

First Nations Elders Who Use Wheeled Mobility: An Exploration of Culture and Health

Lindsay Croxall,¹ Wendy Gifford,² and Jeffrey Jutai³

RÉSUMÉ

Une recherche interdisciplinaire faisant appel à des méthodes qualitatives a été menée pour étudier les obstacles et les facilitateurs relatifs à la participation culturelle des aînés des Premières Nations qui utilisent la mobilité sur roues et vivent dans des réserves en Ontario (Canada). Les thèmes ont été divisés en trois grandes catégories : (1) l'impact de la participation des aînés à des activités culturelles, (2) l'utilité des aides à la mobilité sur roues et (3) les obstacles freinant la participation à des événements culturels. Les obstacles incluent le manque de transports, l'incapacité de sortir du domicile en toute sécurité et de manière indépendante, l'irrégularité du terrain des réserves ; la stigmatisation associée au handicap, et le sentiment d'être un fardeau. Les résultats suggèrent que la mobilité sur roues peut augmenter la participation active des aînés aux événements culturels, mais démontrent aussi la nécessité de faciliter l'utilisation de cette mobilité dans les réserves en Ontario.

ABSTRACT

Interdisciplinary research using qualitative methods was employed to investigate the barriers to and facilitators of cultural participation for First Nations Elders who use wheeled mobility and live on reserve in Ontario, Canada. Themes were extracted into three broad categories: (1) impact of Elder participation in cultural activities, (2) usefulness of wheeled mobility devices, and (3) barriers to participating in cultural events. Barriers included lack of transportation, inability to access the outdoors safely and independently, challenging reserve terrain, stigma of being "disabled", and feeling like a burden. Findings suggest that wheeled mobility can increase the active participation of Elders in cultural events, but demonstrate a need to facilitate the use of wheeled mobility on reserves in Ontario, Canada.

MOHAWK ABSTRACT

Rat'eri'wi:saks toka'ken watie':sen Tsi tesewats tika' ka'wha's Tsi non:we nisewana':kere tsi ni':tson sewa'tstha ne kaie:ri niokakwen:tonte ani'tskwara. T`anon Tsi kanonhsta':ton kora':ne no'n:we nise wahna':kere. Sewa kiese'n:se ken ne iaies'e:we no':nen the':nen iaterihwat'en:kion tis sewana'hkere. Saia'takhe':na's ken ne sani'tskwara aonkwe'n:hake tsi tasa'tsti':kawha. Te':nen the':nen ioterihwate'n:kion tsi sewana':kere. The':nen Ken sewaio't'a:tis ne aiesewaia':ken'ne? I':iah teka'serehta':here ne aiesewati':ta. I':iah thaskwe':ni so'n:ha'a iashia':ke'ne ne a'tste. Iohontsia'ksen tsi no'n:we nihshite'ron. I'iah te'hsere o'nhka aiesaste':riste tsi I':iah teskwe':nie's ase':shon. I':iah ye'hsere o'nka tase' nikonra':ren rotirihwatse'n:rion tsi se'nha ronakio ko'wanen iahonne'htake no':nen te'hnen ioterih wate'n:kion to'ka' akarihwasonni:hake ne aontse she'n:hake to'h ia honne':we. Ron ne':reh ahotitoke'n:se ohni':io't tsi aontahon'tk'a:we ne kaia'takena':tshera ne se'nha aontse se'n:hake tsi tesewatawe'n:re ne tsi kanonhst'a:ton ne kora'hne.

¹ Department of Aging and Health, Queens University, Kingston, Ontario.

² School of Nursing, University of Ottawa, Ottawa, Ontario.

³ Faculty of Health Science, University of Ottawa, Ottawa, Ontario.

* We acknowledge the Elders and council members who partnered with us on this project, and Wayshennine McDonald for her translation services.

Manuscript received: / manuscrit reçu : 22/12/17

Manuscript accepted: / manuscrit accepté : 15/09/19

Mots-clés : vieillissement, technologie d'assistance, mobilité sur roues, communauté, culture, personnes âgées, bien-être

Keywords: aging, assistive technology, wheeled mobility, community, culture, Elders, wellness

Mohawk Keywords: Kaia'takehn'a:tshera rotihshon, Wake'hsen tsi thahsatawe'n:re, Sanakera'h shera, Tsi naho:ten Tishet'a:kwen, Rotiksten'enko:wa, ata' karati':tshera

La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Lindsay Croxall, M.Sc.
Department of Aging and Health
Queens University
31 George Street
Kingston, Ontario
K7L 3N6
Canada
(Lindsay.croxall@queensu.ca)

Introduction

Wheeled mobility (WM) continues to make up the greatest proportion of assistive devices in use in Canada, where there are currently 1,186,800 wheelchair users (Statistics Canada, 2006). Independence in mobility is one of the most significant determinants of quality of life for individuals with disabilities (Koontz, Ding, Jan, Groo, & Hansen, 2015), and suitable assistive technology (AT) has been found to be one of the most important elements in supporting activities and participation of individuals with disabilities (Borg, Lindstöm, & Larsson, 2009).

