

ELDERS WHO USE WHEELED MOBILITY

**FIRST NATION ELDERS WHO USE WHEELED MOBILITY:
AN EXPLORATION OF CULTURE AND HEALTH**

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Preface

Prior to conducting this research, all the necessary approvals were obtained from the University of Ottawa Health Sciences and Sciences Research Ethics Board, from Six Nations Council and from the Mohawk Council of Akwesasne. Research agreements were negotiated with Six Nations and the Mohawk Council of Akwesasne. Ownership, control, access and possession (OCAP) were incorporated into each research agreement.

Lindsay Croxall's contributions to this thesis include being the primary researcher responsible for designing the research project, applying for funding, obtaining ethics approval, the recruitment of participants, data collection, data analysis, and writing the manuscripts for publication. This project engaged the perspectives of community members, Chief and Council, and my thesis advisory committee (TAC).

Thesis Abstract

Objective

To explore wheeled mobility use by First Nation Elders who live on reserves in Canada.

Study

The purpose of this study was to gain an understanding of the importance of Elder cultural participation, the perceptions of the effects of participation on health, how cultural participation has changed since becoming a wheeled mobility user, the barriers to participation, and thoughts on how participation can be improved.

Method

A database search of the literature was conducted in an iterative manner from September 2015-June 2017 to locate research related to wheeled mobility. The population of interest was First Nation Elders who live on reserve in Canada. All types of study designs and methods were considered. An interpretive phenomenological study was also conducted in order learn about the lived experiences of First Nation Elder wheeled mobility users in accessing the cultural elements of their communities. Data were collected using a demographic form and a semi-structured interview.

Findings

The author did not find any studies on wheeled mobility use by Elders on reserve, or their impacts on cultural participation during the literature review. Several barriers to cultural participation were brought forward during the phenomenological study which included: lack of access to outdoors; lack of transportation; inaccessible paths of travel; lack of access at the

events; and feelings of stigma and burden. The Elders explained that they play a central role in the health of the community and that cultural participation is important for individual health and for the health of the community. The transmission of culture to younger generations was said to be necessary for optimal health, and that the community in general serves as a space for cultural transmission. Participants related positively to the usefulness of their devices and most participants found them easy to access. A majority of Elders said that their levels of cultural participation declined specifically due to barriers in using their device(s).

Résumé de Thèse

Objectif

Pour explorer l'utilisation de la mobilité à roues par les aînés des Premières Nations qui vivent sur les réserves au Canada.

Étude

Le but de cette étude était de comprendre l'importance de la participation culturelle des personnes âgées, les perceptions des effets de la participation à la santé, la façon dont la participation culturelle a changé depuis qu'il devient un utilisateur de la mobilité à roues, les obstacles à la participation et les réflexions sur la façon dont la participation peut être améliorés.

Méthode

Une recherche de la littérature a été menée pour localiser les recherches liées à la mobilité à roues. La population d'intérêt était les personnes âgées des Premières Nations qui utilisent la mobilité à roues et vivent sur les réserves au Canada. Tous les types de conceptions et de méthodes d'étude ont été pris en considération. Une étude qualitative a également été menée et a utilisé une approche phénoménologique interdisciplinaire pour découvrir les expériences vécues des aînés des Premières Nations dans l'accès aux éléments culturels de leurs communautés. Les données ont été recueillies à l'aide d'une forme démographique et d'une entrevue semi-structurée.

Résultats

L'auteur n'a pas trouvé d'études sur l'utilisation de la mobilité sur roues par les Aînés en réserve, ni sur leurs impacts sur la participation culturelle lors de la revue de la littérature. Plusieurs obstacles à la participation culturelle ont été avancés lors de l'étude phénoménologique qui comprenait: le manque d'accès à l'extérieur; Manque de transport; Trajets inaccessibles; Manque

d'accès aux événements; Et des sentiments de stigma et de fardeau. Les aînés ont expliqué qu'ils jouent un rôle central dans la santé de la communauté et que la participation culturelle est importante pour la santé individuelle et pour la santé de la communauté. La transmission de la culture aux générations plus jeunes était nécessaire pour une santé optimale et que la communauté en général sert d'espace de transmission culturelle. Les participants se sont intéressés positivement à l'utilité de leurs appareils et la plupart des participants ont eu facilement accès. La majorité des aînés ont déclaré que leurs niveaux de participation communautaire et culturelle ont diminué spécifiquement en raison des obstacles à l'utilisation de leur (s) appareil (s).

Acknowledgements

I would like to begin by saying thank-you to the University of Ottawa for accepting me into the *Interdisciplinary School of Health Sciences* and would like to acknowledge that the university is on traditional unceded Algonquin territory.

