Primary Research

Improving Dementia Care for Gitxsan First Nations People

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ABSTRACT

This project originated from nursing staff's learning need for knowledge, approach, attitude, and skills in dementia care that was identified by the Gitxsan Health Society. In collaboration with the First Nations Health Authority, the Gitxsan Health Society sought to educate nurses on how to provide culturally appropriate care to older Gitxsan persons living with dementia, and also to increase the understanding of nurses, family caregivers, and the wider community about dementia as a chronic condition. This project involved a mixed-methods approach (multiple qualitative approaches, as well as a quantitative component). The team was guided at each stage by a Cultural Advisory Council of four Elders recognized as Knowledge Holder from the community. The project involved a strong element of reciprocal co-learning and knowledge exchange. From discussions and exchange with community members, three large interlinking themes emerged to guide the researchers: (a) loss and grief; (b) relationality; and (c) access and connection. These themes gave voice to the gaps and needs in care, but also highlighted the potential areas of strength that can be built on to improve care for the older Gitxsan person living with dementia. Family and other community members identified the need for more information regarding dementia, the need to access in-community and external supports, and the need to inform nurses about what considerations are required when caring for Gitxsan people living with dementia. A better understanding of the Gitxsan ways of knowing about dementia can help nurses incorporate more culturally safe practices into the care of persons living with dementia.

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We would first like to acknowledge the immense contribution that the Gitksan communities of Kispiox and Sik-e-Dakh have made throughout the project, and the contributions and involvement of other communities over the second half of the project, these being the Gitksan communities of Gitanyow, Gitwangak, Gitsegukla, and Gitanmaax, and the Wet'suwet'en community of Hagwilget. We wish to acknowledge and thank our cultural advisors living in the Gitksan communities (Doreen Angus, Joan Brown, Gloria Blackwater, and Dorothy Lattie) for their guidance and support; the community members who shared their thoughts and opinions through interviews and learning circles; and the nursing teams whose desire to learn and improve dementia care is inspiring. We would also like to acknowledge the Michael Smith Foundation for Health Research as the funding body for this project, and the special contribution of our graduate student and primary analyst, Katie Webb (School of Social Work, University of Victoria, Victoria, British Columbia, Canada).

Introduction

Dementia and Dementia Care

Dementia is a collection of diseases of the brain which affect memory, judgment, reasoning, mood, and behaviour. As the disease progresses, it affects the individual's ability to function and will ultimately cause death (Alzheimer Society of Canada, 2020). Dementia also affects the family and community, who have to watch the person decline while responding to their increased needs and dependency (Livingston et al., 2017). Common diseases of dementia include Alzheimer's disease, vascular dementia and Lewy body dementia.

Although dementia is a chronic disease, there are people in some First Nations communities who view it as part of a normal aging process (Hulko et al., 2010; Jacklin & Walker, 2012). This view may result in a delay in seeking the health care and support they require. Within British Columbia (BC) First Nation communities, only about 1 percent of the home care nursing visits were for an individual with Alzheimer's disease (electronic Service Delivery Reporting Template, 2015, 2016), but we hypothesize that the percentage of care visits for First Nations people with dementia should be higher. There is not one word for dementia in the Indigenous languages of Canada, and First Nations people, communities, and cultures hold different understandings of dementia (Jacklin & Warry, 2015). These different understandings can challenge nurses and the health care system, which are often operating within a non-Indigenous biomedical model.

Globally, about 47 million people were living with dementia in 2015, and this number is expected to triple by 2050 (Livingston et al., 2017). According to the most recent data available, more than 402,000 seniors (65 years and older) are living with dementia in Canada—excluding Saskatchewan (Government of Canada, 2020). Rates of dementia in First Nations people in Canada are believed to be equal to or higher than those for non-Indigenous people, and in time these rates are expected to further increase (Hulko et al., 2010; Jacklin & Walker, 2012) as the average life expectancy of First Nations people continues to rise (Office of the Provincial Health

Officer, 2018). Dementia has been found to occur up to ten years earlier in First Nations people compared to non-Indigenous Peoples (Jacklin et al., 2013). Meanwhile, the number of peoples living with dementia is rising rapidly as people live longer (Alzheimer's Disease International, 2018), so we hypothesize that the percentage of care visits for First Nations people with dementia should be higher. The risk for developing dementia increases not only with age but also with co-morbidities such as diabetes and cardiovascular disease (Alzheimer Society of Canada, 2018), both of which First Nations people experience at higher prevalence rates. It is suggested that one third of dementia cases could be prevented by addressing modifiable risk factors (Livingston et al., 2017). We still do not know enough in this area of First Nations health care. Recent publications recommend further research in order to address the knowledge gap that exists (Finkelstein et al., 2012; Hulko, et al., 2010; Jacklin et al., 2013).

The Gitxsan Nation is located in northern BC and includes the three east Gitxsan communities of Gitanmaax, Kispiox, and Sik-e-Dakh and the three west Gitxsan communities of Gitanyow, Gitwangak, and Gitsegukla. "There are two dialects of the Gitxsan Language, one used by those people living in the villages below Gitanmaax on the Skeena river and another by those from Gitanmaax and above" (Sterritt, 2016). The Gitxsan Nation is a matrilineal society, which means that women are placed in "high regard," with a preeminent role to carry out within the Gitxsan system. Being of the Gitxsan Nation means everybody is a member of their mother's house group (Sterritt, 2016). The people in the father's house group are the Father clan, and part of their role is to be a support for the person and family at the end of life (Sterritt, 2016). See Figure 1 for a map of the Gitxsan Nation's traditional territory.

Figure 1

Gitxsan Nation Traditional Territory Map

The Gitxsan territories make up an area of 33,000 square kilometres (about five times the size of PEI) in northwestern B.C.