Participation is defined as, “the ability of a person to be involved in any life situation, and occurs at the intersection of what the person can do, wants to do, has the opportunity or affordance to do, and is not prevented from doing so by the world in which the person lives and seeks to participate” (Mallinson & Hammel, 2010, p. 29). Participation in society remains a challenge for those who use WM. Even with accessible buildings, housing, schools, and recreational facilities, WM users still make fewer trips outside the home and engage in fewer activities than people without disabilities (National Organization of Disability, 2000).

It remains an even greater challenge on Canadian reserves and in northern communities, because an increasing number of First Nations adults are reporting that their homes are in major need of repair and/or are not modified for accessibility, they have challenges negotiating reserve terrain, there is a lack of adequate transportation, they have difficulty participating in cultural ceremonies, and they experience isolation because of harsh winter weather (Wearmouth & Wielandt, 2009).

A study conducted by Ripat, Brown and Ethans (2015) identified reduced community outing frequency in the winter for those who use WM. Most participants reported that their tires and casters get stuck in the snow and/or slip on the ice, making it difficult to ascend inclines and ramps (Ripat et al., 2015). Many participants also reported that their hands become cold while using controls or pushing rims, and some participants reported difficulties with frozen batteries, seat

cushions, back rests, and electronics (Ripat et al., 2015). Sidewalks and roads were also reported to be problematic, and 80 per cent of participants reported needing additional help in the winter. Limited community access in winter led to a sense of loneliness, isolation, and fear or anxiety related to safety (Ripat et al., 2015).

Indigenous people share many health practices such as hunting and consumption of local foods, participation in ceremonies, rites of passage and end-of-life customs, and the everyday enactment of respectful relations with the natural world (Henry, Lavallée, Styvendale, Innes, & JSTOR, 2018). The medicine wheel is also an important part of holistic Indigenous health and culture, and is divided into four quadrants, which represent the four stages of life, the four medicines, and the four states of well-being, which include emotional, mental, spiritual, and physical health. Colonization and settler colonialism have been associated with the poor health and well-being for Indigenous people, thereby contributing to inter-generational trauma (Evans-Campbell, 2008) that disrupts emotional, mental, spiritual, and physical health (Bombay, Matheson, & Anisman, 2009; Brave Heart, 2003; Kirmayer, Brass, & Tait 2000; Pearce et al., 2008).

According to the Regional Health Survey (RHS), which is the only First Nations-governed longitudinal health survey in Canada, First Nations adults who report being more involved in the cultural elements of their community report more spiritual, mental, emotional, and physical balance (First Nations Information Governance Centre, 2012). Preservation of language and transmission of culture to younger generations has shown to reduce suicide rates, and participation in traditional culture appears to have potential for enhancing health (First Nations Information Governance Centre, 2012).

Colonialism in Canada has made the transmission of language and culture especially challenging through loss of traditional roles in communities and disrupted family structures (Bombay et al., 2009). Elder presence in the community is important, because many Elders

retain the knowledge of their language and cultural traditions, which are an important part of healing (Health Council of Canada, 2013).

The importance for community and culture are left out of the dominant model of aging, which Pace and Grenier (2016), describe as low-probability of disease, high physical and cognitive functional capacity, and active engagement with life. First Nations people view health more holistically via the balance of spiritual, mental, emotional, and physical well-being (First Nations Information Governance Centre, 2012), signifying that the use of WM to address merely physical impairment is insufficient and will result in negative effects on the health and well-being of First Nations communities.

It is better to view the diverse needs of aging people as a continuum of functioning (World Health Organization, 2015), instead of viewing aging as a period of vulnerability and disengagement (Kingsley, 2015). Viewing aging as a period of vulnerability and disengagement creates a focus on care for the elderly instead of on models geared toward the importance of social engagement and the contribution of older people (Low, Yap, & Brodaty, 2011). This is especially important in First Nations communities, because First Nations Elders evaluate their health in relation to the wellness of the entire community (Pace & Grenier, 2016). In order to support older First Nations peoples' wellness, the health of the whole community must be addressed (Pace & Grenier, 2016).

