

Knowledge Network in Rural and Remote Dementia Care

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

Scientific Poster Session

4th Annual Summit

October 27th & 28th, 2011



Thursday October 27, 2011
Wine and Cheese Scientific Poster Program
7:00 PM – 10:00 PM at the Sheraton Hotel (South West Room)

Poster Presenter	Authors & Poster Titles
Rachel Burton	Rachel L. Burton & Megan E. O'Connell Delivering Cognitive Rehabilitation by Telehealth to Individuals with Dementia in Rural Areas
Allison Cammer	A. Cammer, D. Morgan, N. Stewart, M. Crossley Care Aides Understanding of and Reporting of Aggressive Incidents
Donna Dalziel and Steve Kowal	Donna Dalziel, Steve Kowal, and Frontal Temporal Support Group Frontal Temporal Dementia Support Group's Active Engagement Project
Tracy Danylyshen-Laycock	Tracy Danylyshen-Laycock Examining the Relationship Between Facilitation and Sustainability of an Educational Program in Rural Long-Term Care Homes
Nicole Haugrud	N. Haugrud, M. Crossley, M. Vrbancic, M. O'Connell, & D. Morgan Verbal Fluency Changes in Dementia
Paulette Hunter	Paulette V. Hunter, Thomas Hadjistavropoulos, Sharon Kaasalainen Strategies Employed by Health Care Professionals to Manage Conflict in Day-to-Day Dementia Care
Paulette Hunter	Paulette Hunter, Thomas Hadjistavropoulos, Sharon Kaasalainen, William Smythe, David Malloy, Jaime Williams The Personhood in Dementia Questionnaire: Development and Psychometric Testing
Julie Kosteniuk	Debra Morgan, Julie Kosteniuk, Anthea Innes, John Keady, Turner Goins, Norma Stewart, Carl D'Arcy, Drew Kirk Rural Idyll vs. Rural Deficiencies: Dementia Care in Rural Family Practice

Poster Presenter	Authors & Poster Titles
Catherine Lacny	Catherine Lacny, Andrew Kirk, Debra G. Morgan, Chandima Karunanayake Patient Variable Predictors of Cognitive Impairment Severity at Memory Clinic Presentation
Xiangfei Meng *Due to printing time constraints, this poster is not included in this booklet	Xiangfei Meng, Carl D'Arcy, Raymond Tempier, Changgui Kou, Debra Morgan, Darrell D. Mousseau *Survival of patients with incident dementia who had a pre-existing psychiatric disorder: A population-based 7-year follow-up study
Xiangfei Meng *Due to printing time constraints, this poster is not included in this booklet	Xiangfei Meng, Carl D'Arcy, Debra Morgan, Darrell D. Mousseau *Predicting risk of dementia in Canadians in primary care: the diagnosis algorithm for identifying dementia
Megan O'Connell	M. E. O'Connell, M. Crossley, A. Cammer, D. Morgan, & Our Caregiver Collaborators Key Factors Identified by Participants of a Telehealth-Facilitated Support Group for Spouses of Persons Diagnosed With Atypical Dementias
Hannah St. Denis-Katz	Hannah St. Denis-Katz, Margaret Crossley Development Work with the Northern Cultural Assessment of Memory (N-CAM): A Cognitive Screen for the Detection of Cognitive Impairment and Dementia in Aboriginal Seniors
Norma Stewart	Norma Stewart, Debra Morgan, Allison Cammer, Chandima Karunanayake, Duane Minish Gender Differences in Caregiver Distress over Time
Sheena Walls Ingram	Debra Morgan, Sheena Walls-Ingram, Allison Cammer, Margaret Crossley, Dorothy Forbes, Anthea Innes, Megan E. O'Connell, Norma Stewart Pre-Diagnosis Experiences of Informal Caregivers of Individuals Referred to a Rural and Remote Memory Clinic
Summit 2011	Participants of 2010 & 2011 Summit - An evolving interactive poster for collecting feedback Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia

Delivering Cognitive Rehabilitation by Telehealth to Individuals with Dementia in Rural Areas

Rachel L. Burton & Megan E. O'Connell

BACKGROUND

- **What is cognitive rehabilitation?**
 - ✓ Individualized treatment that helps people with cognitive impairments (i.e. memory problems) set and attain personally relevant functional goals.
 - ✓ Can help individuals with dementia and their loved ones find ways to manage better in their daily lives.
 - ✓ Currently, treatment requires approximately eight weekly in-person sessions with a trained clinician.
- **What is the purpose of this project?**
 - ✓ Evaluate the acceptability and feasibility of delivering cognitive rehabilitation through telehealth.

PHASE 1

Interest in Cognitive Rehabilitation

Conduct interviews and administer a questionnaire in order to:

- Ask Memory Clinic patients and caregivers if they are interested in cognitive rehabilitation.
- Understand how those who are interested would like help in their daily lives.
- Ask if travel to Saskatoon for telehealth delivered treatment is feasible and if preferred.

PHASE 2

In Person and Telehealth Delivered Treatment

- Replicate previous research that has provided cognitive rehabilitation to individuals with dementia and their caregivers in person (i.e., Clare et al., 2010).
- Provide cognitive rehabilitation over telehealth to patients and caregivers.
- Compare the efficacy of in person and telehealth delivered treatment.
- Document and explain how cognitive rehabilitation needs to be modified to be implemented using telehealth.



Reference and Acknowledgements

Clare, L., Linden, D. E. J., Woods, R. T., Whitaker, R., Evans, S. J., Parkinson, C. H., ... Rugg, M. D. (2010). Goal-Oriented Cognitive Rehabilitation for People With Early-Stage Alzheimer Disease: A Single-Blind Randomized Control Trial of Clinical Efficacy. *American Journal of Geriatric Psychiatry*, *18*, 928-939. doi:10.1097/JGP.0b013e3181d1d5792a.

