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**Integrated Knowledge Translation Strategies that Enhance the Lives of Persons with
Dementia and Their Family Caregivers**

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Abstract

Purpose: To understand the lived experience of persons with dementia and their family caregivers who receive home care in northern Alberta, Canada, and to reveal how integrated knowledge

translation (iKT) strategies influence the uptake of best available dementia care evidence over time.

Sample: Three persons living with dementia and thirteen family caregivers were interviewed at the beginning of the study, nine months after implementation of the knowledge broker (KB), and six months after termination of the KB role (total interviews = 41).

Method: The PARIHS framework guided our longitudinal case study that included two rural home care centres. A qualitative interpretive descriptive approach was used. A KB was hired for 12 months to facilitate the development of different iKT strategies with staff. Site A developed two strategies: 1) a planning meeting to discuss local needs and suggestions for improving access to dementia care information and community supports; and 2) the development of an information package. Site B focused on working through modules of the U-First program that entailed dementia education and training for the home care providers (HCPs). They then used the U-First wheels with clients during their home visits.

Findings: Persons living with dementia spoke of both positive and negative aspects of their dementia journey and how they attempted to manage their lives. Family caregivers struggled to find the best approaches and supports to use to enable their family member with dementia to remain at home for as long as possible. iKT strategies such as a KB, the information resource package developed by the HCPs, use of the U-First modules and wheels, and a support group were examples of effective iKT.

Conclusion: iKT strategies and projects increased access to dementia care information and supports. These assisted caregivers to better care for their family member for longer periods at home.

Keywords: Persons living with dementia, family caregivers, integrated knowledge translation strategies, rural, and home care.

Integrated Knowledge Translation Strategies that Enhance the Lives of Persons with Dementia and Their Family Caregivers

Dementia refers to a group of neurological conditions typified by a gradual deterioration in behaviour, thinking ability, and memory (Alzheimer Society of Canada, 2010). Worldwide, the total number of new cases each year is nearly 7.7 million, making it an international health priority (World Health Organization, 2012). As of 2010, more than 35.6 million people around the world were living with dementia. This number may almost double to 65.7 million by 2030 and 115.4 million by 2050 (Batsch & Mittelman, Prince et al., 2013).

Canada has an aging population, and the risk of dementia increases with increasing age. The number of Canadians aged 85 and older grew by 19.4% from 2011 to 2016, nearly four times the rate for the overall Canadian population (Statistics Canada, 2017). In 2011, there were 747,000 Canadians diagnosed with dementia and this number is expected to increase to 1.4 million by 2031 (Alzheimer Society of Canada, 2010; Alzheimer Society of Canada, 2017; Forbes & Neufeld, 2008; Jansen et al., 2009).

This increased prevalence of dementia and a movement from institutional to community-based care (Alzheimer Society of Canada, 2010), will result in a larger proportion of persons living with dementia remaining in their own homes. This can substantially increase community care, home care, and caregiver burden, especially in rural areas (Dal Bello-Haas, Cammer, Morgan, Stewart, & Kosteniuk, 2014). The costs of dementia in Canada, including the costs of unpaid care,

were \$10.4 billion in 2016 and projected to rise to \$16.6 billion by 2031 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016).

In addition, rural communities have a faster-growing percentage of older adults than urban centres (Canadian Institute for Health Information [CIHI], 2011; Forbes & Hawranik, 2012). The association of age with Alzheimer's disease and this greater proportion of seniors in rural areas present challenges for both individuals with dementia and their family caregivers. These challenges may include fewer health care services, lack of transportation, longer distances to access care, fewer health care providers, and an increase in the demand for home care services (CHCA, 2015; Di Gregorio, Ferguson, & Wiersma, 2015; Forbes et al., 2012; Forbes & Hawranik, 2012; Forbes, Morgan, & Jansen, 2006; Jansen et al., 2009).

There are specific challenges faced by persons living with dementia and their caregivers in rural communities. For instance, even when family caregivers seek help, receiving a diagnosis can take as long as two years (Morgan et al., 2008). Rural seniors may be more likely to try to rely on an informal support network instead of the health care system (Morgan, Semchuk, Stewart, & D'Arcy, 2002) and their use of formal supports is low (Innes, Morgan, & Kostenuik, 2011). Family caregivers may also be concerned about stigma or lack of privacy and withdraw from social circles (Morgan et al., 2002).

Similarly, persons living with dementia are often excluded from discussions and decisions about their care and treatment because formal and informal caregivers may assume they are not capable of participating. They may also be denied the opportunity to participate in work or social activities because of concerns about safety or stigma. This is often exacerbated in rural areas because of fewer services and fewer qualified home care providers (HCPs) (Forbes et al., 2011).

Access to current information can be more limited in rural areas. The dementia care information that persons living with dementia, caregivers, and health care providers need changes at each stage of the disease process. Caregivers tend to turn to family and friends and assume others have assessed the dependability of the material (Di Gregorio et al., 2015; Forbes et al., 2012). In addition, rural areas may have more limited access to dementia education for both the formal and informal caregivers, leading to a lack of knowledge about dementia and about available services (Innes et al., 2011).