For the purpose of this article, we use the term "Elder" to reflect a particular status of honor, wisdom, and respect. Although Elders are of various ages, we only include Elders chronologically over the age of 54, as most research in Indigenous communities focuses on younger generations (Health Council of Canada, 2013). Age 55 is often used as the lower limit for being of senior age for First Nations populations because of the earlier onset of chronic conditions and lower life expectancy (Health Council of Canada, 2013).

There is an unprecedented need for research that examines WM use, which incorporates First Nations theories of wellness, and which encourages the continuation of and participation in traditional culture. First Nations leadership, youth, community members, and Elders have made it clear that culture must not only guide work, it must also be understood as an important social determinant of health (Health Canada, 2014). Culture as a foundation means that Indigenous knowledge and culture should be the base for current policies, strategies, and frameworks (Health Canada, 2014).

Through this research we sought to learn about the barriers to and facilitators of cultural participation for

First Nations Elders who use WM and live on reserve in Ontario Canada. To the best of the authors' knowledge, there have not been any published studies examining WM use among Elder First Nation populations.

Method

Research Design

This study adopted an interdisciplinary research approach conducted via qualitative methods by incorporating a more holistic view that goes beyond addressing physical impairment, to gain an understanding of the Elders' experiences in using WM to participate in cultural events.

The researchers aimed to equalize power by negotiating an understanding in shared control over the project and its findings by seeking guidance from community members and leaders regarding appropriate research protocols. This project is interdisciplinary in nature because we engaged the perspectives of community members, chief and council, long-term care employees, a senior policy analyst from Indigenous Services Canada, professors in nursing, professors in rehabilitation sciences, members of Carleton Universities Institute on the Ethics of Research with Indigenous People (CUIERIP), the First Nations Information Governance Centre (FNIGC), health advocacy officers, and physiotherapists. Participants were recruited and interviewed until data saturation in each community was reached.

Ethics approval was obtained from the University of Ottawa, the Mohawk Council of Akwesasne, and Six Nations Council. Research agreements were negotiated with the Mohawk Council of Akwesasne, and Six Nations Council. Each community incorporated ownership, control, access, and possession (OCAP) into each agreement as was deemed necessary.

Procedure

Health advocacy officers, chief and council, traditional wellness coordinators, and employees from long-term care facilities made initial contact with potential participants using recruitment flyers provided by the principal investigator. Volunteers were taken on a first come / first served basis. The principal investigator followed up by telephone or e-mail to schedule interviews. Written consents were obtained from the Elders prior to conducting the interviews, and the author assured the Elders that their participation was voluntary and that they could withdraw from the study at any time without penalty. The confidentiality of their contribution was also guaranteed. The interviews were conducted in the homes of the participants, lasting 1 hour or less, and were audiotaped for later transcription if this was agreed to by the participant. All participants

agreed to be audiotaped. Consistent with cultural tradition, a tobacco offering was given to the Elders before asking them to share their experiences and knowledge.

Participants

Eighteen participants, 10 from Akwesasne and 8 from Six Nations, were recruited into the study based on the following inclusion criteria: must be 55 years of age and older, be a First Nations Elder, live on a reserve in Canada, comprehend and converse in English, and use a wheelchair or walker with wheels (for at least 1 year but not since birth). We asked that participants have a minimum of 1 year experience using WM to ensure that they would have sufficient lived experience to contribute to the study, and we asked that participants not be WM users since birth so that we could see if there was a perceived change in participation specific to WM use. These inclusion criteria were established to ensure that a homogeneous sample was obtained, in order to reveal the experience of Elders in accessing cultural events using their WM devices.

Measures

Demographic information was collected prior to the interview. A semi-structured interview was developed based on available literature and with help from members of the interdisciplinary team who had extensive experience working with First Nations populations. The interview included questions such as describing the importance of cultural participation, describing the impact and importance of Elder cultural participation on health, and describing what made it harder or easier to participate in cultural events using a WM device.

The interview was re-examined following the first two interviews, and it became clear that community is also considered an important means for the transmission of culture, and that culture does not need to be explicitly taught in order to be transmitted. Throughout the interview, field notes were taken to capture methodological and theoretical insights from the data, which were later incorporated into the transcribed texts.

An evaluation of scientific rigor for this study demonstrated that the researcher obtained credibility because prolonged engagement in the research setting occurred and trust and rapport were established. Dependability was achieved through record-keeping throughout all stages of the research. All decisions were recorded as was the thinking behind them and a full audit trail is available. Confirmability was achieved through reflexivity on behavioral and emotional responses, and these were also kept as part of the audit trail. The findings were sent for validation from leadership of the participant communities.

