

# Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

## Introduction

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In June 2009 Lori L. Jervis organized a meeting on 'Aging and the Indigenous Peoples of America' in Norman, Oklahoma that was sponsored by the Association of Anthropology and Gerontology. The idea of organizing a session for the 2010 American Anthropological Association meetings in New Orleans arose at this meeting. Subsequently Lori L. Jervis and I organized a session titled 'Culture, Health and Aging in Native North American communities.' This article summarizes the papers and presentations given at that session.

As noted in the AAA Session Abstract, despite the often-stated value of Elders as cultural resources and spiritual leaders, little is known about the actual contemporary social and health statuses of Native North American Elders. The anthropological and health science literature on older Native people is sparse; by some accounts less than 2 percent of all studies focus on seniors. In the United States and Canada the percentage of older Native peoples are projected to double in the next decade. Despite these projected increases, the number of anthropologists studying aging in Native populations has remained small. This AAA session brought together anthropologists from Canada and the United States who are engaged in research with Native/Aboriginal Elders in order to examine how anthropological approaches may further our understanding of this small, but growing component of the Native population— one which has traditionally been influential beyond their numbers with respect to their roles as culture bearers and socializers of future generations. What follows are short summaries of these presentations and papers, following the order of presenters at the session.

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### Marie's Story Of Aging Well: Toward New Perspectives On The Experience Of Aging For Aboriginal\* Seniors In Canada

Sylvia Abonyi, University of Saskatchewan and Marie Favel, Ile a la Crosse, Saskatchewan, Canada

This paper, co-authored by a university researcher (Sylvia) and an Aboriginal community Elder (Marie), considers the construction of a framework of healthy aging for Aboriginal peoples in Canada. There has been limited work in this area, and a clear need for it identified as the cohort of aging Aboriginal people in Canada grows. Our contribution begins with Marie's story of aging well as a launch point from which we plan to collect more stories like hers. Our goal is to build a framework of aging well within which to locate issues like dementia, cancer, and other challenges of aging that are emerging for Aboriginal peoples. Many of these challenges are not unique to Aboriginal populations, but their magnitude and manner of expression and the colonial context in which they have unfolded is different from other populations in Canada, demanding that we build our understanding anchored in these realities. Research by Collings (2001) with the Inuit, and by Edge and McCallum with Métis (2006) noted that the most important determinants of successful aging for their participant groups are ideological (rather than material), noting the importance of history, culture, and language, as well as their successful transmission to new generations, for understanding the health, healing, and wellness needs of these populations. As Marie's story reveals, these ideological themes, coupled with their transmission to younger generations, are key elements of her life as well.

**Marie: A Brief Biography:** Marie was born in 1939 and has lived most of her life in and around the Métis community of Ile a la Crosse in Saskatchewan, Canada. She married her husband Jimmy in 1958 and over the next 58 years she raised 8 children, became a teacher, a religious educator, a community health worker, and an advocate for the inclusion of Aboriginal influence in the education and governance of their people. Throughout this time she attended post-secondary training, worked with her husband to help him overcome an alcohol addiction, and together they reconnected with their Aboriginal heritage. She does not see herself as a strong person, but points to people around her, such as Jimmy, as her source of strength. Together they are dealing with health challenges that come with aging and at the same time continue to make tremendous contributions to the well being of their community and the Métis nation in Saskatchewan. As she looks back on her life, Marie observes:

"...I see that I have moved through the medicine wheel; that my pursuit of more education and experience has taken me through all four quadrants as a teacher (mental & emotional), as a religious educator and sweat leader (spiritual), and in community health education (physical). And having searched the wheel I found the last piece in health education. And this is where I feel I can make the most contribution to the health and healing of my community. So today I am still involved in many things that are about sharing my life experiences, about helping our youth stay in school, about helping our young people parent well and drawing on the old ways, and about dealing with the hurt that is still there in the high suicide rates among our youth."

