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# Dementia Care Knowledge Sharing within a First Nations Community\*

Dorothy Forbes,<sup>1</sup> Catherine Blake,<sup>2</sup> Emily Thiessen,<sup>1</sup> Sara Finkelstein,<sup>3</sup> Maggie Gibson,<sup>4</sup> Debra G. Morgan,<sup>5</sup> Maureen Markle-Reid,<sup>6</sup> and Ivan Culum<sup>7</sup>

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## RÉSUMÉ

Cet article discute l'échantillon d'une étude des Premières Nations plus vaste sur les décisions de soins de la démence et le partage des connaissances. L'objectif de cette étude est de mieux comprendre le processus de partage des connaissances entre les praticiens de la santé (PS), les partenaires de soins, et les personnes atteintes de démence (PAD) au sein d'une communauté rurale des Premières Nations. Une méthodologie de la théorie constructiviste ancrée a été utilisée. Dix-neuf entrevues ont été menées à trois reprises avec deux réseaux de soins de la démence qui comprenait deux PAD, trois partenaires de soins, et deux PS. Un modèle, "Partage des connaissances sur les soins de la démence," a été conçu, centrée sur les PAD et leurs partenaires de soins. Trois grands thèmes du partage des connaissances sont représentés dans le modèle: (1) le développement des relations de confiance, (2) l'accès et l'adaptation aux informations, et (3) application des informations. Des approches sensibles à la culture sont essentiels pour le développement des relations de confiance. Une fois que les relations ont été développées, le partage des connaissances grâce à l'accès, l'adaptation et l'application des informations est devenu possible.

## ABSTRACT

This article discusses the First Nations sample of a larger study on dementia care decisions and knowledge sharing. The purpose is to enhance understanding of the process of knowledge sharing among health care practitioners (HCPs), care partners, and persons with dementia (PWDs) within a rural First Nations community. A constructivist grounded theory methodology was used. Nineteen interviews were conducted at three points in time with two dementia care networks that included two PWDs, three care partners, and two HCPs. A *sharing dementia care knowledge* model was conceived, with the PWDs and their care partners at the centre. Knowledge sharing in the model was represented by three broad themes: (1) developing trusting relationships, (2) accessing and adapting the information, and (3) applying the information. Culturally sensitive approaches were essential to developing trusting relationships. Once developed, knowledge sharing through accessing, adapting, and applying the information was possible.

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## Introduction

In 2008, there were 480,000 Canadians with dementia, and by 2038 the number is estimated to increase to 1,125,200 (Alzheimer Society of Canada, 2010). *Dementia* refers to a large class of brain disorders characterized by a progressive decline in memory, thinking, behaviour, and the ability to perform everyday activities. Alzheimer's disease is the most common cause of dementia, followed by vascular dementia, Lewy body, and various subtypes of frontotemporal dementia. The presence of two or more distinct dementia pathologies (e.g., Alzheimer's disease and vascular dementia) is classified as mixed dementia (Alzheimer Society of Canada, 2010). Aging is the most important risk factor for dementia.

Over the next 20 years, the number of First Nations persons over the age of 65 is expected to triple (Indian & Northern Affairs Canada, 2008). One of the implications of this demographic shift is that the number of First Nations people with dementia will increase correspondingly as a by-product of population aging. Moreover, the risk of dementia in First Nations populations is exacerbated by a higher than average prevalence of heart disease, diabetes, smoking, substance abuse, and hypertension (First Nations Centre, 2005; Weiner et al., 2003), all of which increase the risk of dementia significantly (Craft, 2009; Patterson et al., 2008). However, because dementia has not been well-documented to date in First Nations communities (Andrews, Morgan, & Stewart, 2010; Finkelstein, Forbes, & Richmond, 2012; Henderson & Henderson, 2002; Hendrie et al., 1993), there may be a lack of knowledge regarding the signs, symptoms, treatment, and management by PWDs, their informal caregivers (care partners), and their HCPs. This creates a distinct need to support dementia-focused knowledge translation needs, capacity, and strategies within First Nations populations.

Knowledge translation has many different and complex descriptions. One definition that has been used to describe knowledge translation in First Nations communities is *sharing what we know about living a good life* (Estey, Smylie, & Macauley, 2009). Knowledge-sharing processes are diverse, distinct, and linked to local structures, geography, history, and culture (Estey et al.,

2009; Estey, Kmetc, & Reading, 2010). Understanding local processes of knowledge creation, dissemination, and utilization is a necessary prerequisite to effective knowledge sharing that will promote safe and high-quality dementia care.

This study addressed the need for a better understanding of the knowledge-sharing processes that support dementia care within a First Nations community. Specifically, the purposes of this study were to (1) provide detailed examples of the dementia care knowledge-sharing process among HCPs, care partners, and PWDs in a First Nations community; (2) identify factors that were facilitators and impediments within this process; and (3) inform the culturally sensitive application of dementia care knowledge-sharing strategies.

## Methods

This article reports on the First Nations sample of a larger study – Developing Quality Dementia Care Decisions through Knowledge Sharing in Rural Settings – that included nine rural families who, along with their HCPs, were providing care to a family member with dementia. Prior to beginning the study, ethics approval was received from the Ethics Review Board, University of Western Ontario (approval number 16979E), and the Victorian Order of Nurses (VON) Canada (approval number 070810-01). In addition, approval was sought and received from the Chief and Band Council of the First Nations community included in this study. From the outset, administrators and frontline staff from the community health centre were involved with the study design through face-to-face meetings and telephone consultations. In PWDs, competence to make an informed decision about research participation cannot be adequately determined by standardized assessment tools, is not based on a diagnosis of dementia, and may change during the course of the study (Fisk, Beattie, & Donnelly, 2007). Thus, consent from a proxy (e.g., care partner) and ongoing assent of the PWD were obtained prior to each interview.