Data Analysis

The principal investigator transcribed the interviews and field notes verbatim and NVivo was used to help organize the data during analysis. Thematic analysis was used as a method of “identifying, analyzing, and reporting patterns (themes) within the data” (Castleberry & Nolen, 2018, p. 808). The analysis of the data was conducted using the following five steps: compiling the data, disassembling the data, reassembling the data, interpreting the data, and concluding the results (Castleberry & Nolen, 2018). Data analysis for this study occurred iteratively while data collection was still taking place, and did not wait until all data were collected.

After the data were compiled, they were disassembled by taking them apart and putting them into meaningful groups, also known as codes. Coding is defined as “the process by which raw data are gradually converted into useable data through the identification of themes, concepts, or ideas that have some connection with each other” (Austin & Sutton, 2014, p. 438). A priori coding was used in adjunct with emergent themes that developed during the coding process.

The data were then reassembled within a hierarchy of themes to demonstrate how each theme is related to the other (Castleberry & Nolen, 2018). Similar codes were clustered together to produce higher-order codes, and the data were interpreted by making analytical conclusions from the codes and themes, which were then used in the conclusion to respond to the research question (Castleberry & Nolen, 2018).

The researcher completed three separate data analyses: one for data from Six Nations, one for the data from Akwesasne, and one that looked at all the data for common themes across the two communities. The findings are organized around three broad categories: impact of Elder participation in cultural activities, usefulness of WM device(s), and barriers to participating in cultural events.

Results

Demographic Characteristics

Six males and 12 females between the ages of 55 and 89 participated. The average age was 72, with the males being younger (mean age 69 years) than females (mean age 74 years). Participants had been using WM between 1 and 40 years (40 being an outlier), which was adjusted to between 1 and 11 years without the outlier. The average time that the participants had used their WM devices with the outlier was 6.78 years and the average without the outlier was 4.83 years. All participants lived on reserve, 2 participants had three devices, 5 participants had two devices, and 11 participants had

one device at the time of data collection, which came to a total of 27 devices (10 manual wheelchairs, five power wheelchairs, one transfer chair, and 11 walkers with wheels). Almost all participants said that they had difficulty getting around the community.

Impact of Elder Participation in Cultural Activities

When the Elders were asked what cultural activities they found meaningful, a majority of participants said pow wow's, longhouse, lacrosse, basket-making, quilting, and travelling to other reserves to learn about other cultures. Participants also said that cultural events were not the only avenues for the transmission of culture. The community in general is seen as a means through which culture can be transmitted, and that this knowledge does not have to be taught explicitly; it can be learned just by people being together.

A majority of participants said that Elders have an important role in the health of the community, which includes: sharing knowledge and experience; teaching language, songs, traditions, culture, and history; and providing leadership. Participants said that Elders are a symbol of, and connection to, their culture, and that the youth are learning who their Totas (grandmothers) are, and that all the Totas are their teachers.

We have so much to share and the young people have nothing to look forward to. The young people are losing sight of our traditions, cultures and history. They need something to hang on to and believe in. We need to be out there in the community. So many Elders think they are forgotten and useless and they're not (WM User Six Nations 2).

Several Elders spoke about culture as foundation for health, and how their leadership can help the youth regain the self-respect that has been taken from them.

It gives them respect for themselves and their Elders... mentally it gives them a lot of health. Even physically because you take a little grandchild, I watch sometimes grandchildren want to hug their grandma and that's a form of respect. It's up to the adults to teach them how to give that hug and what it means (WM User Six Nations 9).

Elder participation in cultural activities not only contributes to the well-being of their community, but also has an impact on their own well-being. For example, one Elder talked about how uplifting it is to attend the pow wow and see her grandchildren participating, because when she was younger, she had to keep her culture a secret.

It's uplifting to go and see especially the Pow-wow, to see the little ones and it's so sweet. See when I was growing up there was none of this no, no, no- to be

an Indian you kept it low, so you didn't see none of this stuff and now my great grandchildren are participating in there, so it's good I almost cried it's just...(WM User Akwesasne 1).

Several Elders spoke specifically about their experiences with depression and loneliness caused by a lack of cultural participation:

Depression. It's important to me but not important enough for them to take me out...like if I'm stuck in the house for two weeks, or a week and a half, I can get so depressed, and am I going to have to live like this for the rest of my life? No place to go, nobody to talk to...I think that's my only downfall right now. I can't move the way I want to (WM User Akwesasne 3).

Usefulness of WM Device(s)

A majority of Elders spoke positively about the usefulness of their WM device(s).

If you don't use that you're not doing nothing... it's a big help, it keeps you going, it's a support. It's a support for me because I lose my balance sometimes (WM User Akwesasne 1).

Although most Elders found their devices useful, many also said that their devices could use more maintenance and that the design of their devices should be changed to suit reserve terrain.

