Formal Dementia Care among First Nations in Southwestern Ontario*

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RÉSUMÉ

Cet article traite la façon dont les soins de la démence sont prévus pour les collectivités des Premiers Nations du sud-ouest de l'Ontario. Les données ont été saisies au moyen d'entretiens approfondis avec les prestataires de soins de santé et analysées en utilisant une méthodologie fondée sur une théorie constructiviste. Afin de comprendre les soins de la démence, deux cadres interdépendants ont été identifiés : un cadre de prestation des soins et un cadre de connaissances. Le cadre de prestation des soins a défini des objectifs de soins, des éléments de soins dispensés, les barrières de soins, et des stratégies et des solutions de prestation de soins pour surmonter les obstacles. Le cadre de connaissances a défini quatre groupes de parties prenantes : les personnes atteintes de la démence, les prestataires de soins informels, les prestataires de soins formels et la communauté des Premiers Nations. On a précisé les connaissances qu'il faut que chaque partie possède ou dont elle a besoin et les processus de partage – ou, à défaut de partage – des connaissances dans les soins de la démence. Plusieurs barrières, dont beaucoup sont créées par un manque de connaissances, ont eu un impact négatif sur les soins de la démence. Cependant, les professionels de soins de santé avaient des stratégies efficaces pour la prestation de soins qui ont été conçus pour surmonter les obstacles y compris le partage des connaissances.

ABSTRACT

This article explores how dementia care is provided to First Nations communities in southwestern Ontario. Data were collected through in-depth interviews with health care providers and analysed using a constructivist grounded-theory methodology. Two interrelated frameworks for understanding dementia care were identified: a care delivery framework and a knowledge framework. The care delivery framework identified care goals, care elements being provided, care barriers, and strategies and solutions to deliver care and overcome barriers. The knowledge framework defined four groups of knowledge stakeholders: persons with dementia, informal care providers, formal care providers, and the First Nations community. It identified the knowledge each stakeholder held or needed and processes of sharing – or failing to share – knowledge in dementia care. Several barriers, many created by a lack of knowledge, negatively impacted dementia care. However, health care professionals had effective strategies for providing care, designed to overcome barriers and which encompassed elements of knowledge sharing.

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Background

Over the next two decades, the number of Canadian First Nations persons over the age of 65 is expected to triple (Indian and Northern Affairs Canada, 2008). Paralleling this development is a projected increase in chronic diseases, including dementia (Hendrix & Cloud-LeBeau, 2006). However, our current knowledge regarding how the First Nations population experiences dementia or dementia care is virtually nonexistent (Jervis, Cullum, & Manson, 2006). Although the current rate of dementia in the First Nations population is not known, there is a high prevalence of diabetes, substance abuse, heart disease, hypertension, and smoking (First Nations Centre, 2005; Weiner et al., 2003), all of which represent significant dementia risk factors (Craft, 2009; Li, 2008; Patterson et al., 2008).

Dementia is a relatively new phenomenon in First Nations communities (Henderson & Henderson, 2002), and as a consequence, there may be a lack of community knowledge regarding its signs and symptoms. Ensuring high-quality health care in First Nations communities requires special attention to issues surrounding the interaction of both administrative and cultural knowledge systems, and has yet to be explored in a dementia-specific context. Administration of health care in a First Nations context is complex, as users and providers must navigate "mainstream" provincially operated primary-care, physician, specialist, and hospital services as well as federally funded Aboriginal health programs, including access to non-insured health benefits. Meanwhile, the articulation of First Nations and Western health care knowledge systems, such as through the incorporation of traditional healing practices into disease management, has been well described as a means of ensuring culturally appropriate care (Durie, 2003; Hunter, Logan, Goulet, & Barton, 2006). When these administrative and health care knowledge challenges are overlaid with the additional challenges of dementia care – which often require multidisciplinary teams, respite care, and access to long-term care facilities – exploring First Nations dementia health systems and care delivery becomes of prime importance to understanding how best to structure this care to ensure that it is accessible, effective, and of high quality.

This study aimed to start filling the knowledge gap regarding how First Nations communities experience dementia care. The objective of this study was to explore and describe the experiences of health professionals in providing care for First Nations persons with dementia (PWD) through a qualitative grounded-theory framework. More specifically, the study aimed to: (1) outline the interactions health care providers have with First Nations patients/clients, their families, and other health care providers; (2) identify barriers to care; and (3) identify successes in providing care.

Methods

Creating Community-Based Research

This research attempted to enhance knowledge transfer to and cooperation with the First Nations community with respect to health care and health research by using a community-based approach. Community-based research is consistent with a constructivist paradigm because it emphasizes the participation and influence of community partners in knowledge creation (Israel, Schulz, Parker, & Becker, 1998). In taking this approach, it has the potential to develop existing community strengths and resources, increase community control over the research process, overcome distrust on the part of the First Nations communities that have historically been research "subjects", and empower the community (Fletcher, 2003; Israel et al., 1998).

The community partner involved in this project was a local Aboriginal health access centre. Although not administratively related to other health centres, this health centre maintained ties with nearby reserves through having a representative from each reserve sit on their board of directors. Rapport was developed through existing relationships with one of the researchers, and volunteering at and attending community events hosted by the centre. Prior to beginning the project, a presentation was shared with the board of directors to explain the goals, methods, and potential benefits of the project and to receive initial feedback. Following the board of directors` approval, informal focus groups were held with staff members to develop interview questions for participants. The support of the health centre was instrumental in securing funding for the study and in recruiting initial participants. Throughout the project, the executive director and board of directors were given updates on progress.