## Sample

A convenience sample was recruited through our study collaborators: a local Alzheimer Society and a

First Nations community in southwestern Ontario. Theoretical sampling followed in order to capture the diversity of experiences and perceptions of all those involved in providing dementia care. For example, we specifically approached a geriatrician who assessed, counselled, and treated several of the study participants. The inclusion criteria were that the participant (a) speak English, and (b) had a diagnosis of dementia or provided informal or formal care or support to someone with dementia. The local Alzheimer Society, in partnership with the First Nations community, had hired a First Link coordinator and public education coordinator. The First Link program provides PWDs and their care partners with a network of education and support services specific to their situation and focuses on service coordination, resources, and planning (Alzheimer Society of Ontario, 2013). These individuals informed potential study participants about the project, and if they were agreeable, had them sign the "consent to be contacted" form. The project coordinator then contacted them to further explain the study, and if agreeable, enrolled them in the study. For the purposes of this study, each "dementia care network" included a PWD, associated care partners, and the person's community-based HCPs. Two First Nations dementia care networks were studied; altogether, these included two PWDs, three care partners, and two HCPs.

Data were collected at three points: upon entry to the study ( $n = 7$ ), six months thereafter ( $n = 7$ ), and after one year ( $n = 5$ ), until theoretical saturation was reached (Charmaz, 2009). In total, 19 face-to-face interviews were audiotaped and transcribed verbatim. We removed all identifying information from the transcripts and used pseudonyms to maintain confidentiality.

### Data Collection

We developed interview guiding questions based on our research purpose. Examples of the kinds of questions asked were: "What is it about the relationship you have with your HCPs that makes it easier or more difficult to share and receive information? How do you decide whom to ask for assistance? What kinds of information have your HCPs shared with you? What information/strategies help manage dementia symptoms?" Data collection and analysis occurred simultaneously to ensure that the information collected during our initial interviews informed the types of questions asked during subsequent interviews.

### Data Analysis

This study used a constructivist grounded theory approach (Charmaz, 2009) which contends that theory grounded in the data provides an understanding of the

experience as constructed by the participants and researchers. Grounded theory analysis uses the constant comparative method where coded data are compared within each interview, over time, and between all other interviews to identify similarities and differences in the data (Schreiber, 2001).

Each transcribed interview was initially coded using open coding of the statements and incidents. The purpose of open coding was to ensure that the analysis maintained a fit with the data so that the resultant interpretation was relevant to the structures and events from the data. Open coding ended when patterns became suggestive of categories, and categories began to be named. Selective coding followed; also, data that added to the developing theory and provided explanation and understanding of the core variable were coded. Theoretical coding then let us examine the relationships that were developing between selective codes and categories.

Field notes explicating subtle nuances of the context and non-verbal content of the interviews augmented the data. Memos that captured impressions, as well as ideas arising from the interviews and reflections on the research design and approaches, were also recorded (Schreiber, 2001). Lastly, theoretical sorting, diagramming, and integrating field notes and memos followed (Charmaz, 2009). The core variable, the knowledge-sharing process, and the three themes emerged which we continuously revised through further analysis of the data and discussions with team members. This model provided a means to predict and explain the nature and process of knowledge sharing over time. QRS International's NVivo9 qualitative software was used to store and organize the coded data.

### Qualitative Rigor

To promote trustworthiness of the findings, we adhered to the following criteria: (a) credibility, (b) dependability, (c) confirmability, and (d) transferability (Lincoln & Guba, 1985). *Credibility* included member checking (sharing experiences, interpretations and/or conclusions with select participants in order to determine if their own realities had been adequately represented) and peer debriefing (exposing the research process among the investigators, graduate students, and post-doctoral fellow). *Dependability* was established through the use of triangulation (e.g., diversity of participants and diversity of data collection approaches including interviews and memoing). *Confirmability* was achieved through the use of several researchers analyzing the data and then comparing their interpretations. Memos were also kept regarding decisions that were made related to methods used, analysis, and interpretations (Schreiber, 2001). *Transferability* refers to the acquisition

of “thick description” of the findings that enable readers to determine whether the concepts are similar enough to be transferred to other contexts or time (Lincoln & Guba, 1985).

### *Description of the First Nations Community*

The First Nations community in the study is located in southwestern Ontario, Canada, approximately 30 kilometres from the nearest city. At the time of the study, the population of the community was approximately 1,300 members (Statistics Canada, 2012); of these, 151 were aged 65 or older (Chief’s Assistant, personal communication, May 15, 2012). Community facilities included (a) an elementary school, (b) traditional cultural school, (c) administration-council building, (d) fire hall, (e) ambulance, (f) community centre, (g) family healing lodge, (h) a community health centre with a focus on public health and home care, and (i) a long-term care facility with 64 beds. The home and community care program employed a care coordinator, registered nurses, certified personal support workers, trained home support workers, a physical therapist, and a social worker. A band lawyer assisted with developing power of attorney (POA) documents. Additional supports for the elders included an adult day program, congregate dining, a fitness and exercise program, and bus trips to shopping centres and movies. At the time of our study, a senior services coordinator was in the process of being hired to advocate for the elders who experience problems with paying utility bills or have difficulty finding appropriate housing, and to arrange repairs and yard maintenance. All of these services were used to promote healthy living and enhance elders’ potential for remaining in their own homes for as long as possible.

### *Description of Study Participants*

Our study used pseudonyms to protect the identities of the participants; other identifying information has been removed. Network One consisted of Helen who was in her mid-nineties and had been diagnosed with Alzheimer’s disease. She lived in her own home with a granddaughter who did not appear to be involved in her care. Helen received two to three hours per day (Monday to Friday) of assistance from a personal support worker, including supervision of her medications, meal preparation, house cleaning, laundry, and socializing. Although Helen had been widowed for many years, she had extended family support as she had many children. One daughter, Belinda, who had financial and personal care POA, coordinated her home care services, assisted with banking, shopping, driving to church and medical appointments, and reminding Helen to take her medications. Bridget, a granddaughter, was

similarly involved with Helen’s care as she was a health care provider and had secondary POA for Helen’s personal care. A son, who also had financial POA, lived next door; he and his wife helped with groceries, banking, supplying meals, taking Helen for drives, and managing the yard work and snow shovelling. Other children and grandchildren also visited and maintained contact with Helen.