CARRIE COCKBURN/THE GLOBE AND MAIL. SOURCE: GITXSAN CHIEFS' OFFICE

Note. Retrieved from <https://www.theglobeandmail.com/news/british-columbia/on-gitxsan-land-even-a-landmark-court-ruling-cant-bring-certainty/article19897595/>

In 2017, the executive health director for the Gitxsan Health Society (GHS), which specifically provides programs and services for the two communities of Sik-e-Dakh and Kispiox, contacted the First Nations Health Authority (FNHA) with concerns about the lack of geriatric nursing knowledge for meeting the health care needs for older Gitxsan people living with dementia. This is an especially pertinent gap when the nearest facility with 24-hour nursing care often does not have enough spaces for older persons living with dementia to move into when families feel overburdened or exhausted. As a result, the older persons living with dementia are moved farther from their community to a facility in one of the larger urban settings. In addition to the long geographic distance involved when it comes to family visiting the person with dementia, the move causes stress and trauma both to the older person living with dementia and to their family carers due to separation from family, community, and traditional/ancestral lands. Richmond (2015) reminds us that “a wide body of research demonstrates a special, multifaceted relationship between Indigenous Peoples and their local lands and traditional territories” (p. 47). For Indigenous people, separation from their traditional lands is a significant loss (Richmond, 2015). Additionally, Pace (2020) has noted how this geographic distancing only adds to and exacerbates pre-existing disconnection from and lack of access to traditional lands already present and imposed through the colonial government system.

Nurses stated that they are unsure how to provide support to individuals with dementia and their family caregivers in order to reduce caregiver stress. One nurse articulated the needs graphically (see Figure 2). A learning need for knowledge, attitude, and skills in dementia care was identified by the GHS’s health director, who observed older adults living with dementia being sent to hospital sooner than was necessary. The literature states that an Indigenous lens applied to dementia education is needed, and this is what the project leaders and team attempted to incorporate and to keep in mind at all times. The team tried to remain cognizant throughout the project of the particular positionality of the Elder within the Gitxsan nation, in line with Article 21.2 of the United Nations Declaration on the Rights of Indigenous Peoples or UNDRIP (2007), which states that “particular attention shall be paid to the rights and special needs of indigenous elders.” For Indigenous Peoples, Elders are not just family members; they are also valued teachers and trusted community supports. Most importantly, they are the Knowledge Holders for communities; they protect community history and culture. “As nurses, we value Elders and what they bring to our lives and communities,” says Becky Palmer, FNHA chief nursing officer. “We must work to protect them not only physically, but mentally, emotionally and spiritually as well. We acknowledge that honouring Elders is healing for our communities” (FNHA, 2020). Tonkin et al. (2018) have demonstrated how “First Nations older adults value being active in the community, passing down knowledge and wisdom, and being able to successfully manage their own health and aging. However, a history of colonialism in Canada, including residential schools, has made this especially challenging due to ongoing intergenerational trauma, loss of traditional roles within the community, and disrupted family structures.” Even though our team was unable to determine who was considered an Elder or Knowledge Holder for the purposes of this paper, we are referring to Elders in this study as older

persons living with dementia (please refer to the Relationships section below for details on the project team).

Through this project we aimed to address the question: “How can culturally relevant place-based learning for nurses, families, and community enrich the care for Gitxsan First Nations Elders with dementia?”

Figure 2

Nurse’s Hypothesis About What Individuals With Dementia and Families Require for Wellness

Methods

Ethics approval was obtained from the University of Northern British Columbia’s Research Ethics Board and the Northern Health Authority’s Research Review Committee through the BC Ethics Harmonization Process. A mixed-methods study was conducted between December 2017 and September 2019.

Participants included community members from the Gitxsan Nation (initially the communities of Kispiox and Sik-e-Dakh, which fall under the direct care mandate of the GHS), as well as nursing team members (care aides, licensed practical nurses, registered nurses) from both the community and the local acute care hospital.

Methodology

The research team was conscious of the importance of being inclusive of Indigenous methods and lenses when required and appropriate. We were guided in this by a number of

frameworks and by community partners, Elders from our Advisory Council, and an Indigenous nurse researcher.

The research was an Indigenous community based participatory action research (CBPAR) inquiry such that the process occurred with the Gitxsan people, not to them. Use of this process of discovery provided insights into the everyday realities for the individuals, families, community, and nursing teams who are coping, supporting, and living with dementia. We were guided by the principles of place-based learning, which involved meeting the community and nurses at their physical, mental, emotional, and spiritual place of being, and with no agenda or assumptions (in alignment with FNHA's 7 Directives—see Appendix A). The *First Nations Perspective on Health and Wellness* (FNHA, n.d.-b) is a model that guided us to expand beyond the biomedical model and view the needs of the participants wholistically (see Figure 3).

Figure 3

First Nations Perspective on Health and Wellness

In this project we looked to incorporate a Two-Eyed Seeing frame of reference. This involved recognition that the Indigenous Knowledge Sciences are informed by drawing on a collective Tribal Consciousness, while we also recognize that the latter tends to be negated

within the non-Indigenous sphere by an overwhelming emphasis on formal education. We must, therefore, be diligent in taking the best from our two worlds: Indigenous and non-Indigenous (Marshall & Marshall, 2012). Two-Eyed Seeing is a concept introduced by Albert Marshall, a Mi'kmaw Elder, that addresses both a colonized view and an Indigenized view simultaneously in order to work from a common ground situated in the use of multiple perspectives in a collective community sense (Bartlett et al., 2012). Two-Eyed Seeing enables the integration of Indigenous Knowledge and non-Indigenous Knowledge for increasing and establishing a co-learning situation, which is supported by UNDRIP.