The purpose of this research was to understand the experiences of rural persons living with dementia and their family caregivers who receive home care services. Thus, a better understanding of the approaches that may be supportive and beneficial were revealed as well as sources of information that were the most helpful.

Research Questions

- What is the lived experience of persons with dementia and their family caregivers who receive home care in northern Alberta, Canada?
- What integrated knowledge translation (iKT) strategies influence the uptake of best available dementia care evidence over time?

Methodology

The Promoting Action on Research Implementation in Health Services (PARiHS) framework guided our approach to our research and helped to better explain derived findings (Helfrich et al., 2010). The framework considers: (i) the evidence and knowledge being used, (ii) the context, and (iii) how use of the information is facilitated (Kitson et al., 2008). These were important considerations for our work, thus PARiHS is an appropriate approach for the study. All components of this framework are examined in our research although we do recognize that the

framework has recently been revised as the integrated or i-PARIHS framework. “The core constructs of the i-PARIHS framework are facilitation, innovation, recipients and context, with facilitation represented as the active element assessing, aligning and integrating the other three constructs” (Harvey & Kitson, 2016, p. 8).

The research design was a longitudinal multiple case study (Yin, 2012). Two home care centres in northern Alberta, Canada were selected as the study sites. Due to the large geographical area of the North Zone and long travel distances, these two centres were approached to participate as they were within 30 km of each other and had relatively larger numbers of staff compared to other sites. Both communities and catchment areas meet the Statistics Canada (2016) definition of rural as including all territory lying outside population centres. Basic health services were available in these communities. However, similar to other rural areas in Canada (Morgan et al., 2015), dementia-specific services typically were unavailable. Further detailed characteristics of the communities can be found in Forbes et al. (2015).

A knowledge broker (KB) with experience working as a manager in one of the selected home care settings was hired for 12 months to facilitate the development of different iKT strategies with staff at these two sites. Consultations with the KB and workshops were held to facilitate this process. Site A developed two iKT strategies: 1) a planning meeting with zone and local managers and staff to discuss needs and suggestions for improving access to dementia care information and community supports in their local community; and 2) the development of an information package for persons living with dementia and their family caregivers. This package contained general information about dementia and specific local resources for persons living with dementia and their families, telephone numbers and website links for caregivers, ideas for communicating with the person living with dementia and for responding to responsive behaviours, and suggestions for

interacting with someone with memory difficulties. Site B focused on enhancing the knowledge and skills of the front-line HCPs by working through online modules of the U-First program that entailed dementia education and skill training. The HCPs then used the accompanied U-First wheels with clients during their home visits which summarized the information and offered tips for quick reference.

Persons living with dementia and their family caregivers, who consented to participate, were interviewed in person at the beginning of the study (persons living with dementia = 3, caregivers = 11), nine months after implementation of the iKT strategy (persons living with dementia = 2, caregivers = 13), and six months after termination of the KB role (person living with dementia = 1, caregivers = 11; total interviews = 41). Field notes explicating subtle nuances of the context and non-verbal content of the interviews augmented the data (Schreiber, 2001). The interviews were audio-recorded and transcribed verbatim.

A qualitative interpretive descriptive approach (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004) was implemented to analyze the interviews. Themes and patterns were derived to inform our understanding of the lived experiences of persons living with dementia and their family caregivers. In addition, the knowledge exchanged among rural persons living with dementia and their family caregivers and the uptake of best available dementia care evidence over time were analyzed. Ethical approval was received from the University of Alberta, Health Research Ethics Board (study I.D. Pro00048613).

To promote trustworthiness of the findings, the following criteria were adhered to: a) credibility, b) dependability, c) confirmability, and d) transferability (Lincoln & Guba, 1985). Credibility included member checking (i.e., sharing interpretations and/or conclusions with select participants in order to determine if their own realities had been adequately represented) and peer

debriefing (i.e., 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, diversity of data collection approaches including interviews, field notes, and memoing). Confirmability was achieved through the use of several researchers analyzing the data and then comparing their interpretations. Transferability refers to the acquisition of thick description of the findings to enable readers to determine whether the concepts are similar enough to make a transfer to other contexts or time (Lincoln & Guba, 1985).

Description of Participants

Persons living with dementia are often excluded from participating in research studies as they are considered non-reliable informants. However, the authors of this study considered the voices and perspectives of persons living with dementia as necessary and important in informing our understanding of how best to support them and their family caregivers in continuing to remain in their home environments. Encouraging them to share their perspectives on life assisted us in knowing them as an individual (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Pseudonyms are used to protect the identities of the participants and other identifying information has been removed.

Although several persons living with dementia were invited to participate in the study, only three were able to participate in the interviews. Those who did not participate had difficulty communicating. The three participants, two females and one male, were all diagnosed with having dementia, however their specific type of dementia was unknown. Their ages ranged from 68 to 77 years, two were married and one was separated. The length of time they had lived in their community ranged from 43 to 75 years. All received home care services on average 13 hours per month for assistance with bathing, medication administration, and respite.