Ownership of the research process and results by the First Nations community was accomplished through several mechanisms. Extensive member-checking was conducted, in which participants were invited to comment on, add to, and if necessary, correct the researchers' interpretation of the data. The project's community partner had full access to data derived from the project, including interview transcripts and any write-up of results. Finally, separate meetings were held with the community partner's staff members, the community partner's board of directors, and the staff at the reserve health centre to present and discuss research findings.

Defining Dementia and Developing the Interview Guide

Kaufert and Shapiro (1996) have reported on the challenges in creating a valid dementia screen for use in First Nations communities, due to difficulties in accounting for language, cultural, and situational factors. Dementia prevalence and diagnosis rates in First Nations populations are not well understood, with only a small study indicating that rates of Alzheimer's disease may be lower in certain communities (Hendrie et al., 1993). For these reasons, and because dementia is often underdiagnosed, it was necessary to use an operational definition for dementia. Thus, for the purposes of this study, dementia was defined as "persisting memory and/or cognitive problems", which was felt to capture the client population accessing dementia care services. Accordingly, participants were asked to describe their experiences with clients whose symptoms met these criteria. This definition was arrived at and mutually agreed upon during the informal focus groups held with the community partner's staff members.

The semi-structured interview guide used for initial interviews with participants was also developed during these meetings. One of the researchers presented a draft of potential interview topics and questions to the community partner's staff members. Staff members and the researcher proceeded to discuss the list of topics and ensure that it covered all relevant areas.

For participants who were interviewed twice, the second interview did not follow an interview guide. Rather, participants were asked to expand on and confirm or disconfirm themes and theories that arose during other interviews and throughout data analysis.

Participant Recruitment

Participants were recruited through health centres in an urban centre (city) and on a reserve in southwestern Ontario; the reserve was located within a one-hour driving distance of the urban city centre. These centres were not formally related to one another. On reserve, health care services were funded by the federal government and administered by community members and health centre staff. To be included in the study, participants had to work, or within the recent past have worked, in a health care capacity with First Nations PWD. Convenience sampling was initially used to recruit participants. The study was advertised through emails sent to staff members of the community partner, and all eligible respondents were included in the sample. Snowball sampling was used to enhance the participant pool; initial participants were encouraged to ask colleagues who might be interested in the study for permission for the researcher to contact them. Finally, theoretical sampling was used to expand on themes and develop theoretical categories. We achieved this by purposely seeking out participants from a wide variety of disciplines and – to obtain alternative viewpoints – from both city and reserve communities throughout the project, and by re-interviewing previously recruited participants to confirm or disconfirm emerging theories.

Data Collection

Rich data were collected through 11 in-depth, semi-structured interviews. These were held in a private office at the participant's place of work, and were roughly 1 to 1.5 hours in duration. Questions were open-ended and allowed for flexibility to pursue interesting topics raised by participants. Four of the participants were interviewed twice as part of the theoretical sampling process to develop themes and confirm or disconfirm emerging hypotheses and theories. Interviews were digitally recorded and transcribed verbatim. Additional sources of data included field notes that were written up directly following the interview. Throughout the theoretical sampling stage of data collection, participants were asked questions that took the form of "Other people have told me [blank], has this been your experience? If not, how has your experience differed?" Data collection continued until saturation was reached, defined as the point at which no new themes were raised during interviews and theory was resonating strongly with participants, incorporating the depth and breadth of their experiences (Steward, 2006).

Given that the interviewer was non-Aboriginal, it was important to acknowledge and be sensitive to the cultural and ethnic divide between interviewer and participant. Dunbar, Rodriguez, and Parker had suggested that disclosing information about the interviewer can help to build rapport and trust in cases of cross-cultural interviewing (Dunbar, Rodriguez, & Parker, 2002). Developing this rapport is consistent with a qualitative constructivist research methodology, which is by definition subjective, and may also encourage participants to disclose more about themselves and their own experiences (Charmaz, 2006; Dunbar et al., 2002). As such, before the beginning of the first interview with each participant, the interviewer told "her story" by giving a brief personal background.

Data Analysis

For data analysis, we used a constructivist grounded-theory approach, which focused on understanding processes and co-construction of data, achieved by employing increasingly complex and analytical levels of coding to synthesize data and generate a theoretical understanding of the experience studied (Charmaz, 2006; Waldram, Herring, & Young, 2006). The findings generated through this research represent a construction based on the interactions of the participants and researchers and were influenced by their assumptions, circumstances, and interpretations (Guba & Lincoln, 1994).

A constant comparative method of data analysis was used, with comparisons between data segments made at each stage of analysis – the study was thus iterative, moving through data collection, analysis, and theory building stages multiple times and non-sequentially (Charmaz, 2006). Data were initially coded incident-to-incident, in which active codes (use of verbs) were used to help link interview statements to key processes that participants described. Focused coding was then used to synthesize data from across interviews and to highlight recurring themes. Finally, we used theoretical coding to explore relationships between categories generated during focused coding and to bring the focused codes together under a larger theoretical framework. We used diagramming (Lofland, Snow, Anderson, & Lofland, 2006) and memo writing (Charmaz, 2002) to conceptually map and elaborate on the relationships between initial codes, focused codes, and theory. Memos were also used as a reflexive tool to acknowledge the researcher's preconceptions.