Guiding Council of Elders

Cultural advisors living in the communities guided the project in order to increase sensitivity to culture and tradition. The four advisors have knowledge in both traditional and non-Indigenous worldviews (one had previously been a social worker, another was a nurse, and a third had been a schoolteacher), which kept the project team focused on maintaining a balance in their thoughts and actions, and linked in with our Two-Eyed Seeing perspective. The advisors were integrally linked to the project work: they attended the learning circle, the nurse education workshop, and the final sharing circle. They also provided input into project team meetings, were instrumental in interpreting the analysis from data collection, and reviewed and approved the end-of-project video (First Nations Health Council, 2020). This strong Indigenous lens and input was extremely valuable to the project.

Study Design

The study was divided into four distinct parts, illustrated in Figure 4:

1. Perspective gathering from the multiple stakeholder groups involved in the project, these being those community members with dementia, other community members (including family caregivers), and the nurses.
2. Cultural learning experiences for non-Indigenous nurses through grounding cultural workshops.
3. Dementia co-learning experience, located in community sphere, including multiple stakeholders, guided by cultural advisors.
4. Sharing circle in the community, sharing perspectives on co-learning experiences, evaluating successes and failures, speaking towards next steps and actions.

Figure 4*Gitxsan Dementia Research Study Design* **Data Collection Methods**

In May 2018 the project team undertook interviews in the community with community members with early stage dementia.¹ As a result, three male participants with early stage dementia were able to provide consent and participate. Also in May 2018, the project team arranged and facilitated a learning circle, which included community members with an interest in dementia (including family of persons living with dementia). The circle was facilitated by a Gitxsan community member, who was also a member of the project team. The semi-structured interview questions and the learning circle questions are available in Appendix B. The project team looked to maintain a strong emphasis on OCAP² through the data life cycle, with community guidance, involvement, and direction being incorporated into each element. Data was anonymized and stored according to OCAP rules. Although data needed to be brought to Vancouver, BC, for transcription and analysis, community partners still had access to this data via secure file transfer and encrypted hard drives. At the conclusion of the final sharing circle, all

¹ Following pre-interview assessment it was determined that one person was unable to give consent due to the advancement of the dementia; a second interview was a family member who preferred the one-to-one environment over the group circle environment.

² Standing for ownership, control, access, and possession, OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC; <https://fnigc.ca/ocap>).

data related to the project was left with the GHS. Table 1 provides an overview of all the different data collection and learning components involved in the project.

Table 1

Data Collection Methods

Component	Description
Knowledge test for nurses (<i>N</i> = 35)	A dementia knowledge assessment scale (DKAS) (Annear et al., 2017) was offered online to the nursing teams six months prior to the education workshop to collect quantitative data about knowledge and skills for caring for people with dementia. ¹ This identified knowledge strengths and gaps for workshop curriculum development (<i>n</i> = 15). The DKAS was also used at the beginning of the nurse education workshop and repeated at the end of the workshop to evaluate changes in knowledge over the three days (<i>n</i> = 20).
Learning circle (<i>N</i> = 17)	This learning circle component involved a gathering of community members and took place within the community. Project team members and community members engaged in an initial shared lunch, followed by an interactive dementia presentation by the nurse researcher Project Lead and a retired nurse administrator (volunteer). The learning circle itself was a self-selected smaller group session of community members with lived experience in caring for persons living with dementia. The group sat in a circle, and our guiding questions were facilitated by a member of the Gitxsan Nation.
Interviews (<i>N</i> = 5)	The Project Lead interviewed four Gitxsan people living with dementia in early stages of the disease plus one family member who decided not to attend the learning circle. These interviews were semi-structured in nature, and during these the person being interviewed was asked a number of guiding questions that focused them to reflect more generally on the issue of living with dementia as a member of the Gitxsan Nation.
Cultural learning (<i>N</i> = 2) ²	All non-Indigenous team members were encouraged to attend a one-day cultural learning event jointly sponsored by two health authorities (Northern Health and FNHA). There were multiple stations/booths that helped ground participants in local traditional culture of the Gitxsan communities. This included activities related to traditional food, language, and reconciliation.
Nurse education workshop (<i>N</i> = 26)	The Project Lead facilitated dementia and culturally safe care education to nursing teams. In this three-day session, the different nursing groups shared strengths, limitations, and perspectives on providing care for community members and their families.
Nurse mentorship meeting (<i>N</i> = average 6 per meeting)	As a follow-up to the nurse education workshop, all participants were invited to join a voluntary monthly meeting in order to apply what they had learned at the workshop to their practice through case study analysis (January 2019–April 2019).

¹ There are a number of needs assessments to determine knowledge, but this one was relevant, updated, and generalized for dementia, not specific to Alzheimer's disease. At the time, there was no robust Indigenous assessment tool available.

² This number included the Project Lead and one of the Co-Leads. Additionally, the learning was facilitated partly by one of the Indigenous members of the project team.

Table 1 con't

Component	Description
Sharing circle (N = 29)	The sharing circle was a gathering of community, nurses, Alzheimer Society of BC staff, and project team members to evaluate the outcomes of the project. This involved a presentation on dementia, sharing of results from the study through presentation and discussion, and a sharing circle to discuss these results and to talk about next steps in terms of education support and spread.
Video (N = 6)	Following the feedback received at the sharing circle, a short instructional/educational video, <i>Gitxsan Ways of Knowing about Dementia</i> , was created (First Nations Health Council, 2020). This video was in addition to other supports provided by the team and by the Alzheimer Society of BC.