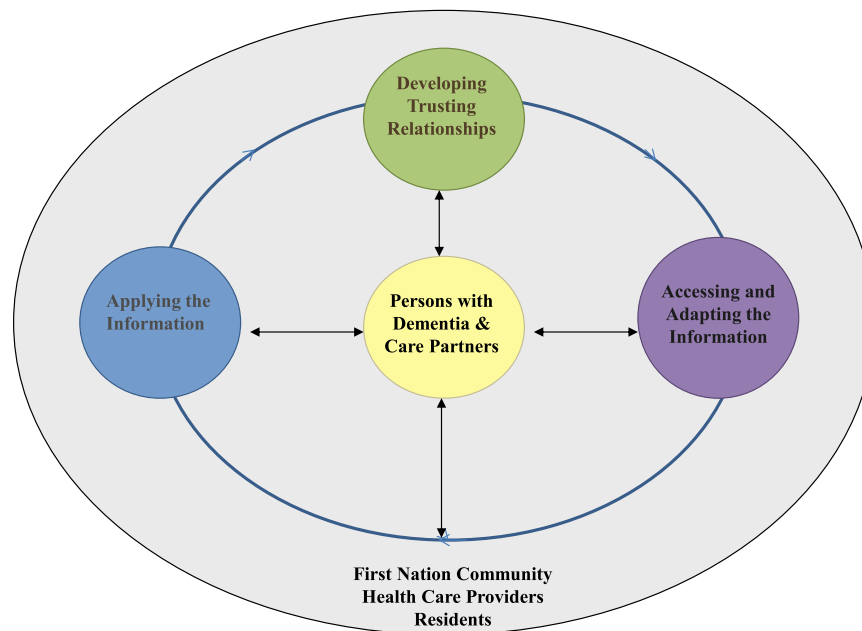
Network Two consisted of Anna who lived alone in her own home. She was in her mid-seventies and was diagnosed with Alzheimer’s disease three years previously. She was a retired health care practitioner who never married. However, she did have extended family members who supported her. A relative, Basil, stayed overnight when able, monitoring her behaviour and mental status closely, and consulting with the home care providers regularly. Relatives and neighbours lived up the road and watched out for Anna; those relatives who lived at a distance visited regularly. Anna received personal support services twice a day to assist with her meals, bathing, laundry, and house cleaning, supervision of her medications, and to enhance her socialization. Anna also received assessment, support, and health-related guidance from Calvin, an Aboriginal social worker, who visited her monthly and was employed part-time by the First Link program (McAiney, Harvey, & Schulz, 2008).

## **Findings**

### *Sharing Dementia Care Knowledge*

We devised a circular *sharing dementia care knowledge* model (see Figure 1), featuring the PWDs and their care partners at the centre of the circle to reflect their interdependence and the need for two-way information flow. The continuous process of knowledge sharing that engaged and connected those in the inner circle was conceptualized as representing three broad themes: (1) developing trusting relationships; (2) accessing and adapting the information; and (3) applying the information. The figure’s largest circle, the First Nations Community, which included HCPs and residents, was the context within which knowledge sharing occurred. A circular depiction of the dementia care knowledge-sharing process was particularly apt for our study: it was culturally relevant and appropriate, reflecting the First Nations philosophy that life represents a circular journey (Waldram, 2008).

We heard many success stories from the study participants, including suggestions for improvement in knowledge sharing, and which were observed and described within the framework of the three overarching themes. Both barriers and facilitative factors related to the broader social context of this First Nations community were identified within these themes.



**Figure 1: Sharing Dementia Care Knowledge.**

### *Developing Trusting Relationships*

#### *Supporting the PWD: A Network of Family and Neighbours*

Members of the dementia care networks demonstrated trusting, supportive relationships which are foundational to members' being able to share information. PWDs specifically acknowledged their care partners as a source of strength that contributed to their overall health and progress.

Interviewer: Is there anything else that you think has contributed to your memory getting better?

Respondent: Just the thought [that] somebody's now trying to help me. I wasn't swimming by myself anymore. ... The first guy is my nephew that lives with me. He is excellent, in fact, he took over my cooking... And he just kinda wiggled in there. So I let him. I'm so thankful to have people like that. (PWD A-2)

This PWD indicated that she felt support not only from her family members but also from neighbours who provided a sense of safety and security:

My neighbours keep a close eye on my place. ... 'cause they know I'm here by myself. ... Any time they see anything different, they'll get on the phone right away and call Basil [nephew] at work. Either that or they'll come over and check on me and say, Are you okay? (PWD A-2)

Family members valued and looked forward to the opportunity to spend time with the PWD. Spending time

listening to and supporting her was clearly a priority of family members.

But basically, the biggest thing is I'm just there to listen to her. ... And whenever she needs to say something ... I always make a point that at least I try to sit down for an hour or two a day with her. (Care partner A-1)

When listening to the PWD and making decisions on her behalf, family members strived to have "her [PWD's] best interest at heart" (Care partner A-3). The family members collaborated to make decisions for the "welfare" (Care partner B1-1) of the PWD when she was no longer able to make these decisions for herself.

Care partners expressed a willingness to keep the PWD at home as long as she desired despite the costs and time commitments by the family. Their desire was to ensure that the PWD was taken care of in the best possible manner.

She [Helen] says if she got to a point where she may need 24-hour care then that's where she said she wants to be. ... if she wants to be at home, then fine ... I think that would be the last place [LTC] ... to go if nothing else could be arranged ... they've got homemaking services here, and they can't provide ... 24-hour service, so then we have to be prepared to help. (Care partner B2-2)

#### *Setting the Stage: HCPs' Culturally Sensitive Client- and Family-Centred Approach*

The HCPs' client- and family-centred approaches set the stage for sharing knowledge. Having a respectful,

caring, and supportive approach was regarded as fundamental in creating an environment within which knowledge could be shared and co-created. A client-centred approach ensured that an HCP was listening carefully and respecting the wishes of the PWD.

I: How consistently do you usually try to see her?

R: It was once a week, ... a lot of time she'd be holding her head so I could tell it was getting confusing or tiring, so I asked her what would be better for you, what would you like, and she said every other week. So now we do it every other week. (HCP A1-1)

HCPs, who were usually First Nations and often from the community, were sensitive to the need for their knowledge-sharing approaches to incorporate the beliefs, values, and language of the First Nations heritage. By recognizing the importance of spirituality during their conversations and assessments with the PWDs and their care partners, HCPs facilitated the development of trusting, therapeutic relationships.

The cultural component of the [First Link] program is much different from other mainstream services. A person's religion or spirituality amongst First Nations is considered just as important as their physical needs, their intellectual needs, and emotional needs. You can't address one without the other. They all have to be addressed together, that's First Nations perspective. (HCP A1-2)

Discussions regarding the PWD's spiritual beliefs were encouraged as these were perceived by the HCP as a source of strength to the PWD.