**Frameworks for understanding aging experiences for older Aboriginal people:**

As Marie and I talk about her story we see there are some important elements of her aging well experience that need to be reflected in frameworks that we might develop to explore other stories of aging for Aboriginal people. Central is the significance of her ongoing contributions to community life. It is clear that she is valued in this role as she can scarcely keep up with the invitations to present in classrooms, workshops, and conferences. Consistent with Collings (2001) research among the Inuit for successful aging, Marie is dedicated to the transmission of her accumulated knowledge and wisdom to younger generations. Her capacity to engage in this way has its roots earlier in her life, when she was able to pursue her passion for further education, to advocate for the inclusion of Aboriginal voices where there were none, and importantly, to connect with cultural traditions that were denied to her earlier in life. These latter two factors are directly linked to the colonial context of Aboriginal populations in Canada. These linkages to culture and agency are also important aspects for inclusion in any framework that would shape our understanding of aging experiences –good and bad, for these populations. Marie's story, and other research, provides evidence that the role and value of older Aboriginal peoples has remained strong in Aboriginal communities, and has been growing, since they are valued as an

*Continued on page 20*

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### Mistreatment and the Meaning of Respect for Native Elders

Lori L. Jervis, *Anthropology and Center for Applied Social Research, University of Oklahoma, William Sconzert-Hall, Anthropology, University of Oklahoma and the Shielding American Indian Elders Project Team\**

Respect – particularly respect for elders – is frequently said to be a central value in many American Indian communities. Assertions of its continued cultural salience are often accompanied by the lament that this important value is in decline. Based on findings from a community based participatory research study of Native elder mistreatment, we examined respect as it appeared in the discourse of what constituted good and poor treatment by family members (as broadly defined) among 100 elders from 2 data collection sites, 50 from a tribal elder center on a northern plains reservation and 50 from Protestant Indian churches in an urban area in the southcentral region of the US. The interview consisted of both a survey meant to assess the usefulness of several measures of elder abuse, neglect, and financial exploitation in this population, as well as a series of open-ended questions that allowed elders to expound on the treatment of elders in their communities. Nearly ¾ of the sample were female (72%), 46% age 70 or older, 52% married, and 26% spoke their tribal language moderately to very well.

The scholarly and academic literature on conceptualizations of respect of elders is scarce among all U.S. ethnic groups, and is especially thin for American Indians. Dillon sees respect as “a particular mode of apprehending something, which is the basis of the attitude, conduct, and valuing, while “To ignore, neglect, or disregard something, or to dismiss it lightly, thoughtlessly, or carelessly is to not respect it” (Dillon, 1992:108). Although frequent assertions are made in Native communities about the importance of respect for elders, the constituent elements of the respect concept are seldom explicated. It is clear, however, that elderhood without respect is not truly elderhood. In Weibel-Orlando’s (Weibel-Orlando, 1989:152) distinction between elders and elderlies, she notes that an American Indian elder is recognized by his/her community for “...one’s embodiment of certain exemplary and ethnically valued traits (e.g., sagacity, high moral standards, responsibility).” An elderly, on the other hand, is dependent, impaired, and non-productive – a social problem rather than a respected member of the community.

#### Findings

In this study, no questions were specifically asked about respect. Participants were asked what it meant to be treated well by family members, however. Here, almost ½ of the participants equated respect with good treatment of elders. A thematic analysis of respect revealed that it had a number of dimensions, with behavior (e.g., the provision of various kinds of assistance) and status (e.g., exhibiting courtesy, demonstrating admiration, asking for and heeding advice, and honoring) the most prominent. Disrespect, on the other hand, was often seen as synonymous with mistreatment (e.g., financial exploitation or verbal abuse). Some participants presented the disrespect leveled at today’s elders as unthinkable in comparison to the traditional tribal norms with which they were raised. These changes were often attributed to assimilation and culture loss, sometimes to alcohol.

