

Knowledge Network in Rural and Remote Dementia Care Newsletter

Summer 2012

Message from Debra

Our research team has had a busy and productive year, working on existing studies and planning new ones. At last year's Summit we talked about our plans to apply for a new primary healthcare initiative launched by the Canadian Institutes of Health Research (CIHR). In October 2012 we held a Planning Session attended by 53 decision-makers, to identify priorities for the study. The report from the meeting was used to develop a Letter of Intent that was submitted to CIHR in May 2012. In June 2012 we held a Planning Retreat with decision-makers to further develop the research proposal. We recently heard that the team was approved to go forward for the full proposal, due in October. We look forward to further developing the research at this year's Summit, to ensure that the research will be meaningful and useful. In developing this research, which expands our team to include co-investigators from the UK, we created a new team name, RaDAR (Rural Dementia Action Research) and logo that reflect our community-based approach. As always, the team is looking forward to this year's Summit and the opportunity to share our research from the past year. We are delighted to have an international keynote speaker, Michele Board, from Bournemouth University in England, who has extensive clinical, teaching, and research experience in dementia care.



5th Annual Summit - Saskatoon November 15th & 16th, 2012

Summit 5: The Knowledge Network in Rural and Remote Dementia Care
Summit returns to the Sheraton Cavalier hotel in downtown Saskatoon.
Watch for reservation information soon.

Michele Board - Senior Lecturer in Nursing Older People at Bournemouth University, England is the invited **keynote** presenter for the **2012 Summit**.

Michele has been an adult nurse since 1985 and has had a broad range of clinical experience with a specific focus on nursing the older person. She started lecturing in 2003, leading units on the Essentials of Nursing Care for the undergraduate nursing programme, and specialist themed days on the nursing care of the older person. She has led the development of dementia education programmes for health and social care staff working in the NHS and the private sector. She is member of the Bournemouth University Dementia Institute (BUDI). BUDI works with relevant parties from the statutory, private and voluntary sector across the south of England to increase the quality of care and support offered to people with dementia and their families. Michele holds an honorary contract with a local acute healthcare trust working as the senior nurse for their memory clinic.



Research Team Updates

Rural Dementia Action Research Team (RaDAR) - working to improve Primary Healthcare Delivery for people with Dementia

The goal of the RaDAR team is to improve primary healthcare delivery to people with mild cognitive impairment and dementia and their caregivers in rural and remote communities. We welcome on to the team researchers from the UK with experience providing dementia care in rural areas of the UK. The team has hosted two stakeholder meetings: October 17th, 2011 with 66 attendees and June 19th, 2012 with 30 attendees. We are responding to an initiative from the Canadian Institutes of Health Research (CIHR) to fund research teams in the area of primary healthcare. Our Letter of Intent to submit a full research proposal to CIHR was accepted, and we will be working on the proposal into summer and fall to meet the October 22nd deadline for submission. We see a critical need for improved primary healthcare delivery to this segment of our population, which has a higher proportion of seniors than cities, but fewer primary healthcare, specialist, and support services available and accessible locally. Summit 5 will include an update from the RaDAR team.



Evaluating the Summit as a Knowledge Exchange Activity

Last year, Summit attendees participated in 5 focus group discussions answering the questions: *In your experience, has the Summit been an effective vehicle for knowledge exchange? (Why/Why not?); What aspects of the Summit activities have been valuable or useful to you in your role with rural dementia care?; What would you change about the Summit to make it a better KTE strategy?* As well, 12 brief interviews were conducted to evaluate the Summit as a vehicle for knowledge exchange. These interviews and focus group discussions were audio recorded, transcribed, and are currently being analyzed by Allison Cammer and Debra Morgan. Findings of this evaluation will be shared at this year's Summit meeting.

Caregiver Needs Assessment

This study is aimed at improving our understanding of the experiences of family members of patients referred to a Rural and Remote Memory Clinic, and the supports and services needed to help them in their role. The caregivers of 32 clinic patients have been interviewed at three points - on clinic day, then at six and 12 months following the initial assessment. Data collection is nearly complete, with nine caregivers still to participate in one-year interviews. Data suggests that caregivers are driven by a "need to know" what is causing the memory-related symptoms in their family member. Prior to diagnosis, caregivers anticipate the benefits of getting a diagnosis will include naming it, treatment, guidance, prognosis, explanation of symptoms, and ruling out other problems. Six months later, caregivers indicate that they have experienced benefits as a result of attaining a diagnosis, including access to supports and services, acceptance, relief, and validation. Data collection and analysis will continue until January, 2013.

2011 and 2010 Summit Presenters Share their Knowledge



Donna Dalziel and Steve Kowal have recorded a presentation about Active Engagement similar to their afternoon session at the 2011 Summit and it is available as a resource to everyone via YouTube. Search YouTube for: engaged caregiving stage-appropriate.



Three of the members of the Frontal Temporal Dementia Caregiver Telehealth Support Group who were members of the panel presentation at the 2010 Summit have also created video-based resources. Members Ernie Morgan, Donna Dalziel, and Sheri Mitchell travelled to Saskatoon in early 2012 to participate in the production of short videos that have been posted to YouTube. Each unique caregiving story is available online.



"I thoroughly enjoyed my participation at the 2011 Summit from the moment I arrived at the evening reception I felt welcomed and engaged in research with the students, academics and policy folks. The variety of presentations and engagement styles (keynote, panelists, and round tables) provided opportunity for everyone to participate. A well organized and informative event - I would highly recommend it."

~ Summit 2011 Keynote Speaker, Dr. Janice Keefe
Mount Saint Vincent University



Visit the Rural Dementia Care team website for more information, and resources from past Summits:
www.cchsa-ccssma.usask.ca/ruraldementiacare



Share your ideas

Do you have news to share back with the Network Members? Do you know of someone doing interesting work in the field of Rural Dementia Care? Please get in touch and share your comments: with us via email at debra.morgan@usask.ca or phone 306-966-7905.

Rural Dementia Care Team Members 2012



Silver Medal Award

On May 25th, 2012, Dr. Debra Morgan was awarded the University of Saskatchewan, Department of Medicine Research Award silver medal for her research activities over the past year. This year was the first time these awards were given in the department.

World Health Organization and Alzheimer's Disease International Co-Developed Report

Dementia: a public health priority, to download a copy:
<http://goo.gl/PHLwt>

Alzheimer Society of Saskatchewan Kaleidoscope of Care Conference September 25th and 26th in Regina

This year's annual Kaleidoscope of Care conference -- for professional caregivers of people with Alzheimer's disease and related dementias -- is being held in Regina at the Delta Hotel. Keynote speakers at the two day event include Dr. Darrell Mousseau, Christene Gordon, and Marleen Collins. More information is available online: www.alzheimer.ca/sk