I [Calvin] usually just reinforce and validate her beliefs and then sometimes I do share with her that I'm very happy that she has that faith to tap into. ... Whatever is important to the individual or whatever is valuable to them, then I hone in on it; work on it. I find it's a strength for them. So that we can keep basically banging away at that source of strength because that may be ultimately all that's gonna be left later on before everything else slips away. (HCP A1-2)

The historical significance and impact of the violence and abuse that former students experienced at residential schools needed to be understood and the related issues addressed by the HCP and the families. This approach facilitated the development of trusting relationships.

I chose a lot of the inner-child type of therapy ... because it looks a lot at spirituality as an important component... Inner child looks at a lot of trauma, and we know that a lot of First Nations people have a long-term history of trauma and people always bring up the residential school, that's a part. But there's other things too ... what goes on in that

particular family and became generational, over and over again. So I found any support type of counselling had to involve something spiritual and something that was consistent with trauma. (HCP A1-1)

Overall, care partners indicated that they trusted the HCPs. Trust is an essential component in developing relationships upon which dementia care information can be accessed, shared, and applied. Belinda explained why she trusted the personal support workers:

They've been dealing with this for years, it's nothing new to them ... they do it and they write it in the book ... So that's why I was able to check there and see. And they take temperature and blood pressure and sometimes they'll call directly back to the health centre ... And if a nurse has to go out, she'll go out. Then they'll call me and let me know if there's something different. I guess I just trust that they're caregivers. (Care partner B2-2)

### *Resolving Conflicts*

In order to foster trusting relationships, disagreements, particularly concerns regarding whether the PWD was being taken advantage of in any way, needed to be resolved. In one family where this concern was identified, a meeting conducted in a respectful manner was successful in resolving the concern.

Within six months, she [PWD] had spent over maybe a couple of thousand, or three thousand. ... So it was after that that I called a meeting. I just told the family, "A meeting over at Ma's, potluck." Because I figured they need to know, and I didn't want to point fingers at anyone. ... I don't know who or what, but they'd probably come to her and ask, "Can I borrow, and borrow, and borrow, and borrow". Next thing we knew, that much was gone out of her account. So I didn't say anything other than, "We shouldn't be doing that, that's not a good thing. Because we want money there, she's going to need it down the road for some things." (Care partner B2-1)

Another common issue that had the potential to cause conflict within families was the selection of family members to have power of attorney. Family members needed to have conversations about this process proactively.

A bit of a surprise ... she (Anna) had put my mom and myself as the two for personal power for care. I'm feeling a bit of a sense of increased anxiety. I'm there listed as her second support for her POA. I expressed that to my mom, I said you need to let your siblings know, need to meet and look at future planning and let them know who she has as her POA. I really don't want that first responsibility. I think that should be something that you as siblings should talk about. And what my grandmother's wishes are. (Care partner B1-3)

### Consistency in Care

Consistency of HCPs was an essential component in developing trusting relationships and sharing knowledge between PWDs, their care partners, and their HCPs. The coordinator of the Home and Community Care program made an effort to ensure that there was consistency in HCPs:

From my personal experience from working with First Nations, you need continuity of care; that is number one. They have to get to know the person that they are working with, because there's been so much distress in the past. Once they form that relationship with that person or those persons then it goes great. But if you have a continual change over and over and over and over, they don't want to know. They get fed up. They get turned off. They take off. They won't be there ... that's the key. You have to form a relationship, and your relationship is not formed in eight minutes [referring to the time nurses in the local Community Care Access Centre (CCAC) have allocated for a visit]. (HCP A2-1)

Providing consistency in care was particularly important with this clientele because of the potential for delusional symptoms that PWDs have.

If you got somebody who is paranoid or somebody who has hallucinations, you don't want to sort of exacerbate that situation by introducing somebody strange. We try to put people in that they know. (HCP A2-2)

### Sustaining Community Programs

In addition to having consistent HCPs for the PWDs and their care partners, the participants also acknowledged the need to have consistent, sustainable community programs. The HCPs identified that historically many programs have been short lived creating distrust within the community:

I think the biggest issue I'm seeing is ... short-lived programs ... the people only benefit while it's here. The benefits are much greater on the other side, for the practitioners getting experience and moving on to bigger and brighter things. And the agencies and the people who fund these pilot programs because it makes them look good. I'm starting to really feel bad for a lot of rural First Nations because they get these temporary band-aid approaches. It's no wonder they don't trust people. (HCP A1-2)

## Accessing and Adapting the Information

### Accessing Information during the Early Stages of Dementia

The term "early stage", which can last two to four years, typically refers to individuals who have mild impairment such as forgetfulness, communication difficulties,

and changes in mood and behaviour (Alzheimer Society of Canada, 2008). When Anna first became aware of her early symptoms, for example, she wondered if it might be Alzheimer's disease and proactively sought out help and information:

I asked the girls [personal support workers], "Do you have anybody there that knows about Alzheimer's?" I had an idea that's what I had, but I wasn't sure. And she says, "No, but we have a new guy started to work at our place" and she named Calvin. And she said, "He's into Alzheimer's, would you like to meet him?" I said, "Yes, I would." (PWD 1-3)

In contrast, Helen (PWD B-1) did not feel she needed to discuss her memory problems, seek information, or assistance from anyone: "I don't think I need to talk to anybody about that".

One of the greatest challenges for families was to help PWDs recognize that they needed assistance and be willing to access information and services. In attempting to remain independent, PWDs tended to deny their symptoms. For example, a daughter reported "Helen stated, 'I don't know why people think I need help, I can do all my work, you [personal support worker] don't need to come ...' So the lady left." (Care partner B2-1)

However, family members who used a supportive, caring approach – "without being pushy with my grandmother, just suggesting, and it's always been her choice" (Care partner B1-1) – tended to have positive outcomes. Bridget described the importance of her mother's being present during the first visit with the personal support worker:

So I think you [mother: Belinda] need to be there, because she [Helen] might ... find that support there if you were there when the worker does come in to sort of break that ice and make her feel comfortable. ... It's not taking things away from her independency. But she says "I need to clean this, I'm going to get to that", and it doesn't happen. So my mom has been very open with her about that, now you know it hasn't happened, that's why we need that support in there and now she's [Helen] come around, and she knows the worker's name, and has positive things to say about the individual and saying that she's a big help. (Care partner B1-2)

Following the recognition of dementia symptoms, care partners found that having a diagnosis of dementia helped them move forward in learning more about dementia.