The fourteen family caregivers enrolled in the study included eight spouses, three daughters, a grandchild, brother, and brother-in-law. Not all of the family caregivers lived with the person living with dementia. Those who did live with their relative with dementia (n= 8) were more likely to provide greater amounts of support in activities of daily living and assistance with personal care. Further socio-demographic information about the family caregivers is available in Table A.

Table A

Socio-Demographic Characteristics of Family Caregivers

Family Caregivers	Two Communities Combined (n=14)
Gender	
Female	10
Male	4
Age	
Mean	67
Range	33 - 85
Relationship to person living with dementia	
Spouse	8
Daughter	3
Grandchild	1
Other family member	2
Do you live with person living with dementia?	
Yes	8
No	6
If no, how far away (kms)?	
Mean	17.8
Range	1 - 82
In which areas do you help?	
Advice or emotional support	13
Household tasks	13
Personal care	7
Number of hours/week helping?	
Mean	46.9
Range	2 - 120
Do you receive support/help?	
Yes	11
No	2
Specify Type of Help	
Family	4

Family Caregivers	Two Communities Combined (n=14)
Home care	3
Respite	2
Take PWD for weekend	1
Driving	1
Visiting	1
Nurses	1
Day program	2
Support group	1
Emotional support	1
Bath	1
Highest level of education	
Elementary school	1
High school	8
College or trade school	2
University	2
Graduate school	1
Employment Status	
Employed	4
Retired	7
Homemaker	3
Access to computer at home	
Yes	9
No	5
Access to internet at home	
Yes	8
No	6
Hours/week you use the computer	
Mean	15
Range	2 - 40
Where do you go for information about dementia care?	
Internet	3
Books	1
Home care nurse	1
Doctor	3
Alzheimer Association	3
Care Centre	2
Friends	1
Newspapers/TV	2
Support group	1
Information package	1
Self-reported health status	
Poor	-
Satisfactory	5

Family Caregivers	Two Communities Combined (n=14)
Good	7
Excellent	2
Caucasian/White	14
Ethnic or cultural group	
Total household income	
\$10,001 - 20,000	1
\$20,000 - \$30,00	3
\$50,001 - \$60,000	2
Greater than \$60,000	2
Don't know	3
Would prefer not to answer	1

Findings

First Research Question

What is the lived experience of persons with dementia and their family caregivers who receive home care in northern Alberta, Canada?

Perspectives of persons living with dementia.

Persons living with dementia openly spoke of both positive and negative aspects of their dementia and how they attempted to manage their lives. Making the most of his situation, Bill (accompanied by a home care aide) was able to continue to go shopping and interact with other community members.

P: We're on a program right now that's about buying our own food, which is really good because I go with one of our gals [HCP] and we go shopping and it's great fun, I really enjoy that...I know that guy, and you say hello and you know it really sort of brings you out into the community a bit (A501-2, Bill).

In the early stages of the disease, persons living with dementia still have goals and projects that they wish to accomplish.

P: Well I have a couple of projects that I want to do. Last winter I shot about 400,

maybe ...1000 shots of film, and I wanted to make a book for my kids so when I pass away there's something there of mine. ... the three [sisters] that are older and myself wanted to go to and I think we're gonna try and do that, want to go to Iceland (A501-1, Bill).

Another person living with dementia was concerned how individuals in her small community would respond to her if they knew she had dementia.

P: I'm a little bit cautious and afraid sometimes ... about letting it (having dementia) out (A504-3, Mary).

However, there comes a time when persons living with dementia and/or their family caregivers recognize that the person living with dementia is no longer able to continue living in his/her own home.

P: I don't remember how to wash dishes and ...in the last little while I have a certain amount of phobia about fire (A501-1, Bill).

The resources required to support persons living with dementia to be safe in their own homes often became too costly to maintain. For example, Bill eventually required the following services: HCPs twice daily for 15 minutes to fill the medication tray, weekly HCPs' assistance with bathing, weekly homemaker, and a volunteer to take him shopping once a week. Bill identified himself that remaining in his own home was not healthy and other options, such as assistant living, were required.

P: I know there are times I just have to sleep and I can't because there's somebody coming through, getting a bath or something...it just becomes, you know you can't sleep. And if you can't sleep, you can't really be healthy in any way (A501-2, Bill).

Family caregivers' perspectives.

Family caregivers, especially those who live with their relative with dementia, know them best and can often be instrumental in ensuring their relative with dementia receives the most appropriate care possible.

P: I suggested to the doctor; I said if the medications that he's on isn't doing him any good, take him off it. And so there was some that he was on that they decided wasn't necessary and so they took him off of that (B205-3, Anne).

The goal for many family caregivers was to keep their relative with dementia at home for as long as possible.