The team instituted a step-by-step approach to analysis, with each component informing the next. However, in alignment with a more Indigenous lens, we also incorporated an iterative approach in our research. This involved a process of going back over what we had learned, checking in with our stakeholders, and opening up and incorporating new levels of understanding with each analysis cycle. This approach informed the dementia education and teachings that took place throughout the project timeline.

For the formulation of our key theme areas, the team's graduate student initially analyzed the responses and pulled out key concepts and patterns of thought that emerged from the various participants. Following this, the wider team reviewed and added additional nuance and explanation to the theme areas. In the conclusion to this component, the combined analysis was brought back to the community for further review prior to finalization in its current iteration.

Relationships

Leadership

This project was co-led by GHS in collaboration with FNHA. An FNHA Project Lead was supported by two GHS Co-Leads. All three investigators are experienced nurses. The two Co-Lead nurses were experienced community health nurses, working in First Nations communities; one nurse is a Gitxsan community member. Four Elder advisors living in the communities formed the Cultural Advisory Council to guide the project through each phase.

Partnerships

In addition to GHS and FNHA, other organizations involved in this project partnership were Thompson Rivers University through the guidance provided by an Indigenous Academic Nurse Partner; University of Victoria through the Indigenous Mentorship Program, which provided an Indigenous graduate student from the School of Social Work to lead the qualitative analysis component; Northern Health Authority through the operational approval provided; University of Northern British Columbia through the Research Ethics Board for the advice and approval provided during the ethics process; and the Alzheimer Society of BC for its support and involvement.

Results

Initially, we analyzed the responses from the interviews (people living with dementia) separately from the learning circle (community and family) and had intended to present findings as separate categories. However, due to the similarity of the themes identified from both the interviews and the learning circle, it was decided to present them jointly. Three major themes were identified, centred on the areas of loss, relationality, and access and connection (see Table 2).

Table 2

Themes From Interviews and Learning Circle With People With Dementia and Families

Key Theme	Description	Quotes
LOSS (includes complex grief)	Dementia exacerbates a pre-existing and overwhelming sense of loss from historical and ongoing influence and experiences	<p>“I think there is a loss to many things, not just one thing to memory loss.” (S, family)</p> <p>“It’s loss of identity, it’s loss of matriarch, it’s loss of history, it’s a loss of many things in our culture.” (S, family)</p> <p>“You’ve lost your independence and all that. Umm ... a person that was so bonded with their family, lost that.” (K, person living with dementia)</p> <p>“Because we lost our native ways, and it’s pretty hard to get a grip on it.” (P, person living with dementia)</p> <p>“Loss of spirit. Because we are spiritual. We were born into the Gitxsan culture and we’ve already been given our spirit before we came here.” (S, family)</p> <p>“But the impact is very great in how we love and support them [the person with dementia] but also the grief that we feel, the loss that we feel, the loss that they feel.” (S, family)</p> <p>“I think one of our biggest losses was communication.” (M, unknown)</p>

Table 2 con't

Key Theme	Description	Quotes
RELATIONALITY (personal relationships)	<p>The actions of the nurse go a long way to establish positive relationships</p> <p>Community has a traditional role in supporting the person with dementia and their family</p>	<p>“Some of these nurses are so willing to learn about us Native People.” (M, unknown)</p> <p>“Usually the people telling them what to do are young and that’s foreign to our people. Being told what to do by a young person. This is unusual for an Elder.” (G, family)</p> <p>“Honestly, if you can get a family member to get in there with them [nurses]. It would be great. Take some of the stress off of the nurses, and have more of your family surrounding.” (D, person living with dementia)</p> <p>“It’s the house groups responsible to care for that loved one that has dementia.” (S, family)</p> <p>“It’s just building that alliance within the community of knowing which families have dementia and letting the family know that they are not alone and that they can get the support.” (S, family)</p> <p>“I really believe that our families get so disconnected when they go into hospital.” (S, family)</p> <p>“Everybody had a trail from one house to another. You know, we got up and went over to have tea in the afternoon and coffee in the evening. But there was always some kind of communication. We don’t have that now.” (M, unknown)</p>

Table 2 con't

Key Theme	Description	Quotes
ACCESS AND CONNECTION (formal information and support/s)	People want to learn but do not know where to turn for information	<p>“One of the things that really helped me was learning about dementia.” (S, family)</p> <p>“Education, support and networking are the three main personal things that I would like to see come through this so that we can continue to work with families that have dementia.” (S, family)</p> <p>“To me, having any kind of support and any kind of education makes a big difference to know that you’re not alone. ’Cause it is a lonely path when you are trying to deal with a person that has dementia.” (S, family)</p> <p>“What they need in the community is workshops with the families about dementia or any other disease.” (O, unknown)</p> <p>“The nurse that was training my nieces held a little workshop like this. Most of us went to it. Things got easier after that. Just, uh, a lot of information you could remember. She was a good teacher because I remember most of it.” (G, family)</p> <p>“Is there any professionals in this area that will be willing to give a workshop to us amateur caregivers? What to watch for? Be more familiar with it?” (G, family)</p>

Nurse Education Workshop

In November 2019 the project team hosted a three-day dementia education workshop for nursing teams in New Hazelton (26 attendees). The aim of this workshop was to build on knowledge, attitude, and skill using interactive strategies such as shared storytelling, discussion, videos, and games. Evaluation of the three-day workshop involved four levels, following the Kirkpatrick Model for evaluation (Kirkpatrick & Kirkpatrick, 1952/2006). The four levels explore satisfaction; changes in knowledge, attitude, and skill; change in practice; and finally but most importantly, change in the patient experience. See Appendix C for the full Nursing Workshop Teaching Plan.

Satisfaction

A survey was created using a Likert scale to assess satisfaction levels with the workshop. 79% answered “strongly agree” to all satisfaction questions. There were no negative responses. 92% of the participants strongly agreed that they would recommend the workshop to their colleagues.