In summary, several themes emerged in this study: The continued centrality of respect as a tribal ideal, the decline of respect as a reality, and the equating of disrespect with mistreatment. The ideational aspects of elder respect are crucial to understand its prominence in Indian country. If attitudes about respect toward elders have indeed so dramatically shifted in such a relatively short period of time, presumably this reflects a decline in their social worth. Where once, in the absence of a written tradition, elders would have been highly valued as the transmitters of tribal culture and history (Weibel-Orlando, 1989), they now must compete with popular culture and a number of pressures that push people toward a “modern” future where elders’ contributions to the community are not nearly so obvious. Unpacking the complexities around respect is essential to understanding how elders are treated in tribal contexts, and will be an important aspect of our continuing analysis.

\* The Shielding American Indian Elders Project Team includes David Baldrige, Janette Beals, Connie Bremner, Dedra Buchwald, John Compton, Alexandra Fickenscher, William Foote, Julie Holden, Yvonne M. Jackson, Lisa James, Chebon Kernell, Anne Libby, Crystal LoudHawk-Hedgepeth, Spero M. Manson, Traci McClellan-Sorell, Lisa Nerenberg, Emily Matt Salois, Bessie Smith, Charlene Smith, and Gloria Tallbull.

*Continued on page 20*

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### Forgetting and Forgotten: Dementia in Aboriginal Seniors

*Kristen Jacklin, Human Sciences, Northern Ontario School of Medicine and Wayne Warry, Anthropology, McMaster University*

Our research concerns Alzheimer's Disease and Related Dementias (ADRD) in Aboriginal communities in Ontario, Canada. The title "Forgetting and Forgotten" is meant to convey that like mainstream society Aboriginal communities are also experiencing high rates of ADRD as their senior population increases. However because of historically low rates of ADRD in these communities their specific needs as Aboriginal people are overlooked by mainstream service providers as well as by the government funding agencies that provide services on reserve. Our research aims to bring light to this new health issue through community-based anthropological investigations into the experience of ADRD in diverse Aboriginal communities in Ontario.

The preliminary results highlighted here focus primarily on the cultural influences on the experiences of ADRD in this population at two of our research sites: (1) The Haudensaune Six Nations Reserve in Southern Ontario and (2) the seven rural Ojibwa, Odawa, and Pottawatomi First Nations of Manitoulin Island in Northeastern Ontario. Our methodology is community-based and participatory and is qualitative. At each site semi-structured depth interviews were conducted by the authors and community based researchers with: seniors ( $\geq 55$ ); persons with dementia (PWD); family caregivers for PWD; health care providers for PWD; and key informant interviews with physicians, traditional knowledge keepers and healers, and specialists (Manitoulin Island  $n=20$ ; Six Nations  $n=16$ ). Focus groups with Personal Support Workers were also carried out in each location. The preliminary results presented concern the similarities and diversity in the experience, knowledge and traditions of Aboriginal people with ADRD at these two culturally distinct sites.

#### Preliminary Results

Differences in access to health care resources are evident between the sites. At Six Nations we see a high degree of medical system involvement in public education, diagnosis and care for people with symptoms of dementia. On Manitoulin Island where medical services are more restricted and focused on primary health care we see much less involvement from physicians and specialists and very few reports of official diagnoses or screening. Other than those who are in nursing homes, at both sites we have found very few people on prescription medications for dementia. The analysis of the interview data has revealed that these two different cultural traditions display many similarities in the way people describe understandings of ADRD and cognitive health. At both sites respondents spoke about how their culture helps them cope and care for those with dementia. For example, cultural beliefs around the role of family was a positive influence on the experience of ADRD; the value of humour is important in coping with ADRD in the family and community; and Aboriginal language use was highlighted as an important part of caring. Further similarities between the sites are noted in relation to understandings of prevention and overall cognitive health. Seniors at both sites noted that listening to Indian music or language tapes, speaking the language, storytelling, taking Indigenous medicine for ailments, and participating in ceremony are good for keeping your mind healthy. Participants at both sites also reported that they did not have knowledge of ceremonies specific for dementia but that traditional remedies that thinned the blood could be used for people with dementia.