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Care Aides Understanding of and Reporting of Aggressive Incidents

A. Cammer¹, D. Morgan¹, N. Stewart², M. Crossley³

¹Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; ²College of Nursing, University of Saskatchewan; ³College of Arts and Science, University of Saskatchewan



Background

Experiencing aggressive behaviour when working in long-term care is very common, particularly from residents with dementia. It is estimated that approximately 38% of care workers experience violence 'more or less every day' (Armstrong, et al., 2009)

This study is a follow-up to a previous study, "Exploring Issues of Physical Aggression Toward Care Aides in Long-term Care (LTC)" (D.Morgan et al)

Findings from that study include:

- *Much physical aggression is not reported nor formally recorded*
- *Care Aides are able to articulate behavioural and systemic factors that precipitate aggressive incidents*
- *When they are reported, aggressive incidents are typically examined from the vantage of an isolated episode*
- *Focusing on the specific incident emphasizes caregiver behaviour and practice but masks broader contextual factors that exacerbate aggression*

Without accurate tracking of aggressive incidents, the magnitude of this issue cannot be fully determined

With this in mind, we explored incident reporting processes and Care Aides' understanding and conception of physically aggressive incidents within their worklives and from a broader, systemic approach

Methods

- **5 focus group discussions** were conducted with a total of 44 Care Aides representing all but one Regional Health Authority in Saskatchewan (far north)
- 4 focus group discussions were **audio recorded and transcribed**; detailed notes were taken in the case of the fifth discussion
- Discussions were **thematically analyzed**



Guiding Questions for Focus Groups:

- *What happens when you experience physical aggression from a resident in your care?*
- *What do you consider to be an aggressive incident? How do you decide what is an 'incident' and what is 'normal'? Is there a definition or standard?*
- *What is the reporting process at your workplace? Are there policies/rules? How do you decide what to report? What happens after reporting?*

Findings

Thematic analysis of focus group discussions yielded 4 salient categories:

Cognitive Impairment and Ability to Control Behavior

Care Aides noted that they determined whether an act of aggression was an 'incident' based partly on whether the resident had cognitive impairment or not - the resident's ability to control his or her personal behaviour:

- *"If he doesn't realize what he's doing is wrong, then that's not an incident." "...because it's somebody's normal behaviour, you don't report a pinch."* "If it's out of character that might be an incident."

Power and Hierarchical Relationships

Care Aides reported limited power to effect change in care practices or policies, that they were often objects of blame when physical aggression was exhibited and that this stymied incident reporting and communication in general, that other carers' perceptions or experiences are more valued, also the societal role of caregiving:

- *"In what other profession can you get slapped and pinched and hit and sworn at ... and it has to become just part of your job?...and that's not right."* "We just get so acclimated to it and we just take it." "It reflects on us as a group of women caregivers, how little we value ourselves." "We are the low-lives of all of it."

Futility with Follow-Up Processes

The lack of follow-up or perceived effect from filing incident reports fostered apathy in reporting:

- *"If I fill out an incident report, it is with the hope there can be something done to give us a protocol, give us something to fall back on the next time ...you address it so that when it comes up again you have some resources, some knowledge learned from previous ones, but unfortunately all the incident reports we have ever filled out, they just kind of float away."* "Nothing becomes of it. Do we really have time to chart for that?"

Systemic Normalization of Aggression

There was a sense of learning to lessen the impact of physical aggression over time, an adaptation over time to view incidents as commonplace or a normal part of the job and therefore not record or report:

- *"What's the sense of writing all this paperwork; it's been going on for 3 or 4 years. We're just so used to it..."* "I used to fill them out all the time ... I'm not even wasting my time." "It becomes such a common thing eventually that you don't pay any attention to it anymore." "We're being conditioned."

Conclusions

- Care Aides implicitly determine the worth of documenting an incident of physical aggression based on a number of complex, interrelated factors
- Reports of physical aggression require thorough investigation and follow-up; the value of the report is relational to its use within the care team and within the facility or department



Acknowledgements



Frontal Temporal Dementia (FTD) Support Group's Active Engagement Project

Presented by Donna Dalziel and Steve Kowal

THE FRONTAL TEMPORAL DEMENTIA (FTD) SUPPORT GROUP'S ACTIVE ENGAGEMENT PROJECT

WE NEED YOUR HELP
Active engaging stimulation centers are a great starting point for devising activities that may be used by all staff, family members, and volunteers to engage residents throughout the day and evening

Joy is found not in finishing an activity but in doing it

- Recreation programs play an important role when it comes to defining our own quality of life
- We tend to do things that are relaxing, bring pleasure, stimulate our curiosity, or expand our knowledge about something significant to us
- Each of us chooses activities based on our interests and abilities

Age and Stage Appropriate Activities

- Activities that give a sense of purpose, stimulate the senses and cater to individual preferences are important to improving the quality of life for people suffering from all forms of dementia
- Actively engaged activities benefit the resident physically, emotionally and cognitively

WE NEED YOUR HELP
We need your help to make our support group a successful one. We need your help to make our support group a successful one. We need your help to make our support group a successful one.

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Examining the Relationship Between Facilitation and Sustainability of an Educational Program in Rural Long-Term Care Homes



Tracy Danylyshen-Laycock
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Background

One of the characteristics of dementia is that individuals may display some type of responsive behaviours (e.g., combative). Many staff in long-term care (LTC) homes report that they do not have the appropriate skills to manage these behaviours. Research has shown that training alone does not support sustained change in caregiver practice. There are many factors that influence the implementation of knowledge. Research utilization and sustainability of practice changes have been studied within acute care studies, however, there is limited research of the factors that influence research use in LTC.

Facilitation

Facilitation is the "process of enabling (making easier) the implementation of evidence into practice" (Harvey, 2002, p. 579). This definition implies that facilitation is conducted by a particular individual, within a specific role, designed to help out others.

Research Purpose

Although the Promoting Action on Research Implementation in Health Services framework (PARIHS) has been utilized in various acute care settings (Brown & McCormack, 2005) little is known about which dimensions of facilitation are most important or how they operate in long term care settings.

The purpose of this research is to examine the relationship between facilitation and the sustainability of best practice guidelines in care homes, with a particular focus on an educational intervention for staff aimed at management of responsive behaviours (Gentle Persuasive Approaches Program).

Research Questions

1. What is the relationship between facilitation and sustainability of training programs in rural long-term care homes? What types of facilitation (roles, skills, and attributes) are associated with sustainability?
2. In what ways do the internal 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?
3. What is the role of leadership in sustainability of the GPA program?

