

Exploring the Appropriateness of Culturally Safe Dementia Information with Indigenous People in an Urban Northern Ontario Community

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RÉSUMÉ

Ce projet en application de connaissances a exploré la pertinence d'une documentation en promotion de la santé élaborée pour une population autochtone nationale en vue de son utilisation dans une communauté autochtone urbaine du nord de l'Ontario. Une approche décolonisée et communautaire de recherche-action participative faisant appel à l'épistémologie tribale a été suivie pour former un groupe consultatif autochtone local et établir un partenariat avec le N'Swakamok Native Friendship Centre. Deux groupes de discussion (n=8) composés d'adultes autochtones et cinq entrevues individuelles avec des aidants autochtones soignant une personne atteinte de démence ont alimenté l'analyse thématique qualitative. Quatre thèmes sont ressortis des données: (1) la nécessité d'une compréhension commune des cultures autochtones et occidentales dans le cadre des soins de santé; (2) l'amélioration de la communication interculturelle dans les discussions sur la santé; (3) l'ancrage du matériel de promotion de la santé dans la culture, et (4) les stratégies autochtones de littératie en matière de santé et la sensibilisation aux maladies neurodégénératives. Considérant que les prestataires de soins de santé cherchent des moyens efficaces pour communiquer avec les peuples autochtones, il est important de fournir de l'information pertinente localement et sur le plan culturel afin d'améliorer l'adoption et l'efficacité chez ces populations.

ABSTRACT

This knowledge translation project explored the appropriateness of utilizing health promotion materials developed for a national Indigenous population with Indigenous people living in a northern Ontario urban community. A de-colonized, community-based participatory action research approach using tribal epistemology assisted in establishing a local Indigenous advisory group and a partnership with the N'Swakamok Native Friendship Centre. Two focus groups ($n = 8$) with Indigenous adults and five one-on-one interviews with Indigenous caregivers of a person with dementia informed a qualitative thematic analysis. Four themes emerged from the data: (1) the need for shared understandings of Indigenous and Western cultures in health care; (2) improving cross-cultural communication within health-related encounters; (3) grounding health promotion materials in culture; and (4) Indigenous health literacy strategies for dementia awareness. As health care providers search for effective ways to communicate with Indigenous people, it is important to deliver locally and culturally relevant information to improve uptake and effectiveness by Indigenous people.

AADZOOKAAN NAAJMOWIN

Maanda enkiichigaadeg binda kenjigemgad gezhi nakaasang dibaajimowinan gaazhitoong giuwedinong anishinaabek endaajig nji. Enanchgwenzigwaa miinwaa N'swakamok Friendship Center maamwi giinaadmaadok nokiitmowaad wii maandonaa'aad waa nkwenmaagenjig. Niish we'aangizijig, kchi aak miinwaa enkiitaagejig gii nibwaachidook nenendamaawziwin nji wii nkmawaad ge minodaapinigaadeg. Niiwin giibi zikaamgatoon ge naadmaagemgak. (1) Zhindawendaagwod nsastaadwin wiiteg Anishinaabe miinwaa Ewaabshkiiwed ezhi naagdawendiwaad; (2) Weweni wii ginoonding nokiitaageng; (3) Wii kinooamaading weweni dibaajimowinan waazhi giniwendizad bemaadziid; miinwaa (4) Anishinaabe ji nsastang enaabiisjigeng nenendamaawziwin nji. Epiichtaawaad bemiikgagejig wii mkamowaad gezhi ginoonaawaad Anishinaaben, kchi piitendaagwad weweni ji nsastamookiwaad mii dash dani naawsek.

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Introduction

Age is the most significant risk factor in the development of dementia. Malenfant and Morency projected in 2011 that “the number of First Nations people aged 60 and older is expected to increase in number by 3.4 times from 54,165 in 2006 to 184,334 in 2031” (as cited in Jacklin, Walker, & Shawande, 2013, p. e39). Walker and Jacklin suggest that there will be a fourfold increase in the number of First Nation people over 60 years of age with dementia in 2031, and a 2.3-fold increase in non-First Nations populations with dementia (Walker & Jacklin, 2019). The increasing number of older Indigenous adults is a concern for health care providers who will need to respond to the age-related health care needs of this population. In the context of health care needs, dementia health promotion materials specific to Indigenous people in Canada are often requested by caregivers, older adults, nurses, personal support workers, and researchers, but are absent (Jacklin, Pace, & Warry, 2015).

Knowledge translation and exchange (KTE) is an interactive, reciprocal, and iterative process among researchers, people with lived experience, health care providers, policy makers, and partner organizations to exchange, synthesize, and apply ethically sound research findings and develop them for strategic action (Canadian Consortium for Neurodegeneration and Aging-Consortium canadien en neurodégénérescence associée au vieillissement, 2019; Kiefer et al., 2005). Recent research on health communication and cultural safety that respond to the needs of local and diverse Indigenous communities reveals that reciprocity between the researchers and Indigenous community members generates results that stay true to the Indigenous

community members’ voices (Jennings, Bond, & Hill, 2018; Smylie, Williams, & Cooper, 2006). To respond to the increased need for cultural safety in dementia health promotion materials in Northeastern Ontario, the authors (S.W. and K.J.) take a closer look at the need to address KTE at the local level and to further refine dementia fact sheets and improve their significance locally.

