

Final Report

The Sixth Annual Summit of The Knowledge Network in Rural and Remote Dementia Care

October 24th & 25th, 2013
Saskatoon, SK



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

NOTE:

THE NEXT SUMMIT MEETING OF THE KNOWLEDGE NETWORK IN RURAL AND REMOTE DEMENTIA CARE WILL TAKE PLACE ON TUESDAY THE 21ST AND WEDNESDAY THE 22ND OF OCTOBER, 2014. THE SUMMIT WILL COINCIDE WITH THE 7TH INTERNATIONAL SYMPOSIUM: SAFETY & HEALTH IN AGRICULTURAL & RURAL POPULATIONS: GLOBAL PERSPECTIVES.

MARK YOUR CALENDAR NOW!

This report summarizes the activities of Summit 6, the Sixth Annual meeting of the Knowledge Network in Rural and Remote Dementia Care in Saskatoon on October 24th & 25th, 2013.

Funding to make this Summit possible was provided by Canadian Institutes of Health Research and Saskatchewan Health Research Foundation.

Support provided by the University of Saskatchewan, and the Canadian Centre for Health and Safety in Agriculture.

Photos from the Summit used in this report were taken by Debra Marshall.

University of Saskatchewan
Saskatoon, Saskatchewan
July, 2014

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Welcome

Dear Knowledge Network Members,

The 6th Summit of the Knowledge Network in Rural and Remote Dementia Care took place in Saskatoon on October 24th and 25th, 2013. The Thursday evening poster session and Friday knowledge exchange day were attended by 69 people. The goals of the annual Summit are to provide an opportunity for knowledge exchange between and among the RaDAR research team members and our research partners and advisors, and to plan future research directions. For the RaDAR team, this exchange is critical to ensuring that our research is relevant and meaningful to those involved in planning and providing dementia care in rural and remote settings in Saskatchewan.

If you did not attend the Summit, and are interested in attending future meetings please contact Debra Morgan at: debra.morgan@usask.ca

As this report shows, the agenda included a full day of presentations by both RaDAR team members and our partners. We learned about the expansion of the Alzheimer Society of Saskatchewan's First Link Program to four rural health regions, and Sun Country Health Region's dementia hoshin. As a key component of the RaDAR team's Dementia Gap Analysis, we are collaborating with the Health Quality Council to examine administrative databases for dementia incidence and prevalence, and patterns of care in Saskatchewan. Preliminary findings from this analysis were reported at the Summit by Dr. Jacqueline Quail, Senior Researcher at HQC. RaDAR team members reported on the development of a dementia Learning Needs Assessment study in Sun Country Health Region, the move to the new Rural and Remote Memory Clinic space on campus, and assessing competence in dementia. As always, time was included for informal networking among participants, which the annual Summit evaluations consistently highlight as an important benefit of the meeting.

I hope you enjoy reviewing the activities of the 2013 Summit, and I look forward to seeing you in 2014! I would like to acknowledge the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation for their support of the Summit through a CIHR-SHRF Applied Chair in Health Services and Policy Research.

Debra Morgan

Debra Morgan





Summit Agenda

Agenda **Summit 6**
2013
Knowledge Network in Rural and Remote Dementia Care
Annual Summit
October 24th & 25th, 2013
Sheraton Hotel – Saskatoon

Thursday, October 24th - Sheraton Hotel – South & West Rooms

7:00 pm – 10:00 pm Registration, Wine and Cheese Poster session and informal networking. Please join us in the South-West room to review posters which highlight a variety of projects from attendees. Appetizers will be served, and a cash bar will be available.

Friday, October 25th - Sheraton Hotel – South & West Rooms

8:00 am – 8:25 am **Registration and Full Breakfast served in the South/West room**

8:30 am – 9:00 am Introduction and welcome – Debra Morgan, RaDAR (Rural Dementia Action Research) Team Lead; Professor, Canadian Centre for Health & Safety in Agriculture

9:00 am – 9:30 am First Link Program Expansion in Saskatchewan -- Joanne Bracken (CEO, Alzheimer Society of Saskatchewan) & Joanne Michael (Program Services Manager, Alzheimer Society of Saskatchewan)

9:30 am – 9:45 am Sun Country Health Region Dementia Hoshin -- Pat Kessler (Regional Home Care Director) & Mark Barnes (Dementia Project Advisor)

9:45 am – 10:00 am Dementia Learning Needs Assessment -- Debra Morgan (RaDAR PI) and Julie Kosteniuk (Post-doctoral Fellow, RaDAR team, U of S)

10:00 am – 10:30 am **Morning Break and Coffee**

10:30 am – 12:00 pm Saskatchewan Dementia Gap Analysis – Debra Morgan, Julie Kosteniuk, Jacqueline Quail (Senior Research, HQC). **Update on Environmental Scan of dementia services by RHA, and preliminary results of the RaDAR-Health Quality Council study of dementia prevalence and incidence from SK health databases.**

Noon to 1:00 pm **Lunch served in the South/West room**

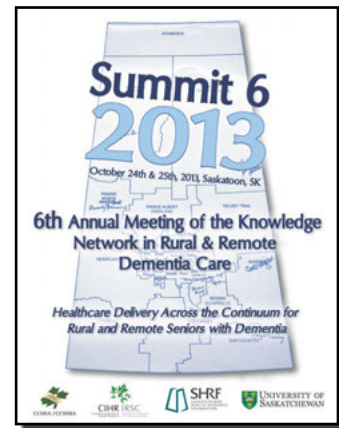
1:00 pm – 1:30 pm The new Rural and Remote Memory Clinic (RRMC) space and the Video Therapy Analysis Laboratory (ViTAL) -- Megan O'Connell (RRMC Clinical Psychologist, Department of Psychology, University of Saskatchewan, Director ViTAL)

1:30 pm – 2:30 pm CIHR Canadian Consortium on Neurodegeneration in Aging Study (CCNA) An update on CCNA Team 20 – Issues in Dementia Care in Rural and Indigenous Populations will be co-presented by Debra Morgan (U of S) and Carrie Bourassa (First Nations University of Canada)

2:30 pm – 2:45 pm **Afternoon Break**

2:45 pm – 3:30 pm Competence and Dementia -- Andrew Kirk (Head, Division of Neurology, University of Saskatchewan, RRMC Neurologist)

3:30 pm – 4:00 pm Closing comments and Summit evaluation



Participants of the Summit were provided with a binder of information, which included copies of the presentations. To request a copy of this information, please see "Supplemental Resources" on page 15.