The Gentle Persuasive Approaches Program

The GPA program is a dementia specific training program designed for all staff in a LTC who work with residents with responsive behaviours. It utilizes the "train-the-trainer" teaching method. GPA Master Trainers are responsible for training GPA Coaches from the LTC homes.

GPA Coaches then return to their individual sites to provide staff from all departments with this training.

Promoting Action on Research Implementation in Health Services (PARIHS) Framework

Successful Implementation is a function of the nature and type of Evidence, the qualities of the Context in which the evidence is being introduced, and the way the process is Facilitated (Kitson et al., 1998).

Sub-elements of the PARIHS Framework:

Evidence = research, clinical experience, patient experience, & local data/information
 Context = culture, leadership, & evaluation
 Facilitation = purpose & skills/attributes

Each of these three elements and their sub-elements can be placed on a continuum from low to high. The higher on the continuum that evidence, context and facilitation fall, the more likely it is that knowledge will be implemented in practice.

Methods

A cross-sectional, retrospective qualitative design will be used for Study 1 (Retrospective), Study 2 (Prospective) will utilize a longitudinal, multi-site, comparative case study method.

Study 1

- Site Selection and Participants

Five rural long-term care homes in Saskatchewan Health Region who have implemented the GPA program.

- Administrators, Directors of Care, Managers, GPA Coaches, nurses, and nursing aides.

- Data Collection/Procedures

Semi-structured interviews with the Administrators, Directors of Care, Managers, GPA Coaches, and nurses.
 Focus groups with the nursing aides.

- Data Analysis

Data will be analyzed using a qualitative, inductive approach, using the constant comparative method (Glaser & Strauss, 1967).

Study 2

- Site Selection and Participants

Two rural long-term care homes in Saskatchewan Health Region where the GPA program has not yet been implemented

All staff within the two long-term care homes.

- Data Collection/Procedures

Four data collection strategies will be used in this study: direct observation, shadowing, semi-structured interviews, and document review.

- Data Analysis

The data from each case will be analyzed as a whole. An inductive, grounded approach will be used within each case, using the constant comparative method.

For the cross-case analysis, relying on theoretical propositions and examining rival explanations will be used.

An interpretive pattern-matching approach will be used to compare the patterns of findings between Study 1 and Study 2.



Verbal Fluency Changes in Dementia

N. Haugrud, M. Crossley, M. Vrbancic,
M. O'Connell, & D. Morgan

Introduction

- **What are verbal fluency tests?**
 - Individuals are required to produce as many words as possible in one minute!
 - Phonemic fluency: all words have to start with a specific letter (e.g. "C", "F", "L")
 - Semantic fluency: all words have to belong to a specific category (e.g. animals or tools)
- **What do these tests tell us about cognitive abilities and brain functioning?**
 - Both tests require the ability to search memory effectively, the ability to inhibit inappropriate responses, and the ability to remember rules
 - **Semantic fluency** requires intact semantic memory or memory for what words mean and how they are related
 - **Phonemic fluency** requires intact lexical memory or memory for word sounds and spelling
- **Strategy use on verbal fluency tests:**
 - People tend to group related words on these tests (clustering) then shift to another group of words (switching)?
 - Groups of words are related by subcategory (semantic fluency) or by sound (phonemic fluency)

Example of clustering and switching:

- Cluster of pets**
Dog
Cat
Hamster
Pig
Cow
Horse
- Switch**
- Cluster of farm animals**
Farm
Fast
Fame
For
Forest
Fold
- Cluster starting with FA**
Switch
- Cluster starting with FO**

Study Goal: Compare verbal fluency performance in different dementia subtypes

- Compared healthy older adults to individuals with:
 - **Amnesic Mild Cognitive Impairment (MCI)**
 - **Alzheimer`s disease (AD)**
 - **Vascular Dementia (VD)**
 - **Lewy Body Dementia (DLB)**
 - **Behavioural variant frontotemporal Dementia (FTD-bv)**
 - **Language variant FTD (FTD-lang)**

Discussion

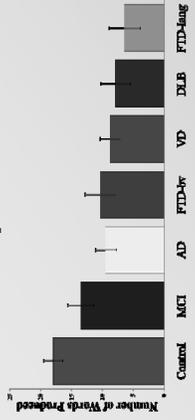
- all clinical groups impaired semantic total words
- **MCI group:**
 - preserved phonemic total words and all clustering and switching variables
- **AD group:**
 - preserved phonemic fluency but impaired semantic cluster size
- **FTD-lang group:**
 - consistently impaired across measures and produced more errors
- **VD and DLB groups:**
 - impaired on all measures except average cluster size
- **FTD-bv group:**
 - more impaired on phonemic compared to semantic fluency

Semantic Fluency

	MCI	AD	FTD-bv	VD	DLB	FTD-lang
Total Words Produced	I	I	I	I	I	I
Total Switches	N	I	N	I	I	I
Average Cluster Size	N	I	N	N	N	I
Number of Errors	N	N	N	N	N	N

I = Impaired; N = Normal

Semantic Fluency Total Words Produced

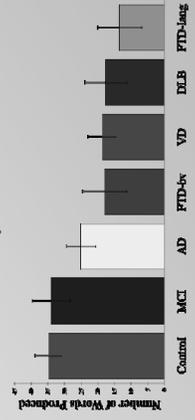


Phonemic Fluency

	MCI	AD	FTD-bv	VD	DLB	FTD-lang
Total Words Produced	N	N	I	I	I	I
Total Switches	N	N	I	I	I	I
Average Cluster Size	N	N	N	N	N	I
Number of Errors	N	N	N	N	N	I

I = Impaired; N = Normal

Phonemic Fluency Total Words Produced



Take Home Message

- Total word production is a sensitive measure of dementia
- Clustering and switching strategies help differentiate groups

References

1. Laning, S., Haugrud, N., & Crossley, M. (2009). The effect of age and sex on clustering and switching during speeded verbal fluency tasks. *Journal of the International Neuropsychological Society*, 15(1), 1-11.
2. Testa, A., Fields, A., Paul, R. H., Blanco, C. R., Hanes, K. A., Salmon, D. P., & Beatty, W. (1998). Cortical and subcortical influences on clustering and switching in the performance of verbal fluency tasks. *Neuropsychologia*, 36, 295-304.