Cultural safety, a model originally developed by Irihapeti Ramsden, highlights how colonial, historical, and socio-political factors have led to health disparities in Indigenous communities (Allan & Smylie, 2015). Colonialism and current policies and practices that remain colonial are implicated in health and social well-being disparities experienced by Indigenous people today (Baker & Giles, 2012; Brascoupé & Waters, 2009). The concept of cultural safety speaks to issues of structural inequities and power differentials between health care providers and Indigenous patients, which contribute to poor health outcomes (Ramsden, 1990). The Health Council of Canada (2012) states that cultural safety “is based on understanding the power differentials inherent in health service delivery, the institutional discrimination, and the need to fix these inequities through education and system change” (p. 5) (Health Council of Canada, 2012). Critically important to health promotion is the understanding that culture, life experiences, and religious beliefs may affect Indigenous peoples’ understanding of aging, dementia, and perceptions of the caregiving role (Hayter, Vale, & Alt, 2008; Jacklin et al., 2015; Luong, Rauer, & Fingerma, 2014). Cultural differences are also crucial in health communication. For example, Indigenous people in Western Australia place a high importance on “talk”,

or communication, in their experiences and as a “core mediator” of health care that is culturally safe (Jennings et al., 2018). It is important to explore Indigenous conceptualizations of health literacy, as they build on Indigenous understandings and perspectives such as holistic health, and may include intrinsic connections (Smylie et al., 2006). To do so, health care providers can address cultural safety and health literacy by considering the languages, cultural and social influences, education levels, reading skills, language-comprehension skills, listening skills, background knowledge, concepts of health-related topics, numeracy skills, emotional and physical factors, and the individual’s level of comfort in the health setting (Korhonen, 2006).

The significance of addressing this topic is that it contributes to a discussion, which has the potential to improve the quality of life for Indigenous people living with dementia. By improving access to culturally appropriate information regarding cultural understandings of dementia and its signs and symptoms, we aim to contribute to Health Canada’s objective to reduce health inequities faced by Indigenous people. To understand the implications of Indigenous cultural diversity on the appropriateness of culturally safe health promotion material at a local level, for her master’s thesis, the primary author (S.W.) worked with a research team led by the senior author (K.J.) to develop a knowledge translation project with members of the Indigenous community of the City of Greater Sudbury.

The aim of this study is to explore the research question: “How can we develop health promotion materials about dementia to meet the needs of Indigenous peoples living in an urban Northern Ontario community?” This project sought to discover (1) the preference for communicating dementia information to Indigenous people in the City of Greater Sudbury, Ontario, (2) the role of Indigenous language in creating suitable materials, and (3) the role of Indigenous traditions of knowledge sharing in developing health promotion tools for an Indigenous audience.

Design and Methods

This research approach sought to apply the principles of community-based participatory action research (Israel, Schulz, Parker, & Becker, 1998; LaVeaux & Christopher, 2009) grounded in tribal epistemology (Kovach, 2009) to examine the appropriateness of culturally safe health promotion materials and to improve their relevance in an urban context. *Nêhiyâw Kiskêyîhtamowin*, or Plains Cree knowledge, is defined as an Indigenous epistemological framework that is easily translatable and provides an inclusive integration of Indigenous ethical considerations (Kovach, 2009). This framework was deemed appropriate as a guiding tool

in developing a de-colonized methodological framework for this study because it was easily transferable, cyclical, and iterative; and was relatable to the primary author, an Indigenous woman, specifically an Anishinaabe-Kwe. By using Kovach’s de-colonizing framework, the methodology of this project contains: (1) tribal epistemology, (2) a de-colonizing and ethical aim, (3) researcher preparations involving cultural protocols, (4) research preparation involving standard research design, (5) making meaning of knowledge gathered, and (6) giving back. The primary author was engaged in each of these methodological stages.

Community Setting

This research took place in a large urban population centre in Northern Ontario called the City of Greater Sudbury, which is also known as N’Swakamok (where the three roads meet). In 2011, the City of Greater Sudbury had a total Aboriginal identity population of 13,405 Indigenous people (Statistics Canada, 2013). Indigenous¹ peoples in Canada identify as First Nation, Métis, and Inuit. They are diverse within their respective groups and across the nation, and have specific tribal affiliations such as Ojibway, Algonquin, and Odawa. The original territory of the City of Greater Sudbury belongs to the Atikameksheng Anishnawbek from the Ojibway, Algonquin, and Odawa Nations located 19 km west of the city (Atikameksheng Anishnawbek, n.d.).