They need to put bigger wheels, just for the lawns they need to put bigger wheels. There's all kinds of imperfections out there (WM User Akwesasne 2).

Five of the Elders had motorized wheelchairs, which they described as providing more independence because they could overcome rough reserve terrain such as mud, rocks, gravel, and grass.

I got approved for that chair so I could go outside and enjoy life... It gave me a sense of freedom because I could go get my own milk...you know freedom (WM User Six Nations 1).

It works well on grass and rocks. Yeah I can do just about anything with it (WM User Six Nations 7).

Barriers to Participating in Cultural Events

Although the Elders detailed the importance of community and cultural participation for their health and the health of their communities, they also expressed an overall decrease in participation because of barriers in using their WM devices. The following five barriers to WM use at community and cultural events emerged: lack of transportation to and from cultural events, inability to access the outdoors safely and independently, challenging reserve terrain, the stigma of being "disabled", and feeling like a burden.

Lack of transportation to and from cultural events

Transportation was seen as the largest barrier to community and cultural participation. Fifteen Elders said that transportation was a direct barrier to attending community and cultural events.

Transportation is the biggest because right now I had a car accident about 3 yrs. ago and I lost my license, so I have to depend on him (husband) or anybody else and wait till they can take me so I can't go...that would be good if we could have that, you know, there's a lot of Elders they got to stay home because there's no way to go anywhere.

Transportation I think is the biggest hindrance for Elders...if there was transportation available where you didn't have to bother somebody else (WM User Akwesasne 3).

The three participants who did not describe transportation to be a barrier to cultural participation are also the only three who still drive. Many Elders discussed how there are several options for transportation to and from medical appointments, but explained that there are not any transportation options available to attend community and cultural activities.

There's no rides or vehicles provided to get us anywhere. There's not one vehicle from Monday to Friday only if the driver is available and you have to book an appointment. If you have an appointment say Monday at 2 pm and he is already picking someone up at 1:30 than you can't use it (WM User Six Nations 1).

Although this Elder has not had the opportunity to use her motorized device at a cultural event because of lack of adequate transportation, she described how useful it would be by relating it to an experience she had had at another event.

My friend took me to blues fest in Kitchener this summer. Good thing for that chair (motorized). Her and her boyfriend made a ramp to get into their van and it fit right in there. I thought ohhhh it was awesome because I didn't have to depend on someone else to push me. This great big crowd all through the streets and it's hard for this (gestures to manual chair she is sitting in) but with that (points to power chair) no problem... and there's different stages, so if I wanted to hear this person over here and they wanted to go over there. I'll meet you back over here and could go on my own. There was vendors and it was freedom (WM User Six Nations 1).

Although Elders found the motorized wheelchair to be the best for overcoming reserve terrain, they explained that these devices cannot be used at cultural events because people have no way to transport them to or from the event locations. Transportation was the

largest barrier to cultural participation for Elders in both communities. When Elders were asked what would make it easier for them to attend community and cultural events, a majority of participants said transportation would be the biggest facilitator:

Transportation. Transportation. I've heard them talking about bus lines...like handibus they have in the city because those are equipped for wheelchairs and walkers. There's space there. Something that can run 2 or 3 times a week. There's a lot of programs in Oshweken but you can't get to it. They need more transportation and it has to be affordable. It has to be geared toward people down here (WM User Six Nations 2).

Having a taxi service even if you have to pay \$10 or \$15 for gas round trip. Drop me off here leave me here for a couple of hours and pick me up (WM User Six Nations 1).

Inability to access the outdoors safely and independently

Eight Elders did not have the ability to get out of their residences independently to access the outdoors safely. Five of these Elders made makeshift ramps that were not up to building code standards.

I had to stay in my house for a month because I didn't have a ramp. Once I came in, I was stuck in here. I thought how can I get groceries. I had to give someone my card to go get me my list...I couldn't afford to get a loan to get a ramp, so my brother came over and built a make shift one. It isn't up to code or nothing. Nobody checks if a ramp is up to code. No one cared. They couldn't help me so oh well (WM User Six Nations 1).

One Elder lived on the ground level in a senior's apartment with no automatic door and therefore could not get through with her walker, which was one of the reasons that she did not use her walker even though she needed it:

When they came to assess me... my balance was that bad and she said I really need to use a walker...but we don't have automatic doors here... I always thought all seniors' buildings would have automatic doors. Anyway, that's what I'm fighting for now (WM User Six Nations 5).

One Elder waited a year and half for a ramp to be built. In the meantime, her granddaughter had to carry her in and out of the house:

She used to have to pick me up and bring me in and out. Yeah and she hurt herself a couple of times (WM User Six Nations 10).