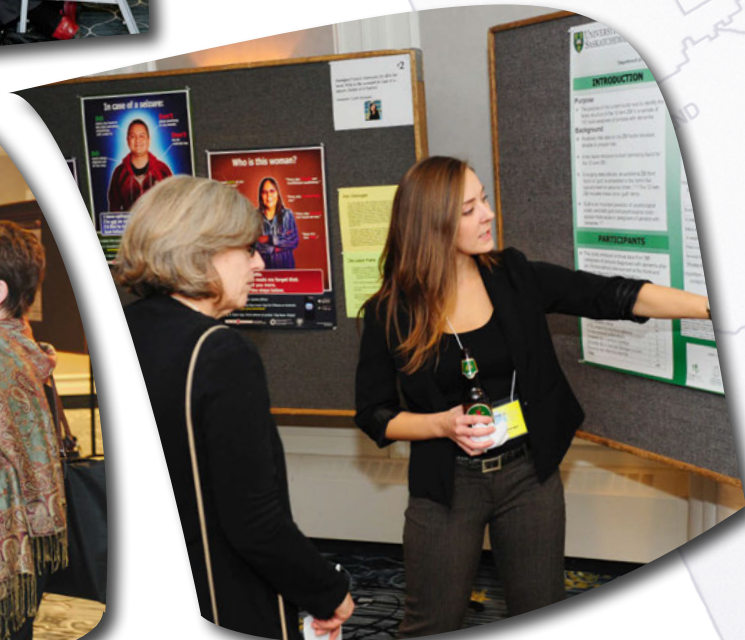
Thursday Evening Poster Session

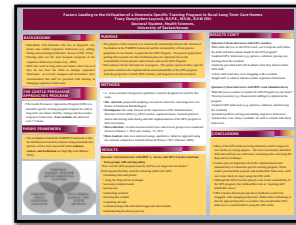
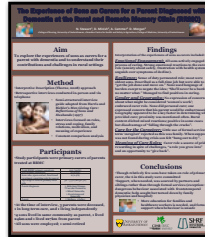
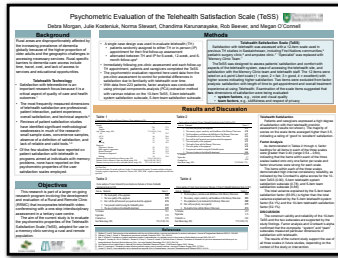
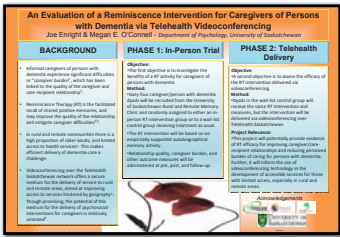
UNIVERSITY OF ALBERTA		Factor Analysis of the 12-Item Zurr-Budner Interview in Congress of Process Disorders with Dementia		UNIVERSITY OF ALBERTA	
INTRODUCTION		CONCLUSIONS		REFERENCES	
Background: The Zurr-Budner Interview (ZBI) is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.		The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.		The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.	
PARTICIPANTS		RESULTS		DISCUSSION	
The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.		The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.		The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists. The ZBI is a 12-item instrument designed to assess the presence of dementia in the context of a psychiatric hospital. The ZBI is a brief, easy-to-use instrument that can be administered by non-psychiatrists.	

A full list of poster titles and authors as presented at the Summit is available in Appendix B, page 18 of this report. A booklet of all of the posters displayed at the Summit was prepared for the event. Page 15 includes information about how to access the booklet.

On Thursday evening participants registered for the Summit and then enjoyed an evening-long scientific poster session and informal networking time. The poster session featured fifteen posters and displays that featured projects from researchers and decision makers.

Presenters were: Mark Barnes and Pat Kessler, Carrie Bourassa, Camille Branger, Allison Cammer, Tracy Danylyshen-Laycock, Joe Enright, Drew Hager, Paulette Hunter, Julie Kosteniuk, Xiangfei Meng, Joanne Michael, Darrell Mousseau, Norma Stewart.





Student Poster Prize

Students from a variety of academic disciplines have played an integral role in the Summit since the first Summit event in 2008. The Summit provides an opportunity for students to strengthen their communication skills as they share their research interests with attendees. Students and attendees also benefit from the connections that are made at the Summit.

Thanks to financial support from Pfizer Canada, a student poster prize was awarded at the Summit Poster session. Posters were adjudicated by a panel of senior researchers and community members. Camille Branger, a Psychology Masters student from the University of Saskatchewan won for her poster: Factor analysis of the 12-item Zarit Burden Interview in caregivers of persons diagnosed with dementia.



Camille Branger and Debra Morgan in front of Camille's prize-winning poster.





Meeting Introduction and Welcome

Decision Maker Advisory Council

- The Council provides **ongoing direction** for the Applied Chair research program in **all phases** of the research cycle:
 - identifying priorities
 - providing advice on communicating with various sectors and accessing study populations
 - evaluating research findings
 - facilitating dissemination and utilization
 - developing policy implications.



Summit 5 (Nov 2012)

Goals of the Summit

1. **Knowledge exchange between and among decision makers and researchers re: current research**
 - Poster presentations
 - Presentations and discussions
2. **Future research directions**
 - Canadian Consortium on Neurodegeneration in Aging (CCNA)



Community-Based Primary Health Care Team Grant Full Proposal

- Submitted to CIHR October, 2012
- Notification April, 2013
- 36 applications submitted
 - 12 funded



Next Steps

- "Courage is going from failure to failure without losing enthusiasm"
 - Sir Winston Churchill
- The silver lining: CCNA opportunity

CCNA Team 20 "Issues in Dementia Care in Rural & Indigenous Populations"



July 29, 2013 (University of Saskatchewan)

On Friday, Dr. Morgan welcomed attendees and reflected on the history of the Rural Dementia Action Research team (RaDAR) at the University of Saskatchewan. This history includes the development of the Decision Maker Advisory Council, composed of people who work in the field of dementia care, and family and caregivers of people affected by dementia. Input and feedback from the council, and the practical knowledge and experience it represents, has been integral to the success of the research undertaken by the team. Dr. Morgan explained how her CIHR-SHRF Applied Chair in Health Services and Policy Research (2009-2015) currently funds the research of the team.

The annual Summit has become an invaluable knowledge translation and exchange activity for both researchers and decision makers and has led to many successes as attendees learn from each other. Last year's Summit helped to develop one of the proposed early research projects of the RaDAR community-based, primary health care team grant proposal. We learned in April of 2013 that our application was not funded, but the preparatory work done at Summit 5 developed the Dementia Care Gap Analysis Study that was presented at this year's Summit.

As we look toward the future, the team focus will be on our joint application with researchers from across Canada as a part of the Canadian Consortium in Neurodegeneration in Aging (CCNA). As CCNA Team 20: *Issues in Dementia Care in Rural & Indigenous Populations*, we will ensure that Indigenous and Rural perspectives are represented in the CCNA research program.