Ethical Considerations

Ethical approval for this project was granted by The University of Western Ontario Health Sciences Research Ethics Board and by the community partner's board of directors. To ensure confidentiality, we gave participants pseudonyms and removed identifying information from transcripts. Trustworthiness was achieved by our adhering to the evaluation criteria of credibility, originality, resonance, and usefulness (Charmaz, 2006).

Findings

Seven participants, encompassing a wide range of health professionals, were recruited to the study (see Table 1). Participants had varying levels of experience working in First Nations communities in southwestern Ontario, ranging from six months to more than 10 years. Five participants self-identified as First Nations. The majority of participants provided care only to seniors living in the community, although two participants also provided care to children and adults of all ages. Participants had varying proportions of dementia clients on their caseloads, ranging from 15 per cent to 100 per cent.

Table 1: Participant pseudonyms and occupations

Participant Pseudonym	Occupation
Alfred	Traditional healer
Aragorn	Social worker
Elana	Personal support worker
Jane	Registered practical nurse
Linda	Community health worker
Mary	Health educator
Rose	Registered nurse

Based on analyses of qualitative interview data, two frameworks emerged that revealed the process of providing health care to First Nations PWD. The first was a care delivery framework, with which we described the elements of care being provided, barriers to care, and strategies to providing care and overcoming barriers. With the second framework, we interpreted health care delivery through the lens of knowledge, and outlined how having or not having knowledge and sharing or failing to share knowledge underlie First Nations dementia care.

Care Delivery Framework

Care delivery in First Nations was based on two underlying, interconnected care goals: (a) ensuring client safety and (b) keeping clients at home and in the community. Health care providers defined elements of care that needed to be provided to ensure that these goals were met, and then strategized with regards to how best to provide this care. Barriers to care were frequently encountered, forcing health care providers to find creative solutions to overcome them.

Identifying Elements of Care: Participant Roles

With the exception of the health educator, participants focused on assessing clients, managing symptoms, and dealing with crises in their day-to-day care. Three of the health care providers we interviewed had roles that encompassed coordinating care for their clients. The traditional healer's role additionally encompassed investigating and determining the cause of the dementia, and treating symptoms. The health educator's role was focused on educating PWD, their family caregivers, and community members about dementia risk factors, signs, and symptoms, disease progression, and available treatments and resources.

Encountering Barriers

Lacking Resources

A lack of basic dementia care resources was apparent in the reserve community: physician services, respite care, crisis support, emergency services, long-term care, visiting nursing services, and medical transportation were all limited or absent. In both the city and reserve locations, participants noted that First Nations community health services lacked personnel, resulting in extremely heavy workloads and participants' having little time for anything other than crisis management.

> …it sometimes feels like you're running around putting out spot fires, but the forest is still burning. (Jane, registered practical nurse)

There were few dementia care programs and resources available that incorporated First Nations knowledge, and as far as participants were aware,

Table 2: Summary of specific elements at each stage of the care delivery framework

Elements of Care	Assessing Managing symptoms Dealing with crises Coordinating care Healing Educating
Barriers	Lacking resources Failing to collaborate Encountering mistrust PWD not accessing care Burning out
Strategies/Solutions	Maximizing available resources Creating culturally appropriate care Relying on family Investigating Developing relationships Encouraging action Using coping strategies

First Nations-specific dementia care literature did not exist. Furthermore, lacking access to this knowledge themselves, health care providers were unable to share potentially pertinent knowledge with clients and families.

> I did take training with [a dementia care organization] and...in that I don't remember them having any culturally appropriate material at all. It was all pretty general. (Linda, community health worker)

Failing to Collaborate

Health care personnel on the reserve were able to work together quite effectively, in part because of their proximity, as many of them had offices in the same building. However, collaboration fell short when personnel attempted to work with health care professionals or institutions outside of the community. Three specific situations in which collaboration was difficult were mentioned: (a) with hospitals, (b) with Community Care Access Centres (CCACs),[1] and (c) with physicians.

Several participants were responsible for transitioning clients home from hospital stays. These transitions almost never happened smoothly, because health care providers did not receive discharge information about what care had been provided to the client. Receiving information about a client's returning home from hospital was vital in order for the provider to be kept apprised of changes in medication, medical condition, and equipment needs; a lack of communication often created safety concerns.

> …once in a while the hospital will call us and work with us and try to get them prepared to come home, other times they're just sent straight home… a lot of that communication is being lost now. (Rose, registered nurse)

CCACs are supposed to have access to medical records from hospital stays. However, despite community members signing forms that legally allowed for the distribution of this information, health care providers on the reserve often did not receive a copy of the hospital discharge papers from the CCAC. Health care personnel affiliated with the CCAC also served clients on the reserve. However, in many cases, communication between these visiting health care providers and the reserve staff was insufficient and the services were inconsistent, leaving reserve staff to fill in gaps in care.

> I do everything. We're not supposed to do wound care, but we do wound care. The visiting nurses do it, but when they don't show up, they come two days out of five or seven, so who else but we do it. We do the bandaids, we do the dressings. (Elana, personal support worker)

Participants frequently mentioned poor collaboration with physicians. Aragorn,[2] a social worker, for example, discussed not receiving follow-up communication: "When I sent that, those [cognitive] assessments, the doctor never said anything, didn't even contact me. I didn't even get a fax back."