Two life-long care program support workers at the N’Swakamok Native Friendship Centre partnered with a graduate student at Laurentian University (first author) to complete this project. Community engagement included bimonthly dialogue with an Indigenous advisory group (IAG) that was composed of knowledgeable community members in the areas of dementia and/or caregiving. The IAG consisted of two life-long care program support workers, an informal and a formal caregiver of a person/people with dementia, and an esteemed Métis Elder of the community who ensured that the approach to the research was appropriate and beneficial for the community at all stages.

Sampling and Recruitment

Snowball sampling was deemed the appropriate recruitment strategy by the IAG (Finkelstein, Forbes, & Richmond, 2012), and because the project had a slow start to recruitment, it was also promoted through advertisements posted throughout the City of Greater Sudbury, Indigenous organizations, the Société Alzheimer Society Sudbury-Manitoulin, and bulk e-mail at Laurentian University. The recruitment protocol involved a discussion of the project and a review of the letter of information and consent form, and the

Anishinaabek protocol of offering cloth and tobacco honoured the gifts that the participants provided to the research project. Inclusion criteria for the study included being Indigenous older adults (55 years of age or older) who expressed an interest in the topic, who lived in the City of Greater Sudbury, and were a caregiver to a family member/friend/or neighbour who had dementia. Exclusion criteria for the study included those under 16 years of age and anyone who self-reported as having dementia, as diagnosed by a health care practitioner.

Data Collection

Data collection occurred during the months of November 2015 to January 2016, and ended when rereading the data revealed no further information or new topics, and saturation was met.

Instruments

Three documents were provided to all participants after the letter of information was read and consent was received. These included two dementia fact sheets and a conversation guide. Generic forms of the two fact sheets titled "What is Dementia? Indigenous Perspectives and Cultural Understandings" and "Signs and Symptoms of Dementia: An Indigenous Guide" were used as prompts and to facilitate discussion (Jacklin, Warry, Blind, Webkamigad & Jones, 2017a, 2017b). The fact sheets, developed for Indigenous people at a national level, were created using a de-colonizing lens of two-eyed seeing that combined Indigenous and Western knowledge of dementia (Jacklin et al., 2017). The conversation guide provided consistency across all discussions with participants, and was developed considering the four aspects of the medicine wheel to discuss physical, mental, emotional, and spiritual considerations of health information sharing. Questions were adopted from two qualitative studies within Indigenous communities that assessed health resources (Lindeman, Taylor, Kuipers, Stothers, & Piper, 2010; Smylie et al., 2009). Further questions have been developed to cover all research questions of this study (see Table 1).

Focus Groups

Light snacks and refreshments were provided prior to the two focus groups, and participants were given time to connect with each other and with the researcher to encourage an open atmosphere, discussion, relationship building, and trust. One focus group was held at the N'Swakamok Native Friendship Centre. The other focus group was held at an undisclosed location to protect the community members' privacy. An oath of confidentiality among participants was gained after a smudge and prayer at each focus group. A sacred bundle including a smudge bowl, an eagle feather, and the four sacred medicines (sage, sweet grass, cedar, and tobacco) provided participants with the option to participate in prayer prior to the discussion. With consent from all participants, both focus groups were audio recorded.

One-on-one Interviews

Five one-on-one interviews with participants who have or were at the time providing care for a family member/friend/neighbour with dementia were interviewed at locations convenient to the participant, and included places such as a local book store, a university meeting room, the N'Swakamok Native Friendship Centre, and a home. With consent from all participants, each interview was audio recorded.

Data Analysis

A qualitative thematic analysis (Luborsky, 1994) was used in this study to categorize and analyze audio-recorded participant dialogues in relation to the conversation guide. The transcribed data were stored in a qualitative software program, NVivo 10. This analysis involved entering, reviewing, and organizing codes developed by the primary author and later reviewed by her thesis committee. The codes represented key ideas that later merged into four key themes.

Techniques to Enhance Rigour

Member checking with the participants was conducted within 2 months of data gathering through individual

Table 1: Conversation Guide

Aspect of Medicine Wheel	Questions
Physical	<ul style="list-style-type: none"> • Was the resource useful to you? In what ways? • If you wanted to spread a health message in this community, how would you do it?
Mental	<ul style="list-style-type: none"> • Did you learn anything new about dementia? • Is it important to have resources in your local language? • Will you understand this information better if it were available in your language? If so, who would you go to in order to get the best translation of health-related topics so you can understand it better?
Emotional	<ul style="list-style-type: none"> • What were you thinking when you were reading the materials?
Spiritual	<ul style="list-style-type: none"> • What types of local, culturally appropriate icons and/or symbols are preferred in resources? • What is your vision of culturally appropriate health promotion materials?

transcript reviews. Validation was also considered through discussion of the themes with the IAG. This group discussion aimed to explore the meaning of the identified themes, as well as to guide the dissemination plan. Giving back to the community, as identified by Kovach's framework, is an important final step in this process and involved a community feast and presentation on the research results.