Knowledge

With author permission, we used Dr. Annear and colleagues' (2017) validated 25-item Dementia Knowledge Assessment Scale. A pre- and post-test strategy (see Appendix D) was used to quantify knowledge gained. Only the 26 participants who completed the pre-test at the start of the workshop were asked to complete the post-test at the finish of the workshop. Four categories of dementia knowledge were evaluated, including causes and characteristics, communication and behaviour, risk factors and health promotion, and care considerations. A significant increase of dementia knowledge was measured in all categories.

Figure 5

Measurement of Dementia Knowledge Before and After Workshop for Nursing Teams

Practice Change

Participants attending the nurse education workshop were asked to write commitment statements before lunch and before the end of each day. Many of the statements reflected a positive change in attitude toward the person living with dementia and an intention to change practice. A second common theme for the statements involved supporting the family of the person living with dementia.

Voluntary monthly check-in phone calls with the nursing teams have further indicated a shift in attitude and behaviour. We found that nurses are now

- questioning care plans and medications that might not reflect the values of the person living with dementia;
- discussing the right to live at risk and exploring the options—this included discussions about respecting individual autonomy versus nurses protecting people living with dementia from potential harms (Berke, 2014);
- identifying family need for support and information, and articulating distress when family caregivers do not receive much-needed community support or respite; and
- brainstorming and problem solving in response to an individual's expressed concerns.

Person Living With Dementia—Improved Experience

This component is the most difficult and yet most important to evaluate. Full evaluation will take longer than the length of this project, but we returned to the community to explore what difference the project has made through a final sharing circle.

Final Sharing Circle

The sharing circle happened almost one year after the initial learning circle. During the final sharing circle in the community, we wanted to determine if the nursing education workshop had made any difference to community members. This second circle demonstrated an over 60% increase in engagement/participation over the initial circle, and also saw participants from four more communities (three Gitksan and one Wet'suwet'en) attend. Three general themes emerged during sharing circle conversation: reflections on the past, learning, and action.

Table 3

Final Sharing Circle Findings

Theme	Description
Reflections on the past	<ul style="list-style-type: none"> • Desire to understand the past and traditional response to caring for people living with dementia • What happened fifty years ago? • Traditionally, the Father clan would come and take care of the person who is ill

Table 3 con't

Theme	Description
Learning	<ul style="list-style-type: none"> • New understanding about dementia and desire to maintain dignity for the person living with dementia • Community members feel they are more aware and paying attention to changes as the disease progresses • New understanding that behaviour is not intentional but a response • Seeking more resources for information • Want to connect with someone about preventing financial abuse • Recognize importance of dignity, respect, choice, control, and asking permission when helping someone with dementia
Action	<ul style="list-style-type: none"> • More aware and grateful with a strong desire to learn more, plus create resources and support • Curiosity and desire to strengthen skill and spirit • Need a day centre so caregivers can access respite • Bring more information into the community so everyone is educated • Work together

Discussion

When we first started the project, we were warned to avoid the term “dementia” and instead use “memory loss.” There was concern that the stigma of dementia would deter community members from participating in the project. During the first community meal, over thirty people attended. A 15-minute presentation took over one hour because community members asked so many questions of the two presenters from the project team. Although not everyone stayed for the learning circle, the event ignited a buzz in the two communities. The term “dementia” was accepted as a collection of diseases from which a person will eventually die. Other Gitksan communities started asking to be included in the project, and nursing teams from six different First Nations communities (Gitanyow, Gitwangak, Gitanmaax, Kispiox, Sik-e-Dakh, and Hagwilget) participated in the nurse education workshop. During the final sharing circle, the project team asked the community to evaluate the 15-month project. The response was positive (see Table 3), and a switch occurred as community members started exploring what they could do to increase knowledge and support, rather than depending on what others could do for them. The three themes from the initial interviews and learning circle—loss and grief, relationality, and access and connection—provided a strong springboard for the remainder of the project. The desire for more knowledge exchange activities was another strong theme.

Loss and Grief

This theme was prevalent for both the individuals living with dementia and for their family. Although loss would be a prevalent theme for any individual and their family, the type of

losses described by Gitxsan people included categories of loss that are not applicable (or at least not as common) for non-Indigenous Peoples; these include loss of identity and role in their community (e.g., matriarch, chief); loss of communication, oral stories, and traditional knowledge; loss of history; separation from traditional land; and loosening of spiritual bonds. Loss led to grief even if the person were still alive. This grief and loss are clearly associated with the impacts of colonization that First Nations people continue to endure. Colonization was the process in which the federal government implemented policies and structures to erode traditional knowledge and wellness practices of Indigenous Peoples in Canada (Allan & Smylie, 2015).

The grief did not fade easily as family shed tears for people who died decades earlier with dementia. This exacerbates a pre-existing and overwhelming sense of loss, which community members have to face on a daily basis due to traumatic experiences emanating from past and continuing colonial practices, including racist attitudes, behaviours, and assumptions, which together further contribute to complex grief. We repeatedly heard that the continuous nature of loss and grief is prevalent with First Nations people. The loss associated with a diagnosis of dementia often acts as an additional layer of burden for families already trying to cope with complex grief, under circumstances of minimal supports.

