourhood at LSCH, and hands-on experience with the Montessori activity kits. On-site start-up support and as-needed consultation were also provided.

Feasibility & Sustainability

Feedback from volunteers, staff, and families suggested that the project was generally positively received by volunteers and residents. Individual visits supplemented, rather than detracted from, group recreational activities. LSCH sees potential to continue to train volunteers and family members in the Montessori method, and says, “is a fresh approach to providing meaningful moments for many of our residents”. The community-research partnership planned a health region-wide workshop to share experiences with the Montessori approach on November 25, 2015.
Simultaneous temporal trends in dementia incidence and prevalence, 2005-2013: a population-based retrospective cohort study in Saskatchewan, Canada


the current issues ---
Original studies published over the last decade regarding time trends in dementia report mixed results. On the one hand, there is evidence of declining incidence [1-3] and prevalence [4-6], and on the other, studies suggest stable [3, 7] and increasing dementia prevalence [8-11].

methods ---
- population-based retrospective cohort study design
- data extracted from 7 provincial administrative health databases linked by a unique anonymized ID number
- case definition algorithm applied to 4 of the 7 administrative health databases (hospital, physician, prescription drug, and long-term care)
- cohort included individuals 45 years and older at their first-ever recorded identification of dementia between April 1, 2005 and March 31, 2013
- Statistical analysis: we calculated the percentage change between 2005/06 and 2012/13 in absolute number, percentage, population-at-risk (PAR), and age-standardized rate per 1,000 PAR, by dividing the difference between the two figures by the earliest figure and multiplying by 100. Percentage changes in age-standardized incidence and prevalence rates per 1,000 PAR were compared to significant differences (a < 0.05) using the 2-tailed test. 95% confidence intervals (CI) were calculated for all crude and age-standardized rates and PARs.

main findings ---
- overall 12-month age-standardized incidence rate declined significantly by 11.07% (p < 0.0001), from 8.41 to 7.48 per 1,000 PAR
- absolute number of incident cases dropped by 3.51% from 3,389 to 3,270 while the population at risk increased by 11.38% (403,123 to 449,012)
- mean age at identification in 2005/06 (81.67 ± 10.70) did not change significantly (p = 0.24) in 2012/13 (81.97 ± 10.70)
- declines over time in the crude incidence rates were significant and similar across three of the four databases (not Prescription Drug)
- Gender differences: Among females, significant decreases occurred only in the three oldest age groups, with the largest decline in the 65-74 age group. Among males, only the 65-74 age group experienced a significant decline over the 8-year period

possible explanations --
- rising education levels and intellectual demands over time have been linked to declining incidence and prevalence of dementia in later cohorts [1, 2, 5-7]
- improved prevention and treatment of vascular risks have been implicated in temporal trends of dementia decline [3,4]
- compression of cognitive morbidity hypothesis suggests that declining dementia trends demonstrate a delay of dementia to older age [5]
- increased uptake of healthy behaviors over time has been linked to declining dementia trends [3,4,7] as have reduced cardiovascular risks such as prevention of heart disease [6] and decreased hypertension [3], cholesterol [3], and stroke [1]

Figure 1. Incidence (Figure 1)
- overall 12-month age-standardized prevalence rate increased significantly by 30.54% (p < 0.0001), from 21.35 to 27.87 per 1,000 PAR
- absolute number of prevalent cases rose 47.95% from 8,795 to 130,120, compared to an increase of 12.16% in the population at risk (411,918 to 462,024)
- majority of increase in prevalence took place in the first 4 years of the study period, with the upward trend slowing between 2009/10 and 2012/13
- Gender differences: Significant increases were apparent in every age group for both sexes (except those 45-64), with the largest increment in the 65-84 age group and the smallest increment in the 85 and older age group for both sexes.

Figure 2. Prevalence (Figure 2)
- between 2005/06 and 2012/13, a significant decline in incidence and significant increase in prevalence of dementia (age-standardized) among adults 45 years and older in Saskatchewan, were observed in administrative health data
- average survival time with dementia increased over the study period (from 2.95 years to 3.73 years), possibly reflecting earlier diagnosis and improved treatment
- as individuals live longer with dementia, they require active care and monitoring for an extended period of time similar to individuals with other chronic diseases
- administrative health data can be a valuable research tool for tracking dementia time trends, however, the limitations of this tool must be kept in mind

Prevalence (Figure 2)
- overall 12-month age-standardized prevalence rate increased significantly by 30.54% (p < 0.0001), from 21.35 to 27.87 per 1,000 PAR
- absolute number of prevalent cases rose 47.95% from 8,795 to 130,120, compared to an increase of 12.16% in the population at risk (411,918 to 462,024)
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Figure 1. Age-standardized 12-month incidence of dementia among adults 45 years of age and older, Saskatchewan, from 2005/06 to 2012/13

