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Complete List of Authors:	Freeman, Shannon; University of Northern British Columbia, Nursing Pelletier, Chelsea; University of Northern British Columbia Ward, Kristin; University of Northern British Columbia Bechard, Lauren; University of Waterloo Regan, Kayla; University of Waterloo somani, salima; University of Northern British Columbia Middleton, Laura; University of Waterloo, Kinesiology
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Factors influencing participation in physical activity for persons living with dementia in rural and northern communities: A qualitative study

Freeman S, Pelletier C, Ward K, Bechard L, Regan, K, Somani S, and Middleton L.

Corresponding Author:

Dr. Shannon Freeman
Associate Professor, School of Nursing
University of Northern British Columbia
3333 University Way
Prince George, BC
V2N 4Z9
Canada
e-mail: shannon.freeman@unbc.ca

Abstract

Objective: In recognition that engagement in physical activities and exercise for persons living with dementia can be challenging in rural and northern communities, the objective of this study was to explore the factors influencing physical activity participation among persons living with dementia in rural/northern communities and identified locally-driven mitigation strategies used to address barriers to physical activity.

Setting: Interviews and focus groups were conducted in two locations in northern British Columbia Canada including a rural community (population less than 10,000 persons) and a medium sized geographically isolated city (population less than 80,000 persons).

Participants: Twenty-nine individuals participated including healthcare providers (n=8), community exercise professionals (n=12), persons living with dementia (n=4), and care partners (n=5).

Results: Rural and northern contextual factors including aspects of the built and natural environment were the main drivers of physical activity for persons living with dementia. Limited capacity in the health system to support physical activity due to a lack of referrals, poor communication mechanisms, and limited resources for programming created challenges for physical activity participation. At the community level, local champions filled gaps in physical activity programming, organizing social and exercise activities by leveraging informal networks. Program level factors included a lack of consistency in staff, and challenges defining program scope given limited population size and the fear of stigma for persons living with dementia.

Conclusions: Rural and northern communities were resilient in providing physical activity opportunities yet remained fragile due to human resource challenges. Without reliable resources and sustained support from the health system, these champions remained vulnerable to burnout.

Enhancing support for local champions through accessible training and mentoring may provide greater stability and support a bottom-up approach to physical activity promotion for rural and northern communities.

Strengths and limitations of this study:

- This study described existing deficits in health system support for physical activity participation for persons living with dementia as well as substantial gaps in tailored exercise program offerings and knowledge necessary to provide accessible, inclusive opportunities for physical activity
- In response to the challenges at the systems level, the community-driven solutions developed to address existing gaps in available services and supports relied on a limited number of community champions to provide physical activity programming.
- Community-specific initiatives were organically tailored to address the needs of persons living with dementia in their community with conscious consideration of the environmental context and finite human and financial resources.
- Although participants living with dementia or mild cognitive impairment were included in this study, we had a greater number of allied health providers and healthcare professionals. While these participants can provide a broad reflection on the challenges facing persons living with dementia from engaging in physical activity, it limited the ability to comment specifically on individual-level factors and the lived experiences of persons living with dementia and their care partners in northern and rural communities.
- This study was conducted prior to the COVID-19 pandemic therefore it is unknown how pandemic restrictions and social distancing protocols have impacted the ability of persons with dementia to engage in physical activity

Keywords: Physical activity**,** exercise, dementia, cognitive impairment, rural health, Alzheimer's disease, social ecological model

INTRODUCTION

Dementia is an umbrella term used to describe progressive declines in cognition which may affect a person's behaviour and ability to perform activities of daily living. The most common form of dementia is Alzheimer's disease. More than 55 million persons are currently living with dementia worldwide.[1] Due to a rapidly aging population, it is projected that this number will rise to 78 million persons in 2030 and 139 million persons in 2050.[1] As there is currently no cure for dementia, there is growing urgency to develop and implement strategies to support the well-being of persons living with dementia and their care partners.

Physical activity is one of the best non-pharmacological strategies to support persons living with dementia to remain active and enhance quality of life.[2,3] For older adults living with dementia or mild cognitive impairment, which includes declines in memory, attention, and cognitive functioning that exceed that typically expected by age or educational level, physical activity can enhance and help maintain physical fitness, balance, mobility, functional ability, and cognition.[4,5,6,7] In addition to physical and cognitive benefits, physical activity has broader impacts including social inclusion and feelings of purpose, that contribute to overall well-being and quality of life.[8,9] Barriers that can prevent persons living with dementia from engaging in physical activity commonly include stigma and lack of knowledge associated with dementia.[10] When compared to age-matched controls, persons living with dementia were found to spend more of their time engaged in sedentary behaviours[11] and were less likely to meet physical activity guidelines.[12]

Despite the well-known benefits of physical activity, there remains a need to develop physical activity interventions for persons living with dementia that address systems-level (e.g., integration with health system) and individual-level barriers.[13] When using a social-ecological

lens, it is important to consider how policy, community, organizational, interpersonal, and individual factors influence physical activity behaviour for persons living with dementia.[14,15] For persons living with dementia, issues affecting memory, declines in cognitive abilities, and changes in mobility may impact physical activity behaviours differently across the course of the illness.[16,17,18] The barriers to engagement in physical activity are amplified by the stigma surrounding diagnosis of dementia and lack of knowledge by exercise providers on how to accommodate and adapt programming for varying and dynamic needs.[8] Care partners are uniquely positioned to raise awareness about factors influencing the behaviours and choices of persons living with dementia. The sharing of this person-specific knowledge with physical activity providers may inform intervention development and allow for tailoring of the program by healthcare professionals and allied health providers to better meet the individual needs of persons living with dementia.[18,19] Taking a systems approach to physical activity promotion, exercise providers and allied health care providers who are aware of the unique needs of persons living dementia can be crucial enablers of physical activity for older adults.[8,19]

Prior research exploring physical activity barriers and opportunities for persons living with dementia has often focused on individual-level factors, with limited attention to environmental and community-specific factors affecting the inclusion of rural-dwelling persons living with dementia in physical activities[15,18] Although there is no clear consensus on what constitutes a rural community,[20] common definitions are based on a combination of population size, distance from an urban centre, and access to services. In Canada, the provincial “north” is a term commonly used to identify the northern and more sparsely populated (e.g., rural, remote) areas which may also experience similarities in arctic/subarctic climates, political marginalization, economic dependency on natural resource development, and larger proportions

of Indigenous populations.[21] Persons living in rural and northern communities face increased barriers to physical activity (e.g., transportation, snow/ice) and have fewer opportunities to engage in physical activity through specialized programming,[22] contributing to an increased risk of noncommunicable disease and disability compared to their urban counterparts. As northern and rural communities have a relatively greater proportion of older adults and a population that is aging faster than the general population,[23] the need to develop strategies to address context-specific barriers is urgent.

Therefore, the objectives of this study were to: 1) explore the factors influencing physical activity participation among persons living with dementia or mild cognitive impairment in rural and northern communities, and 2) identify locally-driven solutions to salient barriers to assist in the development of tools and resources for persons living with dementia, their care partners, allied health providers, and healthcare professionals in rural and northern communities.

METHODS

Patient and Public Involvement: This work was guided by a large stakeholder advisory team including persons with dementia, care partners, physical activity providers, researchers, and health care experts. This advisory team provided direction to the research team which was used to inform design and guide this work.

Study Context: This study was nested within a larger national project aimed at developing resources and materials to support Dementia-Inclusive Choices for Exercise (DICE) project (www.dementiaexercise.com).[19,24] We report on the formative work conducted in northern British Columbia, Canada, highlighting the perspectives of those living in rural and northern geographies. Framed by a social ecological approach to understanding physical activity,

opportunities for persons living with dementia are informed by interpersonal, intrapersonal, social and built environmental, and policy factors.[14] Thus, it is important to co-create knowledge with diverse communities based on population size and geographical location, aligning with basic principles of patient-oriented research.[25] Interviews and focus groups were conducted in two locations in northern British Columbia Canada; a rural community (population less than 10,000 persons) and a medium sized geographically isolated city (population less than 80,000 persons). Both communities are considered rural based on distance from urban centre and access to health services.[26]

Participant Recruitment: Purposive and snowball sampling strategies were employed to recruit exercise providers, allied health providers, persons living with dementia or mild cognitive impairment, and care partners for persons living with dementia. Purposive non-probability sampling, commonly used in qualitative studies, allowed for the invitation of participants who were most representative or informative to participate.[27] Recruitment materials were initially shared in community locations (e.g., posters placed on notice boards at the Alzheimer Society and in a local memory clinic; notice placed in community newsletter) to recruit persons living with dementia and their family care partners. Local health systems stakeholders assisted in recruitment of healthcare professionals and exercise providers who delivered exercise programs for older adults and/or persons living with dementia (e.g., rehabilitation programs, geriatric outreach programs, community exercise programs).

Seven semi-structured focus groups and one interview were conducted with twenty-nine participants, including: healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4);

and care partners of persons living with dementia or cognitive impairment (n=5). Four focus groups involved both healthcare professionals and allied health providers, one focus group involved both care partners and a person living with dementia, one focus group involved only persons with dementia, and one focus group involved only care partners. The interview was conducted with a person living with dementia unable to participate in a focus group setting. Participant age and gender were not collected to protect participant confidentiality especially given the relatively small number of healthcare professionals and allied health providers in this region. Focus groups lasted approximately two hours for healthcare professionals and allied health providers and approximately one hour for care partners and/or persons living with dementia or cognitive impairment. Participants provided informed written consent/assent ahead of the session date and reconfirmed verbal consent/assent prior to the session commencing. All participants living with dementia were deemed to have the capacity to provide consent which was reconfirmed by their care partners. Harmonized ethics approval was received for this study from the University of Northern British Columbia and University of British Columbia (H18-00392).

Focus Group Sessions: Focus group sessions, tailored to the participant type, followed a semi-structured guide based on previous iterations used by the research team.[24] The focus groups were facilitated by an experienced moderator (SF) with support from a research assistant who took notes and managed recording devices. The semi-structured approach allowed probing into emerging issues and themes, where appropriate. Focus groups enabled exploration of interactive social contexts and provided insight on participant perspectives and attitudes.[28,29] Group processes helped participants identify and clarify their perspectives with each other and

encouraged increased depth of description and discussion among participants, providing more detailed responses to prompts.[30]

Data Analysis*:* An inductive thematic analysis of transcripts was used guided by Braun and Clarke's six steps.[31,32] Beginning with familiarization of the data, researchers read and reread the transcripts, writing initial thoughts from the data (step 1). To capture broad perspectives on the data, researchers independently identified and coded the transcripts (step 2) and developed initial themes by identifying patterns in the data set (step 3). Initial themes were then discussed as a group to develop rich descriptions and definitions using a white board to map connections between ideas (step 4). Final themes were established and defined, with sub-themes generated as appropriate within each overall theme (step 5). Data extracts (quotes), identified to best describe each theme/subtheme, are presented with a narrative summary (step 6).

Using the social ecological model as a guide,[14,33] themes were deductively mapped using a white board and post-it notes and plotted according to user, program, health system, and broader community (contextual) levels to describe the factors influencing physical activity for persons living with dementia. Locally driven mitigation strategies and solutions described by participants to overcome barriers to physical activity were identified across each of the four levels. Analysis was conducted using Microsoft Word and Excel software.

RESULTS

Factors influencing participation in physical activity for persons living with dementia were organized into four themes according to the social ecological model: Northern and rural context, health system, physical activity programing, and program participant level (Figure 1). Identified challenges and mitigations strategies were also mapped to the social ecological model (Table 1).

Unique features of the Northern and Rural Context both promote and limit physical activity The northern and rural environmental context underpinned all aspects concerning health and physical activity for persons living with dementia. The local and regional context shaped program opportunities, availability, accessibility, and preferences.

Natural environment. Elements including weather (e.g., harsh winter conditions), geographic location (e.g., isolation from urban centres and from physical activity opportunities), wildlife (e.g., presence of bears, cougars, and moose), and lack of daylight in the winter months influenced willingness and abilities of persons living with dementia to engage in physical activity. One care partner noted: *"By 7 o'clock it's really dark, and I don't really feel that safe going in the dark by myself … the temperature in the winter might be okay, but it might a sheet of ice*". Participants reported the need to adapt to changes in weather to maintain daily physical activities including outdoor walking.

> *I have to wear the tall boots. So, I get my boots on, that means they go right up to the knee and so you can stomp into the snow. Sometimes you put cleats on them so you don't slip. And I always have my poles. It's very important to have the poles. It's beautiful, you know.* (Person living with dementia)

Long-time residents of rural and northern communities described the easy access to natural environments including rivers, lakes, and forest trails as a facilitator of outdoor physical

activity engagement for all persons including those living with dementia. As two participants individually explained:

> *I used to do exercise that was more like go lift weights and workout and now it's like, no, unless it's fun. I like dancing. I like walking the dog in the forest or somewhere off-leash where I can just wander around in the trees and the mushrooms. It's hard to get me to go fast. I don't go fast, but you can get me to go up a hill* (Person living with dementia)

> *I like the freedom of being away from it all in the woods, on the water—that's really important. In the backyard, no phones. And you just respond as you go and you're thinking of something you want to do, you do it. That's freedom. That's exercise. That's a good feeling.* (Care partner of person living with dementia)

Built environment Although a lack of facilities and vast geographic distance to the nearest urban centre were mentioned as barriers, participants described some of the unique built environmental features that facilitated physical activity. Participants valued the accessible infrastructure in their community: *"We actually have this incredible sidewalk system here … [it's] designed so that every street has access to this sidewalk system that is maintained by the municipality to get to downtown, to do grocery shopping, and so on"* (Person living with dementia). Further, participants shared how city planners in their rural community had considered the needs of an aging population when designing the sidewalk (e.g., cloverleaf and crescent patterns) to purposefully support safe and accessible physical activity for persons with cognitive impairments.

Limitations of the health system lead to creative local solutions The overarching structure of the health care system impacted access to physical activity opportunities through three main facets: the referral process and policies, communication processes, and resource

availability. Each subsequently impacted physical activity opportunities for program end-users.

Lack of capacity and mechanisms for referrals: Healthcare professionals and allied health providers struggled with the process of referring persons with dementia to specialized physical activity programs due to lack of capacity and resources throughout the system (e.g., staffing, limited program offerings) and absence of clear mechanisms in place to facilitate the referral process. When responsibility and accountability for referrals was unclear, it led to inaccuracies and gaps in assessment documentation which subsequently resulted in delayed or failed referrals. In some cases, when exercise providers received inaccurate and incomplete documentation during the referral process, it resulted in duplication of health assessments and additional workload. One healthcare professional noted:

> *What's on the piece of paper doesn't quite identify what the person's needs are. So, a lot of extra digging needs to go into that. So, whether the person needs to see a geriatrician which is more sort of the medical component, it's triaged that way.* (Healthcare Professional)

For persons with dementia and their care partners, the lack of a clear referral process or advice from their healthcare provider led to confusion and lack of awareness about where to seek trusted information about safe physical activity opportunities. One participant described their frustration noting:

> *It's been an ongoing question, where can we get more information. "Read about it." Okay, we've read about it. Who can we talk to? "Alzheimer's group" or a contact or "your GP, he can help". We've been through all that and there isn't any*. (Care partner of person living with dementia)

Poor communication and fragmented access to information leads to lack of knowledge:

Challenges with clear and consistent communication were recognized as a barrier across all participant groups. One participant described these communication challenges noting:

> *Word finding difficulties depending on the type of dementia can be a challenge for the person who's struggling to communicate, and for other participants as well. Maybe the person with dementia who also has word finding difficulties they're not intentionally being dishonest, but their stories change depending on the wording that they're using because they can't find their words and then other participants are concerned for them because they just heard a story that's not necessarily true, but the person with dementia couldn't find the words to accurately tell what was going on. So some communication barriers.* (Allied health provider)

Participants expressed a desire for access to resources and information specific to dementia, the disease process, and how to support physical activity opportunities that were safe and inclusive.

Persons living with dementia and care partners described the existing resources as inconsistent, inaccessible, or otherwise unavailable. One participant shared: *"My mother had Alzheimer's, my grandmother had Alzheimer's as well, and I've never come across any information that walks you through what to expect. That would be very helpful"* (Care partner of person living with dementia). While recognizing healthcare professionals as a key communication mechanism for information and educational resources about physical activity, one care partner shared:

> *The professionals don't have the time for this* [sharing information related to dementia]*, unless you have an appointment. Like if you're on a list, it could be 3 months, could be 6 months, it could be a year, or could be really soon.* (Care partner of person living with dementia)

In response, care partners connected informally to each other to promote knowledge sharing by leveraging community networks and using existing communication channels within the community. Close community connections, many based on decades of living in the same community, enabled persons living with dementia and their care partners to communicate their needs directly to healthcare professionals and allied health providers through informal relationships. Within smaller and geographically isolated communities, participants described a lack of anonymity, noting it was common to run into each other at the grocery store, public

events, or in their neighbourhood, allowing for informal connection and information exchange. Participants shared print copies of resources regarding physical activity and communicated by telephone to help compensate for the lack of accessibility to information formally from healthcare professionals and exercise providers.

Limited resources lead to ongoing need for flexibility, creativity, and advocacy: Participants emphasized the complexity of securing necessary resources to support high quality and sustainable exercise programming.

> *Maybe we touched on this when we talked about barriers and the priorities for the health care team at this team, education and community integration doesn't often come up as a high priority. It's very task-oriented health care. Like, this happened, give them this treatment, they're done. But helping with educating on, these are the things that are available in the community for you to participate in because this is going to be an ongoing—aging is not going to stop when you leave this hospital. Having more process-oriented approach and more education and more community integration, but unfortunately, due to resources that isn't always a priority.* (Allied Health Provider)

Participants described the importance of flexibility and creativity to overcome the inability of the health systems to provide physical activity opportunities, often due to limited funding, lack of infrastructure, and substantial gaps in human resources. In particular, participants shared their frustrations surrounding the limited specialized dementia care and services due to the limited human resources. This is especially prevalent within small and heterogeneous populations, as one participant noted:

> *there's just one or two staff for a different, very broad population sometimes because they don't have the same levels of functioning, but we only have … just the bare amount of staff, right. Maybe that's also a challenge. We don't have enough people* (Allied Health Provider)

Inadequate human resources can also lead to lack of specialist knowledge regarding exercise and dementia, contributing to unmet goals and objectives of both the program providers as well as

participants. The shortage and/or absence of trained care providers caused changes in program design commonly by adjusting from physical to psychosocial goals. The flexibility to adjust the focus of the program allowed activities to remain operational. One exercise provider described that when healthcare professionals were unable to provide formal rehabilitation programs or exercise providers were unavailable to provide structured activities in their community, they pivoted to offer a social program instead. However, in doing so, they were also aware of the need to provide supports that fell within their own scope of practice.

> *We have to be really mindful in terms of each other's scopes, so we can't do exercise-whatever's called technically "exercise classes." However, we can do thing that are fun and fitness, which would be like kick ball and badminton* (Allied Health Provider)

To mitigate the lack of trained formal healthcare professionals and exercise providers, community champions built capacity by engaging volunteers and student trainees. One participant emphasized that:

> *Most of the groups … we use the students for. And it was a student actually that made the falls group. He did all the prep for it, everything. Got it all in line and all the stuff out to the doctors. We just kept it. The same with the fit group; we just kept it. And they love it" … "And it works well, too* (Healthcare Professional)

Participants described making use of public spaces such as local recreation centres to organize informal activity opportunities and participate in group programs in lieu of formal exercise facilities, which may or may not be available. In one community, participants shared their use of a public multipurpose area for physical activity.