Other participants had similar concerns. Jane, for example, commented that physicians did not always value her professional opinion. Finally, Alfred, a traditional healer, described how physicians might not accept the validity of traditional healing and alternative medicines, making it difficult to have collaborative client care.

Due to poor collaboration, participants were not always aware of diagnoses, medications, and care plans made by other health care providers. This, in turn, made it difficult for participants to provide high-quality, continuous care and to ensure the safety of clients.

Encountering Mistrust

Health care providers encountered mistrust on the part of clients and community members in several situations. This was described in particular by health workers who were relatively new to the community. For example, Mary, a health educator, spoke about this when describing her experiences meeting community members:

> I think people are embarrassed about that or what have you. And I've seen that [embarrassment] in a lot of people I work with … so I think that kind of general "let's just keep it to yourself" is still pretty predominant, even in the general community, and especially with the older generation.

Aragorn had similar experiences when he first started working in the community, and described it as feeling as though he was "walking on thin ice":

> I think they have every right to be suspicious of everybody and I think they have every right to stand back and say: “Before we participate or open up or take part, let’s see where this is really going. Let’s see if this is really real.” Like wouldn’t you? If you lived in a community and a culture where basically for the last 250 years you’d had the world pulled out from under your feet?

PWD Not Accessing Care

Participants noted that PWD were often unwilling to seek out available dementia care resources, and often kept symptoms “to themselves”.

> I think people are embarrassed about that or what have you. And I’ve seen that in a lot of people I work with…so I think that kind of general ‘let’s just keep it to yourself’ is still pretty predominant, even in the general community, and especially with the older generation. (Mary)

There was wide agreement among participants that PWD and their families frequently did not seek out care until a crisis occurred, such as burning a kettle on the stove or PWD injuring themselves in a fall. A crisis was thus often the motivating factor leading to significant changes in dementia care; it was at this point that health care providers became involved and could begin to assess and address the needs of the PWD.

Participants cited several reasons for PWD not seeking care for symptoms, including denial of symptoms, fearing a diagnosis and its repercussions for personal independence, and not understanding or recognizing symptoms. Many health care providers found that PWD and their families were lacking information, in part because the understanding of dementia symptoms as part of a disease process is a relatively new concept for First Nations communities.

Burning Out

Health care providers spoke about experiencing feelings of stress and burnout, which affected their mental and emotional well-being. Participants often attributed these feelings to being overwhelmed with work. Having an emotional investment in clients compounded these feelings of burnout, as health care providers then had the additional burden of worrying that their heavy workloads were impacting the client’s quality of care. Jane summarized the issue of emotional burnout well:

> It relates to work load versus staffing. It also relates to how much do you care? I think that people who care are more prone to getting burnt out…I mean, what makes me good at what I do also makes me not good at what I do, if that makes sense. (Jane)

Adopting Strategies, Finding Solutions: Successes in Providing Dementia Care

Being Proactive: Maximizing Available Resources. To function effectively amidst limited funding, services, and personnel, health care providers maximized available resources through a number of creative strategies. For example, care was provided at strategic times of the day to maximize client safety and effectively deal with issues such as poor nutrition and missing information about client care. Participants often accompanied clients to their referral appointments as well, capitalizing on this time to ensure effective communication and collaboration with other health care providers:

> With some of our clients, we have to have a personal support worker go in with them to the doctor’s, sit through the whole conversation with the doctor, so she will ensure that the points that need to be raised are, and answered. (Rose)

Health care providers, with the client’s permission, booked referral appointments and medical transportation services, thereby increasing the likelihood of clients following up on health issues. Two participants who coordinated support worker services maximized care by sharing important knowledge.

> Our PSWs [personal support workers], when I have a new client come on board and we go through a care plan, and I sit them down and I read it with them...Because they don’t have the background that I have, I feel it’s important that they understand why I’m looking for the haemorrhage, why I’m looking for the risk of infection here and why it’s so important that we catch it right away if something happens. (Rose)

Finally, in the reserve community, available community health resources were pooled to enhance care. Health care providers relied on each other to fill in gaps in services – taking over the responsibilities of a sick colleague, for example – and thus working together as a team to ensure continuity of care.

Joining Two Halves: Creating Culturally Appropriate Dementia Resources and Care

Given the paucity of First Nations dementia care resources, participants often took the initiative to create their own or adapt mainstream resources to make them more culturally appropriate. Aragorn, for example, created a bereavement program for the families of his clients, which drew from both Western and traditional methods of healing. Mary was also in the process of adapting mainstream dementia education resources to make them First Nations-specific, and had met with community Elders for suggestions.

Health care providers also delivered culturally appropriate care by bringing together Western and traditional medicines in such a way that suited the client's needs. Alfred, the traditional healer, encouraged his clients to seek out Western medicine, and strove to work in partnership with Western health care practitioners. Elana, a personal support worker, collaborated with traditional healers:

> I have two clients working with me…[with their] traditional medicines, and I work with their healers … So, whatever their healer says, I'll do it … if they want their house cleaned out with a seed of the sage, you know, I go in and I clean their houses out.

Caring for Your Own: Involving and Relying on Family

Health care providers increasingly relied on the involvement of family members as dementia symptoms progressed, as clients began to need more care than health care workers could realistically provide. Faced with a lack of time due to heavy client loads, having family members involved in patient care was often the only solution that allowed health care providers to continue to ensure client safety and prolong independence. Participants also noted that at times the entire community would help to take care of a PWD.