Relationality

A second theme focused on the relationship between three groups: the Gitxsan individual living with dementia, the individual's family, and nurses. Negative sub-themes such as apathy, discrimination, racism, and high staff turnover challenged respectful working relationships. However, participants stated that if nurses were willing to take steps to understand the context in which the person living with dementia and the family were living/existing, then a respectful, positive relationship could result. Some cited examples of positive relationship-building behaviour, such as when nurses were willing to learn a few words of the Gitxsan language, used caring body language, understood and acknowledged conceptions of connection to land, learned about the cultural significance of the role the individual with dementia held in the community, or demonstrated an understanding of the house group structure that exists in Gitxsan communities. House groups are an important traditional system that remains active within the Gitxsan Nation. All Gitxsan belong to a Wilp (i.e., house group), which is the basic social, economic and political unit within the Nation. Each Wilp belongs to one of four clans: Lax Gibuu (Wolf), Lax Seel/Ganeda (Frog), Giskaast (Fireweed), and Lax Skiik (Eagle). There are approximately 64 Wilps that make up the Gitxsan Nation. They vary in number of members, and each Wilp has its own territory (Gitxsan, 2020).

This theme also extended into the nurse education workshop and final sharing circle. Discussions emerged about the importance of understanding and honouring the house group structure, with the result that the community, not simply one family member or one health care worker, supports the person living with dementia. Distress was evident when this traditional understanding of relationality was not honoured in community.

Access and Connection

Families and community members highlighted a poor understanding of dementia as a chronic disease. Because dementia was misidentified as the person “gone nuts” (research participant, learning circle), many community members were less tolerant of unusual behaviours and less likely to reach out to others for support. A strong theme was the identified need for education, support, and networking.

An example of poor access and connection was when the project team discovered a major communication gap between the Alzheimer Society of BC and the First Nations communities. The policy of the Alzheimer Society is to visit First Nations communities only when invited, yet the Gitksan communities were unaware that such potential support existed and hence did not know to ask. Gitksan communities fall under the designation of rural and remote, where adequate internet connectivity, cell services, and access to support groups and respite care—services taken for granted in other settings—are not consistently available.

Community members displayed a strong curiosity to learn more about dementia from a variety of sources. Providing access and connection both within the community and between the community and external support elements was a fundamental outcome of the project. This is in alignment with the fundamental rights expressed in Article 24.1 of the UNDRIP, which highlights that “Indigenous individuals also have the right to access, without any discrimination, to all social and health services.” Article 21.1 reinforces this by stating that “Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions,” specifically including the areas of “health and social security.”

Knowledge Exchange Activities

Nursing teams and community members are now aware of the resources available to them through the Alzheimer Society. This includes online resources, newsletters, a 1-800 helpline, plus face-to-face education. The Alzheimer Society of BC has also recognized the importance of increasing access to cultural safety training for their staff so Indigenous people can be assured that if they reach out for help, culturally safe support will be available. Cultural safety is an “outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care” (FNHA, n.d.-a). Indigenous-specific fact sheets created by research in Ontario (Indigenous Cognition & Aging Awareness Research Exchange et al., 2015) were distributed and determined to be meaningful and relevant for the Gitksan context. During the final sharing circle, the community participants supported our request to share our learnings through reports, published papers, and conference presentations. Finally, the community requested a video to share their story based on Gitksan ways of knowing about dementia (First Nations Health Council, 2020):

https://www.youtube.com/watch?v=0XqYd1wo_Uw&t=362s.

Limitations

We hope that the results of this study will help better inform nurse practice and policy on a broad level. However, the results should not be treated as generalizable or applicable verbatim to every Indigenous context or even as applicable in a pan-Gitxsan sense. Much of the analysis and findings come from our first learning circle, which included a predominantly East Gitxsan voice (and specifically members of the Kispiox and Sik-e-Dakh communities). This analysis should therefore be treated as a guide.

This was a foundational research project. Further research is recommended in order to build on these initial steps and so to better understand and provide culturally relevant care.

Due to the lack of staff replacement options, the nursing participation from acute care was lower than anticipated. Therefore, we cannot make formal assumptions about the experiences of nurses working in the local hospital.

Through this project we can facilitate education and other supports, but we have limited control over certain systemic issues particularly prevalent in the north of British Columbia. Specifically, there is the problematic nature of a shortfall of nursing staff living in the region, which lends itself to a proliferation of short-term migratory nurse personnel in the north (Auditor General of BC, 2018). When working short-staffed, nurses lack time to build relationships and might appear abrupt. Temporary nurses brought in from away to fill vacancies are temporary. They are not from the area and lack the history or context to build on relationships. This situation challenges sustained program development, supports, and general knowledge/capacity building. Current nursing shortages and changing demographics will continue to have a negative impact on the health of populations. The issues that will directly impact quality of care to patients and increase adverse outcomes such as higher mortality rates, unsafe working environments, and burnout of nurses are a few of the priority concerns (McGill School of Nursing, 2019).

Conclusion

Family and other community members identify (a) the need for more information regarding the dementia condition, (b) the need to access in-community and external supports (and what those supports might look like), and (c) the need to inform nurses and other caregivers about what considerations are required when caring for the Gitxsan person living with dementia and interacting with family members. A better understanding of the Gitxsan ways of knowing about dementia can help nurses incorporate more culturally safe practices into the care of people with dementia (including verbal cues, body language, and positionality/roles/structures in the community). This was a foundational research initiative, and there is recognition that further research needs to be done in this area. What we hope is that the findings from this initiative will contribute to improving culturally safe care for First Nations people living with dementia in British Columbia, and will help guide and inform future research. In line with our FNHA Leadership Statement (FNHA, n.d.-c.), we strive for excellence and believe First Nations deserve the best we have to offer.

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Appendices

Appendix A

First Nations Health Authority's 7 Directives

7 DIRECTIVES
Shared by the FNHA | FNHC | FNHDA

**DIRECTIVE #1
COMMUNITY-DRIVEN, NATION-BASED**

- The Community-Driven, Nation-Based principle is overarching and foundational to the entire health governance arrangement.
- Program, service and policy development must be informed and driven by the grassroots level.
- First Nations community health agreements and programs must be protected and enhanced.
- Autonomy and authority of First Nations will not be compromised.