Figure 2. Age-standardized 12-month prevalence of dementia among adults 45 years of age and older, Saskatchewan, from 2005/06 to 2012/13

References

takeaway ---
- between 2005/06 and 2012/13, a significant decline in incidence and significant increase in prevalence of dementia (age-standardized) among adults 45 years and older in Saskatchewan, were observed in administrative health data
- average survival time with dementia increased over the study period (from 2.95 years to 3.73 years), possibly reflecting earlier diagnosis and improved treatment
- as individuals live longer with dementia, they require active care and monitoring for an extended period of time similar to individuals with other chronic diseases
- administrative health data can be a valuable research tool for tracking dementia time trends, however, the limitations of this tool must be kept in mind

Disclaimer
This study is based on part de-identified data provided by the Saskatchewan Ministry of Health through the Health Quality Council. The interpretation and conclusions contained herein do not necessarily represent those of the Government of Saskatchewan or the Saskatchewan Ministry of Health.
Empirical relationships between health literacy, numeracy, and treatment decision making

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2Health Services Research Unit, University of Aberdeen

Introduction

Internationally, there is a growing trend toward the implementation, and in some cases legislation, of shared decision making and the use of patient decision aids in clinical practice. This shift is notable given that multiple barriers to their use have been identified. Poor health literacy and numeracy are two barriers.

Health literacy is defined as “the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (Public Health Agency of Canada, 2014, para 1).

In Canada, it has been estimated that 60% of adults and 88% of seniors possess low health literacy (Canadian Council on Learning, 2008).

Figure #1: Estimates of health literacy in Canada by age groups

Some measures of health literacy assess numeracy (e.g., NVS, TOFHLA), while others do not (e.g., REALM).

Numeracy is “the ability to access, use, interpret, and communicate mathematical information and ideas, in order to engage in and manage the mathematical demands of a range of situations in adult life” (Program for International Assessment of Adult Competencies, 2009, p.21).

Poor numeracy is widespread in a number of countries (see Figure 2) and has been identified as a problem in both patients and health professionals. Patients who lack numeracy will have difficulties assessing the probability of any risks and benefits associated with treatment options. Health professionals who lack numeracy will have difficulty explaining numerical information needed to guide patients through difficult treatment decisions.

Figure #2: Numeracy proficiency in 23 different countries

This research sought to answer: What is known about the empirical relationships between health literacy, numeracy and the three stages of the treatment decision making process (information exchange, deliberation, deciding on the treatment to implement)?

Methods

Two scoping reviews were conducted of the literature (Malloy-Weir et al., in press, 2014). Forty-one health literacy and 38 numeracy-related studies were identified after a search of four databases (Medline, Embase, CINAHL) and three levels of relevance screening (see Figure 3).

Figure #3: Flow chart illustrating relevance screening process

Some studies included multiple studies, and there was overlap in the methodologies used. The data quality varied. Overall, there was a lack of attention paid to:

• empirical relationships relevant to the deliberation and deciding on the treatment to implement stages of treatment decision making
• certain patient populations (e.g., patients diagnosed with non-cancer-related disease, patients less than 50 years old, non-white, non-English or non-Spanish speaking, and residing outside of the United States)
• the health literacy and numeracy skills of health professionals.

Findings

• Health literacy and numeracy have largely been treated as separate concepts by researchers in the area of treatment decision making.
• There is a lack of: (1) agreement over the definition and measure of health literacy and numeracy adopted in studies, and (2) overlap in the relationships examined—making the findings difficult to compare.
• Methodological problems undermine the ability to draw causal inferences about the empirical relationships that have been examined.
• There has been a lack of attention paid to:
  • empirical relationships relevant to the deliberation and deciding on the treatment to implement stages of treatment decision making
  • certain patient populations (e.g., patients diagnosed with non-cancer-related disease, patients less than 50 years old, non-white, non-English or non-Spanish speaking, and residing outside of the United States)
  • the health literacy and numeracy skills of health professionals.

Conclusion

The relationships between health literacy, numeracy, and the three stages of the treatment decision making process are not clear. This finding has important implications for efforts to involve patients in treatment decision making, particularly, when risks and benefits are communicated by health professionals to patients. Attention is needed to address the methodological problems and knowledge gaps identified.

