CONSIDERATIONS IN CULTURALLY SAFE CARE FOR INDIGENOUS PEOPLE WITH DEMENTIA IN CANADA

Kristen Jacklin, Wayne Warr, Karen Pitawanakwat, Melissa Blind.

Background: Rates of dementia and Alzheimer’s disease are now a considerable concern for Indigenous populations in Canada. The prevalence of these illnesses increased quickly in this population leaving most health care providers and Indigenous health services searching for ways to provide adequate or appropriate care. As dementia is now more firmly established as a health concern for an aging Indigenous population it is recognized that education, training, services and programs must shift to meet the needs of Indigenous people with dementia and their families. It is increasingly recognized that cultural safety provides an appropriate framework for how health services, including dementia care, in Indigenous communities can be delivered more effectively.

Methods: Community based participatory methods facilitated partnerships with several diverse Indigenous communities in Ontario to collect and analyze a broad spectrum of foundational data concerning dementia and caregiving. From 2011 to 2014, we interviewed 168 people with dementia, informal caregivers, Indigenous knowledge keepers, seniors, and health care providers in Indigenous communities in six regions in Ontario. These data were examined using a cultural safety framework to elicit specific care and service needs and culturally grounded approaches to care.

Results: The labeling of symptoms of dementia and Alzheimer’s as an illness is relatively new in Indigenous communities. Several cultural beliefs concerning the lifecycle and relationships have implications for how Indigenous peoples understand and respond to the illness. These beliefs can vary among Indigenous people, owing to cultural diversity and to varying historical and contemporary experiences with the Government. Culturally safe approaches to care need to incorporate health care provider training on the colonial history of Indigenous peoples; Indigenous explanatory models of dementia; appropriate approaches to the clinical encounter, care and prevention; reducing barriers and improving access to appropriate care and support.

Conclusions: We have identified key areas within the health care experience that can be addressed to improve culturally safe care for Indigenous people with dementia. The community based method resulted in several partnerships that have facilitated knowledge translation activities that will better prepare frontline care providers to provide culturally safe dementia care to Indigenous people in Canada.

PREDICTORS OF DEMENTIA AND MORTALITY IN INDIGENOUS AUSTRALIANS

Leon Flicker, Zoe Hyde, Kate Smith, David Atkinson, Stephen Fenner, Linda Skeaf, Roslyn Malay, Nicola T. Lautenschlager, Osvaldo P. Almeida, Dina LoGiudice.

Methods: We have previously demonstrated that Indigenous Australians have a very high prevalence rate of dementia, 5 times that of non Indigenous Australians. We followed our original cohort to determine predictors of mortality in this population. Methods: Between 2004 and 2006, 363 Aboriginal people over the age of 45 years, living in remote Western Australia (WA) completed a comprehensive questionnaire and culturally appropriate diagnostic assessment for dementia. All participants were invited for reassessment between 2011 to 2013. We obtained mortality records for the cohort from the WA Data Linkage System and compared them to data for the general population. We used Cox proportional hazards regression to identify predictors of mortality over a 9 year follow up period. Results: The leading causes of mortality were diabetes, renal failure, and ischaemic heart disease. Of 40 participants with dementia at baseline, 31 (77%) had died. For the cohort as a whole diabetes and renal failure accounted for 28% of all deaths. This differed from both the Australian population as a whole, and the general Indigenous Australian population. The presence of chronic disease did not predict mortality, nor did behaviours such as smoking.

INDIGENOUS DEMENTIA: GENETIC ADMIXTURE AND ACCULTURATION STATUS VARIATION

J. Neil Henderson. University of Oklahoma, Oklahoma City, OK, USA.

Methods: Community based participatory methods facilitated partnerships with several diverse Indigenous communities in Ontario to collect and analyze a broad spectrum of foundational data concerning dementia and caregiving. From 2011 to 2014, we interviewed 168 people with dementia, informal caregivers, Indigenous knowledge keepers, seniors, and health care providers in Indigenous communities in six regions in Ontario. These data were examined using a cultural safety framework to elicit specific care and service needs and culturally grounded approaches to care.

Results: The labeling of symptoms of dementia and Alzheimer’s as an illness is relatively new in Indigenous communities. Several cultural beliefs concerning the lifecycle and relationships have implications for how Indigenous peoples understand and respond to the illness. These beliefs can vary among Indigenous people, owing to cultural diversity and to varying historical and contemporary experiences with the Government. Culturally safe approaches to care need to incorporate health care provider training on the colonial history of Indigenous peoples; Indigenous explanatory models of dementia; appropriate approaches to the clinical encounter, care and prevention; reducing barriers and improving access to appropriate care and support.