Researcher Positionality

Researcher preparation was established when the primary author, an Anishinaabe-Kwe from the Wiikwemkoong Unceded Territory, situated herself in the appropriate environments such as the community centre. She did so to be able to seek knowledge and connections with the research and community. She also journaled significant dreams, challenges, concerns, new perspectives, visions, and affirmations offered by community members. In offering tobacco to the IAG members and participants, she received further insights into the study topic and proper protocols in interacting with the community members. Overall, the primary author felt connected to the research project and valued the de-colonizing aspect of the study.

Results

Two focus groups brought together older Indigenous males (4) and females (4) 55 years of age or older who expressed an interest in the topic, including three caregivers. Anyone who self-reported as having dementia diagnosed by a health care practitioner was excluded. In addition to the focus groups, five one-on-one interviews were conducted. Four female caregivers who were providing or had provided care for a family member/friend/neighbour with dementia who was living in the City of Greater Sudbury were interviewed one-on-one. In addition, one older male from the first focus group who was interested in speaking further about the topic, but was not a caregiver, was interviewed one-on-one. Caregiver age range was broad, and therefore caregivers of any age were encouraged to participate. Minors under 16 years of age were excluded from this study. Participants were not asked to disclose their age or their Indigenous ancestry; however, one participant openly identified as Métis and another as Inuit.

Four themes emerged from the data analysis: (1) the need for shared understandings of Indigenous and Western cultures in health care, (2) improving cross-cultural communication within health-related encounters, (3) grounding health promotion materials in culture, and (4) Indigenous health literacy strategies for dementia awareness. This study also produced data relevant to the creation of culturally appropriate

dementia-related health information. Specifically, the inquiry considered how the two fact sheets were useful, what thoughts they provoked, and if the participants learned anything new about dementia.

Theme 1: The Need for Shared Understandings of Indigenous and Western Cultures in Health Care

For health care providers to engage in culturally safe discussions concerning dementia with Indigenous people, they first need to know about Indigenous people, and vice versa. This includes a shared understanding of Indigenous history in Canada, as well as an understanding of the cultural values and beliefs of Indigenous and Western ways of life.

Indigenous History

A discussion about dementia generated conversations about changes to Indigenous ways of life. Participants reported that past socio-economic factors such as colonization influenced how Indigenous people have come to have increased rates of dementia. They expressed how elders have said that dementia has existed for a long time; however, people never viewed it as an illness and accepted the condition amongst family members.

And you never know, what if those elderly people have said that used to happen a long time ago. But we never thought anything of it. That's always what they say, you know. Caregiver

Participants also expressed that changes have occurred in Indigenous communities, including a change in the role of the Chief in First Nations communities, an increase in Roman Catholicism, and a reduction in Indigenous ceremonies. These changes have contributed to the changing views of society, memory loss, and spirituality.

Whereas my parents weren't really introduced to ceremonies and all these other things. But they knew it was us, it's who we are. But because they were both raised Roman Catholic, I believe enriched their spirituality. Caregiver

Cultural Values and Beliefs of Indigenous and Western Ways of Life

When discussing language use in the fact sheets, a participant expressed how Anishinaabek people have their own philosophy of life, the medicine wheel, also known as "teachings".

Everyone has ... different teachings, different ways of looking at things ... I started to learn who we are as Anishinaabek and what our teachings are ... but, we're forgetting all of those things ... We're still Anishinaabe ... we have to talk about our own philosophies of life to understand what we need to do today. Caregiver

The participants spoke frequently about the Anishinaabe medicine wheel teachings, which are common to this region. The discussions of the medicine wheel included balancing the aspects of holistic wellness, the stages of life teachings, the four races, and the four sacred medicines. Other Anishinaabek teachings discussed by participants include the Seven Grandfather Teachings, the importance of certain animals, and the importance of the circle. There was no discussion of teachings that would be specific to First Nations, urban Indigenous people, Métis, or Inuit separately.

The most appropriate icon is the medicine wheel and the four colors ... from an Anishinaabe point of view, we know what the four colors are ... it doesn't matter because dementia can affect anyone ... doesn't matter what color you are. So, I just thought like if you're going to do a teaching or something for Anishinaabe, or First Nations, to me that would be the most appropriate one ... And not only that because the medicine wheel is in a circle, and you know, how it affects all colors, all races, and we, as a people, we always say the circle of life. Well it's a circle of the people. And it doesn't matter who we are, it can affect you. Caregiver

When health care providers and Indigenous people engage in culturally safe discussions concerning dementia, having a shared understanding of the cultural values, beliefs, and history of ways of life will lead to improved cross-cultural communication.