> *One of three recreation facilities .. [includes] a multi-purpose facility. There's tennis courts outside. There's community rooms where events could be held, meetings could be held. There's a gymnasium there. They do program sports, so you could go play at badminton"* (Care partner of person living with dementia)

Flexibility is needed to adapt to diverse community needs and preferences, as well as expertise available Healthcare professionals and allied health providers described the value of working towards defining physical activity programs including a clear set of characteristics, naming, and the need for trained program staff. Addressing each aspect is key to creating and sustaining a successful exercise program. However, challenges experienced in northern and rural communities are described below.

Defining physical activity programs is needed but can affect accessibility for persons living with dementia: Participants discussed challenges when determining whether to define and clearly label a physical activity program as focused and inclusive of persons living with dementia or to keep the focus more generic. Use of a clear definition acknowledging a specific focus of the program designed for persons living with dementia was thought to improve clarity in participant eligibility and feelings of inclusion, it was also expressed that this may limit the willingness of some persons living with dementia to attend due to the stigma associated with dementia and cognitive impairment. This sentiment was expressed in relation to those living in small rural settings, where some people who wished to keep their diagnosis of dementia confidential were potentially risking their privacy if they attended a physical activity program designed and labelled for persons living with dementia. The stigma associated with dementia was mitigated in small communities by offering the programs at neutral locations within the community, changing the language to enhance inclusion, and normalizing the environment. One care partner commented that the stigma associated with dementia was still evident in their community and impacted their choices in physical activity: *"And there's a stigma attached to it in our minds. Not necessarily that anymore, but there has been in our past lives -- a person not right,*

something wrong upstairs, here in the cortex." (Care partner of person living with dementia). One health care professional also noted *"If there's an Alzheimer's Group, but somebody doesn't like to acknowledge that they have Alzheimer's then you might not want to suggest that they go to an Alzheimer's group…so that could actually be a barrier"* (Health care professional).

Participants also expressed that labelling a program as 'exercise' can be interpreted in different ways. For some, 'exercise' may be viewed as an opportunity to enhance and maintain health, while for others, exercise can be intimidating and exclusive. One exercise professional described this issue:

> *I have to re-approach all the time. If I approach someone and say, "Do you want to come exercise?" They'll scoff at the thought of exercise. "I'm 94. I'm not going to exercise, today." But then if I say, "Hey, want to come play a game with me." Then they're all for it* (Allied Health Provider)

At the same time, the lack of a clear definition for exercise was not always perceived as detrimental as it can allow for fluidity in roles. For rural communities with limited capacity, flexibility in job roles and volunteer engagement allowed programs to continue to run. For example, one participant described how labelling a program as a social activity allowed it to be offered by a variety of providers:

> *We're not physio. We do fun and fitness. Like [when] physio is unable to come one morning because they're doing other things or when they're short staffed, then we do fun and fitness, so we do a game, like bowling"* (Allied Health Provider)

<u>*Balancing program design to meet everyone's needs and expectations*</u>*:* No singular physical activity program or method of delivery emerged as a one size fits all answer to ensure inclusivity for all persons living with dementia, at all times, and in all locations. Instead, participants shared the importance of intentional decisions around program design and details including scheduling, program location, participant eligibility, and method of program delivery (e.g., standing, sitting, or mixed classes) to meet the needs of those within their area. These decisions can be difficult

when serving a small but diverse group, as in rural communities, when balancing finite human and financial resources. If a program is too general, it may risk not being effective for anyone attending as noted by one exercise provider:

> *The problem is that … I don't think that anybody's really getting enough individual program in order to actually make an impact … Even with the stretching, they're not necessarily getting positioned in the exact right place, but it's one instructor and 20, 25 people. So I think programming where you have a ratio … depending on what the abilities of those four people are, or three people, the helper could be helping the one that's needing more assistance and that could travel* (Allied Health Provider)

Additionally, participants discussed the challenge of balancing routine and structure within the programs, keeping the program flexible enough to keep those participating engaged and meet their expectations while maintaining enough structure to achieve physical fitness goals. Flexibility in program provision, program design and provider roles was identified as a mitigation strategy which enabled providers to be responsive to the needs and preferences of persons living with dementia, scheduling, and practitioner scope of practice.

Supportive providers with flexibility are needed to help persons with dementia overcome challenges and fears. Participants shared unique experiences with physical activity based on the interaction between the rural environmental setting, the person living with dementia and their care partner where applicable.

Motivation and knowledge about physical activity: Participation in physical activity requires a conscious investment of time and personal resources. Persons living with dementia and care partners described difficulties balancing multiple demands and had difficulty prioritizing physical activity due to other scheduled health related appointments or commitments. When asked about what gets in the way of physical activity, one participant living with dementia explained there were often *"Other activities that weren't scheduled, or you're already committed*

to." Participants living with dementia noted the importance of a positive attitude and personal motivation toward physical activity participation as a critical enabler, for example:

> *I would enjoy more exercise. They have to change it up so it's not always the same because you do get bored. I don't care who you are, you get bored, so if you change the program a little bit every once in a while, then you're more likely to keep attending* (Person living with dementia)

Participants living with dementia further expressed how challenging it was to find trustworthy information about physical activity, impacting their ability to engage in regular activity:

> *You know, the world's a big place and I think the internet has a lot of good information. I don't know how to access that, but I know the girls do, and I think it gives you a wide variety of information and choices. I don't know what other source. I mean, I'm sure there are other sources. I haven't a doubt that's the only one* (Person living with dementia)

Similarly, participants identified that having instructors who are knowledgeable about exercise and familiar with supporting persons living with dementia to be active, would be an important facilitator supporting their participation in physical activity.

> *I would like to actually see whether or not they've got trainers there that could show me. I'm not comfortable going into a weight room thinking, "Oh, what I should be doing with this?.....That would be good if there were people there that would teach you how to use weights* (Person living with dementia)

Fear can prevent participation: For persons living with dementia, a variety of fears were reported which prevented engagement in physical activity programming. These fears included: the fear of being institutionalized if the program was held within a long-term care facility, the fear of getting lost when needing to take public transportation to attend an exercise class, and the fear of injury from falling. Care partners further expressed negative feelings towards physical activity participation due to anticipation of the progressive loss of control and declining physical abilities of the person living with dementia as their disease progressed. For one care partner, they

described how the fear not only led to distress, but that it was also an indicator for them of disease progression.

> *Mom doesn't do a lot of exercise. She gets lost very quickly, now, and forgets where she is or where she's going. She's really nervous of falling. She's terrified of snow. Like if there's snow or ice, she doesn't want to walk in it or she gets really stressed. Like she'll panic because there's snow or ice. She's really nervous of falling down. That's her biggest thing that she's going to fall down. And with my mom, if she falls down, she doesn't get, from a crawl to a stand is sometimes impossible. My mom would stand up and it's really hard for her to stand up. And that's something, that for me has been an indicator with both my parents when they couldn't get up from getting down, whether it's in the bathtub or when it's something's on the floor and they go down to get it and then they're stuck and they can't figure out how to get up and it's—and then fear comes because they realize they can't get up, but they're like, "But I'm supposed to be able to get up and I can't get up." And so, I don't know how to explain it, except that it's terrifying for them, and it's heartbreaking to witness, but it's also heartbreaking for each of them*. (Care partner of person with dementia)

In recognition that these fears are common for persons living with dementia, healthcare professionals and allied health providers noted the importance for fall prevention training for those individuals in particular.

> *Building up the confidence [of persons living with dementia] in terms of getting up from a fall I think is important because fear of falling is a barrier to a lot of community participation, recreation and leisure participation in particular is what I'm referring to, but yeah, fear of falling is a big barrier for getting out and then people are at risk for social isolation*. (Allied Health Provider)

DISCUSSION

This study explored factors influencing physical activity participation for persons living with dementia in northern and rural communities and the strategies implemented in these settings to mitigate barriers to physical activity participation. From the perspectives of healthcare professionals, allied health providers, persons living with mild to moderate dementia, and care partners, key points that emerged were the lack of health system support for physical activity participation, and substantial gaps in tailored exercise program offerings and knowledge needed

to provide accessible, inclusive opportunities for physical activity. In response to the substantial gaps experienced at the systems level, community-driven initiatives emerged. Community-based solutions, developed in response to gaps in available services and supports, relied on a limited number of community champions to provide physical activity programming. These community-specific initiatives were organically tailored to address the needs of the community of focus with consideration of the unique environmental context and finite human and financial resources. Fear of injury and stigma associated with a dementia diagnosis demand a multi-program response with flexibility, inclusivity and knowledge, not only for persons living with dementia but also for care partners who support persons living with dementia to engage in physical activity.

The individual-level factors influencing physical activity for persons living with dementia, including fear, stigma, cognitive function, and lack of knowledge, are commonly reported in the literature.[18] While these are still true for people living in northern and rural communities, fear and stigma are heightened due to the smaller population size and lack of dementia-related knowledge due to limited access to trained providers or appropriate facilities. Commonly in rural communities, while individual-level barriers persist, environmental and community-level factors create an additional barrier that must be overcome to engage in physical activity, which is particularly true for persons living with dementia.[34]

Context is essential to understand the factors influencing physical activity participation for persons living with dementia in northern and rural communities. In alignment with our previous work, the natural environment can both enhance physical activity participation and exercise (e.g., proximity to outdoor recreation) and, at times, limit physical activity (e.g., winter weather, ice).[22] While the availability of facilities and accessible locations suitable for exercise provision and access to specialized exercise providers is a facilitator of physical activity for

persons living with dementia in urban areas,[19] our findings highlight the near complete absence of such facilities and providers in rural and northern communities. While it is common for exercise providers to have limited knowledge of dementia and training regarding inclusive practices in physical activities,[24] this is amplified in rural communities by the continued reliance on exercise providers without formal training (e.g., rehabilitation or recreation providers) working 'off the side of their desk' to meet community needs. The lack of trained and specialized staff leads to inconsistent program content and availability, fragmentation of program accessibility across different communities, and limited capacity for formal assessment. The lack of health systems leadership, authority, regulation, and quality control specific to physical activity programming have left individuals living in northern and rural communities to take a community-driven, grass-roots approach to support inclusion of persons living with dementia in physical activity and an overreliance on non-profit community organizations. In response to the lack of leadership from the health system to support northern and rural communities, individual community champions have emerged, focussed on building and enhancing community-level programs to address existing deficits. When access to the program relies on knowledge and awareness of community champions and informal networks, persons living with dementia and care partners who are not well connected and already engaged in the community may be unable to access physical activity programming. The issues identified in this study, which are present at multiple levels, warrant a collaborative response between communities and health systems to enhance equity in the ability of persons living with dementia to access physical activity supports, especially in rural and northern communities.

CONCLUSIONS

Physical activity opportunities and experiences for persons living with dementia living in rural and northern communities are shaped by the environmental context and limited accessibility to specialized programming. Local champions risk burnout by working to fill gaps left by absent health and non-profit sectors in small communities, limiting the long-term capacity and support in rural communities for the aging population. It is important to support existing community leaders in a way that respects local knowledge and expertise.

Figure 1 Legend: Key findings by theme organized according to the social ecological model

Contributorship Statement: All authors were actively engaged in this project in accordance with the ICMJE guidelines for authorship. Freeman and Middleton were involved in all aspects of this research. Pelletier was involved in all aspects of the manuscript development including data analysis, writing, and editing. Bechard was involved in planning the project, data collection, and editing of the manuscript. Regan was involved in planning the project and editing of the manuscript. Ward was involved in data analysis, drafting, and editing the manuscript. Somani was involved in drafting and editing the manuscript.

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Patient and Public Involvement: Our work is guided by a large stakeholder advisory team including persons with dementia, care partners, physical activity providers, researchers, and health care experts. We wish to acknowledge and thank all study participants, members of the DICE team, and Rebecca Ferris for her support.

References

[1] World Health Organization. Dementia fact sheet. World Health Organization 2021. https://www.who.int/news-room/fact-sheets/detail/dementia(accessed Sep 2021).

[2] Vedel I, Sheets D, McAiney C, et al. CCCDTD5: Individual and community-based psychosocial and other non-pharmacological interventions to support persons living with dementia and their caregivers. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 2020;6:1e12086. doi:10.1002/trc2.12086.

[3] Alzheimer Society of Canada. Staying Physically active. https://alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/staying-physically-active(accessed Sep 2021).

[4] Blankevoort CG, Van Heuvelen MJ, Boersma F, et al. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. *Dement Geriatr Cogn Disord* 2010;30:392–402. doi:10.1159/000321357.

[5] Eshkoor SA, Hamid, TA, Mun, CY, et al. (2015). Mild cognitive impairment and its management in older people. *Clin Interv Aging* 2015;10;687. doi:10.2145/CIA.S73922.

[6] Ginis KA, Heisz J, Spence JC, et al. Formulation of evidence-based messages to promote the use of physical activity to prevent and manage Alzheimer's disease. *BMC Public Health* 2017;17:209. doi:10.1186/s12889-017-4090-5.

[7] Erickson KI, Hillman C, Stillman CM, et al. Physical activity, cognition, and brain outcomes: a review of the 2018 physical activity guidelines. *Med Sci Sports Exerc* 2019;51:6:1242. doi:10.1249/MSS.0000000000001936.

[8] Malthouse R, Fox F. Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: a qualitative study. *Physiotherapy* 2014;100:169-175. doi:10.1016/j.physio.2013.10.002.

[9] Cedervall Y, Torres S, Åberg AC. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging Ment Health* 2015;19:8: 679-688. doi: 10.1080/13607863.2014.962004.

[10] Kontos P, Grigorovich A, Dupuis S, et al. Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Crit Public Health* 2020;30:91-102. doi:10.1080/09581596.2018.1508822.

[11] Hartman YAW, Karssemeijer EGA, Van Diepen LAM, et al. Dementia Patients Are More Sedentary and Less Physically Active than Age- and Sex-Matched Cognitively Healthy Older Adults. *Dement Geriatr Cogn Disord* 2018;46:81-89. doi:10.1159/000491995.

[12] Laurin D, Verreault R, Lindsay J, et al. Physical activity and risk of cognitive impairment and dementia in elderly persons**.** *Arch Neurol* 2001;58:498-504. doi:10.1001/archneur.58.3.498.

[13] Bowes A, Dawson A, Jepson R, et al. Physical activity for people with dementia: a scoping study. *BMC geriatr* 2013;13:1-10. doi: 10.1186/1471-2318-13-129.

[14] McLeroy KR, Bibeau D, Steckler A, et al. An ecological perspective on health promotion programs. *Health Educ Q* 1988;15:351–377 doi:10.1177/109019818801500401.

[15] Stubbs B, Eggermont L, Soundy A, et al. What are the factors associated with physical activity (PA) participation in community dwelling adults with dementia? A systematic review of PA correlates. *Arch Gerontol Geriatr* 2014;59:2:195-203. doi: 10.1016/j.archger.2014.06.006.

[16] Hancox JE, van der Wardt V, Pollock K, et al. Factors influencing adherence to home-based strength and balance exercises among older adults with mild cognitive impairment and early dementia: promoting activity, independence and stability in early dementia (PrAISED). *PLoS one* 2019;14:e0217387. https://doi.org/10.1371/journal.pone.0217387.

[17] Dening T, Thomas A. Oxford textbook of old age psychiatry. Oxford University Press 2013:1-823.

[18] van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: a systematic review. *Arch Gerontol Geriatr* 2016;66:109-118. doi:10.1016/j.archger.2016.05.008.

[19] Hobson N, Dupuis SL, Giangregorio LM, et al. Perceived Facilitators and Barriers to Exercise Among Older Adults With Mild Cognitive Impairment and Early Dementia. *J Aging Phys Act* 2020;28:2:208-218. doi:10.1123/japa.2019-0010.

[20] MacGregor-Fors I, Vázquez LB. Revisiting 'rural'. *Sci Total Environ* 2020;741:132789. doi:10.1016/j.scitotenv.2019.06.135.

[21] Coates K, Poelzer G. The next northern challenge: the reality of the provincial north. Macdonal-laurier institute publication 2014 April. https://www.macdonaldlaurier.ca/files/pdf/MLITheProvincialNorth04-14-Final.pdf (accessed Aug 2021).

[22] Ward K, Pousette A, Pelletier CA. Not Everybody's an Athlete, But They Certainly Can Move": Facilitators of Physical Activity Maintenance in Older Adults in a Northern and Rural Setting. *J Aging Phys Act* 2020;28:6: 854-863. doi:10.1123/japa.2019-0393.

[23] Northern Health Authority. (2015) Healthy Aging in the North: Action Plan. Northern Health Authority 2015. https://www.northernhealth.ca/sites/northern_health/files/health-information/seniors/documents/healthy-aging-in-the-north-action-plan-2015.pdf (accessed Aug 2021).

[24] Bechard LE, McDougall A, Mitchell C, et al. Dementia and mild cognitive impairment inclusive exercise: perceptions, experiences, and needs of community exercise providers. *PLOS ONE* 2020;15: e0238187. doi:10.1371/journal.pone.0238187.

[25] Canadian Institutes of Health Research. Strategy for Patient-Oriented Research: Patient Engagement Framework. https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf (accessed Sept 2021).

[26] Rural Coordination Centre of BC. Rural Practice Subsidiary Agreement. https://rccbc.ca/rccbc/about-the-jsc/rsa-communities/ (accessed Sept 2021).

[27] Polit DF, Beck CT. Nursing research: Principles and methods. Lippincott Williams & Wilkins 2004;729.

[28] Morgan DL. Planning and research design for focus groups. Focus groups as qualitative research 1997;16.

[29] Wong LP. Focus group discussion: a tool for health and medical research. *Singapore Med J* 2008;49:256-60.

[30] Tausch AP, Menold N. Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators. *Glob Qual Nurs Res* 2016;3: doi:10.1177/2333393616630466.

[31] Clarke V, Braun V. Thematic analysis. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952.

[32] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.