**DIRECTIVE #2
INCREASE FIRST NATIONS DECISION-MAKING AND CONTROL**

- Increase First Nations influence in health program and service philosophy, design and delivery at the local, regional, provincial, national and international levels.
- Develop a wellness approach to health including prioritizing health promotion and disease and injury prevention.
- Implement greater local control over community-level health services.
- Involve First Nations in federal and provincial decision-making about health services for First Nations at the highest levels.
- Increase community-level flexibility in spending decisions to meet their own needs and priorities.
- Implement the OCAP (ownership, control, access and possession) principle regarding First Nations health data, including leading First Nations health reporting.
- Recognize the authority of individual BC First Nations in their governance of health services in their communities and devolve the delivery of programs to local and regional levels as much as possible and when appropriate and feasible.

**DIRECTIVE #3
IMPROVE SERVICES**

- Protect, incorporate and promote First Nations knowledge, beliefs, values, practices, medicines and models of health and healing into all health programs and services that serve BC First Nations.
- Improve and revitalize the Non-Insured Benefits program.
- Increase access to primary care, physicians, nurses, dental care and other allied health care by First Nations communities.
- Through the creation of a First Nations Health Authority and supporting a First Nations population health approach, First Nations will work collectively to improve all health services accessed by First Nations.
- Support health and wellness planning and the development of health program and service delivery models at local and regional levels.

**DIRECTIVE #4
FOSTER MEANINGFUL COLLABORATION AND PARTNERSHIP**

- Collaborate with other First Nations and non-First Nations organization and governments to address social and environmental determinants of First Nations health (e.g. poverty, water quality, housing, etc.).
- Partnerships are critical to our collective success. First Nations will create opportunities through working collaboratively with federal, provincial, and regional partners.
- Foster collaboration in research and reporting at all levels.
- Support community engagement hubs.
- Enable relationship-building between First Nations and the regional health authorities and the First Nations Health Authority with the goal of aligning health care with First Nations priorities and community health plans where applicable.

**DIRECTIVE #5
DEVELOP HUMAN AND ECONOMIC CAPACITY**

- Develop current and future health professionals at all levels through a variety of education and training methods and opportunities.
- Result in opportunities to leverage additional funding and investment and services from federal and provincial sources for First Nations in BC.
- Result in economic opportunities to generate additional resources for First Nations health programs.

**DIRECTIVE #6
BE WITHOUT PREJUDICE TO FIRST NATIONS INTERESTS**

- Not impact on Aboriginal Title and Rights or the treaty rights of First Nations, and be without prejudice to any self-government agreements or court proceedings.
- Not impact on the fiduciary duty of the Crown.
- Not impact on existing federal funding agreement with individual First Nations, unless First Nations want the agreements to change.

**DIRECTIVE #7
FUNCTION AT A HIGH OPERATIONAL STANDARD**

- Be accountable, including through clear, regular and transparent reporting.
- Make best and prudent use of available resources.
- Implement appropriate competencies for key roles and responsibilities at all levels.
- Operate with clear governance documents, policies, and procedures, including for conflict of interest and dispute resolution.

FNHA, FNHC, FNHDA SHARED VISION >> Healthy, Self-Determining and Vibrant BC First Nations Children, Families and Communities.

First Nations Health Authority
Health through wellness

Appendix B

Learning Circle and Interview Questions

How can culturally relevant, place-based learning for nursing teams, families, and community enrich the care for Gitxsan First Nations Elders with dementia?

All questions were vetted through the Cultural Advisory Council

Conversation guide for community members during first learning circle

1. What is important to the Gitxsan community?

- a) As a community member, what do you personally hope to learn from this project?
- b) What should be our goal? What would you like to see changed? How should we evaluate the project? How will we know that the project has had a positive impact on your community? What does success look like?

2. What does dementia mean to the Gitxsan people?

- a) What is life like when dementia is in the picture? How does this impact your life?
- b) Tell us about dementia from your perspective as a First Nations person? How does Gitxsan tradition explain dementia? Dementia behaviours? Are there traditional treatments? Can we recapture valuable teachings?

3. What does the Gitxsan Nation want settlers and nurses to know and understand?

- a) What traditions or protocols should we know about so we can support you to experience them?
- b) Is there something we might do/say or not do/say which could trigger a negative response? For example, are there traumatic memories from residential school which we might inadvertently trigger?
- c) What worries you the most? What support helps? What should we continue to do?

Conversation guide for 1:1 draw/verbal interview questions with person in early stage of dementia

- 1. What does it mean to have memory problems?
- 2. What does being Gitxsan and having memory problems mean to you?
- 3. How did you care for past relatives with memory problems? What is important?
- 4. Is there anything you would like nurses to know?
- 5. Tell me what you have drawn? (if appropriate)

Pictures are available if participant is more comfortable speaking in third person. Paper and pencil are available if person is more comfortable expressing self on paper than with verbal words. Family welcome to remain in room if that is the wish of the person with dementia.