Conclusions: We have identified key areas within the health care experience that can be addressed to improve culturally safe care for Indigenous people with dementia. The community based method resulted in several partnerships that have facilitated knowledge translation activities that will better prepare frontline care providers to provide culturally safe dementia care to Indigenous people in Canada.
Multivariate predictors of mortality included age (Hazard ratio (95% CI)), 1.03 (1.01, 1.05), male sex, 2.17 (1.39, 3.39), poor mobility, 2.11 (1.34, 3.30) and cognitive impairment 2.19 (1.31, 3.65). **Conclusions:** Cognitive impairment and dementia are major predictors of mortality in remote Indigenous Australians.

### F3-02-04

**A COMMUNITY-BASED APPROACH TO ADDRESSING CAREGIVER STRAIN IN INDIGENOUS CAREGIVERS OF PEOPLE WITH DEMENTIA**

**Kate Smith**¹, Dina LoGiudice², Leon Flicker³, Cathryn Josif⁴, Roslyn Malay⁵, Melissa Lindenma⁶, David Atkinson⁷, Dawn Bessarah⁸, ¹The University of Western Australia, Crawley, Australia; ²Melbourne Health, Melbourne, Australia; ³University of Western Australia, Perth, Australia; ⁴University of Western Australia, Broome, Australia; ⁵Flinders University, Alice Springs, Australia. Contact e-mail: kate.smith@uwa.edu.au

**Background:** This team has previously demonstrated substantial rates of dementia in remote Indigenous communities in the Kimberley region of Western Australia, with reported high levels of carer strain. We aimed to develop a carer strain scale for Indigenous Australians, and to determine the effectiveness of our Strong Carers, Strong Communities project to reduce carer strain through empowering Indigenous caregivers. **Methods:** These projects were conducted in remote Indigenous communities in the north west of Western Australia. The KICA Carer Strain scale was adapted from the 6 item Zarit Burden Interview. The Strong Carers, Strong Communities study is a clustered randomised trial, mixed methods design, involving Community A caregivers receiving a health education program and usual care. Community B is engaged in a participatory action research (PAR) process where caregivers meet to decide ways caregiver lives can be improved, facilitated by Indigenous caregiver champions and researchers. Measurement tools include KICA Carer Strain, Growth Empowerment Measure, KICA Depression and workshops and in interviews. **Results:** The KICA Carer Strain scale was completed by 197 Indigenous caregivers. The scale was readily accepted by caregivers. The mean score was 2.4, with 112 (56.9%) scoring >8/24. It has good internal consistency (α = 0.825). In the first communities involved in the Strong Carers, Strong Communities study 62 carers completed baseline, mean age of 42 (range 18-83yrs), 71% were women. KICA Carer Strain scores differed at baseline with Community A mean score of 2.4, community B mean of 3.5. Community B caregivers identified improving the relationship between generations as their key goal, and the breadth of activities, leading up to a community wide expo celebrating elders. The aggregate measures were developed from community dwelling older adults followed in the Intelligent Systems for Assessing Aging Changes, the Ambient Independence Measures for Assessing Care Transitions (AIMS) and Life Laboratory Cohort studies. Time out of home was examined as a potential primary indicator of social health. A longitudinal mixed effects model was used to relate the daily time out of home to physical ability (daily walking speed), cognitive status (CDR) and emotional state (mood, loneliness). **Results:** Data from participants followed for up to nine years was used to develop summary metrics of daily function: total daily activity, number of room transitions, time out of home, sleep and night time behavior (e.g., time in bed, trips to the bathroom), social interaction (telephone use, visitors), medication adherence, and cognitive function (computer use). A longitudinal tobit mixed effects regression model related daily time out of home to physical ability, cognitive status, and emotional state. More hours spent out of home was associated with better physical ability, cognitive function and emotional state (all p <0.001). Weather, season, and date also affected time out of home. **Conclusions:** Home based continuous assessment methodologies can identify trends in social engagement activities and related behaviors that are ecologically valid and meaningfully related to key health indicators.