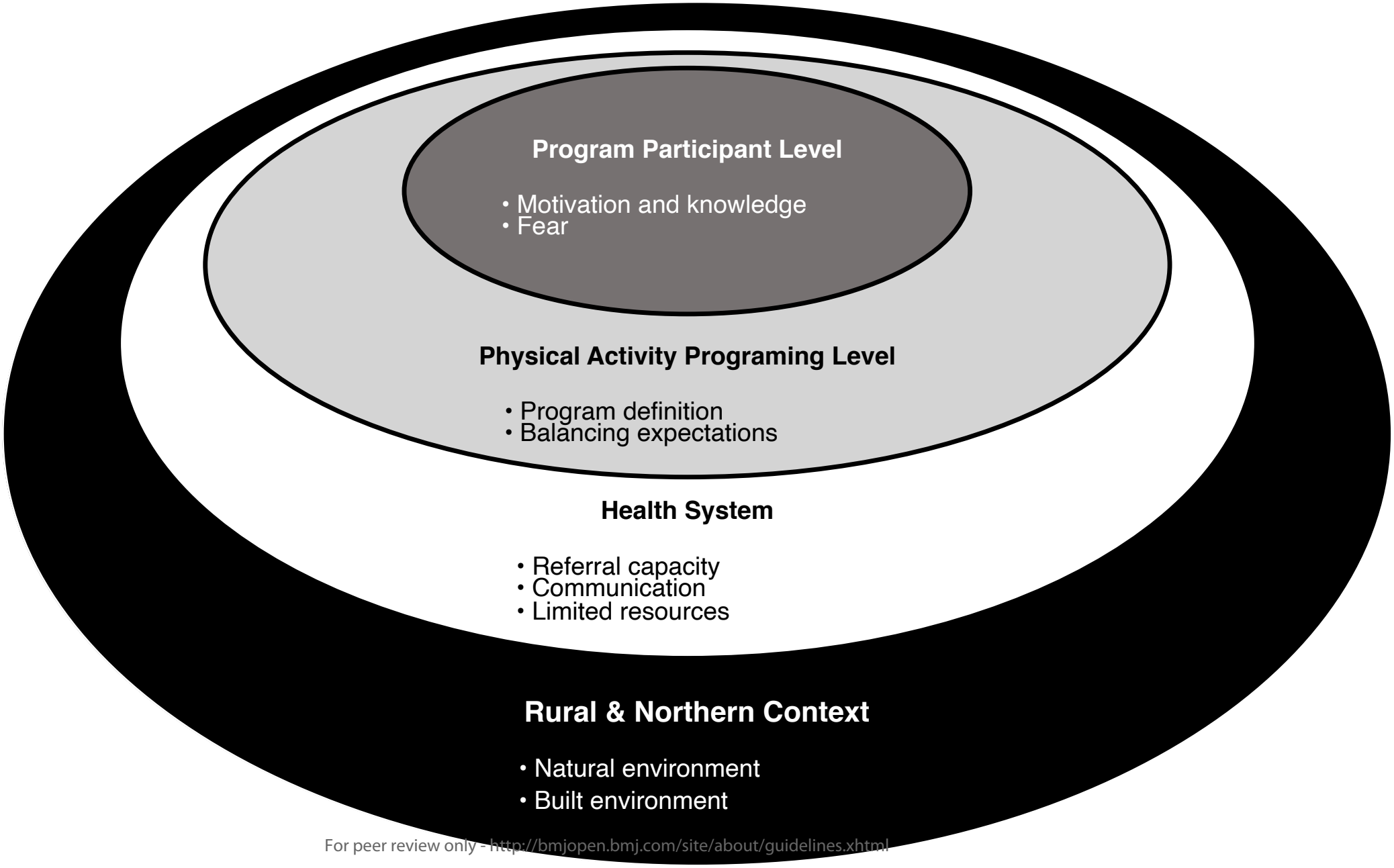
[33] Spence JC, Lee RE. (2003). Toward a comprehensive model of physical activity. *Psychol Sport Exerc* 2003;4:7-24. doi: 10.1016/S1469-0292(02)00014-6.

[34] Pelletier CA, White N, Duchesne A, et al. Barriers to physical activity for adults in rural and urban Canada: A cross-sectional comparison. *SSM Ment Health* 2021;6:100964. doi: 10.1016/j.ssmph.2021.100964.

Table 1: Identified challenges and mitigations strategies mapped to the social ecological model

Level	Identified Challenges	Mitigation Strategies
Northern and Rural Context	• Winter weather and conditions • Inaccessible built environment • Lack of specialized facilities and distance to opportunities	• Appropriate clothing and footwear, knowledge on strategies for being active and staying safe (e.g., walking on ice to prevent falls) • Adjust to seasonal activities • Advocate for connected pathways and accessible sidewalks • Taking transit, sharing of limited facilities between social and physical activity program
Health System	• Fragmented Communication Process • Inconsistent Referral Process	• Community champions leverage informal networks • Take advantage of gaps to allow flexibility in community-driven ground-up response
Physical Activity Program	• Balancing routine and structure with participant choice and autonomy	• Flexibility to allow adjustment to cognitive and physical abilities of participants • Accommodation of diverse abilities in mixed classes and/or by team instruction
	• Lack of consistency in programming	• Developed informal work-arounds through provider collaboration (e.g., job sharing, willingness to work outside scope of practice) • Program scheduling responsive to participant needs, offered when and where demand is high • Engagement of volunteers
	• Lack of definition of program, and meaning of physical activity and exercise	• Allows for flexibility in program provision (switch from physical to psychosocial goals when formal exercise provider unavailable) • Acceptance that no one program is everything to everyone
	• Lack of accessibility to reliable information source	• Knowledge sharing within community social network • Maintain traditional communication strategies (mail out of print activity book, person to person telephone connection)
	• Lack of resources	• Education and training come from multiple sources • Flexible and adaptable in job role and volunteer engagement to address human resource capacity

		• Provider collaboration and sharing of limited resources across programs
Program Participant	• Stigma of dementia	• Offer program in neutral community location • Modified language to describe program to enhance inclusion for persons with dementia • Improved knowledge of benefits of exercise by participant and/or care partner
	• Perception of safety	• Acknowledge fear and provide tailored programming support • Education and training on risk • Confidence and trust in program providers
	• Scheduling priorities	• Participant and/or care partner awareness of program availability and benefits • Multiple programming options • Flexibility among community health providers to accommodate participant scheduling needs • Participants and care partners perceive physical activity as meaningful • Transportation support



Supplementary File 1: Author response to consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Author Response
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	SF conducted all interviews. p. 8
2.	Credentials	SF has a PhD and is experienced in conducting qualitative research.
3.	Occupation	SF is an Associate Professor in the School of Nursing at UNBC.
4.	Gender	Female
5.	Experience and training	SF has previous training in qualitative research and has completed multiple qualitative research studies. p. 8
Relationship with participants		
6.	Relationship established	None
7.	Participant knowledge of the interviewer	The participants knew that the interviews and focus groups were being conducted to learn from participants about their perspectives and experiences with exercise involving persons with dementia.
8.	Interviewer characteristics	None
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Thematic analysis guided by Braun and Clarke's 6 steps (see p.7-8). -- Clarke V, Braun V. Thematic analysis. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952. -- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.
Participant selection		
10.	Sampling	Purposive, non-probability sampling, p. 6
11.	Method of approach	Snowball approach - E-mail, posters, word of mouth, p. 6
12.	Sample size	29 p. 6
13.	Non-participation	0
Setting		
14.	Setting of data collection	Rural and medium sized city in Western Canada p. 7
15.	Presence of non-participants	No
16.	Description of sample	Healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4); and care partners of persons living with dementia or cognitive impairment (n=5). p. 6
Data collection		
17.	Interview guide	Interview guide was reviewed by diverse team of stakeholders including health care professionals, allied health providers, researchers, persons with dementia, and care partners of persons living with dementia. P. 7
18.	Repeat interviews	No
19.	Audio/visual recording	Audio recording was done p. 7

20.	Field notes	Field notes were taken p. 7
21.	Duration	Interviews lasted between 1 - 2 hours p. 7
22.	Data saturation	Yes
23.	Transcripts returned	No

No	**Item**	**Author Response**
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	3
25.	Description of the coding tree	No
26.	Derivation of themes	Derived from data p. 9
27.	Software	Excel, Word p. 9
28.	Participant checking	No
Reporting		
29.	Quotations presented	Yes p. 10-20
30.	Data and findings consistent	Yes p. 9-20
31.	Clarity of major themes	Yes p. 9-20
32.	Clarity of minor themes	Yes p. 9-20

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Factors influencing participation in physical activity for persons living with dementia in rural and northern communities in Canada: A qualitative study

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Factors influencing participation in physical activity for persons living with dementia in rural and northern communities in Canada: A qualitative study

Freeman S, Pelletier C, Ward K, Bechard L, Regan, K, Somani S, and Middleton L.

Corresponding Author:

Dr. Shannon Freeman
Associate Professor, School of Nursing
University of Northern British Columbia
3333 University Way
Prince George, BC
V2N 4Z9
Canada
e-mail: shannon.freeman@unbc.ca

Abstract

Objective: In recognition that engagement in physical activities for persons living with dementia can be challenging in rural and northern communities, the objective of this study was to explore the factors influencing physical activity participation among persons living with dementia in rural/northern communities and to identify locally-driven mitigation strategies participants used to address barriers to physical activity.

Setting: Interviews and focus groups were conducted in two locations in northern British Columbia, Canada including a rural community (<10,000 persons) and a medium sized geographically isolated city (<80,000 persons). Both communities are located at substantial distances (>800km) from larger urban centres.

Participants: Twenty-nine individuals participated including healthcare providers(n=8), community exercise professionals(n=12), persons living with dementia(n=4), and care partners (n=5).

Results: Rural and northern contextual factors including aspects of the built and natural environment were the main drivers of physical activity for persons living with dementia. Limited capacity in the health system to support physical activity due to a lack of referrals, poor communication mechanisms, and limited resources for programming created challenges for physical activity participation. At the community level, local champions filled gaps in physical activity programming by leveraging informal networks to organize opportunities. Program level factors included a lack of consistency in staff, and challenges defining program scope given limited population size and the fear of stigma for persons living with dementia.

Conclusions: Environmental context and limited access to specialized programming affect the opportunities for persons living with dementia to engage in physical activities. Rural and

northern communities showed resiliency in providing physical activity opportunities yet remained fragile due to human resource challenges. Without reliable resources and sustained support from the health system, local champions remain vulnerable to burnout. Enhancing support for local champions may provide greater stability and support to physical activity promotion in rural and northern communities.

Strengths and limitations of this study:

- A study strength includes the engagement of diverse stakeholders (persons living with dementia, care partners, allied health providers experienced in providing community exercise programs, and healthcare professionals) contributing varying perspectives.
- A strength of employing a qualitative approach was our ability to describe in-depth the challenges participants faced at varying levels of the social-ecological model.
- A strength of the study is the inclusion of participants from two separate communities enabling a reflection on different needs and environments
- A limitation of this study is that relatively less participants living with dementia or mild cognitive impairment compared to other participant groups
- As this study was conducted prior to the COVID-19 pandemic, a limitation the impact of the pandemic restrictions and social distancing protocols on physical activity experiences of persons living with dementia is unknown.

Keywords: Physical activity**,** exercise, dementia, cognitive impairment, rural health, Alzheimer's disease, social ecological model

INTRODUCTION

Dementia is an umbrella term used to describe progressive declines in cognition which may affect a person's behaviour and ability to perform activities of daily living. The most common form of dementia is Alzheimer's disease. More than 55 million persons are currently living with dementia worldwide.[1] Due to a rapidly aging population, it is projected that this number will rise to 78 million persons in 2030 and 139 million persons in 2050.[1] As there is currently no cure for dementia, there is growing urgency to develop and implement strategies to support the well-being of persons living with dementia and their care partners.

There is much diversity and heterogeneity across rural communities in Canada based on sociospatial characteristics (e.g., population size, population density, distance from urban centre), social representation, population demographics, and resource availability. [2,3] Although there is no clear consensus on what constitutes a rural community,[4] common definitions are based on a combination of population size, distance from an urban centre, and access to services. In Canada, the provincial "north" is a term commonly used to identify the northern and more sparsely populated (e.g., rural, remote) areas which may also experience similarities in arctic/subarctic climates, political marginalization, economic dependency on natural resource development, and larger proportions of Indigenous populations.[5] Persons living in rural and northern communities face increased barriers to physical activity (e.g., transportation, snow/ice) and have fewer opportunities to engage in physical activity through specialized programming,[6] contributing to an increased risk of noncommunicable disease and disability compared to their urban counterparts. Characteristics specific to the rural context may directly and/or indirectly influence physical activity opportunities and capabilities among older adults.[7] As northern and rural communities have a relatively greater proportion of older adults and a population that is

aging faster than the general population,[8] the need to develop strategies to address context-specific barriers is urgent.

Physical activity is one of the best non-pharmacological strategies to support persons living with dementia to remain active and enhance quality of life.[9,10] For older adults living with dementia or mild cognitive impairment, which includes declines in memory, attention, and cognitive functioning that exceed that typically expected by age or educational level, physical activity can enhance and help maintain physical fitness, balance, mobility, functional ability, and cognition.[11,12,13,14] In addition to physical and cognitive benefits, physical activity has broader impacts including social inclusion and feelings of purpose, that contribute to overall well-being and quality of life.[15,16] Barriers that can prevent persons living with dementia from engaging in physical activity include stigma and lack of knowledge associated with dementia.[17]Persons living with dementia were found to spend more of their time engaged in sedentary behaviours when compared to age-matched cognitively healthy controls [18] and were less likely to meet physical activity guidelines[19] when compared to persons with no cognitive impairment.

Despite the well-known benefits of physical activity, there remains a need to develop physical activity interventions for persons living with dementia that address at each level of a social-ecological model.[20] A social-ecological approach to physical activity considers the interacting factors that influence opportunities at the levels of policy, community, organizational (institutional), interpersonal, and individual.[21,22] For persons living with dementia, individual issues affecting memory, declines in cognitive abilities, and changes in mobility may impact physical activity behaviours differently across the course of the illness.[23,24,25] The barriers to engagement in physical activity are amplified by the stigma surrounding diagnosis of dementia

(e.g., interpersonal relationships) and lack of knowledge by exercise providers on how to accommodate and adapt programming for varying and dynamic needs (e.g., lack of knowledge and programming barriers).[15] Prior research exploring physical activity barriers and opportunities for persons living with dementia has often focused on individual-level factors, with limited attention to environmental and community-specific factors affecting the inclusion of rural-dwelling persons living with dementia in physical activities.[22,25] A focus on environmental and systems-level factors is particularly important for understanding behaviour in rural and northern communities where the context shapes opportunities for active living. Taking a systems approach to physical activity promotion, exercise providers and allied health care providers who are aware of the unique needs of persons living dementia can be crucial enablers of physical activity for older adults by fostering positive (or negative) experiences and environments for physical activity.[15,26]

Care partners are uniquely positioned to raise awareness about factors influencing the behaviours and choices of persons living with dementia. The sharing of this person-specific knowledge with physical activity providers may inform intervention development and allow for tailoring of the program by healthcare professionals and allied health providers to better meet the individual needs of persons living with dementia.[25,26]

Therefore, the objectives of this study were to: 1) explore the factors influencing physical activity participation among persons living with dementia or mild cognitive impairment in rural and northern communities in Canada, and 2) identify locally-driven solutions to salient barriers to assist in the development of tools and resources for persons living with dementia, their care partners, allied health providers, and healthcare professionals in rural and northern communities in Canada.

METHODS

Patient and Public Involvement: This work was guided by a large stakeholder advisory team including persons with dementia, care partners, physical activity providers, researchers, and health care experts. This advisory team provided direction to the research team which was used to inform design and guide this work.

Study Context: This study was nested within a larger national project aimed at developing resources and materials to support Dementia-Inclusive Choices for Exercise (DICE) project (www.dementiaexercise.com).[26,27] We report on the formative work conducted in northern British Columbia, Canada, highlighting the perspectives of those living in rural and northern geographies. Framed by a social ecological approach to understanding physical activity, opportunities for persons living with dementia are informed by interpersonal, intrapersonal, social and built environmental, and policy factors.[21] Thus, it is important to co-create knowledge with diverse communities based on population size and geographical location, aligning with basic principles of patient-oriented research.[28] Interviews and focus groups were conducted in two locations in northern British Columbia Canada; a rural community (population less than 10,000 persons) and a medium sized geographically isolated city (population less than 80,000 persons). Both communities are considered rural based on distance from urban centre and access to health services.[29]

Participant Recruitment: Purposive and snowball sampling strategies were employed to recruit exercise providers, allied health providers, persons living with dementia or mild cognitive impairment, and care partners for persons living with dementia. Purposive non-probability sampling, commonly used in qualitative studies, allowed for the invitation of participants who

were most representative or informative to participate.[30] Recruitment materials were initially shared in community locations (e.g., posters placed on notice boards at the Alzheimer Society and in a local memory clinic; notice placed in community newsletter) to recruit persons living with dementia and their family care partners. Local health systems stakeholders assisted in recruitment of healthcare professionals and exercise providers who delivered exercise programs for older adults and/or persons living with dementia (e.g., rehabilitation programs, geriatric outreach programs, community exercise programs).

Seven semi-structured focus groups and one interview were conducted with twenty-nine participants, including: healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4); and care partners of persons living with dementia or cognitive impairment (n=5). Four focus groups involved both healthcare professionals and allied health providers, one focus group involved both care partners and a person living with dementia, one focus group involved only persons with dementia, and one focus group involved only care partners. The interview was conducted with a person living with dementia unable to participate in a focus group setting. Participant age and gender were not collected to protect participant confidentiality especially given the relatively small number of healthcare professionals and allied health providers in this region. Focus groups lasted approximately two hours for healthcare professionals and allied health providers and approximately one hour for care partners and/or persons living with dementia or cognitive impairment. Participants provided informed written consent/assent ahead of the session date and reconfirmed verbal consent/assent prior to the session commencing. All participants living with dementia were deemed to have the capacity to provide consent which

was reconfirmed by their care partners. While there is no set number of participants or focus groups as a rule in qualitative research, twenty nine participants was considered an acceptable number of participants for this exploratory research as it fits within the commonly accepted sample size ranging from 15-30 participants for qualitative research.[31] At the conceptual level, concordance was observed in findings across differing participant groups and across both sites, suggesting that saturation was achieved.[32] Harmonized ethics approval was received for this study from the University of Northern British Columbia and University of British Columbia (H18-00392).

Focus Group Sessions: Focus group sessions, tailored to the participant type, followed a semi-structured guide based on previous iterations used by the research team.[27] The focus groups were facilitated by an experienced moderator (SF) with support from a graduate student research assistant (RF) who took notes and managed recording devices. The semi-structured approach allowed probing into emerging issues and themes, where appropriate. Focus groups enabled exploration of interactive social contexts and provided insight on participant perspectives and attitudes.[33,34] Group processes helped participants identify and clarify their perspectives with each other and encouraged increased depth of description and discussion among participants, providing more detailed responses to prompts.[35] Two of the focus group scripts used are available in supplemental file 1 (for persons with dementia) and supplemental file 2 (for allied healthcare providers).

Data Analysis*:* An inductive thematic analysis of transcripts was used guided by Braun and Clarke's six steps.[36,37] Beginning with familiarization of the data, a multi-disciplinary team of researchers experienced in qualitative analyses (SF [gerontology] and CP [exercise physiology]) along with a research trainee (KW [health sciences]) read and reread the transcripts, writing

initial thoughts from the data (step 1). All three researchers (SF, CP, and KW) are women who live in northern BC. Each have their own lived experience interacting with and supporting persons living with dementia and care partners as well as experience interacting with community service providers. The engagement of team members from diverse backgrounds enable robust discussion and consideration of patterns in the data and understanding from various viewpoints (e.g., from the perspectives of supporting healthy aging, to optimizing physical activity and exercise opportunities). To capture broad perspectives on the data, researchers independently identified and coded the transcripts (step 2) and developed initial themes by identifying patterns in the data set (step 3). Initial themes were then discussed as a group to develop rich descriptions and definitions using a white board to map connections between ideas (step 4). Final themes were established and defined, with sub-themes generated as appropriate within each overall theme (step 5). Data extracts (quotes), identified to best describe each theme/subtheme, are presented with a narrative summary (step 6).

Using the social ecological model as a guide,[21,38] themes were deductively mapped using a white board and post-it notes and plotted according to user, program, health system, and broader community (contextual) levels to describe the factors influencing physical activity for persons living with dementia. Locally driven mitigation strategies and solutions described by participants to overcome barriers to physical activity were identified across each of the four levels. Analysis was conducted using Microsoft Word and Excel software.

RESULTS

Factors influencing participation in physical activity for persons living with dementia were organized into four themes according to the social ecological model: Northern and rural context, health system, physical activity programing, and program participant level (Figure 1). Identified challenges and mitigations strategies were also mapped to the social ecological model (Table 1).

Northern and rural context: Unique features of the northern and rural context in Canada both promote and limit physical activity The Canadian northern and rural environmental context underpinned all aspects concerning health and physical activity for persons living with dementia. The local and regional context shaped program opportunities, availability, accessibility, and preferences.