> And it's a small world out there, because if you don't know how they are and if they're not doing well, you're going to get a call anyway, by somebody else saying "I think you need to, you know, go see this person" … So, there was that sense of community amongst our people. (Linda, community health worker)

Family members also served as an important source of information about changes in the client's symptoms and care needs:

> 'Course, I like to have the family members sit with me when I go out and do an assessment on an elderly client … The daughter will say "Remember, Mom, you did this last week?" And she goes, "Oh yeah, that's right". You know, so they kind of clue me in to what's really going on in the home. (Rose)

Being Conscientious: Investigating

Health care providers used investigation as a tool to overcome the pervasive gaps in information about client health and care management that occurred due to failures to communicate and collaborate. "Investigating" consisted of conscientiously tracking down missing information and persistently following up with other health care providers involved in the client's care. Rose spoke about how investigating was necessary upon a client's returning home from hospital:

> So it's a lot of – I want to say footwork – it's a lot of "OK, what hospital are you in?" And then getting the information and then calling back to those hospitals, to those people, and saying "All right. You directed them to where?" So we had to call [the] CCAC office, trying to draw information out and work with them.

Investigation was used to explore the severity of dementia symptoms in clients who failed to share information by hiding or denying symptoms, and as a strategy to provide everyday care. Alfred used investigation in his traditional healing, for example, to determine the cause of a dementia condition and to formulate a care plan:

> So it [dementia] stems from somewhere, you know … we got to go back and start to unravel: where did it start, how did it start, what does it need to do? … It stems from what we take in and we get affected by it.

Being Persistent: Developing Community and Client Relationships

To overcome the mistrust of clients and community members, health care providers, particularly those new to the First Nations community, worked hard to develop relationships and build trust. This was accomplished by purposely seeking out the expertise and support of Elders and Chief and Council, attending community events, approaching clients with friendly and honest attitudes, and respecting the values and autonomy of clients and community members.

> And to really say, you know, I'm open to learning, I wanna learn as much about you know the language, the culture as possible. To really be sincere about that. And to really be just open to saying you know this is a collaboration, it's not me coming in and doing this, it's just something that we can work together. (Mary)

Participants associated rushing through interactions with clients as part of a Western model of care, and placed significant importance on (a) taking the time to work with clients to improve health, (b) having open-door policies, and (c) being available for crisis support.

> A lot of them [clients with dementia] don't know how to smile, how to communicate, how to express words, how to speak, but we work with them. Yeah. We work with them. I spend more time with them. (Alfred)

> We promise them dementia's a journey, and we're with you right from the start to the end. You know, we're not going to leave…it's up to them and their families after that if they want the support, then it's there any time. (Aragorn)

Changing Mindsets: Encouraging Clients to Take Action

As a means of encouraging them to access care, several health care providers spoke about the importance of changing community members' mindsets with respect to how the First Nations community understands dementia. This was particularly important in light of the fact that community members and clients were often not seeking dementia care – due to fear and stigmatization of dementia, denial, and a lack of information about the disease – until a crisis occurred. To counter missing information and misinformation, participants educated community members about the signs and symptoms of dementia, available treatments, and emphasized that it was not a normal part of aging.

Highlighting the benefits of getting an assessment, such as retaining independence longer by addressing issues earlier, was another major strategy employed to encourage clients to seek out dementia care. By focusing on the positive aspects of potentially undergoing a diagnosis, participants felt they had more success in encouraging clients to get cognitive assessments and treatment for symptoms.

Alfred, for example, spoke about trying to transform clients' initial fears and negative emotions towards a dementia diagnosis, because these negative reactions only helped feed the disease.

> *Alfred*:…not only dementia but [a client's diagnosis] could be diabetes or whatever. As soon as you find that you may have a history of it, or if you're diagnosed with it, you know what happens to people when they hear that they're diagnosed with whatever? Once you hear that from a doctor, how does it make most people feel?
>
> *Interviewer*: I think it scares most people.
>
> *Alfred*: Yeah. And that makes a lot of things happen after that. Once they leave here, their self-esteem goes down, they kind of want to give up. So what happens there – it's funny how it works: when you allow yourself to feel down a lot, you're actually feeding that sickness, a lot. So what we teach our people is, hey it's ok if you're diagnosed with this, you know, [and] here's how we should receive that: accept it, accept it for now, you know, and then find a solution. But if you're going to get angry, upset about it, or even down about it, you're going to feed that more – it's going to make it worse for you.

Coping as a Health Care Provider

Although study participants experienced feelings of burnout, many of them had effective coping strategies. One strategy was to accept their limitations, which encompassed defining and holding firm to role boundaries, forgiving themselves for only being able to do so much in the limited time they had available, and changing their attitudes when encountering setbacks and frustrations. As Jane observed: "One of the people I work with is very fond of saying, 'You can only do what you can do'. And I need to hear that".

Health care providers accessed personal resources to cope with job stress, for example, by engaging in relaxing activities or sharing problems with and receiving personal support from friends and colleagues. Their passion for their work also helped them cope with job stress.