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I am grateful to my thesis supervisor Jeffrey Jutai (PhD), Director of the University of Ottawa's *Interdisciplinary School of Health Sciences* for the patient guidance, encouragement and advice he has provided throughout this process. He consistently allowed this thesis to be my own work, but steered me in the right direction whenever I needed it.

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List of Abbreviations

ADP	Assistive Device Program
AT	Assistive Technology
CLSA	Canadian Longitudinal Study on Aging
CUERIP	Carleton University's Institute on the Ethics of Research with Indigenous People
EPIC	Early Professional, Inspired Careers
FNIGC	First Nations Information Governance Centre
MS&E	Materials Supplies and Equipment
NHS	National Household Survey
NIHB	Non-Insured Health Benefits
OCAP	Ownership Control Access and Possession
REB	Research Ethics Boards
RHS	Regional Health Survey
SCI	Spinal Cord Injury
TAC	Thesis Advisory Committee
TRC	Truth and Reconciliation Commission
WM	Wheeled Mobility
WSIB	Workplace Safety and Insurance Board

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Thesis Design and Objectives

The overall aim of this thesis is to explore the experiences of First Nation Elders who use wheeled mobility (WM) on reserve, and more specifically their access to cultural ceremonies and events. Specific objectives were: a) to conduct a literature review to examine the body of knowledge concerning: the need for WM; whether WM is currently meeting the users needs and supporting active participation; to review the scope and gaps in the literature; and to identify areas for further research, b) To conduct a phenomenological study to explore the lived experiences of First Nation Elders who use WM in relation to cultural participation and health.

Chapter 1 provides a background on the population of interest and gives context to the need for research in this area. This chapter also outlines the research questions and objectives that guided this research. Chapter 2 is structured as a manuscript and addresses the first main objective of this thesis, which is to conduct a literature review. Chapter 3 is a copy of the approved thesis proposal for this project. The approved thesis proposal demonstrates that the thesis topic addresses a significant problem, that an organized plan was put in place for collecting the data, and that the methods of analysis were identified and appropriate. Chapter 4 is structured as a manuscript and addresses the second main objective of this thesis, by providing the results of the phenomenological study. Chapter 5 provides an integrated discussion of the findings from the literature review and the qualitative study within the broader context of Elder WM use on reserve and highlights the implication for assistive technology, aging and rehabilitation.

Chapter 1 / Introduction

Relevance

Assistive technology (AT) is any device, piece of equipment, software, or other tool that is used by people with disabilities to perform activities that might otherwise be difficult or impossible due to their disability [1]. AT assists individuals in improving their functional abilities and becoming more independent by; increasing their potential to go to school, gaining employment, participating with family and community; and exercising human rights [1]. Appropriate AT meets the users needs and environmental conditions; is safe, durable and effective; is available and accessible, maintained, and sustained at the most economical and affordable price [1]. Suitable AT has been found to be one of the most important elements in supporting activities and participation of individuals with disabilities [1].

Independence in mobility is one of the most significant determinants of quality of life for individuals with disabilities [2]. Wheeled mobility devices (WMD) continue to make up the greatest portion of assistive devices in use in Canada where there are currently over one million (1,186,800) wheelchair users [3]. The powered and manual mobility market globally is projected to grow significantly due to baby boomers and increased longevity [2]. Although the Indigenous population is quite young it is also Canada's fastest growing population, and increased by 20.1% between 2006 and 2011, compared to 5.2% for the non-Indigenous population [4].

Participation in society remains a challenge for those who use wheeled mobility (WM). Even with accessible buildings, housing, schools and recreational facilities, WM users still make fewer trips outside the home and engage in less activities than people without disabilities [5]. It remains an even greater challenge on reserves in Canada because an increasing number of First Nation adults are reporting that they're homes are in major need of repair, homes are often not modified for accessibility, there is a lack of access to appropriate services, there are challenges

negotiating reserve terrain, lack of adequate transportation, difficulty participating in cultural ceremonies, and isolation due to harsh winter weather [6].

There is growing concern that not enough attention is being paid to the health care needs of Indigenous seniors in research or policy because the focus is often on Indigenous youth [7]. First Nation Elders are more likely than younger generations to live in rural and remote communities where it is more challenging and expensive to access care [7]. First Nation Elders often do not fully understand information given to them about their health conditions and many do not have documents such as birth certificates, which are required to obtain a health card [7]. There is also growing concern that First Nation Elders are becoming more isolated because many of the young people are leaving the communities in order to obtain an education and are not returning [7].

Understanding WM use among First Nation Elders is important because as the Regional Health Survey (RHS) demonstrates a healthy person is one who maintains balance with their environment [8]. First Nation adults who reported being more involved in the cultural elements of their community reported more spiritual, mental, emotional and physical balance [8]. The presence of Elders is important in communities because many Elders retain the knowledge of their language and cultural traditions, which are an important part of healing efforts [7]. Preservation of language and transmission of culture to younger generations has shown to reduce suicide rates [8], and participation in traditional culture appears to have potential for enhancing health [8].