Agenda for future research

1. Develop shared definitions and measures of health literacy and numeracy that are specific to the treatment decision making context.
2. Inductively derive, and rigorously test, conceptual models that hypothesize relationships between health literacy, numeracy, and the three stages of the treatment decision making process. Identify the strength, direction, and stability of empirical relationships across the three stages and over time.
3. Refine conceptual models based on the findings from Step 2.
4. Replicate Step 3 through 5 in different treatment decision making settings.

References


Acknowledgments

The research was supported by a Joseph Armand Bombardier Doctoral Scholarship awarded to Leslie J. Malloy-Weir. The authors would like to thank Drs. Matthew Mancini for his help with the literature searches and Dr. Malcolm Weir for his assistance with relevance screening.
This model is based on best practices for individuals with dementia and families in primary health care.

The core of this model is standardized tools, protocols, and guidelines for dementia care (i.e., PC-DATA adapted).

The other 7 elements in this model have been identified as best practices in dementia care within the primary care setting (Aminzadeh et al. 2012).

Most or all of these elements are already part of many PHC team settings in terms of patients with chronic conditions other than dementia (e.g., diabetes).

With each PHC team in our study (1 team/yr), we will conduct Plan-Do-Study-Act cycles to:

- draw on the team’s existing strengths in the elements of this model (e.g., multidisciplinary team)
- identify areas where model elements may require improvement in the team (e.g., care management)

Aminzadeh et al. 2012. A Scoping Interpretive Review of Literature on Perspectives and Practices of Primary Care Physicians Vis-à-vis Diagnosis and Management of Community Living Older Persons with Dementia. Regional Geriatric Program of Eastern Ontario.
Established a 13-member Regional Advisory Council in 1 rural SK health region (Sun Country), including health region management and the Alzheimer Society of SK.

Pre-tested a telephone questionnaire and conducted baseline telephone interviews regarding current dementia care strengths and gaps across Sun Country (with PHC teams, patients, caregivers, and the Advisory Council).

Currently collaborating with one of eight PHC teams in Sun Country to develop a rural primary health care model for dementia.

Released a RaDAR-Health Quality Council report that provides provincial-level data on dementia services across SK, and dementia incidence and prevalence using administrative data.

**Issues in Dementia Care for Rural Populations**
Debra Morgan, Julie Kostenuik, Megan O’Connell, Norma Stewart, Andrew Kirk, Joanne Bracken, Margaret Crossley, Vanina Dal Bello-Haas, Dorothy Forbes, Anthea Innes, Lesley McBain, Haizhen Mou, & Edna Parrott

**OUR MISSION**

**MISSION:** TO IMPROVE THE QUALITY OF PRIMARY HEALTH CARE (PHC) FOR INDIVIDUALS WITH DEMENTIA IN RURAL AND REMOTE COMMUNITIES

We are building a lasting model of family-centered dementia care that combines current best practices, specialist expertise, and the existing strengths of rural PHC teams in delivering effective chronic disease management.

**OBJECTIVES**

- Identify current dementia care practices in rural PHC teams
- Adapt, implement, and evaluate a rural primary health care model for dementia in one SK health region, developed on the basis of best practices (e.g., multidisciplinary team, standard tools and protocols, education/support, regular patient follow-up)
- Investigate the facilitators/barriers of successful adaptation of a rural primary health care model for dementia
- Increase uptake of the new rural model for dementia care by using a community-based participatory approach with decision-makers and PHC teams
- Sustain and spread the rural primary health care model for dementia to PHC teams in additional SK health regions

**MAIN ACTIVITIES**

1. Established a 13-member Regional Advisory Council in 1 rural SK health region (Sun Country), including health region management and the Alzheimer Society of SK.
2. Pre-tested a telephone questionnaire and conducted baseline telephone interviews regarding current dementia care strengths and gaps across Sun Country (with PHC teams, patients, caregivers, and the Advisory Council).
3. Currently collaborating with one of eight PHC teams in Sun Country to develop a rural primary health care model for dementia.
4. Released a RaDAR-Health Quality Council report that provides provincial-level data on dementia services across SK, and dementia incidence and prevalence using administrative data.

**NEXT STEPS**

- Identify quality indicators for rural dementia care, based on a literature review and collaboration with Sun Country Health Region
- Scale up and spread our newly developed rural model of primary health care for dementia to a second PHC team in Sun Country (enroll 1 team/yr)
- Compare dementia epidemiology in SK and ON using administrative health data

**Contact:** debra.morgan@usask.ca
RRITE: Rural/Remote Indigenous Technology needs Exploration
O’Connell, M.E.¹, Morgan, D.¹, Bourassa, C.²,³, Jacklin, K.⁴, Warry, W.⁴, Carter, J.¹ & HQP Osog, C.²,³, Gould, B.¹, & Josdal, M.¹

PURPOSE
To determine user needs of older adults in rural and remote areas, as well as acceptability for Indigenous older adults, in an attempt to increase accessibility of the technologies developed in AGE-WELL.