Some Elders expressed difficulty because of ramps being covered in snow:

It's always full of snow. When I asked them to come in and shovel it off they said as soon as he's

available... cause when they put the ramp in they told me someone would be maintaining it...it's the same thing over and over again. I get so fed up I go out and do it myself (WM User Akwesasne 3).

Challenging reserve terrain

Elders who used walkers with wheels or manual wheelchairs experienced challenges negotiating rough reserve terrain, and there was a general lack of pavement and sidewalks, which Elders said was a barrier to attending community and cultural events.

I like to go to the pow wow but it's kind of hard yeah to get me across that lawn. They usually have them in a field and it's hard to get a wheelchair across the field. I used to go but that's the main reason (WM User Akwesasne 8).

Some Elders talked about the importance of accessible ramps, doorways, and bathrooms.

There's some places where the parking is right in front of the door but the ramp to get up is at the other end...so like somebody wasn't thinking... they should make people that design this stuff get in a damn wheelchair and go...walk a day in your life...or have someone who is in a wheelchair (WM User Six Nations 1).

That's one of the things that stops me. I can't get into the outhouse there. I can't get in. Can we get something more appropriate for us to participate? I don't go because of that.. How will I go to the bathroom? (WM User Six Nations 8)

Elders talked about lack of independence as a barrier at the events.

It's like I can't go and look around. They're right there next to me...and sort of like hurry me up. I hate it when people follow me around and say 'are you almost ready' 'are you almost ready' I hate that (WM User Akwesasne 3).

Overall, half of the Elders said that weather was a barrier to community and cultural participation. Several participants reported that there were fewer opportunities for people to move with their devices in snow and mud, leading to limited activity engagement, isolation, and loneliness. A few Elders mentioned that having a second device for outdoor use would be beneficial.

It's dangerous. You might slip and break a hip. Nowadays you can break a hip. I hate that winter. The snow gets all in the tire. Then you come back in and it's just as dirty (WM User Akwesasne 6).

In the springtime it's the worst because it's muddy and I'll be tracking mud all over the place. It's on my shoes and four wheels. Coming home from an event like that I have to have a towel and wipe it off which takes a lot of time (WM User Six Nations 8).

Stigma of being "disabled"

During the interviews several Elders brought up stigma as a barrier to cultural participation.

They said 'are you coming?' How do they look at me? How do they look at me? I can't do anything (WM User Akwesasne 6).

When this Elder was asked to clarify if she was referring to how others look at her, she said:

Yes they hate me. They treat you rough. They think your nothing when you're using the chair because you have a low life. You can't do anything (WM User Akwesasne 6).

Some Elders try to escape stigma by not using the WM devices that have been prescribed to them.

I felt like people kind of put you in a different category like as soon as they see me with this 'uh disabled'. They put labels on you and it seems like instead of feeling like this you feel like less of a person. I didn't like having to depend on it so I tried not to use it a lot (WM User Six Nations 2).

One Elder explained why she does not give in to stigma.

It makes me happy that I'm still able to get around and not be a shut in. I'll do anything I don't care if I have to go be pushed in a wheelchair to go to these events. I would go. I have no problem using our things and I appreciate that it's there so if they don't like that I'm sitting in a wheelchair so be it (WM User Akwesasne 1).

Feeling like a burden

Feelings of being a burden were also said to be a barrier to community and cultural participation.

I don't want to be a burden to anyone and that's how I feel. They tell me not to feel that way (WM User Akwesasne 4).

One thing I don't like is to hold people up. You know I don't like to be a burden (WM User Six Nations 10).

One Elder said that feeling like a burden was a barrier, and said that she would not feel like a burden if she could use her motorized wheelchair at cultural events.

I could go where I want, nobody pushing me because that's a burden on them...start to hate you because they have to push you around. And that's another reason I won't go anywhere because you feel like you're a burden (WM User Six Nations 1).

Discussion

The purpose of this study was to investigate the barriers to and facilitators of cultural participation by First Nations Elders who use WM and live on reserve in

Ontario Canada. Using an interdisciplinary approach allowed the authors to utilize the expertise from a diverse research team in order to disseminate findings for use across a real life context. Having community members as part of the interdisciplinary team ensured that the information derived from the study was culturally relevant and therefore usable.

A majority of participants said that Elders have an important role that directly affects the health of the community. This finding is in line with the Health Council of Canada's (2013) findings that healing efforts are dependent on the presence of Elders in the community. The Elders in this study said that it is important for younger generations to learn about the culture that they have been disconnected from because culture provides identity and, respect, and gives people something to believe in. These findings are in line with the Regional Health Survey's research demonstrating that connection to culture has a positive effect on health outcomes and reduces suicide rates (First Nations Information Governance Centre, 2012). Participants in our study also confirmed that participation in cultural events was important for their own health because a lack of participation increases loneliness and feelings of depression. This study highlighted increased difficulties maneuvering WM devices in snow, which is in line with Ripat et al.'s. (2015) findings that the frequency of community outings for those who WM devices is reduced further in winter, leading to increased loneliness and isolation.