> I find that you get what you give in this field … So I find if you're a good person, you go in, you talk to them, you treat 'em good, you get good back. I don't care how sick they are, you get what you give. (Elana)

Knowledge Framework

Dementia care in the First Nations community was additionally conceptualized in our study through a framework of knowledge. Four stakeholder groups, forming a dementia care knowledge "system" within the First Nations community, were identified: (a) health care providers, (b) PWD, (c) informal care providers, and (d) the community. All four of these stakeholder groups (see Figure 1) held and needed access to equally important knowledge regarding dementia care, and all occupied equally important roles in the process of providing effective and culturally appropriate dementia care.

A continuum of knowledge, from "knowing" (having knowledge) to "not knowing" (lacking knowledge) was identified. With respect to the sum of their knowledge, study participants occupied various points between these two states, while with respect to discrete pieces of knowledge, participants tended to occupy one of these two states. Two processes mediating the link between these two states were identified: sharing, and failing to share, knowledge. The numerous instances of knowledge sharing that occurred among the four

Figure 1: Knowledge stakeholders in First Nations dementia care

stakeholder groups allowed them to move, with respect to discrete pieces of knowledge, from the state of not knowing to a state of having knowledge, and more globally advance towards a state of "knowing". Conversely, the instances of failing to share knowledge that were identified impeded this process of acquiring relevant and required knowledge.

Knowing (Having Knowledge)

Health care providers, clients, informal care providers, and community members all hold important knowledge regarding dementia care (see Table 3). Health care providers held formal knowledge, as a result of their professional training, and experiential knowledge with respect to providing dementia care. This knowledge allowed health care providers to recognize symptoms and disease progression, recognize when further intervention was needed, assess a client's state of health, manage symptoms, and understand the needs of PWD and their informal care providers. Finally, health care providers had an understanding of the values, beliefs, and culture of their clients and community, either because they themselves were from the community or because they had gained this knowledge through their experience working in the community. Health care workers used this knowledge they held about dementia, client care, and community culture to provide dementia care that was both comprehensive and appropriate.

PWD and family caregivers held knowledge about the PWD's state of health, with respect to symptom frequency and severity, changes in health status, and care needs. PWD, and their family caregivers, by proxy, also held knowledge regarding personal beliefs and values, and how these should ideally be integrated into dementia care.

Table 3: Summary of different types of knowledge held by dementia care knowledge stakeholders

Health Care Providers	Formal training for dementia care delivery Experiential knowledge of dementia care delivery Client's health status Client's care plan Culture, values, and beliefs of clients and community members
Clients & Family Care Providers	Client's health (current status, recent changes) Symptoms (severity, recent changes) Care needs Beliefs, values, care preferences
Community Members	Traditional knowledge Culturally relevant knowledge, including community beliefs and values

> You know, they're [family] the first ones to see their behaviour change, and they'll call. You know, "I don't know what's going on with Mom; I want you to come out and see her" or "I'm having trouble with her medication. She's, ah, she can't tell me what she's taken today, and I don't know what to give her." (Rose)

Members of the First Nations community held traditional and culturally relevant knowledge that encompassed an understanding of how the community functioned and of their values, traditions, beliefs, and attitudes. This knowledge was invaluable, as it was integrated into dementia care models in order to create culturally appropriate care and dementia education.

> But also [some Elders] just saying very frankly to me that the model of doing a group-based education session may not fly in the community. Just because people might not be comfortable coming out, cause it's a small community, and sharing stories, 'cause people are worried about, you know, you know even though it's meant to be 'what's said here stays here' people are maybe a little more realistic about maybe that's not gonna happen. (Mary)

Not Knowing (Lacking Knowledge)

In several important instances, health care workers providing care to First Nations communities did not have the knowledge needed to provide an ideal quality of care. Because of difficulties collaborating between health care providers and institutions, knowledge was often lacking with regards to a client's care plan (e.g., diagnoses, medications, equipment needs, long-term disease management strategy). Health care providers also had varying degrees of knowledge from formal dementia care training, which, when lacking, negatively affected their abilities to provide optimal care.

PWD, informal care providers, and members of the First Nations community all often lacked knowledge about dementia, including information about risk factors, symptoms, progression, and treatments. In some cases, they also had misinformation. Mary, for example, observed: "When I spoke to the congregate dining group [about dementia signs and symptoms] … a couple of people, again, [said] 'Isn't this [cognitive change] just normal?' and kind of, 'Why are we talking about it?'"

As discussed in the care delivery framework, in some instances this lack of professional medical information led to community members delaying accessing dementia care services until a crisis occurred.

Failing to Share Knowledge

Two instances of failing to share knowledge, to the detriment of dementia care, were noted by the study participants. The first was the lack of communication and knowledge sharing between health care providers and institutions, as previously discussed in the care delivery framework. This has been labelled as "failing to share" because clients on the reserve signed release of information forms that allowed health care providers at the reserve, hospital, and CCAC to share their chart information. However, despite the theoretical intent and legal ability to do so, this sharing of information was not effectively occurring in many instances.

The second instance was that of PWD failing to share knowledge about dementia symptoms they were experiencing.

> There are so many factors out there that I think contribute to all of it [failing to share knowledge]. And that is one [situation], where the people themselves don't want to come forward. There's also family too, that – you know, maybe it's a stigma, maybe it's embarrassment, but they don't want to show a sign of weakness, they don't want to come forward and say this is happening to my mom, my grandpa, my dad. So it's kept a family secret. (Aragorn)

Failing to share this information impeded health care providers' abilities to effectively recognize potential dementia cases and symptom severity in PWD. This, in turn, limited their abilities to manage symptoms and ensure that PWD received appropriate care referrals.