P: It just got to the point where he would get up in the middle of the night in the winter and take off out the door and I had to get the RCMP to help find him. And then I wasn't sleeping. Three nights I didn't have any sleep. I said [to her physician], "I need help," so he gave me some pretty strong sleeping pills to give to [person with dementia] so at night at 9 o'clock and then he'd sleep until 9 o'clock the next morning. Then I could sleep (B205-3, Anne).

P: Our goal is we keep her home until death. If we can't, if we can do it, I don't know but this is what we try. I talk to my daughter about it like if it's too much for you, tell me, we have to find other solution. She said no, we are young, mom did everything for us, we now do everything for her and I think, I hope we can keep her to the end; but maybe not. But we want to (B204-3, Tom).

However, family members did not always work together to support their relative with dementia. Their previous relationships and views on life influenced their involvement and approach taken with the person living with dementia.

P: I [husband] says, "in 23 years you [daughter-in-law] come into town probably twice a day," they live at [location]. I says, "you don't make no room for her then" I says, "what

are you gonna do, what have you got in mind?” So I got then the answer was I hung up on her (B603-1, Scott).

P: I have a father who is a stubborn, German man and very set in his ways and mom with the dementia. I have found he is less open to suggestions and help and thinks she can still do everything. It's kind of day by day, fly by night in getting them to agree. Like it took me a year to get them to agree to Meals on Wheels but they're enjoying it (B200-1, Helen).

Family members need to find a way to work together in selecting the approach that will have the best outcomes for their relative with dementia. Roles may need to be renegotiated or new roles developed.

P: If there's going to be something major, I discuss it with my brothers and I have two of my brothers take it to my dad because I'm here all the time and I'm the one they get mad at. If something's going to change, I don't want to be the one that is going to pay the price so to speak (B200-1, Helen).

In desperation, families may reach out for potential remedies that they feel may improve their relative's symptoms.

P: I go to the health care and food store and I got Omega 3 and stuff like that and then lion's mane and that's supposed to help the memory... I know the last few days there, maybe I'm just hopeful, but after that lion's mane, she's been getting dressed better and maybe it's just, I'm kind of an optimistic, you know I always look on the bright side (B203-1, David).

Family caregivers recognized that they needed information and support in meeting all the needs of their relative with dementia and appreciated the information and ideas shared among attendees at a support group.

I: What type of information do you expect to be available through the study or your home

care nurse?

P: More insight to the disease and how to cope with it as a family. I think probably the hardest thing is trying to explain to mom why this is happening to her. She [mother with dementia] knows she's forgetting but to get her to understand why it's happening and to remember why it's happening, like it's short term, right? Long term she could tell me what she did when she was 18. So it'd be nice to have more insight on how to explain to them that they are not alone with this disease (B200-1, Helen).

Some family caregivers, however, did not have adequate supports in place and were struggling to provide care for their relative with dementia. Linda clearly described her need for additional assistance to care for her husband.

P: I would like to see if I can have access to a lift or something to make life a little easier for [name] and myself because he's always having to strain to help me, and I'm straining to help him get up and sit down... I guess I would like to make sure that you got from our interview that I could use more help. That it's, for me to be able to help [name], I need a little bit more help (B201-1, Linda).

Linda was not successful in obtaining additional help prior to her second interview and was experiencing difficulty meeting her own needs.

P: You know, I probably shouldn't be looking after anybody because I'm not looking after myself, you know (B201-2, Linda).

Occasionally, a crisis situation resulted in the family members realizing that they could no longer care for the person living with dementia at home.

P: Well she broke her arm, she fell down the stairs... We went to [location] at the university hospital, had a shoulder transplant. And from there she went to the [location] nursing home

(B 203-2, David).

Most family caregivers shared the challenges of caring for someone with dementia and rarely spoke about positive moments. Thus, it is especially important to be able to treasure the brief moments of connection and expressions of pleasure.

P: Even our grandkids, she is 15, she feeds her sometimes and it takes two hours, it is for me, after an hour, I'm fed up. And my granddaughter feeds her...and [she] was eating, eating normally, she is very, you know sad looking. But then she smiled so much and I joked that the food came out again and I thought, [granddaughter] look there's a life quality for Oma (B204-3, Wendy).

Second Research Question

What iKT strategies influence the uptake of best available dementia care evidence over time?

A major iKT strategy is having access to, assessing and using relevant and reliable information available on the internet. The younger generations of participants especially found the internet to be a useful resource.

P: I've actually given some information that I've got off the internet or that [name] have given me and I've actually made copies and taken it to the doctor... Are you aware of this (B204-2, Wendy)?

However, not all family caregivers were comfortable using information technology such as the internet and cell phones.

P: I have a cell phone now. Which I didn't used to have and I have a heck of a time using it because I didn't really get trained. Someone would say, "Oh yeah, well do this and that and other" but that's where I'm at...

I: So you're not familiar with the internet sites?

P: No, no. I don't have a, a computer (B201-2, Linda).