OBJECTIVES
- Identify needs related to challenges posed by geographic isolation.
- Describe issues in rural user diversity that may impact user needs.
- Discover personally relevant end-user needs in the target populations.
- Determine rural user needs for remote training for AGE-WELL technologies.
- Use a community-based participatory approach to explore cultural relevance of AGE-WELL technologies.

MAIN ACTIVITIES
- Exploration of the digital divide - survey of bandwidth access for all SK residents outside the two main urban areas, including First Nations communities.
- Qualitative and quantitative survey of user needs and needs associated with user diversity in rural/remote participants.
- Relationship building with Indigenous communities in southern SK, northern ON, and PEI necessary for community-based participatory research.

NEXT STEPS
- Providing important information about adaptation or modifications to technology developed in WPs 3-6 to increase accessibility and acceptability for rural/remote and Indigenous older adults.
- Exploring projects cultural relevance for Indigenous older adults; advocacy for to meet needs identified by Indigenous communities
- Simulated remote training for rural/remote older adults and adults with cognitive impairment.

KEY TAKEAWAY
RRITE’s work will inform development and adaptation of technology to increase accessibility for older Canadians who are of Indigenous ancestry or who reside in rural or remote locations.
Neuropsychological Issues in the Diagnosis of Frontal Variant Frontotemporal Dementia (fv-FTD): Executive Function Error Interpretation May Be Useful for the Elusive Assessment of the Ventromedial/orbitofrontal Prefrontal Circuits

M. E. O’Connell1, Andrew Kirk2, & Debra Morgan3

Presented at the 8th Canadian Conference on Dementia, Ottawa, ON

73 yr old M; estimated premorbid function high average
- FBI (interview with highly distressed wife) = 48
- No imaging support
- All other neuropsychological performance within normal limits to superior range

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<thead>
<tr>
<th>FBI (interview with highly distressed wife)</th>
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<td>All other neuropsychological performance</td>
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57 yr old M; estimated premorbid function average
- FBI (interview with wife) = 35
- No imaging support
- All other neuropsychological performance within normal limits

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53 yr old M; estimated premorbid function average
- FBI (interview with wife) = 20
- SPECT support
- All other neuropsychological performance within normal limits

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73 yr old M; estimated premorbid function high average
- FBI (interview with highly distressed wife) = 48
- No imaging support
- All other neuropsychological performance within normal limits to superior range

- Clinical impression from a series of case studies of persons diagnosed with fv-FTD, who demonstrated additional behavioral and neuropsychological evidence when followed prospectively
- Partial Delis Kaplan Executive Functioning (DKEFS) profiles from 3 cases are illustrated plus California Verbal Learning Test (CVLT-II) recall discriminability (immediate intrusions vs free recall)

57 yr old M; estimated premorbid function average
- FBI (interview with wife) = 35
- No imaging support
- All other neuropsychological performance within normal limits

320-325.

320-325.


320-325.


3 Bechara, A., Damasio, A. R., Damasio, H., & Anderson, S. W. (1994). Insensitivity to future consequences following damage to the human 23


6 Cato, M. A., Delis, D. C., Abildskov, T. J., & Bigler, E. (2004). Assessing the elusive cognitive deficits associated with ventromedial prefrontal cortex (SPECT or PET) together with neuropsychological support is helpful

7 Yochim, B. P., Baldo, J. V., Kane, K. K., & Delis, D. C. (2009). D-KEFS Tower Test performance in patients with lateral prefrontal cortex dysfunction. 23


Although not well studied in with the FBI, informant reports are known to be impacted by the psychological state of the informant8,9, which makes converging support from neuropsychological testing or functional imaging for mild to moderate level behavioral changes reported on the FBI all the more important

In the diagnosis of fv-FTD, converging evidence from a collateral informant (we use the Frontal Behavioural Inventory; FBI8; to guide the interview) or imaging (SPECT or PET) together with neuropsychological support is helpful
The present study seeks to:

- Identify barriers to continuing education for rural primary health care team.
- Identify best delivery method of training on diagnosis and management of dementia for rural primary health care team.

To achieve our objectives, we plan to utilize a participatory action research approach.