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ABSTRACT

It has been proposed that beliefs about loss of personhood in dementia (e.g., the belief that personality disappears as dementia progresses) lead to poorer patient care. Since most of the evidence to support this claim is anecdotal, we developed the Personhood in Dementia Questionnaire with the objective of encouraging research in this area. We conducted a literature review and consulted with subject matter experts to develop a 64-item draft questionnaire that was administered to 60 nurses and special care aides at long-term care facilities. We then improved the questionnaire by removing items that reduced the questionnaire's internal consistency or were associated ($r > 0.20$) with a measure of socially desirable response bias. Finally, we studied the convergent validity of the questionnaire by examining its correlation with a person-centred dementia care scale. The resulting 19-item Personhood in Dementia Questionnaire has good internal consistency reliability ($\alpha = 0.873$). It is not significantly influenced by social desirability (no items were significantly correlated with a measure of socially desirable response bias). After controlling for social desirability responding, convergent validity was supported by a moderate and statistically significant ($r = 0.385$) correlation with a scale measuring person-centred care and discriminant validity was supported by a non-significant correlation with a scale measuring beliefs about cancer and its treatment ($r = -.198$). Initial results suggest that the Personhood in Dementia Questionnaire may have good potential for use in empirical research on person-centred dementia care.

INTRODUCTION

- Frameworks for person-centred care are increasing in popularity in Canada. For instance, the Alzheimer's Society of Canada (2011) recently developed a set of person-centred *Guidelines for Care*.
- The premise behind person-centred care frameworks is that negative beliefs about personhood in dementia can result in compromised patient care (e.g., Kitwood, 1997).
- We wanted to contribute to emerging empirical research in this area by testing this claim.
- We decided to develop a questionnaire to measure long-term care workers' beliefs about personhood in dementia.
- This poster describes the development and psychometric properties of the questionnaire, which we called the Personhood in Dementia Questionnaire.

FIGURE 1: SAMPLE PDQ ITEMS

- Most residents with dementia are still capable of making some informed choices about their lives.
- Residents with very advanced dementia are so low-functioning that they are no longer persons.
- Residents with dementia contribute to a sense of community within our long-term care facility.
- As dementia advances, residents with dementia no longer experience basic feelings such as pleasure.

METHOD

- First, we conducted a literature review to identify definitions of personhood in the philosophical and psychological literatures. These definitions were described in terms of the following themes: *Rationality, Sentience, Psychological continuity, Bodily continuity, Emotional capacity, Agency, Human being*.
- Then, we conducted group and individual interviews with key informants (nurses and special care aides who regularly work with patients who have dementia diagnoses). We inquired about the rewards and challenges of their work, and about care practices. Using a qualitative method called thematic content analysis (Burnard, 1991) we identified themes about personhood that were reflected in interviewees' responses.
- Next, we used the themes identified in the literature review and by key informants to generate an initial item pool comprised of 64 items. See Figure 1 for sample items.
- We administered this initial version of the Personhood in Dementia Questionnaire to 60 nurses and special care aides who work in long-term care.
- A survey was used to identify low subject matter expert agreement on item themes. Only items with subject matter expert agreement of 80% or higher were retained (see Figure 2).
- Statistical analyses were then used to identify the items with the weakest psychometric properties. These items were also removed (see Figure 2).

DISCUSSION

- Initial results suggest that the Personhood in Dementia Questionnaire may have good potential for use in empirical research on person-centred dementia care.
- It can be used to test whether beliefs about personhood predict intended or observed behaviour toward patients with dementia.
- It can also be used to evaluate changes in beliefs about personhood following staff training in person-centred care.

FIGURE 2: DEVELOPMENT OF THE PDQ

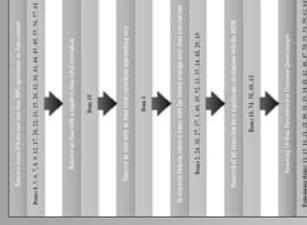


TABLE 1: PARTIAL CORRELATION AMONG THREE MEASURES OF PATIENT-CENTRED CARE, CONTROLLING FOR SOCIAL DESIRABILITY RESPONDING¹

	1	2	3
1. Personhood in Dementia Questionnaire	1.000	.385	.198
2. Person-Directed Care measure ²	.385	1.000	.181
3. Cancer Attitudes Questionnaire	.198	.181	1.000

Note: Significant correlations are printed in bold font. The Blandwin Inventory of Desirable Responding (Blandwin, 1991) was used to control for social desirability responding. This is an abbreviation for the Person-Directed Care and Environmental Support for Person-Directed Care measure (White et al., 2008).

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Introduction

The problem of dementia care in Canada

- Most patients with dementia can be assessed and managed adequately by family physicians (FPs), with the exception of patients requiring specialist referral for specific reasons (CCCDTD3, 2007).
- FPs face numerous obstacles in their efforts to provide quality dementia care: lack of support, time, cost, stigma, diagnostic uncertainty, and difficulties in disclosing a diagnosis.

The problem of dementia care in rural Canada

- Social geographers challenge the assumption that rural living is mainly characterized by a strong sense of community and is more harmonious than urban living, with research that rural people are marginalized by the harmful effects of agricultural chemicals, un(der)employment, income disparity, and inaccessibility to services (e.g., health) (Boyd & Parr, 2008).
- Rural and remote patients with dementia face considerable challenges in obtaining quality care: distance to services, high cost of accessing services, lack of appropriate services, health care professional shortages, insufficient public awareness of dementia, and possible lack of family caregivers living close by.

Collaborative models of dementia care

- Collaborative dementia care is provided by an interdisciplinary team of 2 or more health care professionals, offering continuous support over the course of the illness to both patients and caregivers.
- Supplementing FP-based dementia care with collaborative dementia care models can improve care quality and patient/family satisfaction (Callahan et al. 2011).