Taking an explanatory model approach (Kleinman 1981), we are finding that there are some similarities in the way people think about and experience ADRD at the two sites. At both locations the majority of participants agreed that ADRDs are new diseases in various senses: for example, new in magnitude and new in the way people are now being identified and labeled (i.e., diagnosed). Participants at both sites also suggested that despite the increase in cases, ADRD was not a major health concern in their community because (1) the majority of people face complex health concerns and dementia is very low on their health priority list and that of their physicians; and (2) because the symptoms and behaviours associated with ADRD were consistent with cultural understandings of what is expected as one ages and becomes closer to the eastern doorway on the medicine wheel. Further to this, some commented that the behaviours associated with late stage ADRD (what we call hallucinations) set people apart as "special" as they are closer to the creator. The very idea that "we" would label visions as hallucinations was outright offensive to some participants. When ideas of causation were explored participants cite causes which can be classified as (1) physiological -- genetics, aging, brain chemistry, vascular disease, medication side effects and Parkinson's disease; (2) psychosocial -- unresolved

*Continued on page 21*

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### Understanding Aging: Culture, Cognitive Health and Contemporary Aboriginal People's Experience with Dementia

Jessica Pace, Ph.D. Candidate, Anthropology, McMaster University

#### Introduction

Past research about aging and health has focused on "the elderly" as a homogenous group, resulting in an underrepresentation of the unique concerns of marginalized and minority seniors. This bias can be overcome if researchers attempt to understand the perceived expectations for successful aging of specific groups. Doing so can lead to a better understanding of the impacts of pressures, such as illness, on the aging process and can create opportunities for culturally-relevant health promotion. My PhD research attempts to understand expectations for successful aging among Aboriginal peoples on Manitoulin Island, Ontario with the goal of gaining perspective into the way that individuals, families and communities in this context react to and cope with the pressures associated with age-related memory loss and cognitive decline (i.e. Alzheimer's disease and related dementias [ADRD]). Using qualitative, ethnographic methods (see Jacklin and Warry, this issue), this community-based research attempts to understand 1) How culture shapes the experience of being and becoming old in contemporary Aboriginal communities on Manitoulin Island? And; 2) How perceptions of aging and the elderly impact the knowledge, attitudes, beliefs and behaviours about ADRD in this context?

#### Successful Aging and Expectations for Growing Old

Successful aging theory has been critiqued for the use of biomedically-determined criteria for success in aging and terminology that connotes failure for those who do not achieve these criteria. However, recent research indicates that a successful aging paradigm can be productive when the criteria used to define success in old age are drawn from people in a specific context or community and the focus for success in aging is directed away from physical and cognitive capacity and towards values, attitudes and behaviours. The relevance of this approach for research with Aboriginal peoples has been demonstrated in recent research which shows that for Aboriginal peoples success in aging is characterized more by a positive attitude, ability to manage declining health, community engagement and spirituality than by good physical health. These findings are compatible with my PhD research.

#### Alzheimer's, Dementia and Successful Aging in Manitoulin Island First Nations

In Manitoulin Island Aboriginal communities aging is expected to be a time of teaching and respect, when family and community assist seniors when they need help with day to day tasks and activities. For traditionally-oriented individuals, the process of growing older is shaped by beliefs related to the medicine wheel and the seven Grandfather teachings, which emphasize balance, respect, teaching, acceptance and maintaining a purpose in life by staying engaged in social, physical, spiritual, intellectual and emotional realms. Aboriginal seniors have expressed that these teachings help them to accept the changes that occur as they grow older. Prior research suggests that Aboriginal people are generally respectful and accepting of seniors with dementia, believe dementia is a natural part of life's cycle and that the patient may be moving closer to the creator. Aboriginal people with dementia are thought to be less stigmatized than their mainstream counterparts, but embarrassment and denial about the condition emerge as symptoms worsen.