Can it [dementia] be confirmed [diagnosed] in some way so then after that point in time [diagnosis], to be able to get information, literature that'd come from Calvin, and then being able to distribute that to the family members. (Care partner B1-3)



Following the diagnosis, many questions arose regarding the type of dementia, the symptoms, and the trajectory. For instance, “Is there anything available that might slow its progression?” (Care partner B1-3). And, with the progression of a PWD’s symptoms, “What is the risk of her falling, wandering?” (Care partner B1-2).

How to determine a PWD’s competency to make decisions, especially around legal decisions such as selecting a POA, was another concern about which care partners requested further information.

Is it like an early stage of it and so any decision that she would have made or [document] signed at that time is good, versus when she gets to maybe that middle stage versus the tail end. How do you determine whether or not what she’s saying and what she may be signing is valid? (Care partner B1-3)

Members of the community were fortunate to have access to a local resident with expertise on seniors’ issues.

His background has been law, and he has done various POAs for our seniors in the community. There have been information sessions to the community, and we’ve had him out at different open houses around just specifically addressing seniors’ issues. So we were able to draw on that for support. (Care partner B1-2)

#### *Accessing Information during the Middle Stage of Dementia*

The middle stage of dementia usually lasts from 2 to 10 years. Memory and other cognitive abilities continue to deteriorate, making it necessary to accept assistance with many daily tasks (Alzheimer Society of Canada, 2008). Care partners and HCPs closely monitored the PWDs for signs that their dementia was progressing and if additional information, care, and/or services were required.

I: What kinds of information do you [Carissa] think helps you to kind of plan for the changes that may lie ahead with Anna?

R: Right now they [personal support workers] are assisting with bathing ... If she starts to drop weight, then we know that she’s not eating, then we’d have to make sure when workers go in that they stay there while she eats to make sure that she does eat. ... If she’s been trying to use the stove, take the knobs off the stove and put them away somewhere. And just to kind of reiterate to her about the microwave and the kettle. (HCP A2-2)

HCPs not only monitored the PWDs for deterioration in their symptoms, but they also monitored the care partners for their ability to carry on with their caregiving role and for signs of stress and burnout.

Some families, the support for the PWD isn’t there. Mostly because the family is burnt out and can’t deal [with] it anymore. But yet, they still want different issues resolved surrounding their loved one [whether] it’s wandering or if it’s giving money out, not watching their finances ... and not understanding what they’re doing. Then I’m kinda the buffer between them. (HCP A1-2)

When asked what additional services would be helpful in caring for Anna, Basil (Care partner A1-2) replied that “counselling for her and better respite for myself once in a while” would allow him and his immediate family some vacation time. However, respite services beyond a few hours were not available.

Anticipating further deterioration, HCPs were also looking to the future:

If we could do some early intervention now with the family, they’ll be prepared and they’ll have the tools in place to deal with considering long-term care, eventually her death, and then grieving. (HCP A1-2)

#### *Accessing Information during the Late Stage of Dementia*

In this stage, which usually lasts one to three or more years, PWDs become unable to communicate verbally, cannot look after themselves, and require 24-hour-a-day care. The goal of care is to continue to support the person to ensure the highest quality of life possible (Alzheimer Society of Canada, 2008). This stage was the most difficult period of the dementia care journey for all involved. Calvin explained the kinds of information he provided to families at this stage.

Information on the stages, explaining to them that our goal is not to put people in care except as a very last resort. If it comes to a point where she basically is gonna require long-term care and round-the-clock medical services, then I will work with CCAC and Home and Community Care and try and find a really good place. I would still be there for all of them and a little bit of preparation about what they might see in those later stages ‘coz they’re gonna ask questions. (HCP A1-2)

HCPs attempted to prepare the families for the late stage of the disease by being open and honest about the progression of the disease and care options.

Answering those tough questions, “Well, is she going to die?” “Well, maybe not today but, yeah, she’s going to die.” The brain is gonna shut down, the brain cells are dying, the brain is gonna shrink. ... Sometimes there’s a time to really just tell them the truth. I don’t sugarcoat things to make it sound like it’s all gonna be okay and it’s not ugly. (HCP A1-2)

Care partners requested information on end-of-life decisions, recognizing that this may be a difficult conversation to have with the PWD.

They really need to talk about whether or not if they come upon her does she want to be resuscitated, those sorts of things, right? So that would be a difficult conversation perhaps to have. But I know that from what she's saying, she keeps wondering why she's still here. (Care partner B1-3)

### *Accessing Information from a Variety of Sources*

The participants were fortunate to have a First Link program within their community. This program was affiliated with the local Alzheimer Society and aimed to heighten awareness of dementia, to increase early diagnosis, care, and treatment of Alzheimer's disease. Calvin described the First Link program:

What they have now is much better than having nothing which is what they had before we came on board ... There wasn't anybody to go to the home and just hear the concerns. There wasn't anyone who would go to the family and kinda give tips on communicating or avoiding burnout. There wasn't anyone who would put the time in to advocate for the individual's needs like I will, or do some of that case management paperwork and forms for the individual to alleviate frustration or confusion. (HCP A1-2)

For example, Calvin approached the local geriatric facility to inquire

if referrals have to come directly from a GP [General Practitioner] or can they come from a nurse practitioner? ... So far [facility] says they'll accept them from nurse practitioners ... So quicker access. (HCP A1-2)

Care partners tended to approach HCPs located in the community, and their physicians who were not in the community, for dementia care information rather than seeking information from the Internet, journals, books, or the library. Basil was comfortable connecting with the personal support worker for updates on Anna's health status and shared his observations with her. Together they would discuss and compare their concerns and plan accordingly.

I: How do you exchange information with her as far as care?

R: Usually, outside. ... if I know she's getting ready to leave, I'll go outside and she'll come out and we'll talk. I'll say, "Did you notice this kind of thing?" And she says, "Yeah, yeah." So we just talk." (Care partner A1-2)

Care partners also sought out family members with health care experience for information on how to care for the PWD.