### Specific Issues Pertaining to Dementia diagnosis

**Early and timely diagnosis of dementia means:**
- Better medical management of the patient
- Detection of reversible forms of dementia
- Determining appropriate patient care plans
- Providing necessary support to families

**Barriers to Timely diagnosis:**
- Subtlety of early symptoms
- Disparity in dementia training
- Reliance on family to identify symptoms
- Lack in knowledge of assessment procedures

### Rationale

- Shortage of geriatric specialists means that the bulk of dementia diagnosis will fall on the primary care providers.
- This is even more of a pressing issue in rural areas.
- This necessitates more education in diagnosing and managing dementia for rural primary health care staff.

### Study Objectives

**The present study seeks to:**

- Identify barriers to continuing education for rural primary health care team.
- Identify best delivery method of training on diagnosis and management of dementia for rural primary health care team.

To achieve our objectives, we plan to utilize a participatory action research approach.

---

**Method**

**Step 1:**
- Administration of a paper-based survey to a rural support team composed of: 3 family physicians, 1 nurse practitioner, 1 occupational therapist and 2 home care nurses.

**Step 2:**
- Administration of a pre and post training measure to assess the change in perceived abilities to diagnose, treat, and manage dementia.

**Step 3:**
- Implementation of dementia learning material developed as part of PCData based around identified needs and preferred delivery methods.

**Step 4:**
- Development of new remote models of RRMC specialist to primary care provider supports for specific patients (case-based support).

### Conclusion

- Involving the primary care team in designing their learning objectives should translate to better primary care for dementia.

---

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

- CBRH ISC
- CIRA
- CCNA CNCN
- UNIVERSITY OF SASKATCHEWAN
Trends in medication use over eleven years in patients presenting to a rural and remote memory clinic

Ryan Verity1, Andrew Kirk2, Debra Morgan3, Chandima Karunanayake3

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

BACKGROUND

Anticholinergic medications have been shown to worsen cognition in the elderly and their use has been associated with lower Mini-Mental Status Examination (MMSE) scores. Patients with Alzheimer’s disease are even more susceptible to anticholinergic effects. Current literature maintains that benzodiazepines, opioids, and medications with anticholinergic properties are best avoided in the elderly unless absolutely essential, as they have been shown to worsen cognition and can cause behavior change.

In 2008, Steve et al. analyzed the medication lists that 66 patients brought to their first visit at the Rural and Remote Memory Clinic (RRMC). The focus of that paper was on the prevalence of polypharmacy, anticholinergic medication use, and benzodiazepine use. The present study examined medication use by patients presenting to the RRMC between March 2004 and June 2015 to see whether patterns of medication use have changed over time in patients with cognitive concerns.

METHODS & ANALYSIS

The first 445 patients seen at the RRMC between March 2004 and June 2015 were included in this analysis.

We catalogued medications with anticholinergic properties, central nervous system effects and recorded each patient’s total number of medications. For further analysis we catalogued the score of the Mini Mental Status Exam (MMSE) that is administered during the initial clinic visit.

Patients were assigned to a twelve-month time period based on the date of their initial presentation. Ethics approval for this study was obtained from the Biomedical Research Ethics Board at the University of Saskatchewan.

RESULTS

Mean patient age was 77.4 years (SD = 12.0). Mean MMSE at initial presentation was 22.4 (SD = 5.8). Ninety-one patients (20.5%) were taking at least one anticholinergic medication. Eighty patients (18.0%) were taking one anticholinergic medication, and eleven patients were taking two.

Patients were on an average of 5.2 medications each (n = 444, range 0 – 15, SD = 3.46).

We saw a slight decline in percentage of patients presenting with anticholinergic medications over time (Spearman’s correlation coefficient = -0.04), which was statistically significant (p=0.035). There was no statistically significant relationship between use of medications that affect the central nervous system and time (Spearman’s correlation coefficient = 0.09, p=0.790) (Figure 3).

There was a weak positive correlation between total medications per patient and time (Spearman’s Correlation Coefficient = 0.11), which was statistically significant (p<0.017).

CONCLUSIONS

The most encouraging statistic to come from this study is a decline in anticholinergic medication use in this rural elderly population. Of the 445 patients who have now been seen at the RRMC, 20.5% were taking a medication with anticholinergic properties at initial presentation.

The proportion of RRMC patients is lower than previously reported by Carrathan et al., as only eight of the 63 patients (12.7%) who presented with a cholinesterase inhibitor on their medication list were also taking an anticholinergic medication.

Considering that patients were taking an average of 5.2 medications each, it is critical for caregivers to be aware of the possible impact that polypharmacy may have on a patient’s cognition.

Prescribers must be properly informed to ensure that the number of medications per patient does not continue to rise, that medications are only used when necessary, and that potentially deleterious medications are avoided.

REFERENCES

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