The support group was also seen as a valuable resource of dementia care strategies. For example, Janice learned from other family caregivers, strategies that were beneficial to them and also strategies on how to interact with their family member with dementia.

I: The project's been going on for over a year, what have you been learning personally?

P: Probably how to deal with the stress and day to day, because the support group, those people that ask questions and they have ideas, try this or try that, and this way or try it that way. So I think that's helpful (B606-3, Janice).

Participants appreciated the resource package developed by the HCPs as described above in the methodology section.

P: At one time we got a package and there was a lot of excellent websites and I share information and I talk a lot about it with some of the people from the support group that I go to. I find that, sometimes just talking and sharing your frustrations and as well as your positives is always good and I have one lady in particular that I share information with. I always go online if I want to find something in more detail or whatever.

I: The information that you're finding out of the package and online, has it been relevant to your situation?

P: I think so, you always find bits and pieces that you can relate to in your own situation, or particularly my situation and I thought it was a very well put together resource and obviously a lot of work went into it (B607-3, Marilyn).

Strategies suggested in the resource package assisted family caregivers in appropriately responding to the persons living with dementia.

P: It was in the resource package, it gave you a list of, you know how to deal with, and I think one of the things that I have learned and think sometimes is hard to do is to be very patient and to accept what this person is telling you. I mean the first instinct is to say, “well you’re wrong,” ... And I think that sticks out in my mind, the patience that you have to have and you know, don’t argue with them and yeah that’s always stuck out in my mind because I mean, you know you right away want to say, “well that’s not right, or you’re wrong, this is the way it happened” (B607-3, Marilyn).

Having received information through the resource package, family caregivers felt more comfortable sharing their knowledge with other caregivers and physicians.

P: She’s the total caregiver at home and she does need to take care of herself. I can see that she’s frustrated and stressed about a lot of things and just trying to encourage her to do this and yesterday she came out for a bit while her husband went to the day support and I think that’s important for her. I can see she’s made that change, before she didn’t want to do that, she didn’t want to send him there because she felt guilty. And I said, “You do need time for yourself” because it’s a very stressful road at the moment for her (B607-3, Marilyn).

P: I’ve talked to other people that have patients there and the doc just hadn’t given them any information, you know just that it’s something that happens and you have to deal with it and you know, blah, blah, blah. They’re not giving you any of this background information like some of the people that are coming to these group meetings, I could cry for them. They have no knowledge and it’s like going back 40 years, “if you have a person in your family that’s like that, lock them up in the back bedroom, and forget about it. Don’t talk about it, don’t let your neighbours know what’s going on.” And sometimes I think, with medical staff, they still have that same mentality and they’re the ones that have to reach out and say, okay here’s

this package. I want you to read it and if you've got any questions come back and talk to me (B204-3, Wendy).

The resource package was also found to be useful by staff in other departments. Family caregivers valued and expected an open communication and sharing of information with health care personnel.

I : Do you think that people receiving the package of information find it's a useful tool?

P: I think so, because I know that [Rehabilitation Administrator] gave those out at [place] to some of the spouses or the brothers, sisters or whatever of clients. And he didn't just give them the package, when he had time he actually sat down with some of them and went through, which I thought was just terrific (B204-3, Wendy).

Suggestions were also made on how to improve the resource material. Specifically, a couple of family caregivers felt that information on who to contact in the event of an emergency or difficult situation would be helpful.

P: I think maybe that they could have [included] how do you get hold of something for the person if something happens, say to me, then how do you get hold of somebody...There's a lot of really good material (B206-2, Steve).

I: What type of information is the most useful to you in caring for [name]?

P: Contact information. So I know who is available, when they're available, and who to contact for different situations. Like for example, if she goes missing or something like that, I have an idea of who to call, or if she's experiencing certain symptoms that I think someone should be aware of, or she might need her medications checked. (B205-2, Anne)

Information about the support group and the resource material, as described in the methodology section, should be distributed more widely to inform other family caregivers about

the available support and resources.

P: Just make it [information package] more public, you know. There's an awful lot of people out there that need assistance and I think from our group meetings, you know we reach out to other people. I see people coming into [place] when I go to visit [name] and I haven't seen them at any of our meetings, so you know, just saying are you aware that we do have these group meetings and you know, you're more than welcome to come. I've had a couple of ladies that have come and said, you know thanks (B204-3, Wendy).

Discussion

Involving persons living with dementia in our study provided the opportunity for them to share their perspectives on their daily lives, their needs, wishes, and future plans. Hubbard, Downs, and Tester (2003) described how prior to the 1990s, the perspectives and subjective experiences of people living with dementia tended to be overlooked, as they were perceived to be incapable of verbally communicating their thoughts and feelings. People who are in the early stages of dementia are often capable of expressing their thoughts and experiences in a rich way, although some difficulties with verbal speech may be present as symptoms progress (Pesonen, Remers, & Isola, 2011). It is important to capture these perspectives to better understand persons living with dementia as individuals with hopes and fears (Di Gregorio et al., 2015; Groen-van de Ven et al., 2017). Moreover, participation in an interview is often a meaningful experience for people living with dementia, allowing them to share their views and experiences with the hope that they will be of benefit to others (Pesonen et al., 2011). In the current study, continuing to remain in their own homes and carrying out their normal activities, such as grocery shopping and meeting up with friends, were valued by the persons living with dementia.