She's [cousin] been a nurse in a nursing home for a heck of a long time. She's retired now, but she still does it for certain older folks, she'll go over and she'll help them. So she'll do that too for my aunt. (Care partner A1-2)

Employees of the Home and Community Care Centre in the community accessed information through continuing educational opportunities such as "yearly in-servicing, whether it's formal education or workshops so that they're able to recognize early diseases that our membership might be going through." (HCP B1-2)

### *Adapting the Information to the Target Audience*

Although research-based dementia information, such as "10 warning signs, the healthy brains, the first steps", had been published in monthly community newsletters, an HCP expressed concern about the complexity of the language used. The information was felt to be helpful for

employees and other professionals in First Nations ... I don't find our material that helpful with the general population ... because I think it's maybe a little bit above with how they read or interpret ... Maybe it becomes more talking about the information instead of giving it to them to read. (HCP A1-1)

Being sensitive to the person's readiness and capacity to accept and understand the information was another strategy used by the HCPs: "I don't push it, I leave the door open for her to tell me more if she feels comfortable." (HCP A1-1) Tailoring the information to the specific needs of the PWD and their care partners worked best.

Families do like a little kit made up, and I've prepared kits for families, but I handle it delicately ... Sometimes families request a special one with a lot of detail. I would include the end of life, and things like that, I just don't hand them out to everybody, because some people don't want them. ... I try to tailor it towards the family. (HCP A1-1)

Knowing how much information to give, that would not overwhelm the PWDs or their care partners but would provide them with what they needed to know, was not easy.

The difficulty is in trying to control how much I'm giving them. I don't want to give too much, and make them more upset than what they need to be, but I don't want to give them too little either and make them think everything's going to be okay. So it's finding that medium, that middle ground where everything's honest and accurate, but it's not going to really hurt them, and it's not going to make them believe things are other than what they really are. (HCP A1-1)

Because of the stigma of dementia, PWDs were reluctant to attend support groups as it would require acknowledgement of their disease. In the small First Nations community, this kind of information would likely spread quickly. Thus, HCPs felt that they could not use this approach to share information which would be more efficient and cost-effective than the usual face-to-face approach.

Whereas if we could get the stigma away from groups, it would be easier to help many, many more people because then we could have a larger attendance and cover a lot more ground and topics. ...support groups, that doesn't seem to be wanted. (HCP A1-2)

### *Collaborative Supportive Work Environment*

Trusting relationships between HCPs working within the First Nations community facilitated their access to information. The HCPs involved with the Home and Community Care program appeared to have a good working relationship with the employees of the First Link program. In addition, their offices were in close proximity.

We'll have private consults behind closed doors. I'll talk to the nurses in their office or they'll talk to me in mine. Updating each other ... people can read my clinical notes from a home visit and likewise, I can read theirs. (HCP A1-2)

### *Inequitable Resources in the Community*

The participants expressed concerns that non-Aboriginal persons tend to perceive First Nations communities as unsafe. This was reflected by their reluctance to visit their communities outside of regular working hours, resulting in inequities in services and in access to information.

Services may be hesitant to come in just because it is a First Nations community ... There shouldn't be any reason to stop services after 4:30 if it's needed – to be able to feel comfortable and safe, to be able to come in to provide the services that are needed in the community. (Care partner B1-3)

Similarly, the lack of a physician in the community was perceived as a gap in services and information.

The fact that we don't have a physician here on staff is quite a service gap because it's very difficult because politically you wanna be really careful. I don't wanna sound like I'm casting blame on anybody but a frustration that I have, that is the same as the clients and families, is you don't get cooperation much from the doctors. (HCP A1-2)

Shifting resources from acute care to the community and long-term care was perceived as a viable solution.

You need to put a third [of the funding] to the hospitals. The other two thirds needs to go to long-term care and community. I said the hospitals don't need all that money. You don't need to be paying those CEOs 400,000 to 700,000 a year. The waste that goes on at the hospitals, I've worked there; I've seen the waste ... So let's get our priorities right. (HCP A3-1)

## **Applying the Information**

### *Applying Health Promotion Strategies*

Several strategies, shared by their HCPs and/or care partners, were implemented by PWDs to help trigger and maintain their memory, to maintain or enhance their ability to function independently, and to improve their sense of well-being (e.g., a memory box, calendar, and word puzzles). Eating healthy foods such as fresh fruits, vegetables, and nuts was another strategy promoted by the social worker, educator, and dietician. Keeping the PWDs socially engaged was also encouraged by family members and HCPs. As Belinda reported,

We get her out as much as possible, because she needs people around her. She needs people to talk to and when she eats, she needs people to sit with her and eat. And she eats really good. (HCP B2-1)

Anna also recognized the benefit of keeping socially engaged and appreciated the band council's efforts to promote socialization among the elders in the community.

They take them [elders] somewhere just for lunch or out shopping, just get them out and about, they've got their own bus and it's got in Indian words, 'the old people's driving bus.' (PWD A1-3)

Recognizing the importance of physical activity, family members encouraged their loved one to remain active, even though there was a risk of falling.

In the summertime, she [Anna] spends an hour or maybe three or four hours a week out there in the garden. I think that's good for her. I encourage her to get up and do those kind of things. (Care partner A1-3)

In an effort to decrease the incidence of falls, the Home and Community Care program had five personal support workers certified through the Centre for Activity in Aging. During their home visits, the personal support workers would assist frail older adults in strength and balance exercises.

### *Watching over the PWD*

When a personal support worker witnessed unsafe behaviour, she took the appropriate action by

contacting her supervisor, as exemplified in the following comments:

[The PSW calls] "Helen is here and she's got a pot of corn soup on the stove, and I'm so scared that she's going to scald herself, she's going to burn or scald herself." So I [supervisor] went out and she was right up against the stove ... So I called the granddaughter and I took her outside and I said, "When your grandmother is making this you need to be there with her. You can't leave her on her own." I said, "She could tip that over or she could get close to the stove and catch on fire. It's extremely dangerous. She shouldn't even be doing anything on the stove anymore." (HCP B2-2)

When safety concerns for the PWD were noted by the home care workers, family members were alerted and encouraged to address the issue.

We [HCPs] were concerned about her being on her own and somebody was trying to break in and take stuff ... We had to ... let the family know that this is what was occurring, so that the family should be monitoring a little closer on that especially when we're not here. (HCP A2-2)

An advantage of living in the community was that family members lived close by and neighbours were well-known to the PWDs:

The people on the top of the hill and the woman on this side, she hears and sees everything going on around my house. (PWD A1-2)

#### *Anticipatory Guidance: Sharing the Reality of the Disease Process*

HCPs assisted families in understanding the progressive nature of dementia and in accepting that the time may come when their love ones' symptoms may be too difficult to manage in the home environment.