Natural environment. Elements including weather (e.g., harsh winter conditions and wildfires), geographic location (e.g., isolation from urban centres and from physical activity opportunities), wildlife (e.g., presence of bears, cougars, and moose), and lack of daylight in the winter months influenced willingness and abilities of persons living with dementia to engage in physical activity. One care partner noted: *"By 7 o'clock it's really dark, and I don't really feel that safe going in the dark by myself ... the temperature in the winter might be okay, but it might a sheet of ice*". Participants reported the need to adapt to changes in weather to maintain daily physical activities including outdoor walking.

> *I have to wear the tall boots. So, I get my boots on, that means they go right up to the knee and so you can stomp into the snow. Sometimes you put cleats on them so you don't slip. And I always have my poles. It's very important to have the poles. It's beautiful, you know.* (Person living with dementia)

Long-time residents of Canadian rural and northern communities described the easy access to natural environments including rivers, lakes, and forest trails as a facilitator of outdoor

physical activity engagement for all persons including those living with dementia. As one participant explained:

> *I used to do exercise that was more like go lift weights and workout and now it's like, no, unless it's fun. I like dancing. I like walking the dog in the forest or somewhere off-leash where I can just wander around in the trees and the mushrooms. It's hard to get me to go fast. I don't go fast, but you can get me to go up a hill* (Person living with dementia)

Further, one care partner of a person living with dementia emphasized how immersing themselves in the natural environment contributed not only to their ability to be physically active but also related to how they conceptualize and find positive meaning in activity as a way to be outside and seek goals beyond fitness.

> *I like the freedom of being away from it all in the woods, on the water—that's really important. In the backyard, no phones. And you just respond as you go and you're thinking of something you want to do, you do it. That's freedom. That's exercise. That's a good feeling.* (Care partner of person living with dementia)

Built environment Although a lack of facilities and vast geographic distance to the nearest urban centre were mentioned as barriers, participants described some of the unique built environmental features that facilitated physical activity. Participants valued the accessible infrastructure in their community: *"We actually have this incredible sidewalk system here … [it's] designed so that every street has access to this sidewalk system that is maintained by the municipality to get to downtown, to do grocery shopping, and so on"* (Person living with dementia). Further, participants shared how city planners in their rural community had considered the needs of an aging population when designing the sidewalk (e.g., cloverleaf and crescent patterns) to purposefully support safe and accessible physical activity for persons with cognitive impairments.

Health System: Limitations of the health system lead to development of local solutions

The overarching structure of the health care system impacted access to physical activity opportunities through three main facets: the referral process and policies, communication processes, and resource availability. Each subsequently impacted physical activity opportunities for program end-users.

Lack of capacity and mechanisms for referrals: Healthcare professionals and allied health providers struggled with the process of referring persons with dementia to specialized physical activity programs due to lack of capacity and resources throughout the system (e.g., staffing, limited program offerings) and absence of clear mechanisms in place to facilitate the referral process. When responsibility and accountability for referrals was unclear, it led to inaccuracies and gaps in assessment documentation which subsequently resulted in delayed or failed referrals. In some cases, when exercise providers received inaccurate and incomplete documentation during the referral process, it resulted in duplication of health assessments and additional workload. One healthcare professional noted:

> *What's on the piece of paper doesn't quite identify what the person's needs are. So, a lot of extra digging needs to go into that. So, whether the person needs to see a geriatrician which is more sort of the medical component, it's triaged that way.* (Healthcare Professional)

For persons with dementia and their care partners, the lack of a clear referral process or advice from their healthcare provider led to confusion and lack of awareness about where to seek trusted information about safe physical activity opportunities. One participant described their frustration noting:

> *It's been an ongoing question, where can we get more information. "Read about it." Okay, we've read about it. Who can we talk to? "Alzheimer's group" or a contact or "your GP, he can help". We've been through all that and there isn't any*. (Care partner of person living with dementia)

Difficulty in communication and fragmented access to information leads to lack of knowledge:

Challenges with clear and consistent communication were recognized as a barrier across all participant groups. One participant described these communication challenges noting:

> *Word finding difficulties depending on the type of dementia can be a challenge for the person who's struggling to communicate, and for other participants as well. Maybe the person with dementia who also has word finding difficulties they're not intentionally being dishonest, but their stories change depending on the wording that they're using because they can't find their words and then other participants are concerned for them because they just heard a story that's not necessarily true, but the person with dementia couldn't find the words to accurately tell what was going on. So, some communication barriers.* (Allied health provider)

Participants expressed a desire for access to resources and information specific to dementia, the disease process, and how to support physical activity opportunities that were safe and inclusive.

Persons living with dementia and care partners described the existing resources as inconsistent, inaccessible, or otherwise unavailable. One participant shared: *"My mother had Alzheimer's, my grandmother had Alzheimer's as well, and I've never come across any information that walks you through what to expect. That would be very helpful"* (Care partner of person living with dementia). While recognizing healthcare professionals as a key communication mechanism for information and educational resources about physical activity, one care partner shared:

> *The professionals don't have the time for this* [sharing information related to dementia]*, unless you have an appointment. Like if you're on a list, it could be 3 months, could be 6 months, it could be a year, or could be really soon.* (Care partner of person living with dementia)

In response, care partners connected informally to each other to promote knowledge sharing by leveraging community networks and using existing communication channels within the community. Close community connections, many based on decades of living in the same community, enabled persons living with dementia and their care partners to communicate their

needs directly to healthcare professionals and allied health providers through informal relationships. Within smaller and geographically isolated communities, participants described a lack of anonymity, noting it was common to run into each other at the grocery store, public events, or in their neighbourhood, allowing for informal connection and information exchange. Participants shared print copies of resources regarding physical activity and communicated by telephone to help compensate for the lack of accessibility to information formally from healthcare professionals and exercise providers.

Limited resources lead to ongoing need for flexibility, creativity, and advocacy: Participants emphasized the complexity of securing necessary resources to support high quality and sustainable exercise programming.

> *Maybe we touched on this when we talked about barriers and the priorities for the health care team at this team, education and community integration doesn't often come up as a high priority. It's very task-oriented health care. Like, this happened, give them this treatment, they're done. But helping with educating on, these are the things that are available in the community for you to participate in because this is going to be an ongoing—aging is not going to stop when you leave this hospital. Having more process-oriented approach and more education and more community integration, but unfortunately, due to resources that isn't always a priority.* (Allied Health Provider)

Participants described the importance of flexibility and creativity to overcome the inability of the health systems to provide physical activity opportunities, often due to limited funding, lack of infrastructure, and substantial gaps in human resources. In particular, participants shared their frustrations surrounding the limited specialized dementia care and services due to the limited human resources. This is especially prevalent within small and heterogeneous populations, as one participant noted:

> *there's just one or two staff for a different, very broad population sometimes because they don't have the same levels of functioning, but we only have … just the bare*

> *amount of staff, right. Maybe that's also a challenge. We don't have enough people* (Allied Health Provider)

Inadequate human resources can also lead to lack of specialist knowledge regarding exercise and dementia, contributing to unmet goals and objectives of both the program providers as well as participants. The shortage and/or absence of trained care providers caused changes in program design commonly by adjusting from physical to psychosocial goals. The flexibility to adjust the focus of the program allowed activities to remain operational. One exercise provider described that when healthcare professionals were unable to provide formal rehabilitation programs or exercise providers were unavailable to provide structured activities in their community, they pivoted to offer a social program instead. However, in doing so, they were also aware of the need to provide supports that fell within their own scope of practice.

> *We have to be really mindful in terms of each other's scopes, so we can't do exercise-whatever's called technically "exercise classes." However, we can do thing that are fun and fitness, which would be like kick ball and badminton* (Allied Health Provider)

To mitigate the lack of trained formal healthcare professionals and exercise providers, community champions built capacity by engaging volunteers and student trainees. One participant emphasized that:

> *Most of the groups … we use the students for. And it was a student actually that made the falls group. He did all the prep for it, everything. Got it all in line and all the stuff out to the doctors. We just kept it. The same with the fit group; we just kept it. And they love it" … "And it works well, too* (Healthcare Professional)

Participants described making use of public spaces such as local recreation centres to organize informal activity opportunities and participate in group programs in lieu of formal exercise facilities (e.g., fitness club, community recreation center), which may or may not be available. In one community, participants shared their use of a public multipurpose area for physical activity.

> *One of three recreation facilities ... [includes] a multi-purpose facility. There's tennis courts outside. There's community rooms where events could be held, meetings could be held. There's a gymnasium there. They do program sports, so you could go play at badminton"* (Care partner of person living with dementia)

Physical activity programing: Flexibility is needed to adapt to diverse community needs and preferences, as well as expertise available Healthcare professionals and allied health providers described the value of working towards defining physical activity programs including a clear set of characteristics, naming, and the need for trained program staff. Addressing each aspect is key to creating and sustaining a successful exercise program. However, challenges experienced in northern and rural communities in Canada are described below.

Defining physical activity programs is needed but can affect accessibility for persons living with dementia: Participants discussed challenges when determining whether to define and clearly label a physical activity program as focused and inclusive of persons living with dementia or to keep the focus more generic. Use of a clear definition acknowledging a specific focus of the program designed for persons living with dementia was thought to improve clarity in participant eligibility and feelings of inclusion, it was also expressed that this may limit the willingness of some persons living with dementia to attend due to the stigma associated with dementia and cognitive impairment. This sentiment was expressed in relation to those living in small rural Canadian settings, where some people who wished to keep their diagnosis of dementia confidential were potentially risking their privacy if they attended a physical activity program designed and labelled for persons living with dementia. The stigma associated with dementia was mitigated in small communities by offering the programs at neutral locations within the community, changing the language to enhance inclusion, and normalizing the environment. One

care partner commented that the stigma associated with dementia was still evident in their community and impacted their choices in physical activity: *"And there's a stigma attached to it in our minds. Not necessarily that anymore, but there has been in our past lives -- a person not right, something wrong upstairs, here in the cortex."* (Care partner of person living with dementia). One health care professional also noted *"If there's an Alzheimer's Group, but somebody doesn't like to acknowledge that they have Alzheimer's then you might not want to suggest that they go to an Alzheimer's group…so that could actually be a barrier"* (Health care professional).

Participants also expressed that labelling a program as 'exercise' can be interpreted in different ways. For some, 'exercise' may be viewed as an opportunity to enhance and maintain health, while for others, exercise can be intimidating and exclusive. One exercise professional described this issue:

> *I have to re-approach all the time. If I approach someone and say, "Do you want to come exercise?" They'll scoff at the thought of exercise. "I'm 94. I'm not going to exercise, today." But then if I say, "Hey, want to come play a game with me." Then they're all for it* (Allied Health Provider)

At the same time, the lack of a clear definition for exercise was not always perceived as detrimental as it can allow for fluidity in roles. For rural communities in Canada with limited capacity, flexibility in job roles and volunteer engagement allowed programs to continue to run. For example, one participant described how labelling a program as a social activity allowed it to be offered by a variety of providers:

> *We're not physio. We do fun and fitness. Like [when] physio is unable to come one morning because they're doing other things or when they're short staffed, then we do fun and fitness, so we do a game, like bowling"* (Allied Health Provider)

Balancing program design to meet everyone's needs and expectations: No singular physical activity program or method of delivery emerged as a one size fits all answer to ensure inclusivity

for all persons living with dementia, at all times, and in all locations. Instead, participants shared the importance of intentional decisions around program design and details including scheduling, program location, participant eligibility, and method of program delivery (e.g., standing, sitting, or mixed classes) to meet the needs of those within their area. These decisions can be difficult when serving a small but diverse group, as in rural communities in Canada, when balancing finite human and financial resources. If a program is too general, it may risk not being effective for anyone attending as noted by one exercise provider:

> *The problem is that … I don't think that anybody's really getting enough individual program in order to actually make an impact … Even with the stretching, they're not necessarily getting positioned in the exact right place, but it's one instructor and 20, 25 people. So I think programming where you have a ratio … depending on what the abilities of those four people are, or three people, the helper could be helping the one that's needing more assistance and that could travel* (Allied Health Provider)

Additionally, participants discussed the challenge of balancing routine and structure within the programs, keeping the program flexible enough to keep those participating engaged and meet their expectations while maintaining enough structure to achieve physical fitness goals. Flexibility in program provision, program design and provider roles was identified as a mitigation strategy which enabled providers to be responsive to the needs and preferences of persons living with dementia, scheduling, and practitioner scope of practice.

Program participant level: Supportive providers with flexibility are needed to help persons with dementia overcome challenges and fears. Participants shared unique experiences with physical activity based on the interaction between the rural environmental setting, the person living with dementia and their care partner where applicable.

Motivation and knowledge about physical activity: Participation in physical activity requires a conscious investment of time and personal resources. Persons living with dementia and care

partners described difficulties balancing multiple demands and had difficulty prioritizing physical activity due to other scheduled health related appointments or commitments. When asked about what gets in the way of physical activity, one participant living with dementia explained there were often *"Other activities that weren't scheduled, or you're already committed to."* Participants living with dementia noted the importance of a positive attitude and personal motivation toward physical activity participation as a critical enabler, for example:

> *I would enjoy more exercise. They have to change it up so it's not always the same because you do get bored. I don't care who you are, you get bored, so if you change the program a little bit every once in a while, then you're more likely to keep attending* (Person living with dementia)

Participants living with dementia further expressed how challenging it was to find trustworthy information about physical activity, impacting their ability to engage in regular activity:

> *You know, the world's a big place and I think the internet has a lot of good information. I don't know how to access that, but I know the girls do, and I think it gives you a wide variety of information and choices. I don't know what other source. I mean, I'm sure there are other sources. I haven't a doubt that's the only one* (Person living with dementia)

Similarly, participants identified that having instructors who are knowledgeable about exercise and familiar with supporting persons living with dementia to be active, would be an important facilitator supporting their participation in physical activity.

> *I would like to actually see whether or not they've got trainers there that could show me. I'm not comfortable going into a weight room thinking, "Oh, what I should be doing with this?.....That would be good if there were people there that would teach you how to use weights* (Person living with dementia)

<u>*Fear can prevent participation:*</u> For persons living with dementia, a variety of fears were reported which prevented engagement in physical activity programming. These fears included: the fear of being institutionalized if the program was held within a long-term care facility, the fear of getting lost when needing to take public transportation to attend an exercise class, and the

fear of injury from falling. Care partners further expressed negative feelings towards physical activity participation due to anticipation of the progressive loss of control and declining physical abilities of the person living with dementia as their disease progressed. For one care partner, they described how the fear not only led to distress, but that it was also an indicator for them of disease progression.

> *Mom doesn't do a lot of exercise. She gets lost very quickly, now, and forgets where she is or where she's going. She's really nervous of falling. She's terrified of snow. Like if there's snow or ice, she doesn't want to walk in it or she gets really stressed. Like she'll panic because there's snow or ice. She's really nervous of falling down. That's her biggest thing that she's going to fall down. And with my mom, if she falls down, she doesn't get, from a crawl to a stand is sometimes impossible. My mom would stand up and it's really hard for her to stand up. And that's something, that for me has been an indicator with both my parents when they couldn't get up from getting down, whether it's in the bathtub or when it's something's on the floor and they go down to get it and then they're stuck and they can't figure out how to get up and it's—and then fear comes because they realize they can't get up, but they're like, "But I'm supposed to be able to get up and I can't get up." And so, I don't know how to explain it, except that it's terrifying for them, and it's heartbreaking to witness, but it's also heartbreaking for each of them*. (Care partner of person with dementia)

In recognition that these fears are common for persons living with dementia, healthcare professionals and allied health providers noted the importance for fall prevention training for those individuals.

> *Building up the confidence [of persons living with dementia] in terms of getting up from a fall I think is important because fear of falling is a barrier to a lot of community participation, recreation and leisure participation in particular is what I'm referring to, but yeah, fear of falling is a big barrier for getting out and then people are at risk for social isolation*. (Allied Health Provider)

DISCUSSION

This study explored factors influencing physical activity participation for persons living with dementia in northern and rural communities in Canada and the strategies implemented in these settings to mitigate barriers to physical activity participation. From the perspectives of

healthcare professionals, allied health providers, persons living with mild to moderate dementia, and care partners, key points that emerged were the lack of health system support for physical activity participation, and substantial gaps in tailored exercise program offerings and knowledge needed to provide accessible, inclusive opportunities for physical activity. Often in rural and northern communities these challenges are compounded and interlinked (e.g., accessibility to use a neutral location to offer a program may not be available in the winter months or may experience scheduling challenges in the winter months due to competing demands for limited indoor space; reliability of public transportation may differ between winter and summer schedules or safety in walking outdoors may be affected by hours of sunlight by season or whether wildlife such as bears are active or hibernating).

In response to the substantial gaps experienced at the systems level, community-driven initiatives emerged. Community-based solutions, developed in response to gaps in available services and supports, relied on a limited number of community champions to provide physical activity programming. These community-specific initiatives were organically tailored to address the needs of the community of focus with consideration of the unique environmental context and finite human and financial resources. Fear of injury and stigma associated with a dementia diagnosis demand a multi-program response with flexibility, inclusivity and knowledge, not only for persons living with dementia but also for care partners who support persons living with dementia to engage in physical activity.

The individual-level factors influencing physical activity for persons living with dementia, including fear, stigma, cognitive function, and lack of knowledge, are commonly reported in the literature.[25] While these are still true for people living in northern and rural communities in Canada, fear and stigma are heightened due to the smaller population size and

lack of dementia-related knowledge due to limited access to trained providers or appropriate facilities. With limited populations in rural communities, it can become increasingly difficult for person living with dementia and their care partners to protect their privacy as it is not possible to remain anonymous when attending community programming.[39] In some cases, especially when individuals perceive their actions may be observed and discussed by others in their rural communities, they may prefer to engage in group activities in a neighbouring community, however, this may involve substantial investment of resources for those in rural and northern communities, including travel time and costs.[39] Commonly in rural communities, while individual-level barriers persist, environmental and community-level factors create an additional barrier that must be overcome to engage in physical activity, which is particularly true for persons living with dementia.[40]

Context is essential to understand the factors influencing physical activity participation for persons living with dementia in northern and rural communities in Canada. In alignment with our previous work, the natural environment can both enhance physical activity participation and exercise (e.g., proximity to outdoor recreation) and, at times, limit physical activity (e.g., winter weather, ice).[6] While the availability of facilities and accessible locations suitable for exercise provision and access to specialized exercise providers is a facilitator of physical activity for persons living with dementia in urban areas,[26] our findings highlight the near complete absence of such facilities and providers in northern and rural communities in BC. This reinforces the importance to consider the links between the availability of infrastructure, networks, and resources with the degree of urbanization in the community.[41] While it is common for exercise providers to have limited knowledge of dementia and training regarding inclusive practices in physical activities,[27] this is amplified in rural communities by the continued reliance on

exercise providers without formal training (e.g., rehabilitation or recreation providers) working 'off the side of their desk' to meet community needs. The lack of trained and specialized staff leads to inconsistent program content and availability, fragmentation of program accessibility across different communities, and limited capacity for formal assessment. The lack of health systems leadership, authority, regulation, and quality control specific to physical activity programming have left individuals living in northern and rural communities in BC to take a community-driven, grass-roots approach to support inclusion of persons living with dementia in physical activity and an overreliance on non-profit community organizations. In response to the lack of leadership from the health system to support northern and rural communities in BC, individual community champions have emerged, focussed on building and enhancing community-level programs to address existing deficits. When access to the program relies on knowledge and awareness of community champions and informal networks, persons living with dementia and care partners who are not well connected and already engaged in the community may be unable to access physical activity programming. The issues identified in this study, which are present at the individual, community, and system levels of the social-ecological model, echo the priorities and Canadian call to action described by Njkiforuk (2018) to "support equitable action on rural and remote physical activity promotion across Canada".[42] Further these findings warrant a collaborative response between communities and health systems to enhance equity in the ability of persons living with dementia to access physical activity supports, especially in Canadian northern and rural communities.