In this small northern rural community, one of the participants (Mary) shared that stigma

around dementia remains, and she was hesitant to inform her friends and neighbours that she had a diagnosis of dementia. This is very unfortunate as these individuals could be of assistance and support to her in remaining in her own home as informal community support for people with dementia has been identified as a strength of rural communities (Blackstock, Innes, Cox, Smith, & Mason, 2006). This experience is congruent with previous research suggesting stigma is a salient issue for rural-dwelling persons living with dementia and their caregivers, and may be a barrier to accessing supports (Blackstock et al., 2006; Forbes et al., 2011; Innes et al., 2011; Morgan et al., 2002). In addition to stigma, there is a tradition of independence among rural residents which can discourage help seeking to the detriment of persons living with dementia and their caregivers (Forbes et al, 2012). Much work is needed to better promote the work of the Alzheimer Societies and other dementia support groups in heightening awareness about dementia and how best to support persons living with dementia in their own homes (World Health Organization, 2012).

Occasionally, persons living with dementia require institutional long-term care (LTC) as their symptoms progress and the family members, even with home care assistance, can no longer manage their care needs. One family caregiver could not afford a lift for her spouse to assist her in helping him transfer from a sitting to standing position. Thus, placing him into a LTC facility was necessary, at greater cost to the health care system. Once in a LTC setting, the continued involvement of their family members is very important as the visits may trigger moments of happier times for both the person living with dementia and family caregiver. Although the persons living with dementia may not be able to recall previous visits by family members, their visits mean a great deal to them.

Family caregivers usually do their very best to support the persons living with dementia to

remain at home for as long as possible (Jennings et al., 2017; Lord, Livingston, & Cooper, 2015), often at the expense of their own health. However, this challenging period frequently puts a strain on family relationships. If family members do not normally get along or agree on what is best for the person living with dementia, it can be a very difficult and trying time. Seeking professional advice and consultation may be necessary to ensure that the family members are working together in selecting the approach and medications that will have the best outcomes for their family member with dementia.

Home care assistance can make an important contribution in supporting and caring for the persons living with dementia and their family members. Home care in northern Alberta, Canada provides a variety of services such as care following surgery, long-term care, palliative care, and respite services (retrieved from <https://www.albertahealthservices.ca>, Nov. 24, 2017). Clients within this study received a HCP who completed tasks such as filling a medication tray, bathing assistance, and meal preparation; a homemaker who assisted with cleaning the home; and volunteers who may take the person living with dementia on walks or shopping. However, the long travel distances and lack of funding for rural home care programs has resulted in HCPs not having time for non-urgent clients and their families. Thus, relationships between the families and HCPs cannot be developed and anticipatory guidance and information is not provided (Forbes et al., 2012).

In addition to accessing home care services, other community supports were utilized such as the support group for family caregivers. Most importantly, the family caregivers felt comfortable in acknowledging that their family member has dementia and in sharing their stories of frustration and sadness within an accepting and understanding group. Family caregivers shared successes and helpful tips on strategies and supports that facilitated the care of their loved one with dementia.

This type of support can be especially helpful if run by a trained and knowledgeable facilitator with knowledge about dementia care and the available local supports, treatments, and assisted living institutions. It is then possible to assist the family caregivers in navigating the typical dementia care stages by providing them with anticipatory information and guidance throughout the journey. However, such a person with these required skills and knowledge would not always be available in a northern rural community.

The resource package developed by the HCPs is an excellent example of an iKT strategy to address gaps in knowledge about dementia and available services. The HCPs in this study widely shared the resource package with the persons living with dementia and their family caregivers and encouraged them to use this resource. Because of the positive feedback from our family caregivers, the package was distributed to the local long-term care facilities and to other home care centres in the province. Unfortunately, due to lack of funding, the knowledge broker is no longer employed with the two home care offices. Hopefully, the remaining staff members will be able to keep the resource package current. Very positive feedback was also received from the HCP participants who used the U-First modules to guide their client care (Bayly et al., under review). It is anticipated that this tool is continuing to be used.

Limitations

To participate in this study, persons living with dementia were required to be willing and capable of responding to the interview questions and sharing their stories. Those who were not able to articulate their stories or felt overwhelmed by their symptoms were not included in this study. Thus, our findings were unable to represent a wider range of individuals living with dementia, including those who may have been experiencing greater difficulties. This is a drawback of using only interview methods; previous work has suggested the utility of observational methods

to combine conversation fragments and in-the-moment conversations with nonverbal behavior to obtain the perspectives of persons living with dementia who have difficulties communicating (Hubbard et al., 2003).