Theme 2: Improving Cross-Cultural Communication within Health-Related Encounters

Participants emphasized the importance of communication strategies to reduce barriers caused by differences in belief systems, and to develop meaningful, relational interactions within specific health-related encounters. There is an overarching belief that a relationship developed between an Indigenous and a non-Indigenous person can be fostered by careful attention to appropriate verbal and non-verbal communication.

Barriers

Participants expressed that the Western and Anishinaabek perspectives on communication reflect different values. These differences can cause barriers to communication.

For us, you know, we would, we wouldn't so much rationalize it verbally. We would rationalize it, you know, at a different level. Without saying too much about it in words. Older Adult

And then talking about, umm, the connections for like communication and all that. And you're talking to someone but something interferes with that. Well, you don't get that message across. They call it synapses in the communication. Caregiver

There was consensus amongst participants that when Western belief systems are adopted by Indigenous people, it can lead to a disconnection from Indigenous belief systems. It was believed by one participant that this disconnection leads to mistrust between community members who have different values.

We have a different approach to healing and wellness. It's not like the Western medical model ... when you bring white middle-class values to Anishinaabek, you know it sort of disconnects them from their own community ... So, you know, they become confused ... you know it still causes a problem. You know, like about your own identity ... When I look at it, I see a lot of disconnect there. You see, when our elders, our ancestor told us to get an education, they didn't mean get assimilated. So that's changing our thinking about who we are. You know, that's what education does. It changes our thinking. But what the elders really meant though was, all right, get educated. Get as much education as you can, you know get a university degree. And, but don't forget who you are. Older Adult

Cross-cultural Considerations

To overcome barriers and communicate cross-culturally, participants talked about the need for a level of connection that uses verbal communication such as humor, listening, and Indigenous language as well as non-verbal communication, such as offerings.

An elder participant expressed that humor is needed to communicate.

Yeah. Humor needs to be there ... all our elders are all good-humored. They need to laugh in order to communicate. Older Adult

Participants also emphasized the importance of listening to Indigenous peoples.

It's always the best part, is listening to their stories. Older Adult

You guys, if you want to do Native ways, LISTEN! (laughs). Older Adult

A participant explained how language is an important aspect of Indigenous knowledge and is essential for communicating with elders.

Culturally appropriate workers must know traditional knowledge. Workers have to know compassion. If they can, maybe the ordinary words, like *aanii* [hello, welcome], *baamaapii* [see you later]. All those things that you know you can talk to, and they're mostly elderly people. Elder people. And they know the language. A lot of them know the language. So for a culturally appropriate organization, language is so important. Older Adult

In addition, participants indicated that the connections to language are so intimately tied to self and community

that even those who do not speak the language still feel a connection to it.

So, you know that's a part of language that a lot of the younger generation don't really understand but they still have it ... So that's part of who we are, and when we take a look at some of the things that people understand about us, that's one of the things that's going to be really difficult for them to understand. Older Adult

Furthermore, participants expressed that there are differences when explaining topics in English versus in an Indigenous language. The language spoken provides Indigenous knowledge through culturally grounded and detailed meanings of words, as it describes what the person is seeing or doing. Fact sheets would be useful presented in the language only for those who know how to speak it; however, some participants who are not fluent in their Indigenous language shared that they would not be able to understand.

No ... I'm not very fluent but I understand the language because I heard it, but again I never really experienced conversational language as I was growing up. Caregiver

Participants noted that translators for the elders who are fluent in their language would help them to understand dementia. For those participants who are not fluent in their language, having the cultural component of the medicine wheel is important.

If you are talking to an elder, and they are more fluent in the language, it would be better for them, instead of reading it, it would be better to talk with them. Older Adult

I totally agree in regards to that because they would rather it explained to them in Anishinaabe, its better understanding for them. Especially if they speak their language ... Because even when they come to the city they shy away from the English language, because they don't understand. Caregiver

In addition to verbal communication, participants voiced that non-verbal communication such as offerings of tobacco, food, and drinks can help people connect in a spiritual way, as it will help them be more receptive. Participants articulated that it also helps people connect with the Creator through prayer.

If you are going to have a seminar or workshop, you should make sure that the first thing that you would say is, you know, okay, we are going to provide you with food. There will be food and drinks available. And so that really sets things off, people will want to come. And it's the same way we're meeting right here, at the table. This is when people can sit down and make themselves more receptive to – and it seems almost as if your cause,

you don't put it forefront. You sort of bring it as something that's going to happen. Older Adult

This participant also explained that verbal and non-verbal communication can foster *Anishinaabe-mo*, which is the connection developed between people associating with each other.

In our language when we associate, you know, with one another, you know, we've been associating like that for thousands of years ... So in our language we say, "mo". Just like in the word, *Anishinaabe-mo*. That signifies a level of social interaction ... Sometimes we even, we believe that all humans have that, you know, that type of connection. ...But not everybody connects in that way ... But we would take it to that level, *mo* ... When you take it to that level it's like a higher level of understanding. Older Adult

Consideration of communication styles can include use of verbal and non-verbal communication to reduce cross-cultural barriers. Relationship building continues to be fostered throughout each meaningful, relational interaction and can lead to improved planning for grounding health promotion materials in culture.