Appendix C

Nursing Workshop Teaching Plan

Goals for Culturally Relevant Dementia Education					
Recognizing that the number of people with dementia is increasing ... <ul style="list-style-type: none"> • Be ambitious about prevention • Individualize dementia care • Advocate for appropriate treatment • Appreciate cultural differences and practices • Support the development of a community of care for people with dementia and family 					
Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Introductions Review course Binder Pretest	1–9		30 min	Commitment statement	Recipe cards Poster paper
Part 1 The Science of Dementia <ul style="list-style-type: none"> • Understand the difference between dementia and normal aging. • Know the most common types of dementia. • Appreciate that delirium is a medical emergency that warrants an appropriate response. • Know that late-life depression is not uncommon and can be treated. • Know what drugs are used for people with dementia and the guidelines for their use. 					
Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Discussion Case study Trivial Pursuit Commitment statement	10–70	The Link Between Brain & Behaviour	3.25 hrs	What is dementia? Signs & symptoms of dementia The 3 D's crossword puzzle Cami Prisme M.SIG.E.CAPSS PHQ-9 Geriatric depression scale Cornell scale	Trivial Pursuit Game pieces
Part 2 Communicating: More Than Talking <ul style="list-style-type: none"> • Recognize how important you are in communicating with people with dementia. • Understand how the disease process affects communication. • Identify different strategies to use when communicating with persons with dementia. • Explore the unmet needs which drive behaviour and learn a problem-solving approach. 					
Activities	Slide #	AV/Video	Estimated Time	Handouts	Props

Brainstorm non-verbal Mama bull/Papa bull Role play(Arguing & Yes and ...) Peanut butter sandwich Rose boardwalk Jeopardy Commitment statement	1–41	Gladys Teepa: Tell Me About It Teepa: Advanced Communication Rose	3.25 hrs	Blank paper with 4 squares	Flip chart Peanut butter, jam & bread with knife
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Part 3**Who Is This PERSON With Dementia?**

- Appreciate the uniqueness of each person and know how the person has become who they are.
- Know that good nursing care addresses physical, spiritual, emotional, and mental needs.
- Know that our own values and beliefs impact our actions in the care relationship.
- Know that our actions can honour or dishonour another person.
- Understand that meaningful relationships are a vital component of caring for an Indigenous person with dementia.

Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Discussion Dishonouring boardwalk Tabletop discussion re honouring Family Feud Commitment statement	1–43	6 YouTubes facts, values, beliefs, stereotypes, & sexuality	3.5 hrs	Actions which depersonalize Honouring the person	Sticky notes Poster paper

Part 4**Family Connections and Access**

- Recognize the importance of relationships with family on the well-being of Elders.
- Identify the family experience and what families need.
- Develop strategies to nurture relationships with families.

Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Discussion Brainstorming x 2 Living at risk case study Tooth brushing using hand under hand	1–63	Hand under Hand Massage Alive Inside Real Life Falls	3.25 hrs	The path of dementia What to expect 101 things to do Ethical framework Reciprocal abuse 3 questions	Smell props Flip chart

Smells Commitment statement					
Part 5 How Do We Promote Comfort for People with Advancing Dementia? <ul style="list-style-type: none"> • Understand basic Advance Care Planning concepts. • Describe pain assessment strategies for people with dementia. • Describe approaches to treating pain for someone with dementia. • Understand dementia as a terminal illness. • Recognize when to embed a palliative approach to care. 					
Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Discussion Brainstorming non-drug interventions Tabletop exercise Pain myth busters Frailty care plan Brainstorm— what makes a good death?	1–93	Atul Gawande SPEAK Rose video clip	4.5 hrs	PAINAD Iowa pain thermometer POSS SPEAK Healthcare consent hierarchy Resource links Clinical frailty scale Information for families when end of life is near Greensleeves Personal medication tracker My Voice	
Part 6 Community Engagement and Sustainability <ul style="list-style-type: none"> • Be ambitious about prevention. • Work together as a team despite challenges. • Identify possibilities for dementia care within the community. • Create a model of care that is uniquely designed for the community. 					
Activities	Slide #	AV/Video	Estimated Time	Handouts	Props
Discussion Bus stop game The experience cube	1–26	Teamwork YouTube	2.75 hrs	Risk factors for dementia Preventing dementia Lessons from geese Promise to my co-workers	
Wind-Up <ul style="list-style-type: none"> • Research follow-up/Evaluation • Certificates 					

Appendix D

Dementia Knowledge Survey for Nurses (DKAS Questionnaire)

25-item Dementia Knowledge Assessment Scale (DKAS)

Date: _____

Q #	Statements about dementia	Response scale (Please tick one box ✓)				I don't know
		False	Probably false	Probably true	True	
A1	Dementia is a normal part of the ageing process.					
A2	Alzheimer's disease is the most common form of dementia.					
A3	People can recover from the most common forms of dementia.					
A4	Dementia does not result from physical changes in the brain.					
A5	Planning for end of life care is generally not necessary following a diagnosis of dementia.					
A6	Blood vessel disease (vascular dementia) is the most common form of dementia.					
A7	Most forms of dementia do not generally shorten a person's life.					
A8	Having high blood pressure increases a person's risk of developing dementia.					
A9	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia.					
A10	Symptoms of depression can be mistaken for symptoms of dementia.					
A11	Exercise is generally beneficial for people experiencing dementia.					
A12	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition.					
A13	The sudden onset of cognitive problems is characteristic of common forms of dementia.					
A14	It is impossible to communicate with a person who has advanced dementia.					
A15	A person experiencing advanced dementia will not generally respond to changes in their physical environment.					
A16	It is important to correct a person with dementia when they are confused.					
A17	People experiencing advanced dementia often communicate through body language.					
A18	Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs.					
A19	Medications are the most effective way of treating behavioural symptoms of dementia.					
A20	People experiencing dementia do not generally have problems making decisions.					
A21	Movement is generally affected in the later stages of dementia.					
A22	People with advanced dementia may have difficulty speaking.					
A23	People experiencing dementia often have difficulty learning new skills.					
A24	Difficulty eating and drinking generally occurs in the later stages of dementia.					
A25	Daily care for a person with advanced dementia is effective when it focuses on providing comfort.					

¹ Used with permission from Dr Michael Annear of International Christian University, January 2018.