The findings from this study are consistent with the holistic health perspectives held by most Indigenous people (Bombay et al., 2009; Brave Heart, 2003; Kirmayer et al., 2000; Pearce et al., 2008), and demonstrate the importance of viewing healthy aging as a continuum of functioning in which social engagement and the contribution of older people are important.

Overall, participants reported a decrease in cultural participation since becoming WM users, and several participants stopped participating altogether because of barriers such as lack of transportation to and from an event, inability to access the outdoors, challenging reserve terrain, the stigma of being "disabled", and/or feeling like a burden.

Transportation was the largest barrier to cultural participation, which includes both transportation of the individuals who use WM and transportation of their WM devices. Motorized wheelchairs were found to be the most difficult to transport, which many participants regretted, because the motorized wheelchair was found to be the most useful device to navigate reserve terrain. Interestingly, the only three participants who did not report transportation as a barrier to cultural participation were the only three who still drive.

A little under half of participants stated that they did not have the ability to exit their home independently and safely with their WM device, which made it difficult to attend community and cultural events. Several participants had long wait times for ramps, but others were able to obtain them right away. Those participants who were not able to access funding and could not afford ramps had to resort to building makeshift ramps that were not up to code. Several of the participants said that they could not access their ramps in winter because the ramps were covered in snow.

Some participants said that their WM devices were not suitable for rough reserve terrain, and suggested that the design needed to change to accommodate the challenging exterior paths of travel. Other participants discussed the need for regular maintenance of their devices, and it was also stated several times that having an extra device for outdoor use would increase participation, because some participants are either unable to, or find it extremely difficult to, clean off their wheels after events.

Many Elders said that they do not participate because of the stigma of being "disabled" and/or because they feel like a burden to others. They explained that they feel like a burden when it comes to needing transportation for themselves and their WM devices, as well as needing help physically in order to attend the events, feeling rushed, and feeling an overall lack of independence. Some participants also said that they do not participate because of the stigma related to being in a wheelchair, and feel that more education is needed to teach people about WM in order to reduce the stigma.

Limitations

There were several limitations to this study. Although the focus of this study was on WM, many participants had other health conditions that might have impacted their participation levels. Member checking was not conducted with participants after the interview because it was not feasible within the timeline of the study. Member checking can be a lengthy process, because experiences are always changing and reinterpretation could be ongoing (Robinson & Kerr, 2015). The findings are not meant to be transferable, because First Nation communities have unique languages, cultures, and beliefs.

Clinical Implications

The findings from this study indicate the need to build collaborative relationships and interdisciplinary teams with First Nations Elders in order to provide appropriate WM according to their unique accessibility needs. There is also a need for health professional education aimed

at providing culturally competent care that is informed by culturally competent research programs and policies, including increased access to affordable transportation geared towards those who use WM.

The findings from this study also reveal a gap in research on cultural participation for First Nations Elders who use WM, and demonstrate a need for technological advancements such as designing WM devices specifically for traversing rough reserve terrain. Other technological advancements could include designing components to help with barriers of WM use in winter months such as heated seats, back rests, temperature-controlled batteries, low-cost heating for ramps, and technology to help Elders get in and out of regular vehicles.

Conclusion

This interdisciplinary study used semi-structured interviews to gain a better understanding of the cultural experiences of First Nation Elders who use WM and live on reserves in Canada. This study contributes to the existing literature by underscoring the importance of culture as a foundation for the health of Indigenous communities, as well as the additional difficulties this population experiences in trying to access community and cultural events.

This study also suggests that many First Nations Elders living on reserves who use WM are denied functional independence, as well as the opportunity for engagement in the community and cultural activities that they find meaningful and important for their health and the health of their communities. Findings from this study demonstrate a need for change in funding and policy regarding the allocation of resources for accessibility on reserve such as ensuring that Elders have safe access to the outdoors, providing adequate transportation to and from cultural events, creating accessible paths of travel to and from cultural events, increasing accessibility at the events, and increasing education to reduce stigma.