Objectives

To investigate:

- rural FPs' perceptions of their roles in providing care to patients with dementia
- rural FPs' preferred models of collaborative care
- the implications of FPs' rural setting for caring for patients with dementia



<http://www.cbc.ca/saskatoon/>

Methods

Sample

- Drawn from 99 eligible FPs who referred ≥ 1 patients to the Rural and Remote Memory Clinic, a one-stop clinic in Saskatoon (SK) providing diagnostic support for rural and remote patients presenting with atypical and complex dementia

Data collection

- Oct. 2010 – March 2011
- Semi-structured telephone interviews
- Participants received a \$50 honorarium
- Ethical approval from University of Saskatchewan Behavioural REB



<http://www.cbc.ca/saskatoon/>



<http://www.cbc.ca/saskatoon/>

Results

Participants (N=15)

- 13 male FPs (87%)
- 9 (60%) in practice <10 years in current location
- 12 (80%) practiced with ≥ 1 other FPs
- 9 (60%) managed ≥ 10 patients with dementia monthly

Family physician role

- Family support and education were mentioned more often than any other role
- Other roles included
 - managing treatment and monitoring patients
 - recognizing and diagnosing dementia
 - day-to-day troubleshooting
 - ensuring patient safety
 - coordinating healthcare services

"First of all the family...is anxious and not sure. The individual himself or herself are agitated, unsure, frustrated, so a lot of support for the individual, for the family, for family members, if they have a spouse and children...that's very important to provide that kind of support, reassurance to the entire group." (ID117)

Preferred collaborative models

- All FPs would like to see more collaborative models in dementia care:
 - a role for a nurse or one other healthcare professional trained specifically in dementia care
 - specialty clinics
 - case managers
- FPs cited possible benefits of nurse involvement: making home visits that FPs currently do not conduct, offering specialty care based on the latest developments, offering expert care to patients in advanced stages of the disease, and facilitating urgent referrals to specialists.

"I personally believe there should be more people involved. Especially with more advanced stages of the disease...it doesn't really matter. Anyone with geriatric skills or background in geriatric training. It can be a nurse practitioners, it can be someone in the community that's trained. It doesn't really matter. As long as it's someone that's trained in that field." (ID121)

Acknowledgements

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- Dr. Debra Morgan's Applied Chair in Health Services and Policy Research (2009-2014), funded by CIHR and the Saskatchewan Health Research Foundation for the research program *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia*.
- The CIHR Strategic Training Program in Public Health and the Agricultural Rural Ecosystem (PHARE) and Partner Institutes including the Institute of Cancer Research, Institute of Circulatory and Respiratory Health, Institute of Infection and Immunity, and the Institute of Population and Public Health

Rural Idyll

- FPs valued the close social proximity between themselves, patients, families, and healthcare workers
- Closer social proximity improved FPs' personal knowledge of patients
 - "I think we know our patients personally as well...we know where they work, so I can speak to the people who they work for and I speak to the family, the children, the wife."* (ID149)
- Dual relationship of healthcare workers as both relatives (or friends) and healthcare professionals was perceived as an advantage
 - "Our seniors don't see 30 different home care workers a month..."* (ID30)

Rural Deficiencies

- Rural-urban inequities in access to urban specialists
- Insufficient and non-existent local healthcare and social services
- Lack of physically proximate services caused inequities in patient care between rural and urban regions, and placed a large burden on FPs to fill in the gaps for their patients.
 - "We don't have day respite programs or whatever you have in the city you know where someone who is working can have their elderly parent spend the day – those programs don't exist in the north."* (ID110)

Conclusions

- Collaborative dementia care that reaches out to rural patients and caregivers to improve their access to diagnosis, management, support, and health system navigation may overcome the rural deficiencies of physical distance, transportation, healthcare staff shortages, and dearth of services.

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Patient Variable Predictors of Cognitive Impairment Severity at Memory Clinic Presentation

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Background

- The prevalence of Alzheimer's disease is increasing: it is predicted over one million will have dementia in Canada by 2038¹.
- Dementia patients and their caregivers living in rural communities are disproportionately vulnerable to gaps and barriers in delivery of dementia care compared to urban counterparts².
- The literature suggests patients with dementia and their families benefit from early assessment and diagnosis.

Objective:

To identify socio-demographic, clinical, and functional predictors of greater cognitive impairment severity in dementia patients presenting to a memory clinic in Saskatoon, Saskatchewan.

Methods

- Data collection began in 2004 at the Rural and Remote Memory Clinic in Saskatoon, SK. Patients were referred by their family physicians.
- Patient and caregiver questionnaires and assessments administered at the clinic-day appointment provided the socio-demographic, clinical and functional variables.
- 198 patients participated.
- The dependent variable was patient cognitive impairment, measured by Modified Mini-Mental State Examination (3MS) scores.
- Bivariate linear regression analysis was done to examine the association between each potential independent variable with the outcome variable 3MS scores.
- Multiple regression analysis was performed to determine the influence of the variables on 3MS performance.

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

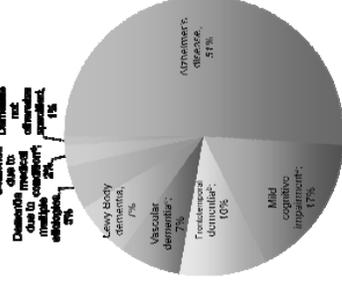
Categorical variable	n (%)
Gender	75 (37.9)
Male	123 (62.1)
Female	0
Missing	0
Ancestry	11 (5.6)
North American Indian/Aboriginal/Métis	150 (75.8)
European	9 (4.5)
Other	28 (14.1)
Missing	0
Marital status	130 (65.7)
Married/common-law	56 (28.3)
Single/divorced/separated/widowed	12 (6.1)
Missing	0
Number of people living with patient	41 (20.7)
0	125 (63.1)
1	32 (16.2)
≥ 2	0
Missing	0
Number of patient comorbidities	8 (4.0)
≤ 1	18 (9.1)
2	26 (13.1)
≥ 3	134 (67.7)
≥ 4	12 (6.1)
Missing	0
Family history of dementia	94 (47.5)
Yes (positive)	87 (43.9)
No (negative)	17 (8.6)
Missing	0
Metropolitan influence zone	71 (35.9)
CMA/CA	20 (10.1)
None	69 (34.8)
Weak	30 (15.2)
Moderate	8 (4.0)
Strong	0
Missing	0
Continuous variable	Mean ± SD
Age	73.9 ± 9.2
Range	42-91
Formal education (years)	10.7 ± 3.0
Range	3.5-19.0
Walk time (days)	173.9 ± 74.7
Range	13-422
Duration of symptoms (years)	1.9 ± 1.8
Range	0-12
3MS score ^a	71.9 ± 18.7
Range	0-99
NPI score ^b	8.3 ± 6.3
Range	1-30
FAQ score ^c	13.8 ± 8.0
Range	0-30
ZBS score ^d	13.5 ± 8.8
Range	0-48
BSI (Global Severity Index score) ^e	51.0 ± 10.0
Range	33-90