Conclusion

This research study revealed the lived experience of persons with dementia and their family caregivers who received home care services in northern Alberta, Canada. When initially diagnosed, persons living with dementia were aware of their symptoms and hesitant to acknowledge that they had dementia due to the negative connotations associated with it. Greater acceptance and education about dementia are desperately needed. Families attempted to support the person living with dementia to remain at home for as long as possible. Home care services may support the family caregiver by assisting with personal care needs of the family member with dementia, housework, meals, medications, and respite. However, there usually comes a time when these services are no longer adequate and the person living with dementia require 24-hour care in a long-term care facility. If family members had a respectful relationship with each other, making the difficult decisions together about placement appeared to be easier. Even after placement, it is important for family members to continue to be involved with the person living with dementia as they do experience precious moments where past memories can be shared.

This study also revealed the value of the iKT strategies that facilitated the uptake of best available dementia care evidence. The KB was essential in facilitating the staff in developing and continuing to use their iKT strategies and projects. Increased access to dementia care information and supports in their local communities were shared through the dementia information package and front-line HCPs continued to use the U-First wheels with clients during their home visits. Support groups for family caregivers that are facilitated by an experienced moderator who is

knowledgeable about dementia care can provide and encourage the sharing of knowledge about the disease process and strategies that support the person living with dementia and their caregivers are an excellent iKT strategy.

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References

Alzheimer Society of Canada (2017). *A new way of looking at the impact of dementia in Canada*.

Retrieved from <http://alzheimer.ca/en/cornwall/Awareness/A-new-way-of-looking-at-dementia>

Alzheimer Society of Canada. (2010). *The rising tide: The impact of dementia on Canadian society: Executive Summary*. Author: Toronto, ON.

Batsch, N.L. & Mittelman, M.S. (Eds) (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. Retrieved from Alzheimer Disease International, <http://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>.

Bayly, M., Forbes, D.A., Blake, C., Peacock, S., & Morgan, D. (under review). “The buzz word is best practice, but sometimes you cannot find the supporting evidence for it”: The development and implementation of dementia-related integrated knowledge translation strategies in rural home care. *Online Journal of Rural Nursing & Health Care*.

Blackstock, K. L., Innes, A., Cox, S., Smith, A., Mason, A. (2006). Living with dementia in rural and remote Scotland: Diverse experiences of people with dementia and their carers. *Journal of Rural Studies*, 22, 161-176. <https://doi.org/10.1016/j.jrurstud.2005.08.007>

- Canadian Home Care Association [CHCA] (2015). *Home care in Canada: Advancing quality improvement and integrated care: A report from accreditation Canada and the Canadian Home Care Association*. Retrieved from: <http://www.cdnhomecare.ca/media.php?mid=4328>
- Canadian Institute for Health Information [CIHI]. (2011). *Health care in Canada, 2011: A focus on seniors and aging*. Ottawa: CIHI.
- Dal Bello-Haas, V., Cammer, A., Morgan, D., Stewart, N., & Kosteniuk, J. (2014). Rural and remote dementia care challenges and needs: Perspectives of formal and informal care providers residing in Saskatchewan, Canada. *Rural and Remote Health, 14*:2747. Retrieved from <http://www.rrh.org.au>
- Di Gregorio, D., Ferguson, S., & Wiersma, E. (2015). From beginning to end: Perspectives of the dementia journey in northern Ontario. *Canadian Journal on Aging, 34* (1), 100– 112. <https://doi.org/10.1017/S0714980814000531>
- Forbes, D., Finkelstein, S., Blake, C., Gibson, M., Morgan, D.G., Markle-Reid, M.,... Thiessen, E.J. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: An interpretive descriptive study. *Rural and Remote Health, 12*, 2201. <http://www.rrh.org.au>
- Forbes, D. A., & Hawranik, P. (2012). Looming dementia care crisis: Are Canadian rural and remote settings ready? In J. Kulig & A. Williams (Eds.), *Health in rural Canada* (pp. 447-461). Vancouver, BC, UBC Press.
- Forbes, D., Morgan, D., & Jansen. B. (2006). Rural and urban Canadians with dementia: Use of health care services. *Canadian Journal of Aging, 25*(23), 321-330. <https://doi.org/10.1353/cja.2007.0003>

Forbes, D.A., & Neufeld, A. (2008). Invited article: Discourse: Looming dementia care crisis: Canada needs an integrated theory of continuing care now! *Canadian Journal of Nursing Research, 40*(1), 9-16.