Stakeholders from across Saskatchewan participated in the Summit, and included representatives from: primary healthcare, chronic disease, long-term care, home care, health region administration, nurse practitioners, family physicians, continuing care consultants, family members, research team members and students, and the Alzheimer Society of Saskatchewan.





First Link Program Expansion in Saskatchewan

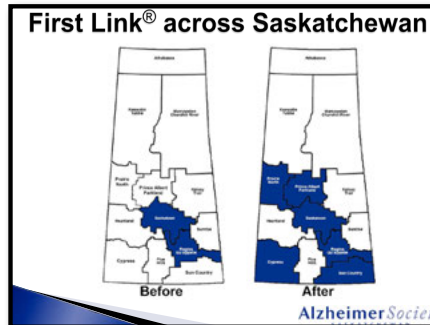


The Alzheimer Society of Saskatchewan had a substantial presence at Summit 6. Executive Director, Joanne Bracken, and Program Services Manager, Joanne Michael took the podium to share the exciting news of the expansion of the Society's First Link program. With new funding offered by the Saskatchewan Ministry of Health, the society has been able to open four new resource centres across Saskatchewan.

There are now six health regions (two urban, four rural) in the province that currently have a First Link Program coordinator, and in each region the plan is to develop a Dementia Advisory Network anchored by the coordinator as a resource for the region. All of the newly hired coordinators from around the province as well as other Alzheimer Society of Saskatchewan staff members were participants at this year's Summit. This was the first face-to-face meeting of all of the First Link program staff.



Alzheimer Society of Saskatchewan 1st Link Coordinators and staff at Summit 6



First Link[®] funding

- Government of Saskatchewan's Ministry of Health increased funding of First Link[®] from \$50,000 to \$400,000 annually
- Opening of 4 new Resource Centres throughout the province
- First Link[®] Coordinators
- Provincial Program Coordinator
- Development of 6 Dementia Advisory Networks

Alzheimer Society

Goals of First Link[®]

- Early access to learning, services and support
- Increase effective & efficient utilization of community resources
- Reduce overall incidence & intensity of caregiving crisis situations
- Strengthen the link between diagnosing physicians, community service providers and the Alzheimer Society of Saskatchewan

Alzheimer Society

Dementia Advisory Networks

- Established in every community with an Alzheimer Society Resource Centre.
- Purpose:
 - To facilitate people and resources coming together locally, regionally and provincially to improve the system of care, which includes service delivery, education and research for persons with dementia, their families and caregivers.
- Will form a committee of representatives including the Alzheimer Society, family physicians and specialists, primary care, home and community care, adult day support programs and long-term care.

Alzheimer Society

Provincial Program Coordinator

Trina Hodgson

First Link[®] Coordinators

<ul style="list-style-type: none"> Cypress Resource Centre <ul style="list-style-type: none"> Laura MacWilliam Prairie North Resource Centre <ul style="list-style-type: none"> Jim Walls Prince Albert Parkland Resource Centre <ul style="list-style-type: none"> Bronwen Porcina Regina Qu'Appelle Resource Centre <ul style="list-style-type: none"> Sheila Loszchuk Connie Snider 	<ul style="list-style-type: none"> Saskatoon Resource Centre <ul style="list-style-type: none"> Alice Germann Cassie Nesbitt Susan Price Sun Country Resource Centre <ul style="list-style-type: none"> Joylyn Roberts
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Alzheimer Society



Sun Country Health Region Dementia Hoshin and Dementia Learning Needs Assessment

DEMENTIA HOSHIN

Who, where, what, why & how

SASKATCHEWAN

- The cost of Dementia in Saskatchewan in 2008 was over \$572 million
- Over 3,900 new cases each year. By 2038 this number is expected to more than double to 8,100 new cases annually

NEXT STEPS



- Screening tools
- Early identification
- Engagement of Primary Care Practitioners
- Research in the field
- Development of specialized resources

Background

Sun Country Health Region Dementia Hoshin

- Background**
- Caregivers, both formal and informal, may not have knowledge and/or access to sufficient best practice education and skills to support clients with dementia
 - Lack of tools to identify early dementia
 - Lack of early dementia screening by primary care providers; which needs to be linked to other services/professionals
- (Sun Country Hoshin Kanri Project Plan 2013-2014)

- Objective**
- "Develop, implement, and evaluate a capacity-building process of dementia care for health care professionals"
- (SCHR Strategy Deployment Wall Walk Report, April 2013)

Dementia LNA Development

1. Review of Literature and Best Practice Recommendations
2. Questionnaire – First draft
3. Focus Groups
4. Questionnaire – Second draft
5. Review of second draft
6. Data Collection pending Ethics Approval

Mark Barnes, Regional Dementia Project Advisor with Sun Country Health Region, spoke to Summit attendees about the work that is on-going in the region. Sun Country Health Region identified dementia as a Hoshin for their region – a focused priority for change and improvement within their region for this year. With the region's Dementia Working Group Mark is developing a dementia-specific education module that will be delivered within the Home Care sector in Sun Country. The RaDAR team is providing support as a key member of the Sun Country Dementia Working Group. It is hoped that this preliminary work within the Home Care sector can then be shared more widely with other employees in Sun Country Health Region.



Dr. Julie Kosteniuk followed Mark with a review of the research that the RaDAR team has conducted in Sun Country Health Region this year. The research team has developed a Dementia Learning Needs Assessment (LNA) for the region that will focus on what health care providers perceive as their knowledge needs and gaps with respect to dementia. The LNA will focus on Home Care Case Managers and Home Health Aides. The research team has completed a literature review and a review of best practice recommendations. Following feedback from focus groups with Homecare staff in Sun Country on an initial draft, a final version of the LNA questionnaire has been developed, and data collection is planned for November 2013, pending ethical approval.

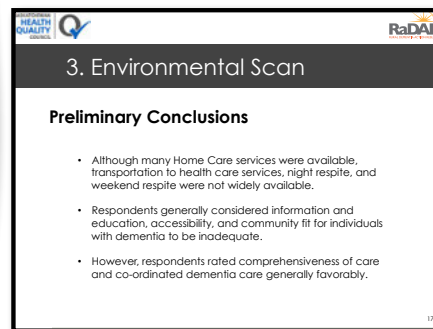
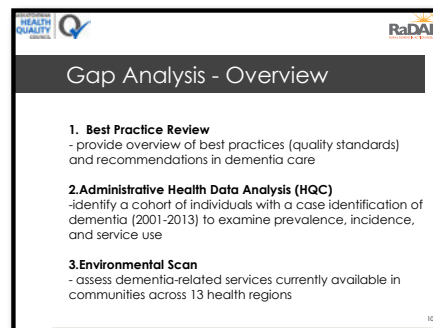
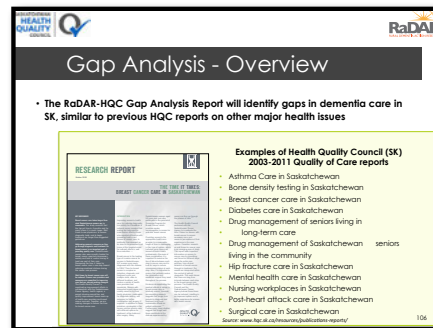