Theme 3: Grounding Health Promotion Materials in Culture

To improve awareness regarding dementia amongst Indigenous people, health care providers can make the fact sheets more Indigenous-specific by using examples from the Anishinaabe culture to overcome the cross-cultural barriers presented in Theme 2. Participants expressed that oral and visual resources are culturally effective styles of education.

Oral Teachings Through Storytelling, Sharing Circles, Health Care Providers, and Community Support Services
Oral teachings are highly regarded by the participants in this study and are defined as visiting, sharing, teachings, and storytelling.

Participants identified that visiting is an important part of transferring knowledge.

I think it's really important in my own experience ... is really taking the time to visit people ... Yeah, and we have always been storytellers and our parents and grandparents taught us lessons through storytelling too. Caregiver

A participant expressed how early education is important and can be done through having a sharing circle with family members and persons with dementia. Participants voiced that sharing circles are small-scale talking circles where the person talking holds talking sticks or an eagle feather fan. This approach helps members of the circle respect what each person has to say.

In addition to sharing circles, educational opportunities can include workshops for the community at large and training for community members, family, and health care workers.

But say the more the family can get in there for that circle, the better it would be so everybody has the same perspective on what dementia is ... So early type of information giving is probably the best, you know, and starting off with the family. Older Adult

Every one that was there, in that panel, they got to voice their opinion, share their story, share their thoughts, share their knowledge. And us, as a people, sitting back, we were the little leaves. Like, they were the seeds. They are the seeds of the community. Spreading out ... So, it's a way of learning ... then you're going to take that knowledge that you learn and you'll share it with someone else and it just goes on. Caregiver

And other times we can refer back to the training. Then let's train our people that are on our First Nations to prepare for this. Caregiver

Acceptable Forms of Visual Resources

Participants voiced that visual learning with pictures is an important part of the culture. DVDs are appropriate for the participants and are most helpful if they are translated into the Ojibway and Cree languages. Participants of the first focus group believed that having a Web site to accompany the fact sheets would be helpful. Some participants had searched online for information about dementia. Older adults use social media more often now, and billboards and bulletins were also identified as important sources of sharing health information.

I'd think it would be more helpful with pictures and stuff ... I can't read something and remember what I read after I read it and stuff ... Because I got to read and read and read and I'll get it ... So sometimes I don't even read stuff like that [fact sheets]. Caregiver

Participants suggested that educating people with pamphlets, PowerPoint presentations, posters, and a binder with all of the information in it would be helpful.

What would be helpful is if a binder was created with all of the information about Alzheimer's, dementia. And then the individual that is caring for them, information to help that person ... and binders for the different programs that are made available for them, like I was saying for the health care centres on our First Nations and stuff ... For the families, caregivers of that person or individual. Caregiver

Effective styles of health promotion resources can be grounded in both oral and visual communication strategies. Participants engaged in deeper conversations

about health literacy strategies for dementia awareness that are grounded in Indigenous ways of knowing.

Theme 4: Indigenous Health Literacy Strategies for Dementia Awareness

Participants discussed data relevant to the creation of culturally appropriate dementia-related health information, which included: whom to involve in developing health promotion material and workshops, how to develop dementia-related material, and where to share the information. The sub-theme, how to develop dementia-related material, also captures how the two fact sheets used as prompts are a source of visual teaching.

Whom to Involve

Participants preferred to learn from Indigenous elders, health care providers, and teachers who are experienced. However, they noted that anyone who is well educated about the topic and is culturally aware is also welcome. Participants also voiced that the process needs to involve community members who have experience with providing care in the planning and presentation of information. They also recommended involving other key members of the community such as the priest and traditional knowledge keepers.

We should have our own people. You know, like involved in anything, even education ... we should get our own people to teach our own kids. That's why we like to see you guys, you know come in there to do the health. Our own teachers teaching our own children. Older Adult

A recommendation by the focus group participants was for people who are dealing with health issues to join groups and speak to a physician or pharmacist for information. Focus group participants felt that talking with a physician is an important source of health information. The participants also expressed that people with experience and education in dementia would help them understand the disease.

But if they're educated and trained in this field in regards to Alzheimer's and dementia that would probably help them a long way also. Caregiver

Participants expressed that the support system is different in the city than on-reserve. In urban centres, participants go to places like the Friendship Centre and the Alzheimer Society of Canada for support. Most participants felt that sharing circles that accompany community programming by nurses, physicians, support workers, and experienced community members could help them understand health issues and new information.