References

- Austin, Z., & Sutton, J. (2014). Qualitative research: Getting started. *The Canadian Journal of Hospital Pharmacy*, 67(6), 436. doi: 10.4212/cjhp.v67i6.1406
- Bombay, A., Matheson, K., & Anisman, H. (2009). Intergenerational trauma: Convergence of multiple processes among first nations peoples in Canada. *Journal of Aboriginal Health*, 5(3), 6.
- Borg, J., Lindström, A., & Larsson, S. (2009). Assistive technology in developing countries: National and international responsibilities to implement the Convention on the Rights of Persons with Disabilities. *Lancet*, 374(9704), 1863–1865. doi: 10.1016/S0140-6736(09)61872-9
- Brave Heart, M. Y. (2003). The historical trauma response among Natives and its relationship with substance abuse: A Lakota illustration. *Journal of Psychoactive Drugs*, 35(1), 7–13. doi: 10.1080/02791072.2003.10399988.
- Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds? *Currents in Pharmacy Teaching and Learning*, 10(6), 807–815. <http://doi:10.1016/j.cptl.2018.03.019>
- Evans-Campbell, T. (2008). Historical trauma in American Indian/Native Alaska communities. *Journal of Interpersonal Violence*, 23(3), 316.
- First Nations Information Governance Centre. (2012). *First Nations Regional Health Survey (RHS) 2008/10: National report on adults, youth and children living in First Nation communities*. Ottawa: Author.
- Health Canada. (2014). *First Nations mental wellness continuum framework-summary report*. Ottawa: Health Canada and Assembly of First Nations.
- Health Council of Canada. (2013). Canada's most vulnerable: Improving health care for First Nations, Inuit, and Metis seniors. Retrieved 12 January 2015 from https://healthcouncilcanada.ca/files/Senior_AB_Report_2013_EN_final.pdf
- Henry, R., LaVallee, A., Van Styvendale, N., Innes, R. A., & JSTOR. (2018). *Global Indigenous health: Reconciling the past, engaging the present, animating the future*. Tucson: The University of Arizona Press.
- Kingsley, D. E. (2015). Aging and health care costs: Narrative versus reality. *Poverty & Public Policy*, 7(1), 3–21. doi: 10.1002/pop4.89
- Kirmayer, L. J., Brass, G. M., & Tait, C. L. (2000). The mental health of Aboriginal peoples: Transformations of identity and community. *The Canadian Journal of Psychiatry*, 45(7), 607–616. doi: 10.1177/070674370004500702
- Koontz, A., Ding, D., Jan, Y., De Groo, S., & Hansen, A. (2015). Wheeled mobility. *BioMed Research International*, 2015(138176), 1–2. doi: 10.1155/2015/138176
- Low, L., Yap, M., & Brodaty, H. (2011). A systematic review of different models of home and community care services for older persons. *BMC Health Services Research*, 11(1), 93. doi: 10.1186/1472-6963-11-93
- Mallinson, T., & Hammel, J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine and Rehabilitation*, 91(9), S29–S33.
- National Organization of Disability. (2000). *NOD/Harris Survey*. Washington, DC: Author.
- Pace, J. E., & Grenier, A. (2016). Expanding the circle of knowledge: Reconceptualising successful aging among North American older Indigenous peoples. *The Journals of Gerontology Series B*, 72(2), 248–258. doi: 10.1093/geronb/gbw128

- Pearce, M. E., Christian, W. M., Patterson, K., Norris, K., Moniruzzaman, A., Craib, K. J. P., et al (2008). The cedar project: Historical trauma, sexual abuse and HIV risk among young Aboriginal people who use injection and non-injection drugs in two Canadian cities. *Social Science & Medicine*, 66(11), 2185–2194. [https://doi:10.1016/j.socscimed.2008.03.034](https://doi.org/10.1016/j.socscimed.2008.03.034)
- Ripat, J. D., Brown, C. L., & Ethans, K. D. (2015). Barriers to wheelchair use in the winter. *Archives of Physical Medicine and Rehabilitation*, 96(6), 1117–1122. [https://doi:10.1016/j.apmr.2015.01.020](https://doi.org/10.1016/j.apmr.2015.01.020)
- Robinson, S., & Kerr, R. (2015). Reflexive conversations: Constructing hermeneutic designs for qualitative management research. *British Journal of Management*, 26(4), 777–790.
- Statistics Canada. (2006). Adult population with disabilities, by use of need for specialized equipment or aids and type of disability. Retrieved 20, March 2016 from: <http://www.statcan.gc.ca/pub/89-628-x/2008005/t/5201108-eng.htm>
- Wearmouth, H., & Wielandt, T. (2009). Reserve is no place for a wheelchair: Challenges to consider during wheelchair provision intended for use in First Nations community. *Disability & Rehabilitation: Assistive Technology*, 4(5), 321–328.
- World Health Organization. (2015). World report on ageing and health. Retrieved 10, January 2016 from: http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=9B183E3C8FDB010BA131A9AD50CA10A7?sequence=1