Morning Presentation & Discussion Saskatchewan Dementia Gap Analysis



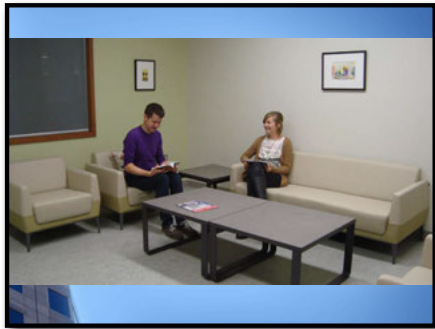
Dr. Jacqueline Quail, Senior Researcher at the Saskatchewan Health Quality Council (HQC) joined Debra Morgan and Julie Kosteniuk to present preliminary results from the collaboration between the RaDAR research team and HQC, which addresses the lack of current epidemiological information about dementia in Saskatchewan. This Gap Analysis consists of three components: a) a review of best practice recommendations in dementia care, b) an administrative health data analysis to examine prevalence, incidence, and service use of a cohort of individuals with dementia between 2001 and 2013, and c) an environmental scan of dementia-related services currently available in the province. The development of this Gap Analysis began at a RaDAR grant planning session in October of 2011, and has evolved into an interactive partnership with HQC that matches the research interests of the team and HQC's quality improvement mandate.

In a small group exercise at Summit 5, participants played an integral role in shaping the focus of the environmental scan of services by identifying ideal services across the care continuum. At Summit 6, the research team shared the preliminary results from the environmental scan which had been completed by 82 respondents from across the province. As well, the team presented preliminary results from the administrative health data analysis highlighting incidence and prevalence rates of dementia in the province, including comparisons across urban and rural populations. Following the presentations, there was a question and answer period moderated by Dr. Margaret Crossley. The next steps of the Gap Analysis include completing the three study components and the release of a final Report of the findings. Practice and policy recommendations from the report will be developed at Summit 7.





New Rural and Remote Memory Clinic (RRMC) and Video Therapy Analysis Lab (ViTAL)



Dr. Megan O’Connell, the Clinical Psychologist with the RRMC team, started the afternoon session with an introduction to the new RRMC space within the new Health Sciences E-wing building on campus. The clinic moved in August of 2013 into the specifically designed space, which incorporates technology support to facilitate the work of the team, and the training of student clinicians. The new RRMC is located within the Canadian Centre for Health and Safety in Agriculture, and was funded in part by a Canadian Foundation for Innovation (CFI) grant. The new RRMC also includes family rooms and space to provide a more comfortable clinic-day experience for patients and families.



Dr. O’Connell also introduced her Videotherapy Analysis Lab (ViTAL) to participants. Located within the department of Psychology on campus, the CFI funded ViTAL uses secure teleconferencing connections within a controlled environment to investigate the provision of therapeutic interventions over videoconference. The lab is an integral support to Dr. O’Connell’s research, and helps to inform the way services – like those provided to RRMC patients – can best be provided to remote locations.



Afternoon Guest Presenter Dr. Carrie Bourassa - Associate Professor, First Nations University of Canada.

Dr. Bourassa is an Associate Professor of Indigenous Health Studies at First Nations University of Canada and the Special Advisor to the President, Research. Carrie completed her Ph.D. (Social Studies) in 2008. Her book, based on her dissertation, was released in the fall of 2012 entitled *Métis Health: The Invisible Problem*. Dr. Bourassa is proud to be the successful Nominated Principal Investigator on a Canada Foundation for Innovation Grant that funded the Indigenous Community-based Health Research Labs at FN Univ. She is also the Nominated Principal Investigator for the Indigenous Peoples’ Health Research Centre. Carrie’s research interests include the impacts of colonization on the health of First Nations and Métis people; creating culturally safe care in health service delivery; Indigenous community-based health research methodology; Indigenous HIV/AIDS research; Indigenous end of life care, Indigenous dementia research and Indigenous women’s health. Carrie is Métis, belonging to the Regina Riel Métis Council #34. She resides in Regina with her husband, Chad and her daughters, Victoria and Lillie.

*Learn more about the new RRMC
on the RaDAR team website:*

www.cchsa-ccssma.usask.ca/ruraldementiacare

Learn more about the ViTAL:

<http://ssrl.usask.ca/vital>



Afternoon Presentation: CIHR Canadian Consortium on Neurodegeneration in Aging Study (CCNA)

Dr. Debra Morgan, and Dr. Carrie Bourassa of First Nations University of Canada co-lead a presentation about a new research study that the RaDAR team is developing. The CCNA is a planned 5 year initiative that will bring together researchers from across Canada from a variety of disciplines to address the challenge of neurodegenerative diseases. Funding for the CCNA will come from a variety of sources, but will be anchored by the Canadian Institutes of Health Research. Dr. Howard Chertkow (McGill University) is the Principal Applicant.



Members of CCNA Team 20 in Saskatoon, July 2013.

Within the CCNA researchers are organized into 20 teams across three themes: prevention, treatment, and quality of life. CCNA Team 20 will focus on "Issues in Dementia Care in Rural & Indigenous Populations". The Team 20 Rural dementia research stream will be led by Dr. Debra Morgan and includes members of the RaDAR team. Dr. Kristen Jacklin (Laurentian University) and Dr. Carrie Bourassa (First Nations University of Canada) will co-lead the Team 20 Indigenous dementia research stream. Drs. Morgan and Bourassa highlighted the proposed research projects that were developed when the Team 20 investigators met face-to-face at a research planning meeting in Saskatoon last July. The Rural and Indigenous research streams are distinct but share a common interest in community-based primary healthcare, appropriate tools, and capacity building. If the CCNA initiative is funded, Team 20 research will be supported by the Saskatchewan Health Services Research Foundation and the CIHR Institute of Aboriginal Peoples Health. Following the presentation Allison Cammer moderated a dialogue with Summit participants as the presenters invited questions and feedback regarding the proposed research.