And getting them there to participate in that caregiver support group at the Alzheimer's Society as

well as myself, was a good learning experience ... I think for me, if it was spoken to me, it depends again on the, umm, on the person. The knowledge that they're carrying. A good example I could give you is like, a presenter from the Alzheimer Society, right. Because that person works in that field. That person is very knowledgeable. So, if you took someone from there that has the skills and the background, and they know what they're talking about. Well then you're going to get something out of it. Caregiver

How to Develop Dementia-related Material

Participants agreed that it is important for the caregiver to learn about the differences between the types of dementia and how to prepare for different stages of the disease. Participants felt that the fact sheets used as prompts were very helpful for them, as they contain a direct, brief overview of dementia. Overall, participants believed that the fact sheets were meaningful and provided them with information that they needed to seek further health advice.

Yeah, again to when it comes to my own health, ensuring that I should make an appointment with my doctor very soon to address some of these symptoms that are outlined in your handout here. Caregiver

Participants also felt that other information should be included: risk factors, causes, and support; differences in mainstream points of views on dementia; how to maintain quality of life; how dementia will impact people mentally, emotionally, physically, and spiritually; and how to cope using the Seven Grandfather Teachings. Participants also felt that additional information could be helpful if included in the fact sheets: responsive behaviours, emotional changes, caregiver coping, and strategies for family members.

The signs are there, and the facts. But like, there could be more to it, I feel in regards to that person, and that individual themselves caring for that person on what they could do. Caregiver

Those teachings, our Seven Grandfather Teachings are very important to us as Anishinaabe people. Caregiver

Where to Share the Information

Participants felt that it was important for the fact sheets to be available at the community level, including doctors' offices, Société Alzheimer Society Sudbury-Manitoulin, the Health Unit, and Indigenous organizations (such as Aboriginal Peoples' Alliance of Northern Ontario and Aboriginal health centres).

And a lot of our First Nations, they always have to come out to the urban setting to find medical help and resources ... If there was somebody that could

go to them sometimes, that would be all the better for them. They would be in their own surrounding, comfortable surrounding at that ... and because, a lot of times if they got to leave their reserve and come to the city it's a big step for them. Caregiver

Creating culturally appropriate dementia-related health information is a process that incorporates strategies outlined by participants in this study, and involves many resources available in the community.

Discussion

This KTE research study sought to determine the appropriateness of nationally developed dementia health promotion materials for use with a local group of Indigenous people in an urban community. Our findings reveal a need for all-embracing education to share a common knowledge of Indigenous culture, ways of life, and Indigenous knowledge in relation to communicating health information. This supports previous examples of how culture, life experiences, and religious beliefs affect Indigenous peoples' understanding of dementia (Jacklin et al., 2015). Findings suggest that conveying health information geared to Indigenous peoples requires a shared understanding by Indigenous people and health care professionals about past and present Indigenous history, culture (values, beliefs, and ways of life), and language usage. Although the research findings display differences between Western and Indigenous beliefs and values, other research evidence suggests that "focusing on the similarities between the two systems of knowledge rather than on their differences may be a more useful place to start when considering how to best introduce educational reform" (Battiste, 2005, p. 6). In many ways, the findings are similar to Dr. Marie Battiste's findings in her literature review of Indigenous knowledge:

"Such rethinking of education from the perspective of Indigenous knowledge and learning styles is of crucial value to both Indigenous and non-Indigenous educators who seek to understand the failures, dilemmas, and contradictions inherent in past and current educational policy and practice for First Nations students" (Battiste, 2005, p. 3).

Drawing from Battiste's standpoint (2005), the application of Indigenous knowledge is also useful in the health care context to prepare for effective knowledge translation with this diverse population. In addition, "developing resources that complement rather than conflict with existing health beliefs and world views is therefore a necessary factor for the uptake of information" (Lindeman et al., 2010, p. 35). As we have found, modifying the existing fact sheets to include important models, values, and beliefs such as the medicine wheel and the Seven Grandfather Teachings will make them

meaningful for this particular group of urban Indigenous people.

De-colonizing the research process assisted the primary author in receiving a teaching about communication. A brief example is explained here and enforces recent work by Jennings et al. (2018) in that cultural differences are embedded in communication styles. *Anishinaabe-mo* in the context of dementia knowledge includes improving cross-cultural communication through connecting at a deeper cultural level. The levels of connection that participants discussed included relationship building, trust, respect, listening, humour, storytelling, and offerings. In highlighting the importance of Elders being involved in the planning stages of development, the authors were reassured by the Report of the Royal Commission on Aboriginal People, which states: “elders are being restored to their former place of respect in communities, and Aboriginal people are turning to them for guidance as they search in increasing numbers for a meaningful identity” (Royal Commission on Aboriginal Peoples, 1996). This is especially important for urban Indigenous people, as the regeneration of the culture will be accomplished by maintaining connections with Elders who carry that knowledge. Furthermore, *Anishinaabe-mo* is a concept that health care providers can be aware of to develop and foster relationships with Indigenous peoples, thereby embracing a level of connection through culturally effective strategies in communication. By embracing *Anishinaabe-mo* in the development of materials and programs, it may be possible to communicate culturally grounded health information in English.