**F3-03-01**

**PERVASIVE COMPUTING AND SENSING APPROACHES TO ASSESSING AND ADVANCING SOCIAL ENGAGEMENT ACTIVITIES**

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**Background:** Social interaction is a fundamental domain of function necessary for cognitive and behavioral health. Strategies for assessing social contact and engagement have relied on self report which is susceptible to bias and is challenging to acquire from those that are socially isolated. The development of objective measures of social engagement and related behaviors that are captured unobtrusively and in the course of everyday life may help overcome these shortcomings. Advances in pervasive computing and embedded sensing provide a means to transform the capture of these behaviors. **Methods:** The home based assessment platform developed by ORCATECH consisting of simple embedded sensors and monitored devices (passive IR motion activity sensors, contact sensors, telephone and personal computer use monitors) and responses to a weekly on line questionnaire provided the data from which were generated continuous metrics across basic domains of function relevant to social engagement: total activity and mobility, computer use, telephone use, visitor records, time out of home. The aggregate measures were developed from community dwelling older adults followed in the Intelligent Systems for Assessing Aging Changes, the Ambient Independence Measures for Assessing Care Transitions (AIMS) and Life Laboratory Cohort studies. Time out of home was examined as a potential primary indicator of social health. A longitudinal mixed effects model was used to relate the daily time out of home to physical ability (daily walking speed), cognitive status (CDR) and emotional state (mood, loneliness). **Results:** Data from participants followed for up to nine years was used to develop summary metrics of daily function: total daily activity, number of room transitions, time out of home, sleep and night time behavior (e.g., time in bed, trips to the bathroom), social interaction (telephone use, visitors), medication adherence, and cognitive function (computer use). A longitudinal tobit mixed effects regression model related daily time out of home to physical ability, cognitive status, and emotional state. More hours spent out of home was associated with better physical ability, cognitive function and emotional state (all p <0.001). Weather, season, and date also affected time out of home. **Conclusions:** Home based continuous assessment methodologies can identify trends in social engagement activities and related behaviors that are ecologically valid and meaningfully related to key health indicators.

**F3-03-02**

**COMPUTATIONAL DESCRIPTION OF WAYFINDING BEHAVIOR IN OUTDOOR ENVIRONMENTS OF PEOPLE WITH DEMENTIA USING ONTOLOGIES AND SENSOR DATA**

Philipp Koldrack¹, Thomas Kirse⁴, Stefan J. Teipel¹, ¹German Center for Neurodegenerative Diseases (DZNE), Rostock, Germany; ²University of Rostock, Rostock, Germany; ³Department of Psychosomatic Medicine, Rostock University Medical Center, Rostock, Germany. Contact e-mail: philipp.koldrack@dzne.de

**Background:** Social interaction is a fundamental domain of function necessary for cognitive and behavioral health. Strategies for assessing social contact and engagement have relied on self report which is susceptible to bias and is challenging to acquire from those that are socially isolated. The development of objective measures of social engagement and related behaviors that are captured unobtrusively and in the course of everyday life may help overcome these shortcomings. Advances in pervasive computing and embedded sensing provide a means to transform the capture of these behaviors. **Methods:** The home based assessment platform developed by ORCATECH consisting of simple embedded sensors and monitored devices (passive IR motion activity sensors, contact sensors, telephone and personal computer use monitors) and responses to a weekly on line questionnaire provided the data from which were generated continuous metrics across basic domains of function relevant to social engagement: total activity and mobility, computer use, telephone use, visitor records, time out of home. The aggregate measures were developed from community dwelling older adults followed in the Intelligent Systems for Assessing Aging Changes, the Ambient Independence Measures for Assessing Care Transitions (AIMS) and Life Laboratory Cohort studies. Time out of home was examined as a potential primary indicator of social health. A longitudinal mixed effects model was used to relate the daily time out of home to physical ability (daily walking speed), cognitive status (CDR) and emotional state (mood, loneliness). **Results:** Data from participants followed for up to nine years was used to develop summary metrics of daily function: total daily activity, number of room transitions, time out of home, sleep and night time behavior (e.g., time in bed, trips to the bathroom), social interaction (telephone use, visitors), medication adherence, and cognitive function (computer use). A longitudinal tobit mixed effects regression model related daily time out of home to physical ability, cognitive status, and emotional state. More hours spent out of home was associated with better physical ability, cognitive function and emotional state (all p <0.001). Weather, season, and date also affected time out of home. **Conclusions:** Home based continuous assessment methodologies can identify trends in social engagement activities and related behaviors that are ecologically valid and meaningfully related to key health indicators.

**TUESDAY, JULY 26, 2016**

**FEATURED RESEARCH SESSIONS**

**F3-03**

**SMART ASSISTIVE DEVICES FOR DEMENTIA: FROM FIXED DECISION TO SITUATION-AWARE DELIBERATIVE SUPPORT OF SOCIAL ACTIVITIES IN PEOPLE WITH DEMENTIA**

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