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Team 20 Rural and Indigenous Research: Cross-Cutting Themes

- Virtual Health Care Technologies
- Gender
- Knowledge Translation and Exchange




Canadian Component

CCNA
Canadian Consortium on Neurodegeneration in Aging

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




Team 20 Investigators

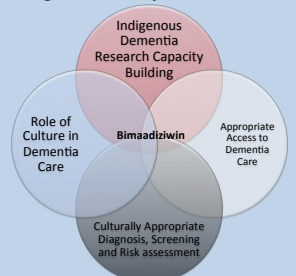
Indigenous Focus	Rural Focus
<p>LEADS:</p> <p>Kristen Jacklin, Northern Ontario School of Medicine</p> <p>Carrie Bourassa, First Nations University</p> <p>Jennifer Walker, Nipissing University</p> <p>Janet E. McElhane, NOSM</p> <p>Brock Pitawanakwat, University of Sudbury</p> <p>Wayne Warry, Laurentian University</p> <p>Eric Corston, Native Women's Association of Canada</p> <p>Lynden Crowshoe, University of Calgary</p> <p>Elder Betty McKenna, Regina</p> <p>Elder, TBD, Ontario</p>	<p>LEADS:</p> <p>Debra Morgan, University of Saskatchewan</p> <p>Margaret Crossley, University of Saskatchewan</p> <p>Vanina Dal Bello-Hasas, McMaster University</p> <p>Dorothy Forbes, University of Alberta</p> <p>Anthea Innes, Bouremouth University</p> <p>Andrew Kirk, University of Saskatchewan</p> <p>Julie Kosteniuk, University of Saskatchewan</p> <p>Lesley McBain, First Nations University</p> <p>Haider Mtu, University of Saskatchewan</p> <p>Megan O'Connell, University of Saskatchewan</p> <p>Edna Parrott, Yorkton (family caregiver)</p> <p>Norma Stewart, University of Saskatchewan</p>

CCNA Rural Research Projects

1. Rural Primary Health Care (PHC) Model Development
2. The Role of Rural Culture and Context in Dementia Care
3. Capacity-building/Mentoring for Rural PHC Providers
4. Standardized Care Pathways and Tools



Indigenous Project Overview



Two-Eyed Seeing

- Two-eyed seeing, as put forward by Mi'kmaq Elder Albert Marshall, recognizes the benefits of seeing from one eye with the strengths of Indigenous ways of knowing, and to see from the other eye with the strengths of Western ways of knowing, and finally to use both of these eyes together. (CIHR-IAPH)



Competence and Dementia

CAPACITY IN NEUROLOGY

- > 1. What is dementia, how does it present and what are the common types?
- > 2. How is capacity assessed by neurologists?

- > Dementia does not necessarily imply incompetence.
- > Neuropsychological or mental status test results do not determine competence.
- > Capacity is a moving target.

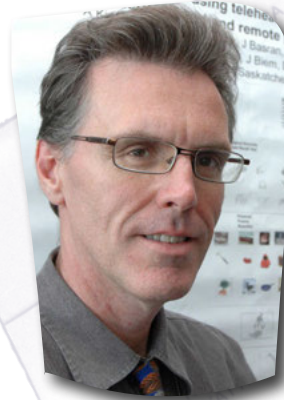
CAPACITY TO DO WHAT?

- > Make a will
- > Drive
- > Consent to medical treatment
- > Manage finances
- > Manage all personal affairs
- > Is he/she competent to do X in Y context?

Next Year
7th International Symposium: October 19-22, 2014
Plan to coordinate Summit with the Symposium

Thank-you & safe travels

Dr. Norma Stewart introduced the last Summit presenter: Dr. Andrew Kirk, the Clinical Neurologist with the Rural and Remote Memory Clinic team. Dr. Kirk's presentation focused on competence in persons with dementia. As a neurologist he is sometimes asked to ascertain whether or not a patient is competent to drive, or competent to direct their own financial affairs. His presentation noted that different facets of the processes underlying a dementia can affect an individual's capacity in different ways, and that this capacity changes or fluctuates as the dementia progresses. Assessing a patient's competency depends



of a variety of factors and incorporates a contextual component: while capacity in one realm or sphere of functioning may be very strong, there may be a deficit in other areas of functioning.

At the end of the Summit, Dr. Debra Morgan encouraged participation in the evaluation of the event. She also shared the news that next year's Summit will be coordinated to occur in concert with the Canadian Centre for Health and Safety's (CCHSA) 7th International Symposium. Dr. Morgan is a faculty member at CCHSA and the 7th International Symposium (Safety & Health in Agricultural & Rural Populations: Global Perspectives) October 19th to 22nd, 2014 will draw national and international researchers to Saskatoon. The Summit will be hosted during the Symposium, and will allow for members from each event to share information and knowledge.



2013 Summit Evaluation

Of the sixty-nine attendees at this year's Summit, forty completed and returned the Summit evaluation form at the end of the day. Their responses provide valuable feedback on this year's event, and give us important insights and suggestions for planning for Summit 7.

Those who attended the poster session on Thursday reported that the session provided good value for their time, and gave them an opportunity to learn about research and projects relevant to dementia care in Saskatchewan. The session also provided opportunities for interaction with researchers and others interested in dementia care.

In general, respondents strongly agreed that Friday's meeting was a good use of their time. Respondents felt that there was a good flow to the order of events, and that the meeting content and agenda met the day's objectives.

We heard that what people enjoyed most at this year's Summit were: the updates about ongoing research and information about new projects; Dr. Kirk's presentation about Competence; the opportunities to network and to meet new people; the opportunity to listen and learn; the range of topics covered in the Summit sessions, and the range of participants from different fields; and the welcoming atmosphere of the Summit.

We heard that next year we can improve on our successes by: opening up the poster session to more participants and a broader audience; including stories and perspectives from families of people with dementia in the presentations - especially the perspective of working caregivers; including more opportunities for networking; introducing practical examples of dementia specific programs and services that are already in place; engaging senior Ministry of Health and University of Saskatchewan leadership so that they can learn more about the research and knowledge user exchanges that take place at the Summit.

One of the questions we asked on the Summit Evaluation was "Did you receive, or download, a pre-Summit newsletter this year" Of those who answered this question the majority replied that yes they did receive a pre-Summit newsletter. To ensure that you receive updates and information about Summit plans, please email Duane at duane.minish@usask.ca and ask to be added to our mailing list.

Congratulations to Arden Moore who was the winner of the draw for the glass paperweight drawn from the names of all Summit attendees who returned their Summit evaluation form.

(what I liked best was) "... great background on research being done. Being new to this group I did not feel lost or left behind in the knowledge."

"Can't think of anything I didn't enjoy"

"Great opportunity to also meet people and network"

"Creative idea for next year to coordinate to the symposium"

"A great event, good presenters, lots of great info, well organized."

"Thank you for invite to Summit. Very well organized & presented. Definitely worth my time to be present."