Our research adds to that of others who have explored Indigenous conceptualizations of health literacy (Smylie et al., 2006). Findings suggest that a mixture of both human and material resources are required for effective health promotion. Although visual materials such as fact sheets are significant in conveying health information, it is equally important to include oral aspects such as sharing circles and community workshops. Bridging essential Western-based strategies such as billboards, binders, expert knowledge, and media with Indigenous modalities such as sharing circles and community and cultural events demonstrates cross-cultural consideration. For example, in this study, two younger participants agreed that using several forms of media such as billboards, the Internet, and Facebook will help to bring awareness about dementia. In addition, participants noted that elders were also in agreement with these modalities as more people are accepting the mode of information sharing. This finding supported other researchers’ work, as “information presented in an engaging and accessible format can make a profound difference to people’s awareness and understanding of an issue such as dementia” (Taylor,

Lindeman, Stothers, Piper, & Kuipers, 2012, p. 215). The findings suggest that fact sheets should be part of a larger strategy utilizing an extensive list of resources that are culturally safe and factual.

When developing tools for urban Indigenous groups, health care providers can include various organizations such as the Alzheimer Society and local Indigenous community centres to deliver culturally safe health promotion strategies. In 1996, roughly half of Indigenous Canadians lived in cities (Graham & Peters, 2002), and as Newhouse notes, “Aboriginal people are reformulating Western institutions and practices to support Aboriginal cultures and identities, so that Aboriginal people can survive as distinct people in contemporary societies” (as cited in Graham & Peters, 2002, p. 21). Revitalization of culture within urban Indigenous communities is engaged through selecting aspects of the old ways and blending them with the new, and Indigenous organizations such as friendship centres can provide effective cultural programming in the urban setting (Royal Commission on Aboriginal Peoples, 1996).

Limitations

The use of tribal epistemology of *Anishinaabemowin* in this study meant that the Anishinaabek approach (a First Nations view) is more prominent than the other two (Inuit, Métis). Although the project aimed to include Inuit and Métis values and beliefs, the medicine wheel model was used because the Anishinaabek in this region; specifically, the Ojibway, Odawa, Cree, and Algonquin, particularly respond to it. However, the Inuit and Métis participants did not suggest that these values or teachings are inappropriate. Diverse Indigenous ways of knowing by means of the medicine wheel or Seven Grandfather Teachings may not be suitable for all Indigenous people, and further analysis would suggest different models and beliefs within the diverse Indigenous communities across Canada. To reduce this limitation, it is suggested that an exploration of this topic specifically with Inuit and Métis individuals will enhance understanding. A Métis Elder of the community was part of this project’s IAG. The involvement of this Elder encouraged the contribution of the Métis culture, values, and beliefs. The results suggest that even within an Indigenous community there can be diversity that challenges the creation of locally culturally appropriate materials. Diversity in language is one such challenge. The participants’ comments suggest that there are different needs for those who do and do not speak *Anishinaabemowin*. Many of the participants who speak the language believe that Indigenous knowledge is shared through language and is beneficial for those who understand it. However, other participants who did not speak the language would be challenged by materials or sessions provided in *Anishinaabemowin*.

This small qualitative study presents limitations to the research that warrant further attention. Contributing to a master's thesis, this study assisted in developing the research skills of the primary author, who had specific time and funding limitations to complete her degree. Further research on this topic should draw from a larger number of participants living in many types of communities (urban, rural, on/off-reserve) across Canada.

Conclusion

Our results add to what has been reported concerning the understanding of the inter-relationships among literacy, language, culture, and health in a local urban Indigenous community (Lindeman et al., 2010; Schoen, Balchin, & Thompson, 2010; Smylie et al., 2006; Taylor et al., 2012). This research also responds to the need for a better understanding of cultural safety in health promotion material related to dementia (Jacklin et al., 2015). Urban Indigenous conceptualizations of literacy are demonstrated as oral and visual avenues of sharing information, whether through storytelling by an esteemed Elder or by a health care worker from the community who understands the health information contained in the material. When developing culturally safe health promotion material, it is important to consider how to deliver a comprehensive approach that includes materials such as fact sheets in conjunction with an overall strategy to address relationships with health care providers and systems, cross-cultural communication, and local culture. The study demonstrated that although many aspects of the national Indigenous dementia materials were appropriate and accepted, it is important that there be room for local adaptation to improve uptake by and effectiveness for Indigenous people. In response to the findings of this research, this project informs the development (and modified versions) of a series of Indigenous dementia health promotion fact sheets developed by the research team (www.I-CAARE.ca/factsheets). We encourage Indigenous and non-Indigenous organizations to collaborate with local community members, caregivers, Elders, support care workers, and researchers to continue to decolonize the approaches to health promotion to reflect the ways of Indigenous people.

Note

- ¹ Indigenous: a variable term used to identify communities, peoples, and nations original to the land that they occupy (Allan & Smylie, 2015).

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