Although Aboriginal people on Manitoulin Island are aware that Alzheimer's disease (AD) exists and that it causes memory loss, there is little clinical knowledge of what causes AD or that there are other conditions that can cause similar symptoms. However, experiential knowledge of the symptoms of cognitive decline in old age has resulted in local explanatory models that accurately describe symptoms of ADRD. These symptoms include memory loss, a tendency to return to previous life stages, lack of recognition of family members, wandering, suspiciousness and a loss of awareness of time and place. Beliefs about the causes of memory loss are varied, and include food, environmental contaminants, stress and emotional trauma, imbalance in the medicine wheel, substance abuse and prescription medications.

Aboriginal people's beliefs about dementia and cultural tendency for acceptance and respect act as both enablers and barriers to the care of persons with dementia. Although acceptance can be beneficial, attempts to normalize the symptoms may cause people to put off seeking help until the person with dementia's condition has deteriorated beyond the point where the family is able to cope and provide adequate care.

*Continued on page 22*

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### **Perspectives on Brain Autopsy, Diabetic Amputation, and End-of-Life Issues among Elderly American Indian People**

*Neil Henderson, Health Promotion Sciences, University of Oklahoma Health Sciences Center, L. Carson Henderson, Health Promotion Sciences, University of Oklahoma Health Sciences Center, Ryan Blanton, Anthropology, University of Oklahoma and Steven Gomez, Anthropology, University of Oklahoma*

The American Indian (AI) population is rapidly aging and, consequently, at increased risk for dementing diseases like Alzheimer's disease and other dementias (AD/RD). While the exact epidemiology of AD/RD among AI people is unknown, current research shows that AD/RD is certainly present among North American indigenous people. The net result is that more cases of AD/RD will increase among AI's due to more people living into the ages of greatest risk. Moreover, there is an association between AD/RD and diabetes which remains at epidemic proportions among AI's.

AD/RD are fatal diseases and/or contribute to mortality. Unfortunately, very little is known about contemporary AI beliefs and practices regarding end-of-life (EOL) phenomena in general. Even less is known about EOL in relationship to death caused by dementia. This gap is important because 1) caregiving and coping are stressful and benefit from appropriate information and counseling, and 2) neuroscience efforts to ameliorate AD/RD require post-mortem brain tissue for pathophysiologic process examination and definitive diagnosis. However, a common cultural principle demands that bodies be buried intact which, in turn, reduces post-mortem opportunities for AI-specific research.

#### **Cultural Context Of Post-Mortem Body Alteration**

Among many AI's there is a belief that the body should be physically whole at burial. "Physically whole" means without loss of body parts from amputations, other surgical interventions, or retention of body parts at autopsy. The overarching reason for this belief is that in the after-life, the person will need all body parts in order to be as functional as they were in life. The implied concept is that in some way, the death of the person who has had pre- or post-mortem body part loss will be hampered in their ability to travel the spiritual path to the after-life. Stated more emically, the concept is that all body parts are required for full spiritual coherence, peace, and function in the after-life.

Clearly, the value placed on body intactness at burial is a significant one of long-standing history. Surgical resection of diseased body parts, particularly for life-saving purposes, is commonly accepted by AI people. Surgical amputations of limbs and digits to prevent general sepsis beyond the local dead tissue are also unfortunately common. For many people, these surgical procedures evoke a conflict of belief and practice even if they are not always voiced. However, because autopsy, of course, does not save the autopsied person's life, it still is subject to the intact body value referred to above.

#### **Methodology**

The research design is from the interpretivist paradigm using grounded theory. The theoretical wellsprings include David Mechanic's Health Belief Model, Help-Seeking Behavior and Arthur Kleinman's Explanatory Model of disease. Data was collected by a one-time, 45-minute, semi-structured interview with AD/RD caregivers in five Federally recognized Oklahoma AI Nations (n=77). There was an assessment of the Degree of Cultural Identification (DCI) using a 20 item questionnaire.