"It was all very informative and it is so exciting to see all the research being done"



Supplemental Resources

Web based resources

There are a number of excellent web-based resources related to dementia that are available on-line. Be sure to check some of these out:

The RaDAR team maintains their own site about team-based research and projects:
www.cchsa-ccssma.usask.ca/ruraldementiacare

The Canadian Dementia Action Network (CDAN) - brings together Canada's world-class biomedical researchers and clinicians for the purpose of quickly identifying promising treatments for ADRD:
www.cdan.ca

Canadian Dementia Resource and Knowledge Exchange (CDRAKE) - is a network of people dedicated to improving the quality of life for persons with dementia and their family:
www.dementiaknowledgebroker.ca/

Canadian Dementia Knowledge Translation Network (CDKTN) - a resource for current research, news, events and information about dementia.
www.lifeandminds.ca

Alzheimer's Disease International (ADI) - the international federation of Alzheimer associations around the world, runs the Alzheimer University, and holds an annual international conference on dementia.
www.alz.co.uk

The Alzheimer Society of Saskatchewan - access Saskatchewan specific news and resources for people with Alzheimers and other dementias.
www.alzheimer.ca/Saskatchewan

The Gateway for Rural International Initiatives in Dementia (GRID) - a website that connects rural based research and services from around the world and invites users to contribute content and share rural initiatives from their area.
www.ruraldementia.com





Supplemental Resources

Attendees of the Summit come from a variety of backgrounds and all share a common interest in rural and remote dementia care. Page 16 of this report includes contact information for the attendees of Summit 6.

Copies of participant binders, the poster booklet from Thursday evening, and information provided during this year's Summit are available. Please contact Duane Minish, Research Assistant, at duane.minish@usask.ca or phone: 306-966-4098 for assistance in obtaining these resources.

Alzheimer's Disease International released an updated estimate of the global prevalence of dementia for 2013-2050. The updated information was released for the G8 Summit in the UK in 2013. The report is available for download: www.alz.co.uk/research/GlobalImpactDementia2013.pdf

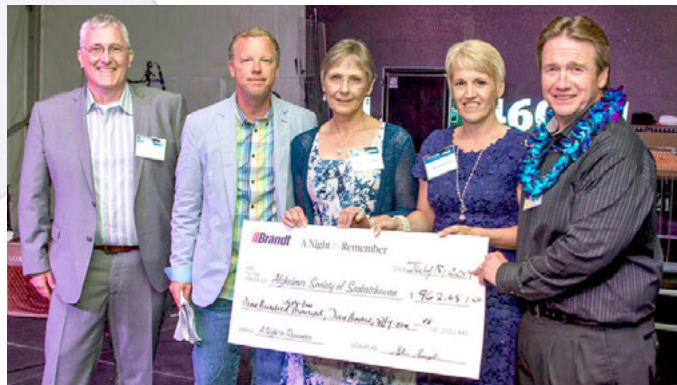
Alzheimer's Disease International published World Alzheimer Report 2013 - Journey of Caring: An analysis of long-term care for dementia. The report is available online: www.alz.co.uk/research/WorldAlzheimerReport2013.pdf

In July 2014 the Rural Dementia Action Research (RaDAR) Team published a report from the Dementia Learning Needs Assessment for Sun Country Health Region (as Dr. Julie Kosteniuk reported on the development of the Assessment at the Summit in 2013 - see page eight of this report for more information). To request a copy of the report, please phone Julie at 306-966- 8773 or email: julie.kosteniuk@usask.ca

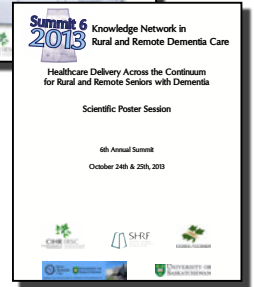
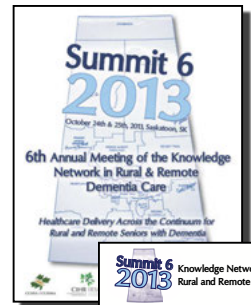
Partner News Update

On July 18, 2014 The Alzheimer Society of Saskatchewan (ASOS) received a donation of over \$962 000 from A Night to Remember. The fundraising event raised over \$1 million with \$100 000 donated to Football Saskatchewan and the remainder to ASOS. The Brandt Group of Companies was a major sponsor of the event. A Night to Remember included an auction, dinner, and performances by George Canyon and Blue Rodeo. The auction featured a unique Saskatchewan Roughriders themed 1969 Shelby GT500 Mustang Convertible.

"We're so thankful to Brandt and all the sponsors who made this event possible, and we're humbled by the generosity of those who stepped up to create such an incredible event," said Joanne Bracken, CEO of the Society.



left to right: Darrell Mousseau, U of S researcher; Premier Brad Wall; Kathleen Defoe, ASOS; Joanne Bracken, ASOS; Shaun Semple, Brandt Group of Companies.

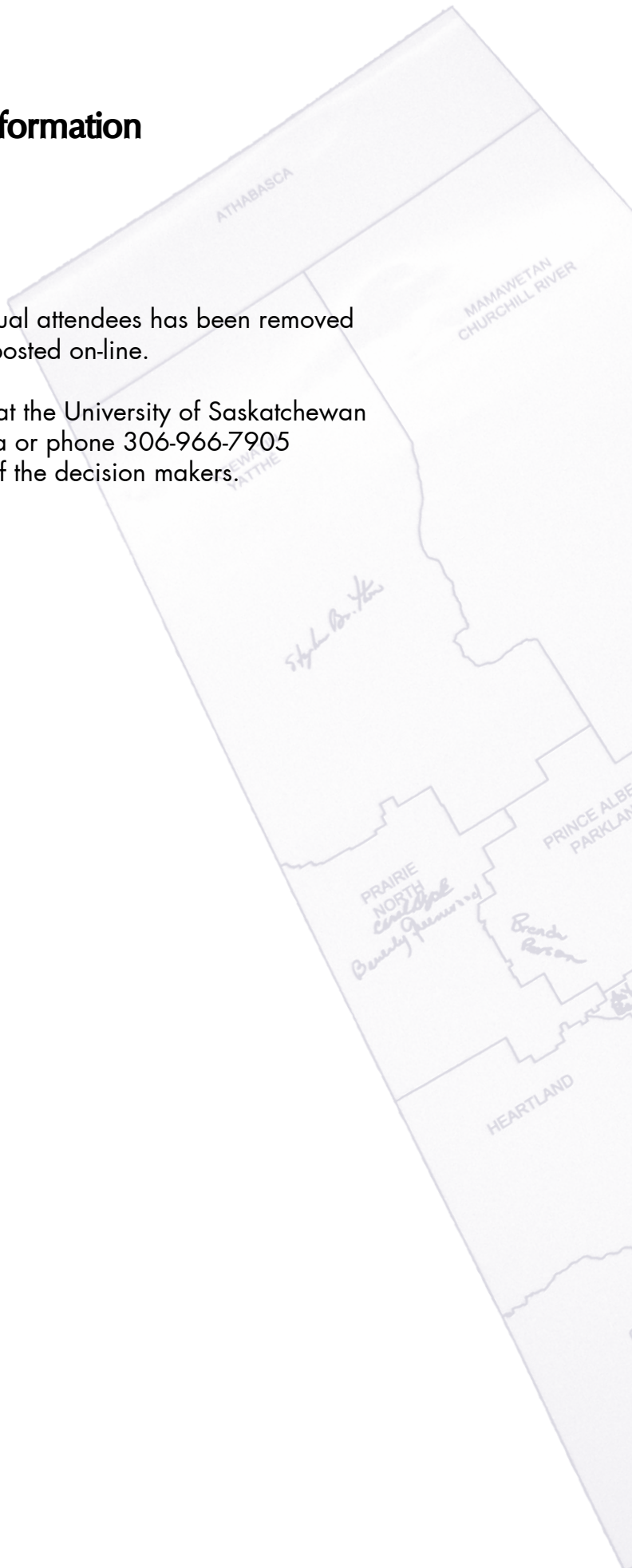




Appendix A Summit Contact Information

Contact information for individual attendees has been removed from this version of the report posted on-line.