The author was unable to find published studies examining WM use among Elder First Nation populations. There is an unprecedented need for interdisciplinary research that examines

WM use that incorporates First Nations theories of wellness, and that encourages the continuation of and participation in traditional culture.

This study is designed to develop a greater understanding of how First Nation Elders who use WM and live on reserve participate in the cultural activities they find meaningful. The following research questions and objectives needed to be met in order to learn about these experiences.

Research Question:

What are the processes, barriers, and facilitators that impact cultural participation for First Nation Elders who use wheeled mobility and live on reserve in Canada.

Objectives:

1. To learn about participants perceptions on the effects of participation on individual and community health.
2. To gain an understanding of how cultural experiences have changed since becoming a WM user.
3. To explore the processes, barriers, and facilitators to cultural participation.

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Chapter 2: Literature Review

**Wheeled mobility: meeting the needs of First Nation Elder
populations on reserve in Canada**

This chapter is based upon an unpublished manuscript formatted for submission to the Journal of
Disability and Rehabilitation: Assistive Technology

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Wheeled mobility: meeting the needs of First Nation Elder populations on reserves in Canada: literature review

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Wheeled mobility: meeting the needs of First Nation Elder populations on reserves in Canada: literature review

Abstract

Purpose

The aim of this review is to examine the body of knowledge concerning the need for wheeled mobility devices, whether wheeled mobility meets the users needs and supports the active participation of First Nation Elders who live on reserves in Canada. The aim of this review is also to review the scope and gaps in the literature in order to identify areas for future research.

Method

A search of the literature was conducted to locate research related to wheeled mobility. The population of interest was First Nation Elders who use wheeled mobility and live on reserve in Canada. All types of study designs and methods were considered. The following databases were searched: CINAHL, Embase, Medline (Ovid), Scopus, Web of Science. Relevant journals, references and potential grey literature were investigated for pertinent data sources.

Results

This analysis is useful because it demonstrates that there is a gap in the availability of wheeled mobility literature between Indigenous and non-Indigenous Canadians. The first aim of this study was to examine the body of knowledge concerning the need for wheeled mobility among Elders who live on reserves in Canada. The database search yielded zero results. Grey literature on the current health status of Indigenous adults and Elders on reserves in Canada demonstrates that there are much higher levels of chronic illness, injury and disability which are all associated with reduced mobility. High rates of chronic illness, injury and disability can be linked to more frequently evolving wheeled mobility needs resulting in the need for new devices more often.

Conclusions

The literature on Elder wheeled mobility use on reserves in Canada is non-existent. In order to advance the field of assistive technology the author recommends increased research on the needs of Elder wheeled mobility users, and their caregivers. More culturally relevant research is required to learn about wheeled mobility use and the unique experiences to using and accessing these devices on reserve.

Implications for Rehabilitation

- An increase in the quality and quantity of research is required on the wheeled mobility needs of First Nation Elders who live on reserves in Canada
- To identify barriers to wheeled mobility use in order to increase accessibility to community and cultural events thus improving health and quality of life.

Keywords: Wheelchairs, walkers with wheels, assistive technology, wheeled mobility, First Nations, Elders, Aging

Introduction

According to the National Household Survey (NHS) Canada has more than one million four hundred thousand people who identify as being Indigenous, which represents 4.3% of the total Canadian population [1]. Statistics Canada describes the Indigenous population as being younger due to higher fertility rates and shorter life expectancy [1]. Indigenous children aged 14 and under in Canada represent 28.0% of the total Indigenous population whereas; non-Indigenous children aged 14 and under in Canada represent 16.5% of the total non-Indigenous population [1]. Seniors make up a lower proportion of the total Indigenous population where approximately 6% are seniors aged 65 and over, which is less than half of the proportion of the senior population (14.2%) in the non-Indigenous populace [1].

The most recent report by the Health Council of Canada describes First Nation, Inuit and Metis seniors as being among the most vulnerable people in Canada because a significantly larger proportion of these seniors live on low incomes, in poor health, and with multiple chronic conditions compared to the larger Canadian population [2]. According to the First Nations Regional Health Survey (RHS) 62.2% of First Nation adults report having been diagnosed with a minimum of one chronic health condition, and by the age of 60 approximately half of First Nation adults had been diagnosed with four or more chronic health conditions [3]. Evidence shows that non-communicable diseases account for a large share of observed disabilities in older adults [4], and that the prevalence of disability among Indigenous Canadians is twice the national average (32%) [5].