a. 3MS Possible score range = 0-100.
 b. NPI possible score range = 0-99.
 c. FAQ possible score range = 0-30.
 d. ZBS possible score range = 0-48.
 e. BSI possible score range = 33-90 (female) and 35-80 (male).
 3MS = Modified Mini-Mental State Examination, NPI = NeuroPsychiatric Inventory, FAQ = Functional Assessment Questionnaire, BSI = Brief Symptom Inventory, ZBS = Zung Depression Index, CMA = Census Metropolitan Area, CA = Census Agglomeration.



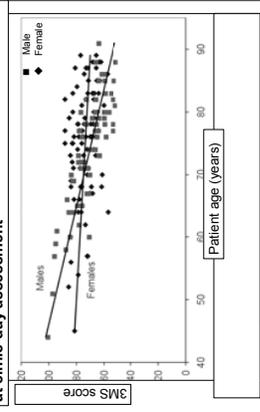
Picture 1: Rural and Remote Memory Clinic team

Figure 1: Neurologist's diagnosis at clinic day



- a. Mild cognitive impairment (MCI) includes MCI, MCI due to other, MCI non-amnesic, and MCI amnesic diagnoses
 b. Frontotemporal dementia (FTD) includes FTD non-affective and FTD affective
 c. Vascular dementia includes vascular dementia and vascular mild cognitive impairment
 d. Dementia due to medical condition includes Parkinson's disease, Huntington's disease, normal pressure hydrocephalus, alcohol induced persisting dementia, alcohol induced amnesic disorder, and dementia due to medical conditions

Figure 2: The effect of age and gender on 3MS score at clinic-day assessment



Picture 2: Patient undergoing neuro-psychological assessment

Results

Table 2: Multiple regression analysis

Variable	Estimate ± SE	95% CI for Estimate	p value
Intercept	63.16 ± 15.24	(33.05, 93.27)	<0.0001
Age	-0.034 ± 0.175	(-0.38, 0.31)	0.844
Gender (patient)	40.55 ± 19.68	(1.68, 79.42)	0.041
Male ^a	0.914 ± 0.417	(0.09, 1.74)	0.030
Formal education (years)	-0.791 ± 0.164	(-1.11, -0.47)	<0.0001
FAQ ^b	0.263 ± 0.125	(0.02, 0.51)	0.037
BSI (Global Severity Index score) ^c	-0.580 ± 0.264	(-1.10, -0.06)	0.029
Age × Gender (Male)			

a. Gender (patient), female is reference.
 b. Higher FAQ score indicates higher level of patient dependency.
 c. Higher BSI score indicates higher level of caregiver dependency.
 Notes: R² (coefficient of multiple determination for regression) = 0.278, p < 0.05
 SE = Standard Error, CI = Confidence Interval, FAQ = Functional Assessment Questionnaire, BSI = Brief Symptom Inventory

Conclusions

- Increased cognitive impairment (lower 3MS) at clinic presentation was predicted by fewer years of formal education, poorer functional ability, and less caregiver psychological distress.
- The relationship between gender and level of cognitive impairment at initial assessment (3MS) depended on age. For younger patients, females were more cognitively impaired (lower 3MS) at clinic day, but for older patients, males were more impaired at clinic day.

Acknowledgements

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Key Factors Identified by Participants of a Telehealth-Facilitated Support Group for Spouses of Persons Diagnosed With Atypical Dementias

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Background

In a support group, spousal carers of persons diagnosed with atypical dementias, such as the frontotemporal variants, can obtain both practical information and support from others who are experiencing similar troubling behaviours in their spouse

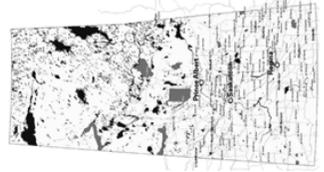
In rural and remote regions it is difficult to find many carers of individuals diagnosed with these uncommon atypical dementias – cannot connect in-person and must do so via videoconferencing

We collaborated on developing a novel use of videoconferencing via Telehealth to deliver a support group for rural spouses of Rural and Remote Memory Clinic (RRMC) patients diagnosed with atypical dementias

We use Telehealth videoconferencing to connect 10 caregivers from 6 regions of the province with the facilitators located in Saskatoon

The group meets once monthly for 1 ½ hours; emotional processing rather than psychoeducation is the focus

First intervention session was held March 2009



Key Ingredients

After 1 year of the intervention, we held an in person meeting where one goal was to have support group participants describe their view of the key ingredients of the group's success. These are summarized below.

Caregiving in similar circumstances (atypical dementias)

"because you know the Alzheimer's was different."

And since these dementias are typically early-onset, having caregivers of similar age was important

"...the age, it's been the best."

The group composition of spousal caregivers was important

"...this huge loving relationship that makes you feel lonely."

"...not a wife and a lover, but you've become a caregiver. It changes a lot of things."

Inclusion of caregivers whose spouses were in different stages of dementia was helpful

"On the other side of it, sometimes I hear things that scare me. I don't want to hear that, I don't want to know that's coming. I know I need to know, but I don't want to know. You know what I mean?"

More recently it has become apparent that it is important to have caregivers continue to attend group after the death of their spouse – this allows not only for closure for the group members, but it is also helpful to see members emerge as healthy after and, eventually, happy after the death of their spouse

Group Structure

Each session is without an agenda, but includes a brief check in with each member which was seen as helpful

"I know how much they need it so I'll just shut up here."

The check in also ensured inclusion of members who had a tendency to defer sharing their needs

Key Ingredients

Group Structure (Continued)

The open group format was described as important because members leaving when they decided it was right for them as opposed to at a predetermined time

Group Process – Emergent Key Ingredients

Socialization

Caregiving related socialization where they felt they could freely share with and not continually wonder *"Do I tell them the truth and all the horrors of the truth or do I just say you know what?"*

Non-caregiving related socialization

"...like trying not to lose ourselves in the whole thing."