It's moving into another realm where I'm also becoming the breaker of some hard news ... There comes a time you gotta let the people who are around this person know that there's not a whole lot we can do about it. The best thing is to make them as comfortable as we can and try and provide tips of how to alleviate the stress so that the person does not get agitated or more confused. That's the nature and progression of a dementia. (HCP A1-2)

### **Involving Care Partners in the Decision Making**

Involving as many of the family members who wished to participate in the decision-making process was also seen as important. Basil described the importance of family member's involvement, as long as they had the PWD's best interest at heart.

I: You also mentioned that you would like to have more than one decision maker.

R: Yes, I don't want it to be just me. I think it should be like a committee of the family. Like I don't want them to all say, "Alright [Basil], what are you going to do?" I said, "No, we all have to make this [decision] as a family." Even though I'm the one that she probably trusts the most but I still think enough of the family will want to have some kind of say to what happens with her. As long as they have Anna's best interest at heart, then I welcome their input kind of thing. (Care partner A1-3)

Bridget described the process that would occur in her family when her grandmother eventually required more services than were available through the Home and Community Care program. The following excerpt reflects the commitment Bridget had to maintaining her grandmother in her own home for as long as possible.

I know they're limited in the hours that they can provide. If she [Helen] needed 24-hour care, then I guess that would be up to the family to see what we can do. Can we schedule our days so that we're there for her? I'm sure something could probably be worked out. I think the last thing would be to put her in a home. (Care partner B2-3)

#### *Involving the PWD in Decision Making*

Knowing if, when, and how to involve the PWD in difficult decisions was not easy for the care partners. While PWD participation was considered valuable, family members were concerned about the impact this may have on them and tended to leave these decisions until the PWD was no longer capable of making them.

That's why I'm really dreading doing this POA thing because she's going to take it like, "Okay, I'm one step closer to the grave"... "I can't look after myself anymore. Now it's going to be downhill from here." She might get depressed. And that will affect her physiologically. So I know it's a step thing where it's psychological too. If they know that they can't look after themselves, look after their own affairs anymore, then that's a little bit of loss of self-esteem. So I don't want to do that to her until I think I've no choice. (Care partner A1-3)

#### *Impact of Applying the Evidence*

Having consistent, caring, and skilled home care workers who ensured that PWDs ate appropriate meals, took their medications as prescribed, were socially engaged, and in a safe, clean environment resulted in several positive outcomes. Anna reported a better quality of life:

Before I knew there was something wrong [before being diagnosed with dementia], I was getting confused, the harder I tried to think the more confused I got ... [Now] it doesn't take me as long to do my end of the month payments...I used to do all my hydro, my bell, everything...I do it a lot quicker now. (PWD A1-2)

Anna appreciated the advice and assistance from her HCPs regarding the home invasions made by local boys that she had endured. "Just knowing that people are watching you makes a big difference for me ...I'm not as scared to be by myself." (PWD A1-1)

Another strategy that provided some piece of mind for Anna was her Life Line support:

Handy gadget. If you hear somebody trying to get in the house, all you have to do is press the button, talk to the lady, tell her what's going on and she'll send the police right over ... That took a lot of worry off my mind. (PWD A1-1)

## Discussion

The need is clear for culturally sensitive knowledge-sharing strategies to build capacity to meet the growing dementia care needs within the many First Nations communities in Canada. This study explored the process, facilitators, and impediments to knowledge sharing within one cultural context, a First Nations community. In many ways, the factors identified were similar to those identified in other research (e.g., Finkelstein et al., 2012). The model core category, *sharing dementia care knowledge*, in the First Nations community included developing trusting relationships between and among PWDs, their care partners, and HCPs. This major theme was foundational for the sharing of knowledge as "people with dementia exist within a complex relational network ... the confounding variable of cognitive competence should not lift the person out of their network and set them apart from it" (Keady, 2010, p. 2). An aspect of this concept that was uniquely nuanced within the First Nations community was that HCPs developed trusting, therapeutic relationships with the PWDs and their care partners by using a culturally sensitive, holistic, client- and family-centred approach that recognized the importance of spirituality and the historical significance of residential schools on First Nations people. In caring for First Nations people, it is important to understand the violence and abuses that former students experienced at residential schools and the lasting consequences this has had on their ability to function within their communities (Aboriginal Affairs and Northern Development Canada, 2012). This shared recognition of historical context contributed to a foundation of trust and positive relationships, essential to the sharing of knowledge between the PWDs, their care partners, and HCPs.

The second theme, *accessing and adapting the information*, once again had many commonalities with other cultural contexts. For example, our previous dementia care research, conducted with PWDs, their care partners, and HCPs in rural Ontario, Manitoba, and Saskatchewan revealed similar themes such as the difficulty in accessing timely, appropriate, flexible, supportive client-centred home care services (Forbes et al., 2008). One difference identified in the larger Ontario study (Forbes et al., 2012) was that PWDs often denied their symptoms and saw no reason to access dementia care information or to reach out for assistance. This left their spouses potentially isolated in their dementia journey. Fortunately, in the First Nations networks, the family members were able to work with their loved one by being open about the needs of the PWD in our study and the family's own needs. As a consequence, they were able to convince the PWD, "without being pushy", that by accepting some assistance she would be able to remain in her own home longer and the services would be beneficial to her daughter as well. Having the daughter present during the HCP's initially home visit was also helpful.

Our findings re-confirm the importance of not assuming that PWDs by virtue of their diagnosis are "incapable" of being active participants in decision making (O'Connor & Purves, 2009). Indeed, research evidence is suggesting that persons in advanced stages of their dementia may still be capable of participating in some degree of decision making (McCormack, 2002). As well, there is a growing recognition that PWDs as citizens have inherent rights (Bartlett & O'Connor, 2010). It is critical that knowledge-sharing efforts to enhance dementia care include the PWDs as well as their formal and informal care providers. Using a narrative approach creates the space for the PWD to tell his or her story. This positions the person being assessed as the "expert" about his or her story and has the potential to allow others to gain insights into how the person is making sense of a particular decision. Recognizing and maintaining a PWD's strengths rather than presuming and looking for loss, and "assisting" rather than "substituting" in decision making should be the focus (O'Connor, 2010).