Please contact Debra Morgan at the University of Saskatchewan
email: debra.morgan@usask.ca or phone 306-966-7905
for assistance contacting any of the decision makers.







Appendix B

List of Posters Presented at Summit

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

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



Appendix C RaDAR Research Team

Selected Publications

PEER REVIEWED PAPERS

Published/In Press/Accepted:

Kosteniuk, J., Morgan, D., O'Connell, M., Crossley, M., Kirk, A., Stewart, N., & Karunanayake, C. (accepted April 28, 2014). Prevalence and covariates of elevated depressive symptoms in rural memory clinic patients with mild cognitive impairment or dementia. *Dementia and Geriatric Cognitive Disorders Extra*.

Morgan, D., Kosteniuk, J., Stewart, N., O'Connell, M., Karunanyake, C., & Beever, R. (accepted March 12, 2014). The Telehealth Satisfaction Scale (TeSS): Reliability, validity, and satisfaction with telehealth in a rural memory clinic population. *Journal of Telemedicine and Telecare*.

O'Connell, M., Dal Bello-Haas, V., Crossley, M., & Morgan, D. (accepted January 15, 2014). Attitudes toward physical activity and exercise: comparison of memory clinic patients and their caregivers and prediction of activity levels. *Journal of Aging and Physical Activity*

Dal Bello-Haas, V., Cammer, A., Morgan, D., Stewart, N., & Kosteniuk, J. (accepted January 8, 2014). Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada. *Rural and Remote Health*.

Stewart, N., Morgan, D., Karunanayake, C., Wickenhauser, J., Cammer, A., Minish, D., O'Connell, M., & Hayduk, L. (online before print, January 26, 2014). Rural caregivers for a family member with dementia: Models of burden and distress differ for women and men. *Journal of Applied Gerontology*. doi: 10.1177/0733464813517547

Morgan, D., Crossley, M., Stewart, N., Kirk, A., Forbes, D., D'Arcy, C., Dal Bello-Haas, V., McBain, L., O'Connell, M., Bracken, J., Kosteniuk, J., & Cammer, A. (accepted for publication June 14, 2013). Evolution of a community-based participatory approach in a Rural and Remote Dementia Care Research Program. *Progress in Community Health Partnerships: Research, Education, and Action*.

Branger, C., Burton, R., O'Connell, M., Stewart, N., & Morgan, D. (online before print June 20, 2014). Coping with cognitive impairment and dementia: Rural Caregivers' Perspectives. *Dementia: The International Journal of Social Research and Practice*. doi: 10.1177/1471301214539956

Branger, C., O'Connell, M., & Morgan, D. (ePub ahead of print, Jan 30, 2014). Factor Analysis of the 12-item Zarit Burden Interview in caregivers of persons diagnosed with dementia. *Journal of Applied Gerontology*. doi: 10.1177/0733464813520222

O'Connell, M., Dal Bello-Haas, V., Crossley, M., & Morgan, D. (2014). Clinical correlates of awareness for balance, function, and memory: Evidence for the modality specificity of awareness. *Journal of Aging Research*, 2014, 1-12. doi: 10.1155/2014/674716

Kosteniuk, J., Morgan, D., Bracken, J., & Kessler, P. (2014). Adventures in rural and remote health services innovation: the role of researcher as collaborator [editorial]. *Rural and Remote Health*, 14, 2898. Available from www.rrh.org.au

Morgan, D., Walls-Ingram, S., Cammer, A., O'Connell, M., Crossley, M., Dal Bello-Haas, V., Forbes, D., Innes, A., Kirk, A., & Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science and Medicine*, 102, 111-118. doi: 10.1016/j.socscimed.2013.11.023

Kosteniuk, J., Morgan, D., Innes, A., Keady, J., Stewart, N., D'Arcy, C., & Kirk, A. (2014). Who Steers the Ship? Rural Family Physicians Views on Collaborative Care Models for Patients with Dementia. *Primary Health Care Research & Development*, 15(1), 104-110. doi:10.1017/S146342361300011X