#### **Findings**

There is a range of willingness to have post-mortem brain autopsies. The range is a function of age and degree of tribal cultural identification. For example, the post-mortem intact body preservation value is strong among those with age above 60 and high DCI loading. However, for those younger and with low DCI loading, the value is weak. There is also a "Conditional Belief-Flexibility" in which post-mortem brain autopsy is potentially acceptable if, there would be a small amount of brain tissue removed, there were a way to non-intrusively extract brain tissue (e.g., nose, mouth, eye orbit, ear canal), the brain tissue was examined and returned for burial, or medical progress was an outcome. This "Conditional Belief-Flexibility" position may represent a conceptual adaptation between contemporary sociocultural conditions abutting older more non-Western cultural systems. Such an interpretation may also help explain that post-mortem brain autopsy was often reconceptualized as similar to the more generally familiar "organ donation" concept which is commonly noted on driver's licenses.

*Continued on page 21*

## Conference Report: 2009 Meeting of the American Anthropological Association Session on Culture, Health and Aging in Native North American Communities

### Discussion

*Robert C. Harman, Professor Emeritus, Cal State, Long Beach and Wayne Warry, McMaster University.*

We conclude by noting some general comments on the papers and presentations. As most of the papers are coauthored, for simplicity's sake we refer to the papers by the first author or presenter's name.

The papers submitted are based on recent, qualitative and in some cases ongoing research among Aboriginal/Native American peoples of Canada and the United States. All the papers differ somewhat in methods and interpretive orientations. Jervis's and Abonyi's papers most explicitly address the cultural ideal of the preeminence of Elder's status or role within Aboriginal cultures; but several of the papers speak to the changing perceptions and roles of Elders, and of course, cite idealized conceptions of health and appropriate behavior that cannot or are sometimes not met by others. Abonyi and Jervis's papers concern more general aspects of aging and qualities of health and care. In contrast Jacklin, Pace and Henderson's papers address aspects of dementia or end of life health within the cultural and social context of Aboriginal health and illness.

Each of the four papers has somewhat different objectives and data. Abonyi's paper is a biographical account of Maria's life that reflects on traditional ways and changes affecting the lives of older Aboriginal peoples. The research highlights beliefs about healthy aging which are linked to notions of community, community involvement and engagement. That is, the analysis suggests that health is produced not simply by individual action, but through socially constructed behaviors and interactions. Jervis analyzes Respect as an American Aboriginal concept, specifically as it applies to the social and cultural status of Elders. Her analysis shows the linguistic complexity of the concept "Respect," as it pertains to elders. Jervis's paper also addresses changes in Aboriginal society and culture. Professor Harman notes at one point Jervis found that some, perhaps most, Aboriginal families want to enjoy the presence of older relatives and provide them with care. Harman says he believes that "Implicit conventional understandings and generous care giving, smack of what Westerners call unconditional love."

Jacklin's analysis in two cultural and geographic areas of Ontario emphasizes attitudes toward Alzheimer's disease from both traditional Aboriginal and Western Perspectives. She develops explanatory models of diagnosis and treatment that contrast traditional Aboriginal and biomedical understandings. Her analysis makes the important point that language and ceremonial participation with the requisite knowledge of traditional teachings and values are integral to good health. That implies healthy living, cognitive health, and developing meaningful systems of care. Pace is primarily concerned with cognitive aspects of Aboriginal health and aging and with cultural constructions of healthy aging. Henderson's research focuses on beliefs and behaviors around end of life and medical interventions that necessitate bodily interventions or transformations of the "whole" body and thus clash with traditional beliefs.