Forbes, D.A., Strain, L., Blake, C., Peacock, S., Harrison, W., Woytkiw, T.,... Gibson, M. (2015). Dementia care evidence: Contextual factors that influence use in northern home care centres. *Online Journal of Rural Nursing and Health Care, 15*(1), 117-149.
<http://dx.doi.org/10.14574/ojrnhc.v15i1.344>

Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). "Her world gets smaller and smaller with nothing to look forward to": Dimensions of social inclusion and exclusion among rural dementia care networks. *Online Journal of Rural Nursing and Health Care, 11*:27. Retrieved from <http://rnojournal.binghamton.edu/>

Groen-van de Ven, L., Smits, C., de Graaff, F., Span, M., Eefsting, J., Jukema, J., & Vernooij-Dassenet, M. (2017). Involvement of people with dementia in making decisions about their lives: A qualitative study that appraises shared decision-making concerning daycare. *BMJ Open. <https://doi.org/10.1136/bmjopen-2017-018337>*

Harvey, G.H. & Kitson, A. (2016). PARIHS revisited: From heuristic to integrated framework for the successful implementation of knowledge into practice. *Implementation Science, 1*(33). Retrieved from <https://implementationscience.biomedcentral.com/articles/10.1186/s13012-016-0398-2>

Helfrich, C., Damschroder, L.J., Hagedorn, H.J., Daggett, G.S., Sahay, A., Ritchie, M.,...Stetler, C.B. (2010). A critical synthesis of literature on the Promoting Action on Research Implementation in Health Services (PARiHS) framework. *Implementation Science, 5*(82).

Online Journal of Rural Nursing and Health Care, 18(1)
<http://dx.doi.org/10.14574/ojrnhc.v18i1.512>

<https://doi.org/10.1186/1748-5908-5-82>.

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, 7, 351-362. <https://doi.org/10.1080/1360786031000150685>

Innes, A., Morgan, D., & Kosteniuk, J. (2011). Dementia care in rural and remote settings: A systematic review of informal/family caregiving. *Maturitas*, 68, 34-46. <https://doi.org/10.1016/j.maturitas.2010.10.002>

Jansen, L., Forbes, D., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S.,...Leipert, B. (2009). Formal service providers' perceptions of in-home care: Informing dementia service quality. *Home Health Care Services Quarterly*, 28(1), 1-23. <https://doi.org/10.1080/01621420802700952>

Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T.,... & Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Qualitative of Life Research*, 26, 685 -693. <https://doi.org/10.1007/s11136-016-1471-7>

Kitson, A., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation of evidence into practice using the PARIHS framework: Theoretical and practical challenges. *Implementation Science*, 3(1), 1-12. <https://doi.org/10.1186/1748-5908-3-1>

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage

Lord, K., Livingston, G., & Cooper, C. (2015). A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, 27, 1301-1312. <https://doi.org/10.1017/S1041610215000411>

Online Journal of Rural Nursing and Health Care, 18(1)
<http://dx.doi.org/10.14574/ojrnhc.v18i1.512>

- Morgan, D., Crossley, M., Kirk, A., D'Arcy, C., Stewart, N., Biem, J.,...McBain, L. (2008). Improving access to dementia care: Development and evaluation of a rural and remote memory clinic. *Aging & Mental Health*, 13(10): 17-30. <https://doi.org/10.1080/13607860802154432>
- Morgan, D.G., Kosteniuk, J.G., Stewart, N.J., O'Connell, M.E., Kirk, A., Crossley, M.,...Innes, A. (2015) Availability and primary health care orientation of dementia-related services in rural Saskatchewan, Canada, *Home Health Care Services Quarterly*, 34:3-4, 137-158. <https://doi.org/10.1080/01621424.2015.1092907>
- Morgan, D. G., Semchuk, K. M., Stewart, N. J., D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science & Medicine*, 55, 1129-1142. [https://doi.org/10.1016/S0277-9536\(01\)00255-6](https://doi.org/10.1016/S0277-9536(01)00255-6)
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14(6), 800–824. <https://doi.org/10.1177/1471301213512489>
- Pesonen, H.M., Remers, A. M., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics*, 18, 651-661. <https://doi.org/10.1177/0969733011408046>
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's & Dementia*, 9, 63-75. <https://doi.org/10.1016/j.jalz.2012.11.007>
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people living with dementia*. Alzheimer's Disease International (ADI), London.

- Schreiber, R.S. (2001). The “how to” of grounded theory: Avoiding the pitfalls. In R.S. Schreiber & P.N. Stern (Eds.), *Using grounded theory in nursing* (pp. 55-83). New York, NY: Springer.
- Statistics Canada (2016). *Dictionary, census of population 2016*. Retrieved from <http://www12.statcan.gc.ca/census-recensement/2016/ref/dict/geo042-eng.cfm>
- Statistics Canada (2017). *A portrait of the population aged 85 and older in 2016 in Canada*. Statistics Canada Catalogue no. 98-200-X2016004. Ottawa, Ontario. Retrieved from <http://www12.statcan.gc.ca/census-recensement/2016/as-sa/98-200-x/2016004/98-200-x2016004-eng.cfm>
- Thorne S., Reimer-Kirkham S., O’Flynn-Magee K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-21. <https://doi.org/10.1177/160940690400300101>
- World Health Organization (WHO). (2012). *Dementia: A public health priority*. Geneva, Switzerland. WHO Press. Retrieved from: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1
- Yin, R. K. (2012). *Applications of Case Study Research*. Thousand Oaks: Sage Publications. ISBN 978-1-4129-8916-9.