This study provides insight into the factors affecting physical activity participation for persons living with dementia involving participants across two rural and northern communities in BC Canada. The engagement of diverse stakeholders in this geographic region using a

qualitative approach allowed us to capture diverse perspectives on the existing deficits and has helped to identify gaps in tailored exercise program offerings and knowledge necessary to provide accessible, inclusive opportunities for physical activity. However, as the geographical focus of this work was limited to two northern and rural communities in Canada, findings may not be transferable to other communities such as urban centres or other countries with differing health care systems and resources. More research is needed to understand whether other northern and rural communities in Canada rely heavily on local community-specific initiatives. Further, a limitation of this study is the limited number of participants living with dementia or mild cognitive impairment who participated in this study (n=4/29). While allied health providers and healthcare professionals who participated in the study provided valuable reflections on the challenges they have observed, they are limited in their ability to comment specifically on individual-level factors and the lived experiences of persons living with dementia and their care.

In Canada, unintended consequences of pandemic restrictions (e.g., physical distancing protocols) include reductions of physical activity.[43, 44] Disruptions in daily routines and limited engagement in physical activity during the COVID-19 pandemic have been reported to severely impacted persons living with dementia.[45] Emerging evidence suggests that interdisciplinary prevention approaches to address physical inactivity related to pandemic restrictions and isolation are urgently needed especially for persons living with dementia.[46] As our work was conducted prior to the COVID-19 pandemic, future research is needed to examine how pandemic restrictions and social distancing protocols were experienced in rural and northern communities in Canada and subsequently how COVID-19 pandemic may have impacted the ability of persons with dementia to engage in physical activity and have impacted the provision of local community-driven initiatives.

CONCLUSIONS

Physical activity opportunities and experiences for persons living with dementia living in northern and rural communities in Canada are shaped by the environmental context and limited accessibility to specialized programming. Local champions risk burnout by working to fill gaps left by absent health and non-profit sectors in small communities, limiting the long-term capacity and support in northern and rural communities for growing number of persons aging with dementia in Canada. It is important to support existing community leaders in a way that respects local knowledge and expertise.

Figure 1 Legend: Key findings by theme organized according to the social ecological model

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References

[1] World Health Organization. Dementia fact sheet. World Health Organization 2021. https://www.who.int/news-room/fact-sheets/detail/dementia(accessed Sep 2021).

[2] Laurin, F., Pronovost, S., & Carrier, M. (2020). The end of the urban-rural dichotomy? Towards a new regional typology for SME performance. *J Rural Stud*, 80, 53-75.

[3] Keating, N., & Phillips, J. (2008). A critical human ecology perspective on rural ageing. Rural ageing: A good place to grow old, 1-10.

[4] MacGregor-Fors I, Vázquez LB. Revisiting 'rural'. *Sci Total Environ* 2020;741:132789. doi:10.1016/j.scitotenv.2019.06.135.

[5] Coates K, Poelzer G. The next northern challenge: the reality of the provincial north. Macdonald-Laurier Institute publication 2014 April. https://www.macdonaldlaurier.ca/files/pdf/MLITheProvincialNorth04-14-Final.pdf (accessed Aug 2021).

[6] Ward K, Pousette A, Pelletier CA. Not Everybody's an Athlete, But They Certainly Can Move": Facilitators of Physical Activity Maintenance in Older Adults in a Northern and Rural Setting. *J Aging Phys Act* 2020;28:6: 854-863. doi:10.1123/japa.2019-0393.

[7] Winterton, R., Warburton, J., Keating, N., Petersen, M., Berg, T., & Wilson, J. (2016). Understanding the influence of community characteristics on wellness for rural older adults: A meta-synthesis. *J Rural Stud*, 45, 320-327.

[8] Northern Health Authority. (2015) Healthy Aging in the North: Action Plan. Northern Health Authority 2015. https://www.northernhealth.ca/sites/northern_health/files/health-information/seniors/documents/healthy-aging-in-the-north-action-plan-2015.pdf (accessed Aug 2021).

[9] Vedel I, Sheets D, McAiney C, et al. CCCDTD5: Individual and community-based psychosocial and other non-pharmacological interventions to support persons living with dementia and their caregivers. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 2020;6:1e12086. doi:10.1002/trc2.12086.

[10] Alzheimer Society of Canada. Staying Physically active. https://alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/staying-physically-active (accessed Sep 2021).

[11] Blankevoort CG, Van Heuvelen MJ, Boersma F, et al. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. *Dement Geriatr Cogn Disord* 2010;30:392–402. doi:10.1159/000321357.

[12] Eshkoor SA, Hamid, TA, Mun, CY, et al. (2015). Mild cognitive impairment and its management in older people. *Clin Interv Aging* 2015;10;687. doi:10.2145/CIA.S73922.

[13] Ginis KA, Heisz J, Spence JC, et al. Formulation of evidence-based messages to promote the use of physical activity to prevent and manage Alzheimer's disease. *BMC Public Health* 2017;17:209. doi:10.1186/s12889-017-4090-5.

[14] Erickson KI, Hillman C, Stillman CM, et al. Physical activity, cognition, and brain outcomes: a review of the 2018 physical activity guidelines. *Med Sci Sports Exerc* 2019;51:6:1242. doi:10.1249/MSS.0000000000001936.

[15] Malthouse R, Fox F. Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: a qualitative study. *Physiotherapy* 2014;100:169-175. doi:10.1016/j.physio.2013.10.002.

[16] Cedervall Y, Torres S, Åberg AC. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging Ment Health* 2015;19:8: 679-688. doi: 10.1080/13607863.2014.962004.

[17] Kontos P, Grigorovich A, Dupuis S, et al. Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Crit Public Health* 2020;30:91-102. doi:10.1080/09581596.2018.1508822.

[18] Hartman YAW, Karssemeijer EGA, Van Diepen LAM, et al. Dementia Patients Are More Sedentary and Less Physically Active than Age- and Sex-Matched Cognitively Healthy Older Adults. *Dement Geriatr Cogn Disord* 2018;46:81-89. doi:10.1159/000491995.

[19] Laurin D, Verreault R, Lindsay J, et al. Physical activity and risk of cognitive impairment and dementia in elderly persons**.** *Arch Neurol* 2001;58:498-504. doi:10.1001/archneur.58.3.498.

[20] Bowes A, Dawson A, Jepson R, et al. Physical activity for people with dementia: a scoping study. *BMC Geriatr* 2013;13:1-10. doi: 10.1186/1471-2318-13-129.

[21] McLeroy KR, Bibeau D, Steckler A, et al. An ecological perspective on health promotion programs. *Health Educ Q* 1988;15:351–377 doi:10.1177/109019818801500401.

[22] Stubbs B, Eggermont L, Soundy A, et al. What are the factors associated with physical activity (PA) participation in community dwelling adults with dementia? A systematic review of PA correlates. *Arch Gerontol Geriatr* 2014;59:2:195-203. doi: 10.1016/j.archger.2014.06.006.

[23] Hancox JE, van der Wardt V, Pollock K, et al. Factors influencing adherence to home-based strength and balance exercises among older adults with mild cognitive impairment and early dementia: promoting activity, independence and stability in early dementia (PrAISED). *PLoS one* 2019;14:e0217387. https://doi.org/10.1371/journal.pone.0217387.

[24] Dening T, Thomas A. Oxford textbook of old age psychiatry. Oxford University Press 2013:1-823.

[25] van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: a systematic review. *Arch Gerontol Geriatr* 2016;66:109-118. doi:10.1016/j.archger.2016.05.008.

[26] Hobson N, Dupuis SL, Giangregorio LM, et al. Perceived Facilitators and Barriers to Exercise Among Older Adults With Mild Cognitive Impairment and Early Dementia. *J Aging Phys Act* 2020;28:2:208-218. doi:10.1123/japa.2019-0010.

[27] Bechard LE, McDougall A, Mitchell C, et al. Dementia and mild cognitive impairment inclusive exercise: perceptions, experiences, and needs of community exercise providers. *PLOS ONE* 2020;15: e0238187. doi:10.1371/journal.pone.0238187.

[28] Canadian Institutes of Health Research. Strategy for Patient-Oriented Research: Patient Engagement Framework. https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf (accessed Sept 2021).

[29] Rural Coordination Centre of BC. Rural Practice Subsidiary Agreement. https://rccbc.ca/rccbc/about-the-jsc/rsa-communities/ (accessed Sept 2021).

[30] Polit DF, Beck CT. *Nursing research: Principles and methods*. Lippincott Williams & Wilkins 2004;729.

[31] Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

[32] Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The Sage handbook of qualitative research*. Sage.

[33] Morgan DL. *Planning and research design for focus groups. Focus groups as qualitative research* 1997;16.

[34] Wong LP. Focus group discussion: a tool for health and medical research. *Singapore Med J* 2008;49:256-60.

[35] Tausch AP, Menold N. Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators. *Glob Qual Nurs Res* 2016;3: doi:10.1177/2333393616630466.

[36] Clarke V, Braun V. *Thematic analysis*. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952.

[37] Braun V, Clarke V. *Using thematic analysis in psychology*. *Qual Res Psychol* 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.

[38] Spence JC, Lee RE. (2003). Toward a comprehensive model of physical activity. *Psychol Sport Exerc* 2003;4:7-24. doi: 10.1016/S1469-0292(02)00014-6.

[39] 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*(7), 1129-1142.

[40] Pelletier CA, White N, Duchesne A, et al. Barriers to physical activity for adults in rural and urban Canada: A cross-sectional comparison. *SSM Population Health* 2021;6:100964. doi: 10.1016/j.ssmph.2021.100964.

[41] Gansefort, D., Brand, T., Princk, C., & Zeeb, H. (2018). Community readiness for the promotion of physical activity in older adults—A cross-sectional comparison of rural and urban communities. *International journal of environmental research and public health*, *15*(3), 453.

[42] Nykiforuk Candace, I. J., Kayla, A., Sara, B., Wayne, C., Tracey, G., Jason, G., ... & Jonathan, M. (2018). Evidence synthesis Promotion of physical activity in rural, remote and northern settings: a Canadian call to action. *Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice*, *38*(11), 419.

[43] Di Sebastiano, K. M., Chulak-Bozzer, T., Vanderloo, L. M., & Faulkner, G. (2020). Don't walk so close to me: physical distancing and adult physical activity in Canada. *Frontiers in Psychology*, 1895.

[44] Gierc, M., Riazi, N. A., Fagan, M. J., Di Sebastiano, K. M., Kandola, M., Priebe, C. S., ... & Faulkner, G. (2021). Strange days: adult physical activity and mental health in the first two months of the COVID-19 pandemic. *Frontiers in Public Health*, *9*, 325.

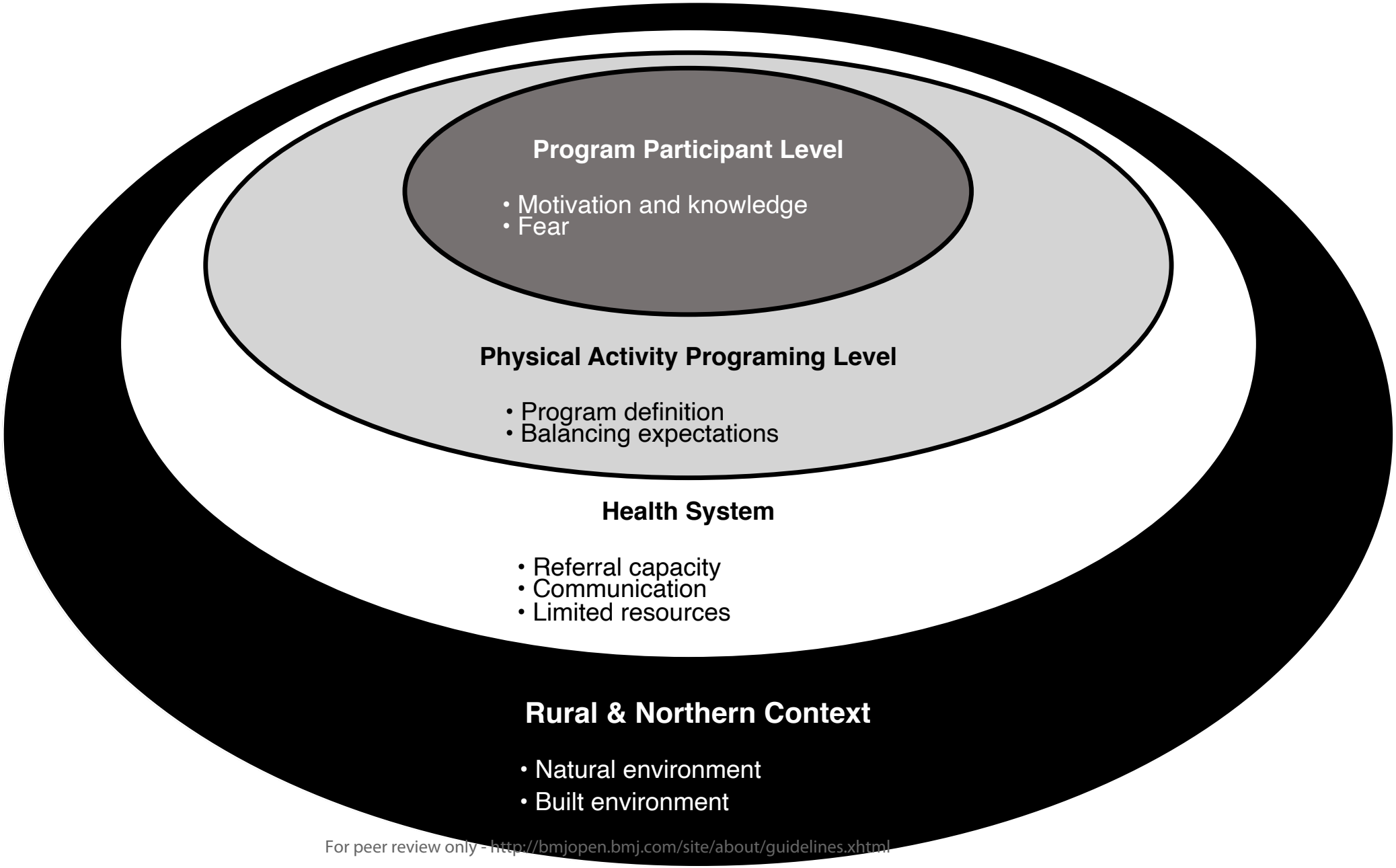
[45] Bacsu, J. D. R., O'Connell, M. E., Webster, C., Poole, L., Wighton, M. B., & Sivananthan, S. (2021). A scoping review of COVID-19 experiences of people living with dementia. *Canadian Journal of Public Health*, *112*(3), 400-411.

[46] Müller, P., Achraf, A., Zou, L., Apfelbacher, C., Erickson, K. I., & Müller, N. G. (2020). COVID-19, physical (in-) activity, and dementia prevention. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *6*(1), e12091.

Table 1: Identified challenges and mitigations strategies mapped to the social ecological model

Level	Identified Challenges	Mitigation Strategies
Northern and Rural Context	• Winter weather and conditions • Inaccessible built environment • Lack of specialized facilities and distance to opportunities	• Appropriate clothing and footwear, knowledge on strategies for being active and staying safe (e.g., walking on ice to prevent falls) • Adjust to seasonal activities • Advocate for connected pathways and accessible sidewalks • Use public transit, share limited facilities between social and physical activity program
Health System	• Fragmented Communication Process • Inconsistent Referral Process	• Community champions leverage informal networks • Take advantage of gaps to allow flexibility in community-driven ground-up response (e.g., include persons identified to potentially benefit from support informally connected through personal and community networks in contrast to requiring formal referral from locum practitioner)
Physical Activity Program	• Balancing routine and structure with participant choice and autonomy	• Flexibility to allow adjustment to cognitive and physical abilities of participants • Accommodation of diverse abilities in mixed classes and/or by team instruction
	• Lack of consistency in programming	• Develop informal work-arounds through provider collaboration (e.g., job sharing, willingness to work outside scope of practice) • Program scheduling responsive to participant needs, offer when and where demand is high • Engagement of volunteers
	• Lack of definition of program, and meaning of physical activity and exercise	• Allow for flexibility in program provision (switch from physical to psychosocial goals when formal exercise provider unavailable) • Accept that no one program is everything to everyone
	• Lack of accessibility to reliable information source	• Knowledge sharing occurs within community social network • Maintain traditional communication strategies (mail out of print activity book, person to person telephone connection)
	• Lack of resources	• Education and training provided by multiple sources

		• Flexible and adaptable job roles and volunteer engagement to address human resource capacity • Provider collaboration and sharing of limited resources across programs
Program Participant	• Stigma of dementia	• Offer program in neutral community location • Modify language to describe program to enhance inclusion for persons with dementia • Improve knowledge of benefits of exercise by participant and/or care partner
	• Perception of safety	• Acknowledge fear and provide tailored programming support • Education and training on risk • Confidence and trust in program providers
	• Scheduling priorities	• Participant and/or care partner awareness of program availability and benefits • Multiple programming options • Flexibility among community health providers to accommodate participant scheduling needs • Participants and care partners perceive physical activity as meaningful • Transportation support



Expanding Exercise Opportunities for Persons living with dementia

(FOCUS GROUP DISCUSSION SCRIPT AND QUESTIONS)

PERSONS WITH MCI/DEMENTIA *Start with some icebreakers to get the group more acquainted with one another.*

1. What does the word exercise mean to you?

2. Do you feel that physical activity is different from exercise, and if so how?

3. What are some exercises that you do?
    a. Potential prompts:
        i. Where do you do these exercises?
        ii. Who do you do these exercises with?
        iii. How often do you do these exercises?
        iv. What time of day do you prefer to exercise?

4. Tell me about the things that you do that would be considered physical activity?
    a. Potential prompts:
        i. Where do you do this?
        ii. With who?
        iii. How often?

5. Do you have any ideas about how physical activity or exercise might affect your health?
    a. Potential prompts:
        i. Effects on heart health
        ii. Effects on bone or joint health?
        iii. Effects on sleep?
        iv. Effects on mood?
6. Do you have any ideas about how physical activity or exercise might affect your thinking ability?

7. From your perspective, are there any risks you are worried about from doing physical activity or exercise?

8. Tell me about any additional physical activity or exercise that you would like to do but are not doing now.
    Prompts:
    a. What type of physical activity or exercise?
    b. Where would you like to do the physical activity or exercise?
    c. Who would you like to do the physical activity or exercise with?
    d. How much would you like to exercise?

9. What would help you get more physically active?

10. What gets in the way of you doing physical activity or exercise?

11. Who do you look to for advice about the things you can do to improve your health?

12. Who do you look to for advice about physical activity and exercise?

Expanding Exercise Opportunities for Persons living with dementia

(FOCUS GROUP DISCUSSION SCRIPT AND QUESTIONS)

ALLIED HEALTH PROFESSIONALS WHO PROVIDE SERVICES TO PEOPLE WITH MCI/DEMENTIA

1. What is your role in the health and wellbeing of people with dementia?

2. What is your role in prescribing or suggesting exercise to people with dementia?

3. What do you know about the benefits of physical activity and exercise to the health of people with dementia?

4. What do you know about the benefits of physical activity and exercise to the thinking ability of people with dementia?

5. Tell me about how you currently talk about and prescribe or suggest exercise to people with dementia?
   Prompts:
   a. Do you discuss their current exercise habits?
   b. Do you suggest exercise for people with dementia?
   c. Do you suggest specific frequencies or intensities of exercise?
   d. Do you refer people with dementia to specific people or programs?