The common threads that seem to run through these research projects are that of changing or contested values and beliefs which come with what Henderson calls degrees of cultural identification and which other authors refer to as traditional or cultural orientation. The flip side of such analytic focus is the extent to which biomedicine, and the values represented by the dominant medical system, have been accepted by individuals and communities. The papers quite naturally analyze the nature of changing systems of care, emerging values around health and aging, and the diversity of behaviors that arise from the interaction of Western and Indigenous values and health beliefs. The tension between cultural identification and biomedical values or power are manifested in many ways throughout the papers, for example, in how Abonyi refers to Aboriginal Peoples relying less than other segments of the population on formal care

*continued on page 20*

*Abonyi, continued from page 11*

important part of the cultural renewal process taking place for many years now among Aboriginal people in Canada. The importance of retaining aging seniors in communities and supporting their aging well in place requires us to consider, for example, the nature and value of community- and kin-based informal care systems in Aboriginal contexts. This one example highlights that there are substantive and meaningful differences in the aging experiences of Aboriginal and non-Aboriginal seniors. It is timely that we now turn in Canada to the inclusion of Aboriginal ideas about aging in frameworks applied to Aboriginal contexts. In collecting more stories about aging well, we will ask, "what does aging well mean to you?" The answers to this question may allow us to be better positioned collectively to navigate the interface between western and other contexts in the design of effective policies, programs, and support for the growing cohort of aging Aboriginal seniors in Canada.

\* The term Aboriginal refers to the descendants of the original inhabitants of Canada, as defined by the Constitution Act 1982; Indians, Inuit and Métis.

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*Harman and Warry continued from page 16*

and more on the informal sector, especially within their large tended family networks and in Jacklin's observations about negative perceptions of Nursing homes and a preference for family care giving for elders with memory loss.

Whether these ideological tensions are framed in terms of older notions of resistance, cultural resiliency or more contemporary notions of post colonialism or hybridity anthropologists are confronted with the analytic challenge of teasing out the nature of contemporary Aboriginal health beliefs and behaviors that are the product of culture change and the contestation of beliefs that ultimately shape peoples pursuit of health, their desire for appropriate care, and their experience of illness and disease. Collectively these papers exemplify anthropologists' desire to ensure the best of biomedicine, while identifying the hazards potentially dangerous aspects of mainstream medical care in the Aboriginal cultural context. The papers advocate on behalf of safe and effective care for aged Aboriginal peoples. Agencies that provide health care for Aboriginal communities must become better informed about the cultural orientations of those Aboriginal individuals and communities they serve. More collaboration by mainstream health care personnel with anthropologists will help to ensure that Aboriginal beliefs and values are honored by Western practitioners.

identifying the hazards potentially dangerous aspects of mainstream medical care in the Aboriginal cultural context. The papers advocate on behalf of safe and effective care for aged Aboriginal peoples. Agencies that provide health care for Aboriginal communities must become better informed about the cultural orientations of those Aboriginal individuals and communities they serve. More collaboration by mainstream health care personnel with anthropologists will help to ensure that Aboriginal beliefs and values are honored by Western practitioners.



In summary, a post-mortem intact body preservation value exists as a strongly positive relationship among those with high age and DCI loading whereas it is an inverse relationship among those with low age and DCI loading. Essentially, those older, more “traditional” people were more likely to reject brain autopsy and those less traditional and younger were more likely to accept it. Those with the Conditional Belief-Flexibility” position that made brain autopsy potentially acceptable was characterized by two positions: 1) if changes to the medical protocol could be made that honored the value, then it could be more acceptable, and 2) if there is general social benefit, then it could be more acceptable. To the extent that AI’s may have some unique characteristics due to the indigenous origins compared to the majority population, participation in medical research could generate significant insights that could assist with the development of better understandings and treatments for all people. Consequently, there is a significant need to better understand EOL sociocultural phenomena so that at least a chance for negotiation of AI models and biomedical models can be tried.