Problems involving access to necessary information such as a health diagnosis are pervasive across cultures. Only 20 to 50 per cent of PWDs receive a diagnosis in high-income countries; even fewer in lower-income countries. Early diagnosis "empowers PWD to participate as fully as possible in planning their own lives ... and in making important decisions about future treatment and care ... The diagnosis can mark a new start to the rest of their lives" (Prince, Bryce, & Ferri, 2011, p. 4). However, barriers to access to care are locally determined, and therefore, the solutions need to be adapted to suit the local context as well. For example, in the

First Nations community of our study, a First Link program was implemented to assist PWDs to receive an accurate diagnosis.

Recognizing the importance of receiving an early diagnosis and the difficulty in getting a diagnosis from some general practitioners, the HCP affiliated with the First Link program in our study received permission from the local geriatric facility to have a potential nurse practitioner in the community refer clients directly to this facility (the community was in the process of hiring a nurse practitioner). General practitioners often

do not appropriately diagnose and treat those with dementia usually because of a lack of knowledge, but often also because the diagnosis is taboo, the therapeutic options are apparently limited, or because it is feared that the doctor-patient relationship will suffer by bringing bad news. (Donath et al., 2010, p. 2)

Having an accurate diagnosis of the type of dementia allowed the PWDs and their care partners to move forward in seeking out information about the disease process, treatment options, available services and supports, and the legal implications of the PWD's making decisions regarding power of attorney.

Home and Community Care and the First Link program were available in the community to the PWDs and their care partners to support them during the current stage of dementia and to prepare them for the next stages. Information was usually requested from the First Link program, their personal support workers, physicians, or a family member with health care expertise rather than from the Internet, organizations outside the community, or library.

Information was provided one-on-one as meeting in groups was not desired by the PWDs or their care partners due to the stigma related to dementia. Support groups can be useful, versatile, and cost-effective approaches to improve outcomes and quality of life for both the PWDs and their care partners (Alzheimer Disease International & World Health Organization, 2012). Continued efforts to heighten awareness about dementia, addressing the misunderstandings about dementia (e.g., that it is an inevitable part of aging and that nothing can be done about it), and introducing conversations about promoting "dementia friendly communities" will lessen the stigma surrounding dementia (Department of Health, 2012; Keady et al., 2012). Evidence of this was found in this close-knit, culturally homogeneous community just as in other settings (Keady et al., 2012).

Stigma was also identified as a broader concern for this community. Whereas information was readily shared

among the HCPs in the community, there did not appear to be the same level of sharing of information with HCPs and organizations outside the community. Indeed, there was a sense that some physicians and other HCPs were reluctant to service members of the First Nations community. There is a need for research and interventions that focus on stigma reduction not only for dementia, but also for the other social and cultural issues that may be embedded in a multi-ethnic society and which contribute to inequities and ultimately to knowledge sharing.

A concern raised by an HCP was the sustainability of the First Link program as the pilot funding was close to ending. This uncertainty perpetuated the historical distrust within the community of short-lived pilot projects that are funded for only two to three years and then disappear. First Link HCPs were just beginning to be trusted and able to work with PWDs and their care partners. These "temporary band-aid approaches" may do more long-term harm than good as they are detrimental to establishing and maintaining trusting relationships between HCPs, First Nations PWDs, and their care partners over time. At the very least, the community should be informed of the length of the confirmed funding from the onset of the program. This concern is not unique to this community as Canadian research funding is primarily limited to just a few years. It is thus extremely important to build into the research projects ways of sustaining the work, if at all possible.

The third overarching theme in our model, *applying the information*, revealed consistencies in the use of health promotion strategies implemented by PWDs and their care partners in this community as in others, such as healthy eating, exercising, and social engagement. The HCPs were instrumental in promoting these strategies, in alerting family members and colleagues to safety concerns, and in preparing the families for what to expect in the future. Rather than aiming for *independence* of the PWD, these achievements reflect the *interdependent* relationship of the PWD with care partners and HCPs as an achievable goal. However, care partners appeared to need information on how to include the PWD in planning for the future as there was a reluctance to do so for fear of upsetting the person. As we have described, PWDs have a right to have a voice and should be enabled to participate in decisions that are important to them (Cook, 2008). Our study participants suggested that the First Nations context may provide advantages for achieving this inclusion due to familiarity and proximity among members of the community. It is important that generic knowledge-sharing efforts to enhance dementia care be nuanced to capitalize on cultural and contextual opportunities such as these.

## Limitations

What is most significant to this research is that in order to share an experience, PWDs, their care partners, and HCPs must be willing and capable of participating in the study.

Those who are less articulate, and/or feel overwhelmed and consumed by their symptoms or by their caregiving or provider role, may not be willing to participate. The stories we heard in our study were primarily success stories. It may be that all stories are not as positive.

## Conclusion

Commonalities between the findings of this study and other research on knowledge sharing within dementia care networks include the importance of developing trusting relationships among PWDs, their care partners, and HCPs (e.g., Finkelstein et al., 2012). Trusting relationships were developed through the use of strategies such as (a) having a supportive network of PWDs, care partners, and neighbours; (b) HCPs' approaches that were culturally sensitive and client and family-centred; (c) resolving conflict; (d) continuity of care; and (e) sustaining community programs. These results confirm that different types of information are accessed at different stages of dementia primarily from HCPs and family members with health care experience and that the information is adapted according to the readiness, readability, capability, and preference of the target individual. Strategies used for applying the information included watching over the PWD, anticipatory guidance, and involving care partners and the PWD in decision making. Further research is needed on how to ensure that PWDs have a voice in the decisions that affect them.

Findings unique to the First Nations cultural context of our study included the impact of historical events on present expectations and relationships (such as the residential school experience in Canada) and the perception of bias or stigma extending beyond the context of dementia to include other aspects of discrimination such as access to health care. This study also supports the research of others (e.g., Estey et al., 2010; Finkelstein et al., 2012) who identified that knowledge-sharing strategies should be culturally sensitive and "context-dependent" (Estey et al., 2010, p. 85). Culturally sensitive approaches are essential to developing trusting, therapeutic relationships. Once developed, knowledge sharing through accessing, adapting, and applying the information would be possible for all cultures.

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