Sharing Knowledge

Health care providers shared knowledge with clients, family care providers, and community members, as a strategy to provide care and overcome barriers. Often, this involved the sharing of professionally acquired knowledge about dementia, such as the signs, symptoms, risk factors, and treatments and services available. Sharing this information helped to ease the fears of clients about undergoing a cognitive assessment and/or receiving a dementia diagnosis, and helped to counter a possible denial of symptoms on their part. This, in turn, made community members more likely to access dementia care resources.

> The individuals that do have that memory loss at whatever level … I try to go and talk to them and explain to them about our ways of healing, methods of healing. And, what I say is, they need to go back, and live our old ways, because the way we're living now, society's too fast for us. (Alfred)

Formal and informal knowledge sharing between health care providers was an important aspect of the dementia care process. Shared professional knowledge was used to improve client care, through an enhanced understanding of dementia symptoms and progression, and was passed on to clients and informal care providers. This knowledge sharing was important, given that different health professions held different types of knowledge and levels of training.

Despite encountering difficulties, some health care providers were able to collaborate effectively by sharing knowledge about client health and care. Sharing this knowledge was useful as it made health care providers cognizant of potential health issues:

> I have one nephrologist who is absolutely fabulous because he carbon copies me on all the communications regarding that one client. That is the absolute only one that I have had do that. And it's really helpful to me, because I'm providing – you know, our program – is providing service to that individual and it helps us to know what the underlying conditions are, because then we can tell the support worker, "These are the things that you might see. These are things that should make you think 'Oh! Maybe someone needs to be contacted'." (Jane)

By sharing information about their symptoms and needs, clients alerted health care providers to the need for cognitive assessments, changes in care needs, dementia care, and referrals to other health care professionals. Because PWD sometimes failed to share information about symptoms or were in some instances unable to articulate changes in symptoms due to their cognitive status, informal care providers were important secondary sources of information about the health status and needs of a PWD.

First Nations community members are important holders of cultural knowledge, and the sharing of this knowledge with health care providers allowed the providers to enhance care. Often, this knowledge was integrated into the Western biomedical model to create care that was both culturally appropriate and relevant.

> And that's, again, initially why I approached this group of Elders: to get feedback. And they did give me some great feedback about how to look at the caregiver [education] series. (Mary)

Discussion

Integrating Care Delivery and Knowledge Frameworks

The care delivery and knowledge frameworks intersected at multiple points. Having appropriate knowledge contributed positively to providing the elements of care identified in the care delivery framework. Conversely, lacking appropriate knowledge negatively impacted health care providers' abilities to provide dementia care (see Figure 2).

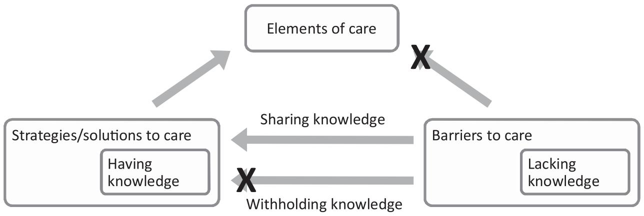

Figure 2: Integration of care delivery and knowledge frameworks

Knowledge sharing was used as a strategy to gain knowledge, and was crucial to ensuring that elements of care were met and safety concerns minimized. This was demonstrated in two ways: first, sharing knowledge was an underlying factor in a number of the strategies and solutions identified through the care delivery mechanism. Through knowledge sharing with community members, health care providers were able to create culturally appropriate resources, understand the culture and values of their clients, and encourage clients to seek out dementia care. Through knowledge sharing with formal and informal care providers, health care providers were able to better understand client needs, severity of symptoms, and care plans.

The second way in which the importance of knowledge sharing became evident was when it failed to occur. Two major instances of failing to share knowledge were noted by our study participants: failing to collaborate among health care providers and institutions, and PWD failing to share information about their symptoms. The former represented a frustrating and time-consuming issue for health care providers, as they were forced to spend significant resources investigating changes in care and filling gaps in knowledge. In addition to wasting resources, this failure to share knowledge led to serious safety concerns regarding clients' medication changes or medical equipment needs.

It is noteworthy that while the two frameworks presented here intersected at multiple points, the knowledge framework did not underlie all barriers and strategies to providing care. For example, although lacking resources was a significant barrier to care, in most instances (with the exception of dementia care literature) a lack of knowledge did not underlie this issue. Rather, the barrier to care arose mainly as a function of not having enough funding, personnel, and time. Similarly, the strategic elements of spending time, developing relationships, and maximizing resources did not directly relate to having or sharing knowledge.

Integrating Study Results with the Literature

First Nations PWD often reached a state of crisis before accessing care resources. Participants attributed this phenomenon, in part, to a lack of knowledge about dementia and available treatments. This is in keeping with the current literature, which notes that First Nations persons do not always recognize that dementia signs and symptoms need to be treated, due to a belief within the community that losing one's cognitive abilities is a natural part of aging (Henderson & Henderson, 2002; Griffin-Pierce et al., 2008). It has also been noted that health care providers may need to establish trust with First Nations clients in order for them to begin sharing information relevant to their health status (Kelly & Brown, 2002). As such, the mistrust encountered by several participants may have contributed to First Nations community members failing to share knowledge regarding their dementia symptoms.