#### Acknowledgements

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#### *Jacklin and Warry, continued from page 13*

grief and historical trauma, stress, alcohol and drug abuse; and (3) Indigenous -- Disruptions in the relationship to the land and traditional life ways and bear-walking (we understand bear-walking to refer to a form of ‘bad medicine’ that is directed towards an individual). We have found the relative proportion of people placing importance on physiological explanations of causation to be much greater at Six Nations suggesting that in a relatively short period of time a medicalized explanatory model of causation has emerged for participants at Six Nations. This is likely related to the availability and accessibility of western health care services. In contrast, the communities on Manitoulin Island appear to still be in a period of explanatory model negotiation. The tendency has been for respondents to look at the onset of dementia as a natural part of aging or to engage in a discourse of social dis-ease; for example, failure and suspicion of the medical systems especially in relation to prescription medications, Indigenous beliefs about balance, historical trauma, and bear walking. Very few people recognized this as a genetic disease, vascular disease or a brain disease. We feel comfortable in saying that at this time ADRD has not been medicalized for the First Nations on Manitoulin Island.

#### Conclusion

In the case of new illnesses explanatory models and specifically those around causation serve to highlight cultural dis-ease as it is related to the struggle between biomedical and traditional approaches to aging and health and much broader socio-political struggles to protect Indigenous epistemologies under the pressures of colonial and post-colonial states. The process of medicalization we see in relation to dementia provides us with an opportunity to examine the relationship between the colonial system of biomedicine and modern indigenous communities; and, the struggle to negotiate models of understanding that incorporate traditional values and understandings with biomedical explanations. This site-specific depth of understanding will allow for knowledge translation activities that are sensitive to the specific needs and beliefs of these diverse communities.

While the sites differ in their level of adoption of biomedical ideas of causation of dementia we see at both locations a model emerging that places value and emphasis on traditional values, cultural attributes, and traditional methods of prevention and healings in the prevention and care of individuals with memory loss and confusion. This represents a strong assertion of the place of Indigenous health in an increasingly medicalized domain.

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*Pace continued from page 14*

This can lead to increased caregiver burden and can also raise the level of stress faced by the person experiencing symptoms. Further, poor understanding of the condition, what causes it, and how to manage symptoms may increase the risk for shame and stigma. Knowledge about how to support a person with dementia, and available medical interventions are low. Culturally-appropriate educational materials and increased health promotion would be of value to the seniors and families in these communities. In particular, education about when, where and how to get help for dementia is needed.

It is inherently difficult for people with dementia to meet the criteria for successful aging. Fear about their condition or stigma related to mental health often cause people to withdrawal from social activities, and the symptoms of dementia can make it difficult for individuals to participate in activities and interests in the way they were able to before the onset of the condition. If people with dementia withdrawal and isolate themselves, or are isolated by family members out of embarrassment or shame, the problem becomes invisible to the community, and potentially to healthcare providers. This can be a barrier to both care provision and awareness. However, cultural perceptions of aging and what it means to age successfully can be used to positively impact the lives of people experiencing dementia. The value of maintaining a purpose in life and an active engagement with the intellectual, spiritual, emotional and physical realms is particularly relevant in the context of promoting personhood and the continued integration of persons with dementia in community activities. If we can determine what 'purpose' elders in contemporary Aboriginal communities want to have we can better assist people with dementia to achieve value in their lives in a way that has meaning to them thus, allowing for the promotion of better quality of life. With adequate support from family, friends and health care providers many elements of successful aging can be approached, if not achieved, for people with dementia. However, in today's changing world, the challenge is to continue to keep families engaged in the care and support of seniors with dementia, which can be difficult when adult children work or move away from the reserve.

#### Conclusion

Aboriginal peoples on Manitoulin Island hold values that are generally supportive of seniors and that promote healthy and active aging, even in the face of complex health concerns. However, the care needs of seniors with dementia are complex and demanding and the lack of access to information, services and culturally-appropriate supports put a great deal of pressure on individuals with ADRD as well as family caregivers. In a discourse about acceptance and respect there is denial and a lack of knowledge about the realities of the needs of people and families coping with dementia. This lack of awareness of dementia can lead to inherently disrespectful actions which can compromise the dignity and safety of elders with dementia. It is necessary to better promote culturally safe knowledge, education and training related to this condition for seniors, families and care providers and to work with the cultural values of purpose, acceptance and respect to promote better health and quality of life for Aboriginal people dealing with dementia.

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