6. What are the barriers to discussing and prescribing/suggesting exercise to people with dementia?

7. What would you need in order to better discuss and prescribe/suggest exercise to people with dementia?

8. Who should be discussing and prescribing/suggesting exercise to people with dementia?
   Prompts: Physician, nurse, PT/OT, kinesiologist or CEP, trainer, other?

9. Describe the ideal physical activity or exercise program for people with dementia.
   a. Where would the physical activity or exercise take place?
   b. Who would the person with dementia do the physical activity or exercise with?
   c. How often would the person with dementia do this physical activity or exercise?
   d. When should the physical activity or exercise take place?
   e. Should exercise programs for people with dementia require referral or be open to all?
10. What are some challenges for people with dementia to be physically active?

11. What do you think would make it easier for people with dementia to be physically active?

Supplementary File 1: Author response to consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Author Response
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	SF conducted all interviews. p. 8
2.	Credentials	SF has a PhD and is experienced in conducting qualitative research.
3.	Occupation	SF is an Associate Professor in the School of Nursing at UNBC.
4.	Gender	Female
5.	Experience and training	SF has previous training in qualitative research and has completed multiple qualitative research studies. p. 8
Relationship with participants		
6.	Relationship established	None
7.	Participant knowledge of the interviewer	The participants knew that the interviews and focus groups were being conducted to learn from participants about their perspectives and experiences with exercise involving persons with dementia.
8.	Interviewer characteristics	None
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Thematic analysis guided by Braun and Clarke's 6 steps (see p.7-8). -- Clarke V, Braun V. Thematic analysis. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952. -- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.
Participant selection		
10.	Sampling	Purposive, non-probability sampling, p. 6
11.	Method of approach	Snowball approach - E-mail, posters, word of mouth, p. 6
12.	Sample size	29 p. 6
13.	Non-participation	0
Setting		
14.	Setting of data collection	Rural and medium sized city in Western Canada p. 7
15.	Presence of non-participants	No
16.	Description of sample	Healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4); and care partners of persons living with dementia or cognitive impairment (n=5). p. 6
Data collection		
17.	Interview guide	Interview guide was reviewed by diverse team of stakeholders including health care professionals, allied health providers, researchers, persons with dementia, and care partners of persons living with dementia. P. 7
18.	Repeat interviews	No
19.	Audio/visual recording	Audio recording was done p. 7

20.	Field notes	Field notes were taken p. 7
21.	Duration	Interviews lasted between 1 - 2 hours p. 7
22.	Data saturation	Yes
23.	Transcripts returned	No

No	**Item**	**Author Response**
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	3
25.	Description of the coding tree	No
26.	Derivation of themes	Derived from data p. 9
27.	Software	Excel, Word p. 9
28.	Participant checking	No
Reporting		
29.	Quotations presented	Yes p. 10-20
30.	Data and findings consistent	Yes p. 9-20
31.	Clarity of major themes	Yes p. 9-20
32.	Clarity of minor themes	Yes p. 9-20

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Factors influencing participation in physical activity for persons living with dementia in rural and northern communities in Canada: A qualitative study

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Factors influencing participation in physical activity for persons living with dementia in rural and northern communities in Canada: A qualitative study

Freeman S, Pelletier C, Ward K, Bechard L, Regan, K, Somani S, and Middleton L.

Corresponding Author:

Dr. Shannon Freeman
Associate Professor, School of Nursing
University of Northern British Columbia
3333 University Way
Prince George, British Columbia
V2N 4Z9
Canada
e-mail: shannon.freeman@unbc.ca

Abstract

Objective: In recognition that engagement in physical activities for persons living with dementia can be challenging in rural and northern communities, the objective of this study was to explore the factors influencing physical activity participation among persons living with dementia in rural/northern communities and to identify locally-driven mitigation strategies participants used to address barriers to physical activity.

Setting: Interviews and focus groups were conducted in two locations in northern British Columbia, Canada including a rural community (<10,000 persons) and a medium sized geographically isolated city (<80,000 persons). Both communities are located at substantial distances (>800km) from larger urban centres.

Participants: Twenty-nine individuals participated including healthcare providers(n=8), community exercise professionals(n=12), persons living with dementia(n=4), and care partners (n=5).

Results: Rural and northern contextual factors including aspects of the built and natural environment were the main drivers of physical activity for persons living with dementia. Limited capacity in the health system to support physical activity due to a lack of referrals, poor communication mechanisms, and limited resources for programming created challenges for physical activity participation. At the community level, local champions filled gaps in physical activity programming by leveraging informal networks to organize opportunities. Program level factors included a lack of consistency in staff, and challenges defining program scope given limited population size and the fear of stigma for persons living with dementia.

Conclusions: Environmental context and limited access to specialized programming affect the opportunities for persons living with dementia to engage in physical activities. Rural and

northern communities showed resiliency in providing physical activity opportunities yet remained fragile due to human resource challenges. Without reliable resources and sustained support from the health system, local champions remain vulnerable to burnout. Enhancing support for local champions may provide greater stability and support to physical activity promotion in rural and northern communities.

Strengths and limitations of this study:

- A study strength includes the engagement of diverse stakeholders (persons living with dementia, care partners, allied health providers experienced in providing community exercise programs, and healthcare professionals) contributing varying perspectives.
- A strength of employing a qualitative approach was our ability to describe in-depth the challenges participants faced at varying levels of the social-ecological model.
- A strength of the study is the inclusion of participants from two separate communities enabling a reflection on different needs and environments
- A limitation of this study is that relatively less participants living with dementia or mild cognitive impairment compared to other participant groups
- As this study was conducted prior to the COVID-19 pandemic, a limitation the impact of the pandemic restrictions and social distancing protocols on physical activity experiences of persons living with dementia is unknown.

Keywords: Physical activity**,** exercise, dementia, cognitive impairment, rural health, Alzheimer's disease, social ecological model

INTRODUCTION

Dementia is an umbrella term used to describe progressive declines in cognition which may affect a person's behaviour and ability to perform activities of daily living. The most common form of dementia is Alzheimer's disease. More than 55 million persons are currently living with dementia worldwide.[1] Due to a rapidly aging population, it is projected that this number will rise to 78 million persons in 2030 and 139 million persons in 2050.[1] In Canada, 6.7% of persons aged over 65 are living with dementia [2]. As there is currently no cure for dementia, there is growing urgency to develop and implement strategies to support the well-being of persons living with dementia and their care partners.

There is much diversity and heterogeneity across rural communities in Canada based on sociospatial characteristics (e.g., population size, population density, distance from urban centre), social representation, population demographics, and resource availability. [3,4] Although there is no clear consensus on what constitutes a rural community,[5] common definitions are based on a combination of population size, distance from an urban centre, and access to services. In Canada, the provincial "north" is a term commonly used to identify the northern and more sparsely populated (e.g., rural, remote) areas which may also experience similarities in arctic/subarctic climates, political marginalization, economic dependency on natural resource development, and larger proportions of Indigenous populations.[6] Persons living in rural and northern communities face increased barriers to physical activity (e.g., transportation, snow/ice) and have fewer opportunities to engage in physical activity through specialized programming,[7] contributing to an increased risk of noncommunicable disease and disability compared to their urban counterparts. Characteristics specific to the rural context may directly and/or indirectly influence physical activity opportunities and capabilities among older adults.[8] As northern and

rural communities have a relatively greater proportion of older adults and a population that is aging faster than the general population,[9] the need to develop strategies to address context-specific barriers is urgent.

Physical activity is one of the best non-pharmacological strategies to support persons living with dementia to remain active and enhance quality of life.[10,11] For older adults living with dementia or mild cognitive impairment, which includes declines in memory, attention, and cognitive functioning that exceed that typically expected by age or educational level, physical activity can enhance and help maintain physical fitness, balance, mobility, functional ability, and cognition.[12,13,14,15] In addition to physical and cognitive benefits, physical activity has broader impacts including social inclusion and feelings of purpose, that contribute to overall well-being and quality of life.[16,17] Barriers that can prevent persons living with dementia from engaging in physical activity include stigma and lack of knowledge associated with dementia.[18]Persons living with dementia were found to spend more of their time engaged in sedentary behaviours when compared to age-matched cognitively healthy controls [19] and were less likely to meet physical activity guidelines[20] when compared to persons with no cognitive impairment.

Despite the well-known benefits of physical activity, there remains a need to develop physical activity interventions for persons living with dementia that address at each level of a social-ecological model.[21] A social-ecological approach to physical activity considers the interacting factors that influence opportunities at the levels of policy, community, organizational (institutional), interpersonal, and individual.[22,23] For persons living with dementia, individual issues affecting memory, declines in cognitive abilities, and changes in mobility may impact physical activity behaviours differently across the course of the illness.[24,25,26] The barriers to

engagement in physical activity are amplified by the stigma surrounding diagnosis of dementia (e.g., interpersonal relationships) and lack of knowledge by exercise providers on how to accommodate and adapt programming for varying and dynamic needs (e.g., lack of knowledge and programming barriers).[16] Prior research exploring physical activity barriers and opportunities for persons living with dementia has often focused on individual-level factors, with limited attention to environmental and community-specific factors affecting the inclusion of rural-dwelling persons living with dementia in physical activities.[23,26] A focus on environmental and systems-level factors is particularly important for understanding behaviour in rural and northern communities where the context shapes opportunities for active living. Taking a systems approach to physical activity promotion, exercise providers and allied health care providers who are aware of the unique needs of persons living dementia can be crucial enablers of physical activity for older adults by fostering positive (or negative) experiences and environments for physical activity. [17,27]

Care partners are uniquely positioned to raise awareness about factors influencing the behaviours and choices of persons living with dementia. The sharing of this person-specific knowledge with physical activity providers may inform intervention development and allow for tailoring of the program by healthcare professionals and allied health providers to better meet the individual needs of persons living with dementia. [26,27]

Therefore, the objectives of this study were to: 1) explore the factors influencing physical activity participation among persons living with dementia or mild cognitive impairment in rural and northern communities in Canada, and 2) identify locally-driven solutions to salient barriers to assist in the development of tools and resources for persons living with dementia, their care

partners, allied health providers, and healthcare professionals in rural and northern communities in Canada.

METHODS

Patient and Public Involvement: This work was guided by a large stakeholder advisory team including persons with dementia, care partners, physical activity providers, researchers, and health care experts. This advisory team provided direction to the research team which was used to inform design and guide this work.

Study Context: This study was nested within a larger national project aimed at developing resources and materials to support Dementia-Inclusive Choices for Exercise (DICE) project (www.dementiaexercise.com). [27,28] We report on the formative work conducted in northern British Columbia, Canada, highlighting the perspectives of those living in rural and northern geographies. Framed by a social ecological approach to understanding physical activity, opportunities for persons living with dementia are informed by interpersonal, intrapersonal, social and built environmental, and policy factors.[22] Thus, it is important to co-create knowledge with diverse communities based on population size and geographical location, aligning with basic principles of patient-oriented research.[29] Interviews and focus groups were conducted in two locations in northern British Columbia Canada; a rural community (population less than 10,000 persons) and a medium sized geographically isolated city (population less than 80,000 persons). Both communities are considered rural based on distance from urban centre and access to health services.[30]

Participant Recruitment: Purposive and snowball sampling strategies were employed to recruit exercise providers, allied health providers, persons living with dementia or mild cognitive

impairment, and care partners for persons living with dementia. Purposive non-probability sampling, commonly used in qualitative studies, allowed for the invitation of participants who were most representative or informative to participate.[31] Recruitment materials were initially shared in community locations (e.g., posters placed on notice boards at the Alzheimer Society and in a local memory clinic; notice placed in community newsletter) to recruit persons living with dementia and their family care partners. Local health systems stakeholders assisted in recruitment of healthcare professionals and exercise providers who delivered exercise programs for older adults and/or persons living with dementia (e.g., rehabilitation programs, geriatric outreach programs, community exercise programs).

Seven semi-structured focus groups and one interview were conducted with twenty-nine participants, including: healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4); and care partners of persons living with dementia or cognitive impairment (n=5). Four focus groups involved both healthcare professionals and allied health providers, one focus group involved both care partners and a person living with dementia, one focus group involved only persons with dementia, and one focus group involved only care partners. The interview was conducted with a person living with dementia unable to participate in a focus group setting. Participant age and gender were not collected to protect participant confidentiality especially given the relatively small number of healthcare professionals and allied health providers in this region. Focus groups lasted approximately two hours for healthcare professionals and allied health providers and approximately one hour for care partners and/or persons living with dementia or cognitive impairment. Participants provided informed written consent/assent ahead

of the session date and reconfirmed verbal consent/assent prior to the session commencing. All participants living with dementia were deemed to have the capacity to provide consent which was reconfirmed by their care partners. While there is no set number of participants or focus groups as a rule in qualitative research, twenty nine participants was considered an acceptable number of participants for this exploratory research as it fits within the commonly accepted sample size ranging from 15-30 participants for qualitative research.[32] At the conceptual level, concordance was observed in findings across differing participant groups and across both sites, suggesting that saturation was achieved.[33] Harmonized ethics approval was received for this study from the University of Northern British Columbia and University of British Columbia (H18-00392).

Focus Group Sessions: Focus group sessions, tailored to the participant type, followed a semi-structured guide based on previous iterations used by the research team.[28] The focus groups were facilitated by an experienced moderator (SF) with support from a graduate student research assistant (RF) who took notes and managed recording devices. The semi-structured approach allowed probing into emerging issues and themes, where appropriate. Focus groups enabled exploration of interactive social contexts and provided insight on participant perspectives and attitudes.[34,35] Group processes helped participants identify and clarify their perspectives with each other and encouraged increased depth of description and discussion among participants, providing more detailed responses to prompts.[36] Two of the focus group scripts used are available in supplemental file 1 (for persons with dementia) and supplemental file 2 (for allied healthcare providers).

Data Analysis*:* An inductive thematic analysis of transcripts was used guided by Braun and Clarke's six steps. [37,38] Beginning with familiarization of the data, a multi-disciplinary team

of researchers experienced in qualitative analyses (SF [gerontology] and CP [exercise physiology]) along with a research trainee (KW [health sciences]) read and reread the transcripts, writing initial thoughts from the data (step 1). All three researchers (SF, CP, and KW) are women who live in northern British Columbia. Each have their own lived experience interacting with and supporting persons living with dementia and care partners as well as experience interacting with community service providers. The engagement of team members from diverse backgrounds enable robust discussion and consideration of patterns in the data and understanding from various viewpoints (e.g., from the perspectives of supporting healthy aging, to optimizing physical activity and exercise opportunities). To capture broad perspectives on the data, researchers independently identified and coded the transcripts (step 2) and developed initial themes by identifying patterns in the data set (step 3). Initial themes were then discussed as a group to develop rich descriptions and definitions using a white board to map connections between ideas (step 4). Final themes were established and defined, with sub-themes generated as appropriate within each overall theme (step 5). Data extracts (quotes), identified to best describe each theme/subtheme, are presented with a narrative summary (step 6).

Using the social ecological model as a guide, [22,39] themes were deductively mapped using a white board and post-it notes and plotted according to user, program, health system, and broader community (contextual) levels to describe the factors influencing physical activity for persons living with dementia. Locally driven mitigation strategies and solutions described by participants to overcome barriers to physical activity were identified across each of the four levels. Analysis was conducted using Microsoft Word and Excel software.

RESULTS

Factors influencing participation in physical activity for persons living with dementia were organized into four themes according to the social ecological model: Northern and rural context, health system, physical activity programing, and program participant level (Figure 1). Identified challenges and mitigations strategies were also mapped to the social ecological model (Table 1).

Northern and rural context: Unique features of the northern and rural context in Canada both promote and limit physical activity The Canadian northern and rural environmental context underpinned all aspects concerning health and physical activity for persons living with dementia. The local and regional context shaped program opportunities, availability, accessibility, and preferences.

Natural environment. Elements including weather (e.g., harsh winter conditions and wildfires), geographic location (e.g., isolation from urban centres and from physical activity opportunities), wildlife (e.g., presence of bears, cougars, and moose), and lack of daylight in the winter months influenced willingness and abilities of persons living with dementia to engage in physical activity. One care partner noted: *"By 7 o'clock it's really dark, and I don't really feel that safe going in the dark by myself ... the temperature in the winter might be okay, but it might a sheet of ice*". Participants reported the need to adapt to changes in weather to maintain daily physical activities including outdoor walking.

> *I have to wear the tall boots. So, I get my boots on, that means they go right up to the knee and so you can stomp into the snow. Sometimes you put cleats on them so you don't slip. And I always have my poles. It's very important to have the poles. It's beautiful, you know.* (Person living with dementia)

Long-time residents of Canadian rural and northern communities described the easy access to natural environments including rivers, lakes, and forest trails as a facilitator of outdoor

physical activity engagement for all persons including those living with dementia. As one participant explained:

> *I used to do exercise that was more like go lift weights and workout and now it's like, no, unless it's fun. I like dancing. I like walking the dog in the forest or somewhere off-leash where I can just wander around in the trees and the mushrooms. It's hard to get me to go fast. I don't go fast, but you can get me to go up a hill* (Person living with dementia)

Further, one care partner of a person living with dementia emphasized how immersing themselves in the natural environment contributed not only to their ability to be physically active but also related to how they conceptualize and find positive meaning in activity as a way to be outside and seek goals beyond fitness.

> *I like the freedom of being away from it all in the woods, on the water—that's really important. In the backyard, no phones. And you just respond as you go and you're thinking of something you want to do, you do it. That's freedom. That's exercise. That's a good feeling.* (Care partner of person living with dementia)

Built environment Although a lack of facilities and vast geographic distance to the nearest urban centre were mentioned as barriers, participants described some of the unique built environmental features that facilitated physical activity. Participants valued the accessible infrastructure in their community: *"We actually have this incredible sidewalk system here … [it's] designed so that every street has access to this sidewalk system that is maintained by the municipality to get to downtown, to do grocery shopping, and so on"* (Person living with dementia). Further, participants shared how city planners in their rural community had considered the needs of an aging population when designing the sidewalk (e.g., cloverleaf and crescent patterns) to purposefully support safe and accessible physical activity for persons with cognitive impairments.

Health System: Limitations of the health system lead to development of local solutions

The overarching structure of the health care system impacted access to physical activity opportunities through three main facets: the referral process and policies, communication processes, and resource availability. Each subsequently impacted physical activity opportunities for program end-users.

Lack of capacity and mechanisms for referrals: Healthcare professionals and allied health providers struggled with the process of referring persons with dementia to specialized physical activity programs due to lack of capacity and resources throughout the system (e.g., staffing, limited program offerings) and absence of clear mechanisms in place to facilitate the referral process. When responsibility and accountability for referrals was unclear, it led to inaccuracies and gaps in assessment documentation which subsequently resulted in delayed or failed referrals. In some cases, when exercise providers received inaccurate and incomplete documentation during the referral process, it resulted in duplication of health assessments and additional workload. One healthcare professional noted:

> *What's on the piece of paper doesn't quite identify what the person's needs are. So, a lot of extra digging needs to go into that. So, whether the person needs to see a geriatrician which is more sort of the medical component, it's triaged that way.* (Healthcare Professional)

For persons with dementia and their care partners, the lack of a clear referral process or advice from their healthcare provider led to confusion and lack of awareness about where to seek trusted information about safe physical activity opportunities. One participant described their frustration noting:

> *It's been an ongoing question, where can we get more information. "Read about it." Okay, we've read about it. Who can we talk to? "Alzheimer's group" or a contact or "your GP, he can help". We've been through all that and there isn't any*. (Care partner of person living with dementia)

Difficulty in communication and fragmented access to information leads to lack of knowledge:

Challenges with clear and consistent communication were recognized as a barrier across all participant groups. One participant described these communication challenges noting:

> *Word finding difficulties depending on the type of dementia can be a challenge for the person who's struggling to communicate, and for other participants as well. Maybe the person with dementia who also has word finding difficulties they're not intentionally being dishonest, but their stories change depending on the wording that they're using because they can't find their words and then other participants are concerned for them because they just heard a story that's not necessarily true, but the person with dementia couldn't find the words to accurately tell what was going on. So, some communication barriers.* (Allied health provider)

Participants expressed a desire for access to resources and information specific to dementia, the disease process, and how to support physical activity opportunities that were safe and inclusive.