RaDAR Research Team

Selected Publications - *continued*

- O'Connell, M., Crossley, M., Cammer, A., Morgan, D., Allingham, W., Cheavins, B., Dalziel, D., Lemire, M., Mitchell, S., & Morgan, E. (2014). Development and evaluation of a Telehealth videoconferenced support group for rural spouses of persons diagnosed with atypical early-onset dementias. *Dementia: The International Journal of Social Research and Practice*, 13(3), 382-395. doi:10.1177/1471301212474143
- Dal Bello-Haas, V., O'Connell, M., Morgan, D., & Crossley, M. (accepted for publication 26 November, 2013). Lessons learned: feasibility and acceptability of a telehealth delivered exercise intervention for rural-dwelling individuals with dementia and their caregivers. *Rural and Remote Health*.
- Forbes, D., Blake, C., Thiessen, E., Finkelstein, S., Gibson, M., Morgan, D., Markle-Reid, M., & Culum, I. (2013). Dementia care knowledge sharing within a First Nations community. *Canadian Journal on Aging*. 32(4), 360-374. doi: 10.1017/S0714980813000457
- Kosteniuk, J., Morgan, D., & D'Arcy, C. (2013). Use and perceptions of information among family physicians: sources considered accessible, relevant, and reliable. *Journal of the Medical Library Association*, 101(1), 32-37. doi:10.3163/1536-5050.101.1.006
- Saleh, S., Kirk, A., Morgan, D., & Karunanayake, C. (2013). Less education predicts anticholinesterase discontinuation in dementia patients. *Canadian Journal of Neurological Science*, 40(5), 684-690.
- Estabrooks, C., Poss, J., Squires, J., Teare, G., Morgan, D., Stewart, N., Doupe, M., Cummings, G., & Norton, P. (2013). A profile of residents in prairie nursing homes. *Canadian Journal on Aging*, 32(3), 223-231. doi: 10.1017/S0714980813000287
- Cammer, A., Morgan, D., Stewart, N., McGilton, K., Rycroft-Malone, J., Dopson, S., & Estabrooks, C. (ePub July 15, 2013). The hidden complexity of long-term care: How context mediates knowledge translation and use of best practices. *The Gerontologist*, doi:10.1093/geront/gnt068
- O'Connell, M., Germaine, N., Burton, R., Stewart, N., & Morgan, D. (2013). Degree of rurality is not related to dementia caregiver distress, burden, and coping in a predominantly rural sample. *Journal of Applied Gerontology*, 32(8), 1015-1029. doi:10.1177/0733464812450071
- Meng, X., D'Arcy, C., Morgan, D., Mousseau, D. (2013). Predicting the risk of dementia among Canadian seniors: A useable practice-friendly diagnostic algorithm. *Alzheimer Disease & Associated Disorders* 27(1) 23-29. doi:10.1097/WAD.0b013e318247a0dc
- McCormack, B., Roberts, T., Julienne, M., Morgan, D., & Boscart, V. (2012). Appreciating the 'Person' in long-term care. *International Journal of Older People Nursing*. 7, 284-294. doi:10.1111/j.1748-3743.2012.00342.x
- Forbes, D., Finkelstein, S., Blake, C., Gibson, M., Morgan, D., Markle-Reid, M., Culum, I., & Thiessen, E. (online 2012). Knowledge exchange throughout the dementia care journey by rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. *Rural and Remote Health*, 12, 2201.
- Cranley, L., Birdsell, J., Norton, P., Morgan, D., & Estabrooks, C. (2012). Insights into the impact and use of research results in a residential long-term care facility: A case study. *Implementation Science*, 7, 90 doi:10.1186/1748-5908-7-90
- Lacny, C., Kirk, A., Morgan, D., & Karunanayake, C. (2012). Predictors of cognitive impairment severity in rural patients at a memory clinic. *Canadian Journal of Neurological Science*, 39(6), 774-781.

Appendix E

RaDAR Research Team

Selected Publications - *continued*

- Kosteniuk, J., Morgan, D., & D'Arcy, C. (2012). Diagnosis of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician, 58*, 144-151.
- Kosteniuk, J., Morgan, D., & D'Arcy, C. (2012). Treatment and follow-up of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician, 58*, 152-158.
- Slaughter, S., & Morgan, D. (2012). Functional outcomes of nursing home residents in relation to features of the environment: Validity of the Professional Environmental Assessment Protocol. *Journal of the American Medical Directors Association, 13*(5), 487.e1-487.e7.
doi: 10.1016/j.jamda.2012.01.003
- Morgan, D., Cammer, A., Stewart, N., Crossley, M., D'Arcy, C., Forbes, D., & Karunanayake, C. (2012). Nursing aide reports of combative behavior by residents with dementia: Results from a detailed prospective incident diary. *Journal of the American Medical Directors Association, 13*(3), 220-227. doi: 10.1016/j.jamda.2011.07.003
- Heggie, M., Morgan, D., Crossley, M., Kirk, A., Wong, P., Karunanayake, C., & Beever, R. (2012). Quality of life in early dementia: Comparison of rural patient and caregiver ratings at baseline and one-year. *Dementia: The International Journal of Social Research and Practice, 11*(4), 521-541.
doi: 10.1177/1471301211421085
- Andrews, M.E., Stewart, N., Morgan, D., & D'Arcy, C. (2012). More alike than different: a comparison of male and female RNs in rural and remote Canada. *Journal of Nursing Management, 20*(4), 561-570. doi: 10.1111/j.1365-2834.2011.01195.x
- Forbes, D., Montague, P., Gibson, M., Hirdes, J. & Clarke, K. (2011). Social support deficiency in home care clients. *Perspectives, 34*(3), 5-17.

Technical Reports

- Morgan, D., & Minish, D. (Feb 2013). Summit 5 final report. Final report from the fifth annual summit of the knowledge network in rural and remote dementia care, November 15th & 16th 2012. Report printed at the University of Saskatchewan (26 pages).
- Forbes, D., Harrison, W., Strain, L., Peacock, S., Morgan, D., Hawranik, P., Woytkiw, T., & Blake, C. (March, 2012). *Contextual Factors within Northern Home Care Centres that Influence the Spread and Uptake of Research Evidence: A Pilot Study*. Report printed at University of Alberta (39 pages).
- Morgan, D., & Minish, D. (February, 2012). *Knowledge network in rural and remote dementia care: Final Report, 4th Annual Summit Oct 27th and 28th, 2011*. Report printed at the University of Saskatchewan (28 pages).

**If you would like assistance accessing any of these publications, or if you would like more information about research conducted by the team, please contact
Duane Minish, Research Assistant:
duane.minish@usask.ca or by phone at 306-966-4098**


Rural Dementia Care UNIVERSITY OF SASKATCHEWAN

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

Home - People - Projects & Research - Resources - Summit - Knowledge Exchange -

Welcome

The Rural Dementia Care Website was initially created to support the research initiatives of members of a **New Emerging Team grant (2003-2009)** funded by the Canadian Institutes of Health Research (CIHR). New funding through an **Applied Chair in Health Services and Policy Research (2009-2014)** from CIHR and the Saskatchewan Health Research Foundation has allowed the research team at the University of Saskatchewan to build on the momentum gained during the previous five years. A growing area of need in the current health care system, Rural Dementia Care is demanding the attention of health care providers, researchers, and policy makers.




Doreen Morgan
RDC Team Members

Research by the Rural Dementia Care (RDC) Team is inspired by the needs of Saskatchewan's aging population:

- The province of Saskatchewan is home to the largest proportional population of seniors, a number that is growing across Canada.
- Prevalence of dementia among this aging population will continue to increase, according to the *Rising Tide Report*.
- Seniors in Saskatchewan are much more likely to live in rural areas and face multiple disparities in access to health care services.
- There is a growing need for more research into new approaches for delivering services to rural and northern communities.

We are guided by these strategies for care:



- The members of the RDC Team are facing the challenge to improve the delivery of rural dementia care across the continuum: from early detection and diagnosis to end of life care.
- Early diagnosis and treatment have proven to be key components in alleviating stress, providing direction for treatment, and allowing patients and families to plan for the future.
- The use of telecommunications and information technology are improving the delivery of health care services across distances.

This page was last updated 24-Jun-2013 © University of Saskatchewan | contact webmaster

The RaDAR Team at the University of Saskatchewan has a website with information about team members, research projects, and contact information. The site also features reports and photos from past Summit events. Learn more online:

www.cchsa-ccssma.usask.ca/ruraldementiacare



Summit 6 2013

Report from the Knowledge Network in Rural and Remote Dementia Care Summit 2013
For more information: debra.morgan@usask.ca