Health care providers, while conducting a home care visit, often noticed the development of, or changes in, dementia symptoms and their related safety issues. As Hendrix and Fee (2004) noted, it is common for First Nations PWD to enter the health care system for a reason other than dementia. Given this situation, it is important for health care providers to have current and relevant knowledge regarding dementia symptoms to be able to recognize potential dementia cases and progressing cognitive issues. Further, the on-reserve Home and Community Care programs established by the Canadian federal government (Health Canada, 2005) can play an important role in dementia care, as they may help to ensure that PWD who would not otherwise seek care are recognized by the health care system.

To identify and overcome safety concerns, health care providers in our study relied on family and community members to share knowledge regarding dementia symptoms and potential safety concerns, and to share care responsibilities. This is a well-recognized strategy; by including family members in formal assessments, for example, health care providers were following best-practice dementia care guidelines (Feldman et al., 2008). They also attempted to compensate for clients' reluctance to access dementia care by sharing knowledge with clients and family members about risk factors, symptoms, treatment, and available care resources. Highlighting the positive aspects of seeking treatment in this manner has been recommended as an appropriate dementia care strategy in First Nations populations (Cattarinich, Gibson, & Cave, 2001).

Home care staffing, training, and infrastructure have been found lacking on many reserves, and the Home and Community Care program was designed in part to address these issues (Wentworth & Gibbons, 2000). However, study participants noted that they were overworked due to a lack of funding, services, and personnel; therefore, it is clear that a lack of health services and personnel on reserves still persists. Indeed, the 2002–2003 First Nations Regional Health Survey noted that although 48 per cent of seniors living on reserve required home care, only 34 per cent were receiving any (First Nations Centre, 2006).

Lack of resources was identified as a major barrier to dementia care. Geographic location played a large role in this, as clients on the reserve often had to travel to access care in the face of limited medical transportation. This has been noted as an important issue for all First Nations persons, not just those with dementia, living in rural areas (Assembly of First Nations, 2007; Hotson, Macdonald, & Martin, 2004). Our study participants similarly echoed the literature when noting that available resources were often not culturally appropriate (Assembly of First Nations, 2007). Participants also found that available resources were fragmented, such that communication, collaboration, and continuity of care were lacking. Fragmentation and inadequacy of health services in both First Nations- and dementia-specific contexts have previously been reported in the literature (Forbes, Morgan, & Janzen, 2006; Kirby & LeBreton, 2002; Morgan, Semchuk, Stewart, & DÀrcy, 2002).

The lack of services and resources available for First Nations dementia care frequently prompted health care providers to take the initiative to create culturally appropriate resources. These resources often involved blending elements of Western medicine, traditional healing, and cultural practices. Health care providers either relied on their own cultural knowledge or sought that of community members in order to accomplish this. Providing care that is a mixture of Western and traditional models – to greater or lesser extents depending on the client – has been recognized in the literature as culturally appropriate for First Nations (Roberts, 2006; Wilson, 2003).

Limitations

This study had several limitations. First, there were limitations to the participant sample, as our study included only dementia health care providers. Accordingly, the perspectives of First Nations PWD and their informal care providers were not represented, except as second-hand information from the experiences of health care providers. Second, because an operational definition rather than a diagnosis was used for dementia, it is possible that some of the experiences described were not true cases of dementia. Without an official diagnosis, symptoms could potentially have been the result of other conditions including depression, mismanagement of blood sugar levels or medications, or delirium. Further, because First Nations persons may conceptualize dementia differently from some other groups (Kaufert & Shapiro, 1996), there may have been individuals within the community experiencing dementia symptoms (as conceptualized by a Western-centric model of the disease) who were not accessing care services and whose experiences could not be reflected upon by participants.

Finally, a limitation was that study participants were drawn only from one urban centre and reserve community, and the experiences of health care providers offering dementia care in other parts of the province or country may differ. Many First Nations communities are located much farther from an urban centre than the reserve community included in this study, and relationships with government-funded, “mainstream” health services in these more rural and remote communities may differ significantly from those reported here. Thus, results may be transferable only to and resonate with health care workers who provide care to First Nations communities in southwestern Ontario that are located in or near urban centres.

Conclusion

This study has contributed to the literature through an understanding of how dementia care is delivered to First Nations communities. Care delivery was focused on ensuring client safety and keeping clients independent (or interdependent). Knowledge systems played an important role in effective care delivery, as a lack of knowledge often underscored care barriers, whereas possession of knowledge and knowledge sharing contributed to successes in care delivery. By recognizing and valuing the knowledge of clients, informal care providers, and First Nations community members, health care providers were able to improve care strategies, create culturally appropriate care models, and build high-quality therapeutic relationships.

Knowledge systems could further be improved upon by continuing efforts on the part of health care personnel and health care organizations to provide members of the First Nations community with education regarding dementia symptoms, risk factors, and treatments, and through the creation of more First Nations-focused dementia care resources and literature. In the future, studies should focus on understanding First Nations dementia care from the perspectives of PWD, informal care providers, physicians, and major health care institutions.

End Notes

1 Community Care Access Centres are organizations in the province Ontario, funded by the Local Health Integration Networks (LHIN) through the Ministry of Health and Long-Term Care, designed to coordinate community care, provide information about and mediate long-term care options, and arrange for visiting health care services

from nurses, physiotherapists, social workers, dieticians, occupational therapists, speech therapists, and personal support workers.

2 Aragorn, like all other names mentioned in this article, is a pseudonym for a study participant.

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