Persons living with dementia and care partners described the existing resources as inconsistent, inaccessible, or otherwise unavailable. One participant shared: *"My mother had Alzheimer's, my grandmother had Alzheimer's as well, and I've never come across any information that walks you through what to expect. That would be very helpful"* (Care partner of person living with dementia). While recognizing healthcare professionals as a key communication mechanism for information and educational resources about physical activity, one care partner shared:

> *The professionals don't have the time for this* [sharing information related to dementia]*, unless you have an appointment. Like if you're on a list, it could be 3 months, could be 6 months, it could be a year, or could be really soon.* (Care partner of person living with dementia)

In response, care partners connected informally to each other to promote knowledge sharing by leveraging community networks and using existing communication channels within the community. Close community connections, many based on decades of living in the same community, enabled persons living with dementia and their care partners to communicate their

needs directly to healthcare professionals and allied health providers through informal relationships. Within smaller and geographically isolated communities, participants described a lack of anonymity, noting it was common to run into each other at the grocery store, public events, or in their neighbourhood, allowing for informal connection and information exchange. Participants shared print copies of resources regarding physical activity and communicated by telephone to help compensate for the lack of accessibility to information formally from healthcare professionals and exercise providers.

Limited resources lead to ongoing need for flexibility, creativity, and advocacy: Participants emphasized the complexity of securing necessary resources to support high quality and sustainable exercise programming.

> *Maybe we touched on this when we talked about barriers and the priorities for the health care team at this team, education and community integration doesn't often come up as a high priority. It's very task-oriented health care. Like, this happened, give them this treatment, they're done. But helping with educating on, these are the things that are available in the community for you to participate in because this is going to be an ongoing—aging is not going to stop when you leave this hospital. Having more process-oriented approach and more education and more community integration, but unfortunately, due to resources that isn't always a priority.* (Allied Health Provider)

Participants described the importance of flexibility and creativity to overcome the inability of the health systems to provide physical activity opportunities, often due to limited funding, lack of infrastructure, and substantial gaps in human resources. In particular, participants shared their frustrations surrounding the limited specialized dementia care and services due to the limited human resources. This is especially prevalent within small and heterogeneous populations, as one participant noted:

> *there's just one or two staff for a different, very broad population sometimes because they don't have the same levels of functioning, but we only have … just the bare*

> *amount of staff, right. Maybe that's also a challenge. We don't have enough people* (Allied Health Provider)

Inadequate human resources can also lead to lack of specialist knowledge regarding exercise and dementia, contributing to unmet goals and objectives of both the program providers as well as participants. The shortage and/or absence of trained care providers caused changes in program design commonly by adjusting from physical to psychosocial goals. The flexibility to adjust the focus of the program allowed activities to remain operational. One exercise provider described that when healthcare professionals were unable to provide formal rehabilitation programs or exercise providers were unavailable to provide structured activities in their community, they pivoted to offer a social program instead. However, in doing so, they were also aware of the need to provide supports that fell within their own scope of practice.

> *We have to be really mindful in terms of each other's scopes, so we can't do exercise-whatever's called technically "exercise classes." However, we can do thing that are fun and fitness, which would be like kick ball and badminton* (Allied Health Provider)

To mitigate the lack of trained formal healthcare professionals and exercise providers, community champions built capacity by engaging volunteers and student trainees. One participant emphasized that:

> *Most of the groups … we use the students for. And it was a student actually that made the falls group. He did all the prep for it, everything. Got it all in line and all the stuff out to the doctors. We just kept it. The same with the fit group; we just kept it. And they love it" … "And it works well, too* (Healthcare Professional)

Participants described making use of public spaces such as local recreation centres to organize informal activity opportunities and participate in group programs in lieu of formal exercise facilities (e.g., fitness club, community recreation center), which may or may not be available. In one community, participants shared their use of a public multipurpose area for physical activity.

> *One of three recreation facilities ... [includes] a multi-purpose facility. There's tennis courts outside. There's community rooms where events could be held, meetings could be held. There's a gymnasium there. They do program sports, so you could go play at badminton"* (Care partner of person living with dementia)

Physical activity programing: Flexibility is needed to adapt to diverse community needs and preferences, as well as expertise available Healthcare professionals and allied health providers described the value of working towards defining physical activity programs including a clear set of characteristics, naming, and the need for trained program staff. Addressing each aspect is key to creating and sustaining a successful exercise program. However, challenges experienced in northern and rural communities in Canada are described below.

Defining physical activity programs is needed but can affect accessibility for persons living with dementia: Participants discussed challenges when determining whether to define and clearly label a physical activity program as focused and inclusive of persons living with dementia or to keep the focus more generic. Use of a clear definition acknowledging a specific focus of the program designed for persons living with dementia was thought to improve clarity in participant eligibility and feelings of inclusion, it was also expressed that this may limit the willingness of some persons living with dementia to attend due to the stigma associated with dementia and cognitive impairment. This sentiment was expressed in relation to those living in small rural Canadian settings, where some people who wished to keep their diagnosis of dementia confidential were potentially risking their privacy if they attended a physical activity program designed and labelled for persons living with dementia. The stigma associated with dementia was mitigated in small communities by offering the programs at neutral locations within the community, changing the language to enhance inclusion, and normalizing the environment. One

care partner commented that the stigma associated with dementia was still evident in their community and impacted their choices in physical activity: *"And there's a stigma attached to it in our minds. Not necessarily that anymore, but there has been in our past lives -- a person not right, something wrong upstairs, here in the cortex."* (Care partner of person living with dementia). One health care professional also noted *"If there's an Alzheimer's Group, but somebody doesn't like to acknowledge that they have Alzheimer's then you might not want to suggest that they go to an Alzheimer's group…so that could actually be a barrier"* (Health care professional).

Participants also expressed that labelling a program as 'exercise' can be interpreted in different ways. For some, 'exercise' may be viewed as an opportunity to enhance and maintain health, while for others, exercise can be intimidating and exclusive. One exercise professional described this issue:

> *I have to re-approach all the time. If I approach someone and say, "Do you want to come exercise?" They'll scoff at the thought of exercise. "I'm 94. I'm not going to exercise, today." But then if I say, "Hey, want to come play a game with me." Then they're all for it* (Allied Health Provider)

At the same time, the lack of a clear definition for exercise was not always perceived as detrimental as it can allow for fluidity in roles. For rural communities in Canada with limited capacity, flexibility in job roles and volunteer engagement allowed programs to continue to run. For example, one participant described how labelling a program as a social activity allowed it to be offered by a variety of providers:

> *We're not physio. We do fun and fitness. Like [when] physio is unable to come one morning because they're doing other things or when they're short staffed, then we do fun and fitness, so we do a game, like bowling"* (Allied Health Provider)

Balancing program design to meet everyone's needs and expectations: No singular physical activity program or method of delivery emerged as a one size fits all answer to ensure inclusivity

for all persons living with dementia, at all times, and in all locations. Instead, participants shared the importance of intentional decisions around program design and details including scheduling, program location, participant eligibility, and method of program delivery (e.g., standing, sitting, or mixed classes) to meet the needs of those within their area. These decisions can be difficult when serving a small but diverse group, as in rural communities in Canada, when balancing finite human and financial resources. If a program is too general, it may risk not being effective for anyone attending as noted by one exercise provider:

> *The problem is that … I don't think that anybody's really getting enough individual program in order to actually make an impact … Even with the stretching, they're not necessarily getting positioned in the exact right place, but it's one instructor and 20, 25 people. So I think programming where you have a ratio … depending on what the abilities of those four people are, or three people, the helper could be helping the one that's needing more assistance and that could travel* (Allied Health Provider)

Additionally, participants discussed the challenge of balancing routine and structure within the programs, keeping the program flexible enough to keep those participating engaged and meet their expectations while maintaining enough structure to achieve physical fitness goals. Flexibility in program provision, program design and provider roles was identified as a mitigation strategy which enabled providers to be responsive to the needs and preferences of persons living with dementia, scheduling, and practitioner scope of practice.

Program participant level: Supportive providers with flexibility are needed to help persons with dementia overcome challenges and fears. Participants shared unique experiences with physical activity based on the interaction between the rural environmental setting, the person living with dementia and their care partner where applicable.

Motivation and knowledge about physical activity: Participation in physical activity requires a conscious investment of time and personal resources. Persons living with dementia and care

partners described difficulties balancing multiple demands and had difficulty prioritizing physical activity due to other scheduled health related appointments or commitments. When asked about what gets in the way of physical activity, one participant living with dementia explained there were often *"Other activities that weren't scheduled, or you're already committed to."* Participants living with dementia noted the importance of a positive attitude and personal motivation toward physical activity participation as a critical enabler, for example:

> *I would enjoy more exercise. They have to change it up so it's not always the same because you do get bored. I don't care who you are, you get bored, so if you change the program a little bit every once in a while, then you're more likely to keep attending* (Person living with dementia)

Participants living with dementia further expressed how challenging it was to find trustworthy information about physical activity, impacting their ability to engage in regular activity:

> *You know, the world's a big place and I think the internet has a lot of good information. I don't know how to access that, but I know the girls do, and I think it gives you a wide variety of information and choices. I don't know what other source. I mean, I'm sure there are other sources. I haven't a doubt that's the only one* (Person living with dementia)

Similarly, participants identified that having instructors who are knowledgeable about exercise and familiar with supporting persons living with dementia to be active, would be an important facilitator supporting their participation in physical activity.

> *I would like to actually see whether or not they've got trainers there that could show me. I'm not comfortable going into a weight room thinking, "Oh, what I should be doing with this?.....That would be good if there were people there that would teach you how to use weights* (Person living with dementia)

<u>*Fear can prevent participation:*</u> For persons living with dementia, a variety of fears were reported which prevented engagement in physical activity programming. These fears included: the fear of being institutionalized if the program was held within a long-term care facility, the fear of getting lost when needing to take public transportation to attend an exercise class, and the

fear of injury from falling. Care partners further expressed negative feelings towards physical activity participation due to anticipation of the progressive loss of control and declining physical abilities of the person living with dementia as their disease progressed. For one care partner, they described how the fear not only led to distress, but that it was also an indicator for them of disease progression.

> *Mom doesn't do a lot of exercise. She gets lost very quickly, now, and forgets where she is or where she's going. She's really nervous of falling. She's terrified of snow. Like if there's snow or ice, she doesn't want to walk in it or she gets really stressed. Like she'll panic because there's snow or ice. She's really nervous of falling down. That's her biggest thing that she's going to fall down. And with my mom, if she falls down, she doesn't get, from a crawl to a stand is sometimes impossible. My mom would stand up and it's really hard for her to stand up. And that's something, that for me has been an indicator with both my parents when they couldn't get up from getting down, whether it's in the bathtub or when it's something's on the floor and they go down to get it and then they're stuck and they can't figure out how to get up and it's—and then fear comes because they realize they can't get up, but they're like, "But I'm supposed to be able to get up and I can't get up." And so, I don't know how to explain it, except that it's terrifying for them, and it's heartbreaking to witness, but it's also heartbreaking for each of them*. (Care partner of person with dementia)

In recognition that these fears are common for persons living with dementia, healthcare professionals and allied health providers noted the importance for fall prevention training for those individuals.

> *Building up the confidence [of persons living with dementia] in terms of getting up from a fall I think is important because fear of falling is a barrier to a lot of community participation, recreation and leisure participation in particular is what I'm referring to, but yeah, fear of falling is a big barrier for getting out and then people are at risk for social isolation*. (Allied Health Provider)

DISCUSSION

This study explored factors influencing physical activity participation for persons living with dementia in northern and rural communities in Canada and the strategies implemented in these settings to mitigate barriers to physical activity participation. From the perspectives of

healthcare professionals, allied health providers, persons living with mild to moderate dementia, and care partners, key points that emerged were the lack of health system support for physical activity participation, and substantial gaps in tailored exercise program offerings and knowledge needed to provide accessible, inclusive opportunities for physical activity. Often in rural and northern communities these challenges are compounded and interlinked (e.g., accessibility to use a neutral location to offer a program may not be available in the winter months or may experience scheduling challenges in the winter months due to competing demands for limited indoor space; reliability of public transportation may differ between winter and summer schedules or safety in walking outdoors may be affected by hours of sunlight by season or whether wildlife such as bears are active or hibernating).

In response to the substantial gaps experienced at the systems level, community-driven initiatives emerged. Community-based solutions, developed in response to gaps in available services and supports, relied on a limited number of community champions to provide physical activity programming. These community-specific initiatives were organically tailored to address the needs of the community of focus with consideration of the unique environmental context and finite human and financial resources. Fear of injury and stigma associated with a dementia diagnosis demand a multi-program response with flexibility, inclusivity and knowledge, not only for persons living with dementia but also for care partners who support persons living with dementia to engage in physical activity.

The individual-level factors influencing physical activity for persons living with dementia, including fear, stigma, cognitive function, and lack of knowledge, are commonly reported in the literature.[26] While these are still true for people living in northern and rural communities in Canada, fear and stigma are heightened due to the smaller population size and

lack of dementia-related knowledge due to limited access to trained providers or appropriate facilities. With limited populations in rural communities, it can become increasingly difficult for person living with dementia and their care partners to protect their privacy as it is not possible to remain anonymous when attending community programming.[40] In some cases, especially when individuals perceive their actions may be observed and discussed by others in their rural communities, they may prefer to engage in group activities in a neighbouring community, however, this may involve substantial investment of resources for those in rural and northern communities, including travel time and costs.[40] Commonly in rural communities, while individual-level barriers persist, environmental and community-level factors create an additional barrier that must be overcome to engage in physical activity, which is particularly true for persons living with dementia.[41]

Context is essential to understand the factors influencing physical activity participation for persons living with dementia in northern and rural communities in Canada. In alignment with our previous work, the natural environment can both enhance physical activity participation and exercise (e.g., proximity to outdoor recreation) and, at times, limit physical activity (e.g., winter weather, ice).[7] While the availability of facilities and accessible locations suitable for exercise provision and access to specialized exercise providers is a facilitator of physical activity for persons living with dementia in urban areas,[27] our findings highlight the near complete absence of such facilities and providers in northern and rural communities in British Columbia. This reinforces the importance to consider the links between the availability of infrastructure, networks, and resources with the degree of urbanization in the community.[42] While it is common for exercise providers to have limited knowledge of dementia and training regarding inclusive practices in physical activities,[28] this is amplified in rural communities by the

continued reliance on exercise providers without formal training (e.g., rehabilitation or recreation providers) working 'off the side of their desk' to meet community needs. The lack of trained and specialized staff leads to inconsistent program content and availability, fragmentation of program accessibility across different communities, and limited capacity for formal assessment. The lack of health systems leadership, authority, regulation, and quality control specific to physical activity programming have left individuals living in northern and rural communities in British Columbia to take a community-driven, grass-roots approach to support inclusion of persons living with dementia in physical activity and an overreliance on non-profit community organizations. In response to the lack of leadership from the health system to support northern and rural communities in British Columbia, individual community champions have emerged, focussed on building and enhancing community-level programs to address existing deficits. When access to the program relies on knowledge and awareness of community champions and informal networks, persons living with dementia and care partners who are not well connected and already engaged in the community may be unable to access physical activity programming. The issues identified in this study, which are present at the individual, community, and system levels of the social-ecological model, echo the priorities and Canadian call to action described by Njkiforuk (2018) to "support equitable action on rural and remote physical activity promotion across Canada".[43] Further these findings warrant a collaborative response between communities and health systems to enhance equity in the ability of persons living with dementia to access physical activity supports, especially in Canadian northern and rural communities.

This study provides insight into the factors affecting physical activity participation for persons living with dementia involving participants across two rural and northern communities in British Columbia Canada. The engagement of diverse stakeholders in this geographic region

using a qualitative approach allowed us to capture diverse perspectives on the existing deficits and has helped to identify gaps in tailored exercise program offerings and knowledge necessary to provide accessible, inclusive opportunities for physical activity. While a qualitative approach was deemed the most appropriate method to answer our research questions, further research may consider employing a quantitative research approach to gather both objective and subjective perspectives of participants and to increase the sample size. As the geographical focus of this work was limited to two northern and rural communities in Canada, findings may not be transferable to other communities such as urban centres or other countries with differing health care systems and resources. More research is needed to understand whether other northern and rural communities in Canada rely heavily on local community-specific initiatives. Further, a limitation of this study is the limited number of participants living with dementia or mild cognitive impairment who participated in this study (n=4/29). While allied health providers and healthcare professionals who participated in the study provided valuable reflections on the challenges they have observed, they are limited in their ability to comment specifically on individual-level factors and the lived experiences of persons living with dementia and their care.

In Canada, unintended consequences of pandemic restrictions (e.g., physical distancing protocols) include reductions of physical activity.[44, 45] Disruptions in daily routines and limited engagement in physical activity during the COVID-19 pandemic have been reported to severely impacted persons living with dementia.[46] Emerging evidence suggests that interdisciplinary prevention approaches to address physical inactivity related to pandemic restrictions and isolation are urgently needed especially for persons living with dementia.[47] As our work was conducted prior to the COVID-19 pandemic, future research is needed to examine how pandemic restrictions and social distancing protocols were experienced in rural and northern

communities in Canada and subsequently how COVID-19 pandemic may have impacted the ability of persons with dementia to engage in physical activity and have impacted the provision of local community-driven initiatives.

CONCLUSIONS

Physical activity opportunities and experiences for persons living with dementia living in northern and rural communities in Canada are shaped by the environmental context and limited accessibility to specialized programming. Local champions risk burnout by working to fill gaps left by absent health and non-profit sectors in small communities, limiting the long-term capacity and support in northern and rural communities for growing number of persons aging with dementia in Canada. It is important to support existing community leaders in a way that respects local knowledge and expertise.

Figure 1 Legend: Key findings by theme organized according to the social ecological model

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References

[1] World Health Organization. Dementia fact sheet. World Health Organization 2021. https://www.who.int/news-room/fact-sheets/detail/dementia(accessed Sep 2021).

[2] Public Health Agency of Canada. (2022). A dementia strategy for Canada: Together we achieve -2021 annual report. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy-annual-report-parliament-2021.html (accessed May 2022).

[3] Laurin, F., Pronovost, S., & Carrier, M. (2020). The end of the urban-rural dichotomy? Towards a new regional typology for SME performance. *J Rural Stud*, 80, 53-75.

[4] Keating, N., & Phillips, J. (2008). A critical human ecology perspective on rural ageing. Rural ageing: A good place to grow old, 1-10.

[5] MacGregor-Fors I, Vázquez LB. Revisiting 'rural'. *Sci Total Environ* 2020;741:132789. doi:10.1016/j.scitotenv.2019.06.135.

[6] Coates K, Poelzer G. The next northern challenge: the reality of the provincial north. Macdonald-Laurier Institute publication 2014 April. https://www.macdonaldlaurier.ca/files/pdf/MLITheProvincialNorth04-14-Final.pdf (accessed Aug 2021).