Imparting information and alternate suggestions

"Because you know, because it won't last very long and I learned that from you."

Altruism

"Knowing that I'm helping someone else. And to see ___ smile a little bit after something I've said, or to see somebody laugh about, you know,..."

The group has become activist and some are volunteering many hours of time helping others

Acknowledgments

We thank our caregiver collaborators & Telehealth Saskatchewan

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



Development Work with the Northern Cultural Assessment of Memory (N-CAM): A Cognitive Screen for the Detection of Cognitive Impairment and Dementia in Aboriginal Seniors

Indigenous Peoples' Health Research Centre (IPHC) Undergraduate Research Award 2011
Hannah St. Denis-Katz & Margaret Crossley (Supervisor)

Introduction

- Performance on mental status screening tests (e.g., MMSE) is influenced by culture, language, and education.
- Culturally appropriate assessment protocols are needed to advance knowledge about normal aging and the prevalence of dementia among Aboriginal seniors.
- The Northern Cultural Assessment of Memory (N-CAM) was developed through a partnership between faculty and graduate students from the University of Saskatchewan, Rural and Remote Memory Clinic (RRMC), and home-care staff and health managers residing and working in the North (Keewatin Yatthee Regional Health Authority).

Qualities of the N-CAM

- The N-CAM does not assume formal education and is administered in the preferred or first language of the senior
- The N-CAM has been designed for home-based assessment by front-line health workers and includes family caregivers in the assessment of activities of daily living and changes in functional status
- The N-CAM has been designed to incorporate colour, humour, and familiar images and materials to better engage Aboriginal seniors
- When the N-CAM is used in a clinical setting, family caregivers are included in the assessment of activities of daily living to better identify potential changes in functional status, and to ensure that it can be administered in the preferred language of the senior.



Figures: Neuropsychology faculty and undergraduate research students traveled to Ile a la Crosse to participate in a one day workshop (July 2011) with home care staff and managers with the Keewatin Yatthee Regional Health Authority.

Experience at Westside Clinic

- With the IPHC Undergraduate Research Award normative data was collected at Westside Community Clinic in Saskatoon
- Summer research project began with shadowing the neuropsychology team at the RRMC during clinic days, as well as familiarization with the N-CAM and the Grasshoppers & Geese (G & G), another neuropsychological test developed for cross-cultural assessment.
- Data collection at Westside Community Clinic began in early June.
- My favorite part of the study was collecting stories from participants about important experiences during their previous week that I would ask them about later as a measure of recall for recent autobiographical events.
- Although most participants did very well at recalling the details of their autobiographical stories, it was the stories themselves that amazed me because they ranged from what seemed to me to be ordinary to the most tragic events I could ever imagine happening.
- Working with an Aboriginal population was not easy due to the high percent of participants that suffered from addictions, but at the same time, that work could not have been more rewarding, seeing the happiness I brought many participants as an Aboriginal youth trying to make a difference in the Aboriginal community.
- I also had some amazing experiences such as the trip up North to Ile a la Crosse to help out with a workshop about the administration of the N-CAM.
- During the workshop I had a chance to meet some of our Northern partners who have been working with us to develop the N-CAM for many years, as well as talk to them about the work I was doing at Westside Community Clinic.

Methods, Participants, Results, and Conclusions

- A health and culture interview, standardized cross-cultural measures of memory and language (G & G; Lanting et al., 2011), and the N-CAM were administered to volunteers recruited through the Westside Clinic.
- Participants ($N = 81$, 41 males, 92% Aboriginal, age range from 19 to 81 yrs) endorsed high levels of chronic health and social problems, including 70% with addiction problems, 48% with hepatitis C, 38% with a history of head injury, and 68% with less than high school education.
- N-CAM scores ranged from 73 to 99 ($M = 93.4$) on a scale from 1 to 100, and had statistically non-significant and small associations with age ($r = -.165$) and education ($r = .20$). Importantly 95% of participants were rated as fully cooperative and only 16% as test-anxious.
- Associations were highly significant with standardized tests of memory ($r = .513$), confrontational naming ($r = .508$), and semantic associations ($r = .601$), demonstrating good construct validity.
- Participants with scores below 80 ($N=5$) on the N-CAM performed in the impaired range on one or more of the standardized tests.
- In conclusion**, the N-CAM, developed through community-based partnerships, is a brief and well-tolerated cognitive screening protocol that demonstrates sensitivity to differences in higher brain functions and impairment, but not to age- or education-effects in Aboriginal adults and high-risk inner city residents.
- These data increase our confidence in using the N-CAM with individuals of Aboriginal background and highlight the strengths and weaknesses of the tool. With the normative data in place, the N-CAM is now much closer to being ready for release and use across Canada.

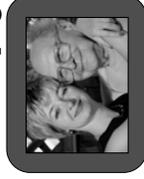
References: Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (in press). Aboriginal experiences of aging and dementia in a context of sociocultural change: Qualitative analysis of key-informant interviews with Aboriginal seniors. *Journal of Cross Cultural Gerontology*.



Gender Differences in Caregiver Distress over Time

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University of Saskatchewan

P087



26th International Conference of Alzheimer's Disease International, Toronto, Mar. 26 – 29, 2011

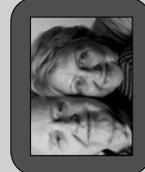
Objective

The aim of this retrospective study was to examine differences in family caregiver distress by gender and relationship (spouse vs. child) over three annual time points of a longitudinal study. Family members identified themselves as primary caregivers for the person diagnosed with dementia at a Rural and Remote Memory Clinic (RRMC).



Methods

Questionnaire data from primary caregiver wives, husbands, daughters, and sons were collected at the RRMC at time of dementia diagnosis and repeated annually after diagnosis for two years (Year 1 & Year 2).



Ethics approval was obtained and family members signed an informed consent form.