[7] Ward K, Pousette A, Pelletier CA. Not Everybody's an Athlete, But They Certainly Can Move": Facilitators of Physical Activity Maintenance in Older Adults in a Northern and Rural Setting. *J Aging Phys Act* 2020;28:6: 854-863. doi:10.1123/japa.2019-0393.

[8] Winterton, R., Warburton, J., Keating, N., Petersen, M., Berg, T., & Wilson, J. (2016). Understanding the influence of community characteristics on wellness for rural older adults: A meta-synthesis. *J Rural Stud*, 45, 320-327.

[9] Northern Health Authority. (2015) Healthy Aging in the North: Action Plan. Northern Health Authority 2015. https://www.northernhealth.ca/sites/northern_health/files/health-information/seniors/documents/healthy-aging-in-the-north-action-plan-2015.pdf (accessed Aug 2021).

[10] Vedel I, Sheets D, McAiney C, et al. CCCDTD5: Individual and community-based psychosocial and other non-pharmacological interventions to support persons living with dementia and their caregivers. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 2020;6:1e12086. doi:10.1002/trc2.12086.

[11] Alzheimer Society of Canada. Staying Physically active. https://alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/staying-physically-active (accessed Sep 2021).

[12] Blankevoort CG, Van Heuvelen MJ, Boersma F, et al. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. *Dement Geriatr Cogn Disord* 2010;30:392–402. doi:10.1159/000321357.

[13] Eshkoor SA, Hamid, TA, Mun, CY, et al. (2015). Mild cognitive impairment and its management in older people. *Clin Interv Aging* 2015;10;687. doi:10.2145/CIA.S73922.

[14] Ginis KA, Heisz J, Spence JC, et al. Formulation of evidence-based messages to promote the use of physical activity to prevent and manage Alzheimer's disease. *BMC Public Health* 2017;17:209. doi:10.1186/s12889-017-4090-5.

[15] Erickson KI, Hillman C, Stillman CM, et al. Physical activity, cognition, and brain outcomes: a review of the 2018 physical activity guidelines. *Med Sci Sports Exerc* 2019;51:6:1242. doi:10.1249/MSS.0000000000001936.

[16] Malthouse R, Fox F. Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: a qualitative study. *Physiotherapy* 2014;100:169-175. doi:10.1016/j.physio.2013.10.002.

[17] Cedervall Y, Torres S, Åberg AC. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging Ment Health* 2015;19:8: 679-688. doi: 10.1080/13607863.2014.962004.

[18] Kontos P, Grigorovich A, Dupuis S, et al. Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society. *Crit Public Health* 2020;30:91-102. doi:10.1080/09581596.2018.1508822.

[19] Hartman YAW, Karssemeijer EGA, Van Diepen LAM, et al. Dementia Patients Are More Sedentary and Less Physically Active than Age- and Sex-Matched Cognitively Healthy Older Adults. *Dement Geriatr Cogn Disord* 2018;46:81-89. doi:10.1159/000491995.

[20] Laurin D, Verreault R, Lindsay J, et al. Physical activity and risk of cognitive impairment and dementia in elderly persons. *Arch Neurol* 2001;58:498-504. doi:10.1001/archneur.58.3.498.

[21] Bowes A, Dawson A, Jepson R, et al. Physical activity for people with dementia: a scoping study. *BMC Geriatr* 2013;13:1-10. doi: 10.1186/1471-2318-13-129.

[22] McLeroy KR, Bibeau D, Steckler A, et al. An ecological perspective on health promotion programs. *Health Educ Q* 1988;15:351–377 doi:10.1177/109019818801500401.

[23] Stubbs B, Eggermont L, Soundy A, et al. What are the factors associated with physical activity (PA) participation in community dwelling adults with dementia? A systematic review of PA correlates. *Arch Gerontol Geriatr* 2014;59:2:195-203. doi: 10.1016/j.archger.2014.06.006.

[24] Hancox JE, van der Wardt V, Pollock K, et al. Factors influencing adherence to home-based strength and balance exercises among older adults with mild cognitive impairment and early dementia: promoting activity, independence and stability in early dementia (PrAISED). *PLoS one* 2019;14:e0217387. https://doi.org/10.1371/journal.pone.0217387.

[25] Dening T, Thomas A. Oxford textbook of old age psychiatry. Oxford University Press 2013:1-823.

[26] van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: a systematic review. *Arch Gerontol Geriatr* 2016;66:109-118. doi:10.1016/j.archger.2016.05.008.

[27] Hobson N, Dupuis SL, Giangregorio LM, et al. Perceived Facilitators and Barriers to Exercise Among Older Adults With Mild Cognitive Impairment and Early Dementia. *J Aging Phys Act* 2020;28:2:208-218. doi:10.1123/japa.2019-0010.

[28] Bechard LE, McDougall A, Mitchell C, et al. Dementia and mild cognitive impairment inclusive exercise: perceptions, experiences, and needs of community exercise providers. *PLOS ONE* 2020;15: e0238187. doi:10.1371/journal.pone.0238187.

[29] Canadian Institutes of Health Research. Strategy for Patient-Oriented Research: Patient Engagement Framework. https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf (accessed Sept 2021).

[30] Rural Coordination Centre of BC. Rural Practice Subsidiary Agreement. https://rccbc.ca/rccbc/about-the-jsc/rsa-communities/ (accessed Sept 2021).

[31] Polit DF, Beck CT. *Nursing research: Principles and methods*. Lippincott Williams & Wilkins 2004;729.

[32] Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

[33] Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The Sage handbook of qualitative research*. Sage.

[34] Morgan DL. *Planning and research design for focus groups. Focus groups as qualitative research* 1997;16.

[35] Wong LP. Focus group discussion: a tool for health and medical research. *Singapore Med J* 2008;49:256-60.

[36] Tausch AP, Menold N. Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators. *Glob Qual Nurs Res* 2016;3: doi:10.1177/2333393616630466.

[37] Clarke V, Braun V. *Thematic analysis*. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952.

[38] Braun V, Clarke V. *Using thematic analysis in psychology*. *Qual Res Psychol* 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.

[39] Spence JC, Lee RE. (2003). Toward a comprehensive model of physical activity. *Psychol Sport Exerc* 2003;4:7-24. doi: 10.1016/S1469-0292(02)00014-6.

[40] 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*(7), 1129-1142.

[41] Pelletier CA, White N, Duchesne A, et al. Barriers to physical activity for adults in rural and urban Canada: A cross-sectional comparison. *SSM Population Health* 2021;6:100964. doi: 10.1016/j.ssmph.2021.100964.

[42] Gansefort, D., Brand, T., Princk, C., & Zeeb, H. (2018). Community readiness for the promotion of physical activity in older adults—A cross-sectional comparison of rural and urban communities. *International journal of environmental research and public health*, *15*(3), 453.

[43] Nykiforuk Candace, I. J., Kayla, A., Sara, B., Wayne, C., Tracey, G., Jason, G., ... & Jonathan, M. (2018). Evidence synthesis Promotion of physical activity in rural, remote and northern settings: a Canadian call to action. *Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice*, *38*(11), 419.

[44] Di Sebastiano, K. M., Chulak-Bozzer, T., Vanderloo, L. M., & Faulkner, G. (2020). Don't walk so close to me: physical distancing and adult physical activity in Canada. *Frontiers in Psychology*, 1895.

[45] Gierc, M., Riazi, N. A., Fagan, M. J., Di Sebastiano, K. M., Kandola, M., Priebe, C. S., ... & Faulkner, G. (2021). Strange days: adult physical activity and mental health in the first two months of the COVID-19 pandemic. *Frontiers in Public Health*, *9*, 325.

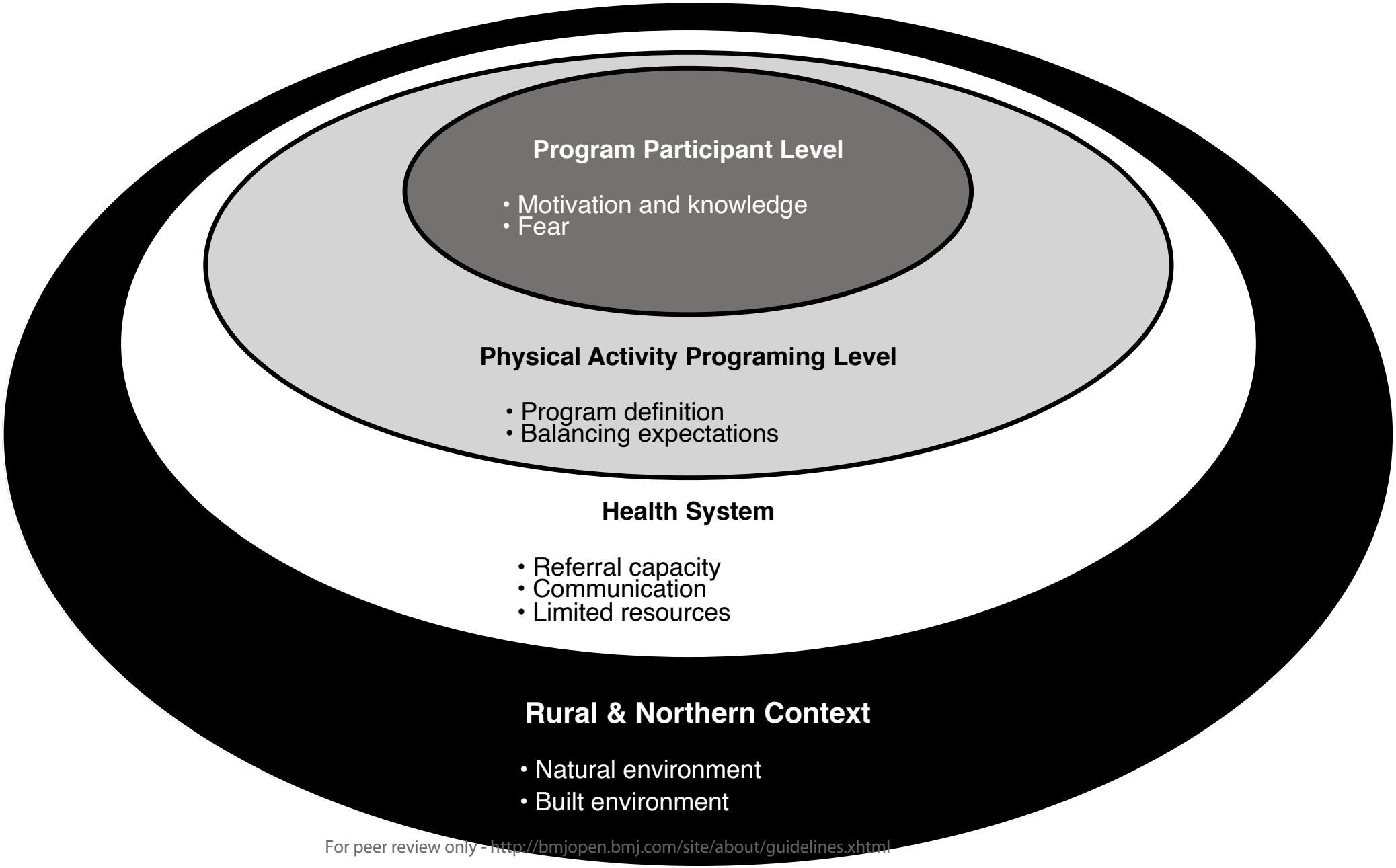
[46] Bacsu, J. D. R., O'Connell, M. E., Webster, C., Poole, L., Wighton, M. B., & Sivananthan, S. (2021). A scoping review of COVID-19 experiences of people living with dementia. *Canadian Journal of Public Health*, *112*(3), 400-411.

[47] Müller, P., Achraf, A., Zou, L., Apfelbacher, C., Erickson, K. I., & Müller, N. G. (2020). COVID-19, physical (in-) activity, and dementia prevention. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *6*(1), e12091.

Table 1: Identified challenges and mitigations strategies mapped to the social ecological model

Level	Identified Challenges	Mitigation Strategies
Northern and Rural Context	• Winter weather and conditions • Inaccessible built environment • Lack of specialized facilities and distance to opportunities	• Appropriate clothing and footwear, knowledge on strategies for being active and staying safe (e.g., walking on ice to prevent falls) • Adjust to seasonal activities • Advocate for connected pathways and accessible sidewalks • Use public transit, share limited facilities between social and physical activity program
Health System	• Fragmented Communication Process • Inconsistent Referral Process	• Community champions leverage informal networks • Take advantage of gaps to allow flexibility in community-driven ground-up response (e.g., include persons identified to potentially benefit from support informally connected through personal and community networks in contrast to requiring formal referral from locum practitioner)
Physical Activity Program	• Balancing routine and structure with participant choice and autonomy	• Flexibility to allow adjustment to cognitive and physical abilities of participants • Accommodation of diverse abilities in mixed classes and/or by team instruction
	• Lack of consistency in programming	• Develop informal work-arounds through provider collaboration (e.g., job sharing, willingness to work outside scope of practice) • Program scheduling responsive to participant needs, offer when and where demand is high • Engagement of volunteers
	• Lack of definition of program, and meaning of physical activity and exercise	• Allow for flexibility in program provision (switch from physical to psychosocial goals when formal exercise provider unavailable) • Accept that no one program is everything to everyone
	• Lack of accessibility to reliable information source	• Knowledge sharing occurs within community social network • Maintain traditional communication strategies (mail out of print activity book, person to person telephone connection)
	• Lack of resources	• Education and training provided by multiple sources

		• Flexible and adaptable job roles and volunteer engagement to address human resource capacity • Provider collaboration and sharing of limited resources across programs
Program Participant	• Stigma of dementia	• Offer program in neutral community location • Modify language to describe program to enhance inclusion for persons with dementia • Improve knowledge of benefits of exercise by participant and/or care partner
	• Perception of safety	• Acknowledge fear and provide tailored programming support • Education and training on risk • Confidence and trust in program providers
	• Scheduling priorities	• Participant and/or care partner awareness of program availability and benefits • Multiple programming options • Flexibility among community health providers to accommodate participant scheduling needs • Participants and care partners perceive physical activity as meaningful • Transportation support



Expanding Exercise Opportunities for Persons living with dementia

(FOCUS GROUP DISCUSSION SCRIPT AND QUESTIONS)

PERSONS WITH MCI/DEMENTIA *Start with some icebreakers to get the group more acquainted with one another.*

1. What does the word exercise mean to you?

2. Do you feel that physical activity is different from exercise, and if so how?

3. What are some exercises that you do?
    a. Potential prompts:
        i. Where do you do these exercises?
        ii. Who do you do these exercises with?
        iii. How often do you do these exercises?
        iv. What time of day do you prefer to exercise?

4. Tell me about the things that you do that would be considered physical activity?
    a. Potential prompts:
        i. Where do you do this?
        ii. With who?
        iii. How often?

5. Do you have any ideas about how physical activity or exercise might affect your health?
    a. Potential prompts:
        i. Effects on heart health
        ii. Effects on bone or joint health?
        iii. Effects on sleep?
        iv. Effects on mood?
6. Do you have any ideas about how physical activity or exercise might affect your thinking ability?

7. From your perspective, are there any risks you are worried about from doing physical activity or exercise?

8. Tell me about any additional physical activity or exercise that you would like to do but are not doing now.
    Prompts:
    a. What type of physical activity or exercise?
    b. Where would you like to do the physical activity or exercise?
    c. Who would you like to do the physical activity or exercise with?
    d. How much would you like to exercise?

9. What would help you get more physically active?

10. What gets in the way of you doing physical activity or exercise?

11. Who do you look to for advice about the things you can do to improve your health?

12. Who do you look to for advice about physical activity and exercise?

Expanding Exercise Opportunities for Persons living with dementia

(FOCUS GROUP DISCUSSION SCRIPT AND QUESTIONS)

ALLIED HEALTH PROFESSIONALS WHO PROVIDE SERVICES TO PEOPLE WITH MCI/DEMENTIA

1. What is your role in the health and wellbeing of people with dementia?

2. What is your role in prescribing or suggesting exercise to people with dementia?

3. What do you know about the benefits of physical activity and exercise to the health of people with dementia?

4. What do you know about the benefits of physical activity and exercise to the thinking ability of people with dementia?

5. Tell me about how you currently talk about and prescribe or suggest exercise to people with dementia?
   Prompts:
   a. Do you discuss their current exercise habits?
   b. Do you suggest exercise for people with dementia?
   c. Do you suggest specific frequencies or intensities of exercise?
   d. Do you refer people with dementia to specific people or programs?

6. What are the barriers to discussing and prescribing/suggesting exercise to people with dementia?

7. What would you need in order to better discuss and prescribe/suggest exercise to people with dementia?

8. Who should be discussing and prescribing/suggesting exercise to people with dementia?
   Prompts: Physician, nurse, PT/OT, kinesiologist or CEP, trainer, other?

9. Describe the ideal physical activity or exercise program for people with dementia.
   a. Where would the physical activity or exercise take place?
   b. Who would the person with dementia do the physical activity or exercise with?
   c. How often would the person with dementia do this physical activity or exercise?
   d. When should the physical activity or exercise take place?
   e. Should exercise programs for people with dementia require referral or be open to all?
10. What are some challenges for people with dementia to be physically active?

11. What do you think would make it easier for people with dementia to be physically active?

Supplementary File 1: Author response to consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Author Response
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	SF conducted all interviews. p. 8
2.	Credentials	SF has a PhD and is experienced in conducting qualitative research.
3.	Occupation	SF is an Associate Professor in the School of Nursing at UNBC.
4.	Gender	Female
5.	Experience and training	SF has previous training in qualitative research and has completed multiple qualitative research studies. p. 8
Relationship with participants		
6.	Relationship established	None
7.	Participant knowledge of the interviewer	The participants knew that the interviews and focus groups were being conducted to learn from participants about their perspectives and experiences with exercise involving persons with dementia.
8.	Interviewer characteristics	None
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Thematic analysis guided by Braun and Clarke's 6 steps (see p.7-8). -- Clarke V, Braun V. Thematic analysis. In Encyclopedia of critical psychology. Springer New York NY 2014;1947-1952. -- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:2:77-101. doi: 10.1191/1478088706qp063oa.
Participant selection		
10.	Sampling	Purposive, non-probability sampling, p. 6
11.	Method of approach	Snowball approach - E-mail, posters, word of mouth, p. 6
12.	Sample size	29 p. 6
13.	Non-participation	0
Setting		
14.	Setting of data collection	Rural and medium sized city in Western Canada p. 7
15.	Presence of non-participants	No
16.	Description of sample	Healthcare professionals (e.g., physiotherapists, rehabilitation assistants, registered nurses; n=8); allied health providers experienced in providing community exercise programs (n=12); persons living with mild to moderate dementia or cognitive impairment (n=4); and care partners of persons living with dementia or cognitive impairment (n=5). p. 6
Data collection		
17.	Interview guide	Interview guide was reviewed by diverse team of stakeholders including health care professionals, allied health providers, researchers, persons with dementia, and care partners of persons living with dementia. P. 7
18.	Repeat interviews	No
19.	Audio/visual recording	Audio recording was done p. 7

20.	Field notes	Field notes were taken p. 7
21.	Duration	Interviews lasted between 1 - 2 hours p. 7
22.	Data saturation	Yes
23.	Transcripts returned	No

No	**Item**	**Author Response**
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	3
25.	Description of the coding tree	No
26.	Derivation of themes	Derived from data p. 9
27.	Software	Excel, Word p. 9
28.	Participant checking	No
Reporting		
29.	Quotations presented	Yes p. 10-20
30.	Data and findings consistent	Yes p. 9-20
31.	Clarity of major themes	Yes p. 9-20
32.	Clarity of minor themes	Yes p. 9-20