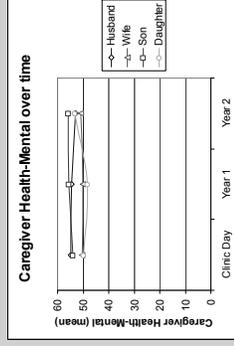
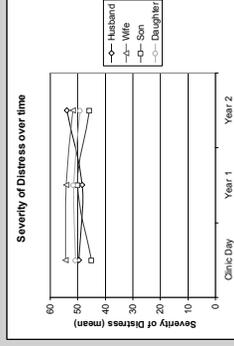
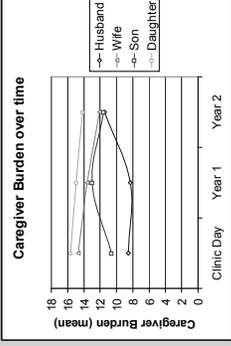
Of 210 caregiver participants, there were 80 wives, 59 daughters, 52 husbands, and 19 sons.

Self-report measures of caregiver burden (N=333), severity of distress (N = 294), and health - mental (N = 331) were analyzed over time using the Generalized Estimating Equation (GEE). Change of caregiver status was treated as missing data to maintain consistency in comparisons over time.



Results

From the initial diagnostic clinic day until Year 2, women reported more caregiver burden ($z = -2.81$; $p = 0.0049$); more severe distress; ($z = -2.50$; $p = 0.0125$); and lower mental health ($z = 2.57$; $p = 0.0103$). There was no difference based on caregiver relationship (spouse vs. child) and no statistical interaction effect (gender x relationship) across the three time points.



Conclusion

These results provide support for an ongoing need to develop gender-specific strategies to address the distress of family caregiving and enhance the mental health of those who provide the primary support for a family member with dementia living at home in rural or remote Canadian settings.



Although women had more negative psychological effects than men, there was substantial distress reported by all caregiver groups in the study, while mental health remained relatively high.



Sons had a unique trajectory of burden and distress over time. We are currently doing a follow-up study to help us understand the challenges and benefits of caregiving for sons.

Acknowledgements



Pre-Diagnosis Experiences of Informal Caregivers of Individuals Referred to a Rural and Remote Memory Clinic

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¹University of Saskatchewan ²University of Western Ontario ³University of Stirling
 40th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology, October 21-23, Ottawa

Setting	Study Design	Demographics
Saskatoon's Rural & Remote Memory Clinic (RRMC) combines interprofessional clinical practice, research and training to provide convenient "one day" access to diagnostic assessment for patients with memory problems living in remote or rural regions of Saskatchewan. RRMC patients are referred by their family doctor, and are followed up by the Clinic team via Telehealth and in-person visits. The RRMC operates under a family-centred model of care, involving the patient's family and/or caregivers at all points.	Informal caregivers who accompany the patient to the initial full-day diagnostic assessment at the RRMC are invited to participate in interviews at 3 points over the year following their first visit to the RRMC: Clinic Day : initial in-person interview Six Months later : telephone interview } <i>In progress</i> One-Year follow-up : in-person interview Interviews were analyzed using a grounded theory approach	30 Clinic Day interviews 44 participants (caregivers) 16 spouses; 24 adult children; 6 other Diagnoses: 15 Alzheimer Disease; 4 Mild Cognitive Impairment; 3 Frontal Temporal Dementia; 1 Vascular Cognitive Impairment; 5 Normal; 2 Inconclusive

Noticing First Signs >> A

Caregivers and Patients typically notice first symptoms of memory problems around 2 years before they arrive at the RRMC.

Sometimes an incident triggers the help-seeking process, and sometimes it is a gradual recognition that symptoms are not "normal". Caregivers see being proactive as important.

"...I noticed a lot over the holidays and thought we'd better...tackle this earlier than later..."
Son of RRMC Patient

For some, getting a referral from the family physician is a straightforward process. Many however experience **getting stuck**, either by patient resistance to seek assessment but more often by the family physician.

"I went for how many years now I've been mentioning it [to the Doctor] that I've noticed ... mentioning about her memory and they did these kind of little tests or something and asked her like, what date it was, and he would say well he didn't really see any, uh, difference. And only last year he finally, he would refer us."
Daughter of RRMC Patient

"I tried to phone the [Doctor's] clinic, wrote more letters, never to be answered back."
Daughter of RRMC Patient

Getting a Referral N e e d t o K n o w >>

We See It

"...as a caregiver...you know the symptoms. You notice there's a change and ... [doctors] don't believe you...and maybe the changes are so small that there's really nothing they can do about it but I think they should at least acknowledge that...we're...we're not imagining it. It's for real. You know, that's the frustrating part."
Daughter of RRMC Patient

"...my brother didn't think there was anything wrong... [With a diagnosis] ...we have... something ... more concrete to deal with rather than just observations that [Brother] won't deal with."
Daughter of RRMC Patient

Taking Charge

"... so then my daughter phoned and she says, 'what did [Doctor] say?' and I say well there's nothing wrong. Well she says 'I'm going to go back to... the original doctor and find out.' So she went in and I don't know what she said to him but she said we want some action. So he said 'okay I will make arrangements.'"
Husband of RRMC Patient

"I went to see his most recent doctor and I basically... I said can you please write a referral to this remote memory clinic. And he did."
Daughter of RRMC Patient

Achieving a referral is an intervention itself; it is a response to the caregivers' need to **do something**.

"...just finally the fact that somebody is seeing him and trying to sort out what's the problem for him"
Wife of RRMC Patient

Getting a Diagnosis

The pre-diagnosis journey culminates at the RRMC Diagnostic Assessment appointment.

What do caregivers expect the Assessment to provide?

Answers - Guidance - Explanation - Confirmation

"... To know where to go from here. Like what decision should we be making? Do we need to step in, and, we don't even know if she's able to look after her own finances."
Daughter of RRMC Patient

"...you have a person go from day to night, uh, just to know...what caused it...would help."
Wife of RRMC Patient

"... sometimes when you know what's happening it's a relief...then you learn to deal with it and move forward."
Daughter of RRMC Patient

Conclusion

Most caregivers in this study were actively seeking help for the patient and sometimes had to "take charge" to keep the process moving. They described "needing to know" so that they could move forward, both practically (decision-making) and psychologically (accepting the diagnosis, dealing with it). Providing a diagnosis for suspected dementia is therapeutic and a positive outcome in its own right.



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