Assistive technology (AT) is any device, piece of equipment, software, or other tool that is used by people with disabilities to perform activities that might otherwise be difficult or impossible due to their disability [6]. AT assists individuals in improving their functional

abilities and becoming more independent by; increasing their potential to go to school, gaining employment, participating with family and community; and exercising human rights [6].

Appropriate AT meets the users needs and environmental conditions; is safe, durable and effective; is available and accessible, maintained, and sustained at the most economical and affordable price [6]. Suitable AT has been found to be one of the most important elements in supporting activities and participation of individuals with disabilities [6].

Independence in mobility is one of the most significant determinants of quality of life for individuals with disabilities [7]. Wheeled mobility devices (WMD) continue to make up the greatest portion of assistive devices in use in Canada where there are currently over one million (1,186,800) wheelchair users [8]. The powered and manual mobility market globally is projected to grow significantly due to baby boomers and increased longevity [7]. Although the Indigenous population is quite young it is also Canada's fastest growing population, and increased by 20.1% between 2006 and 2011, compared to 5.2% for the non-Indigenous population [1].

Participation in society remains a challenge for those who use WMD's. Even with accessible buildings, housing, schools and recreational facilities, wheeled mobility (WM) users still make less trips outside the home and engage in less activities than people without disabilities [9]. It remains an even greater challenge on reserves in Canada because an increasing number of First Nation adults are reporting that they're homes are in major need of repair, homes are often not modified for accessibility, there is a lack of access to appropriate services, there are challenges negotiating reserve terrain, lack of adequate transportation, difficulty participating in cultural ceremonies, and isolation due to harsh winter weather [10].

There is growing concern that not enough attention is being paid to the health care needs of Indigenous seniors in research or policy because the focus is often on Indigenous youth [2].

First Nation Elders are more likely than younger generations to live in rural and remote communities where it is more challenging and expensive to access care [2]. First Nation Elders often do not fully understand information given to them about their health conditions and many do not have documents such as birth certificates, which are required to obtain a health card [2]. There is also growing concern that First Nation Elders are becoming more isolated because many of the young people are leaving the communities in order to obtain an education and are not returning [2].

Understanding WM use among First Nation Elders is important because as the Regional Health Survey (RHS) demonstrates a healthy person is one who maintains balance with their environment [3]. First Nation adults who reported being more involved in the cultural elements of their community reported more spiritual, mental, emotional and physical balance [3]. The presence of Elders is important in communities because many Elders retain the knowledge of their language and cultural traditions, which are an important part of healing efforts [2]. Preservation of language and transmission of culture to younger generations has shown to reduce suicide rates [3], and participation in traditional culture appears to have potential for enhancing health [3].

The author was unable to find published studies that examine WM use among Elder First Nation populations. There is an unprecedented need for interdisciplinary research that examines WM use while encouraging the continuation of and participation in traditional culture. The aim of this review is to examine the body of knowledge concerning the need for WM devices, whether WM currently in use meets the users needs and supports the active participation of First Nation Elders who live on reserve, to review the scope and gaps in the literature, and to identify areas for future research.

Research Question

This search was designed to address the following broad level question: What evidence is available on wheeled mobility use by Elders who live on reserves and in northern communities in Canada.

Method

CINAHL, Embase, Medline (Ovid), Scopus, Web of Science databases and potential grey literature were investigated for pertinent data sources. Searches were conducted in an iterative manner from September 2015 to June 2017. Searches were conducted with the Health Sciences Librarian in order to locate research related to WM using terms such as: wheelchairs, walkers with wheels, assistive device, assistive technology, wheeled mobility. The population of interest was First Nation Elders who use WM and live on reserve in Canada.

Procedure

Three groups of words were combined: those relating to aging populations (keywords: ageing, aging, elderly, Elders, seniors, older adults), those relating to WM (keywords: assistive device, assistive product, assistive technology, medical device, wheelchair, walker with wheels), and those relating to First Nation populations (First Nation, Indigenous, and Aboriginal).

Material was included if it followed a culturally informed interpretation process and extended appreciation to all First Nations people who participated, it addressed or focused on Elder First Nation people, assistive technology systems or policies, it addressed WM and met at least one of the following criteria: a literature review, a report or proceedings from an

international conference. The searches yielded zero results. Grey literature was sourced in order to identify potential wheeled mobility needs.

Included documents were retrieved and reviewed for information of relevance to the objective of this study. Data were analyzed thematically and a narrative synopsis of the study findings within each theme is provided. This approach was chosen because a systematic review encompassing the scope of the study would not have been feasible due to lack of relevant studies; however, the selection of the literature provides sufficient measurements to draw conclusions, provide guidance for future research and policy development as well as to provide a broad perspective on meeting the WM needs of First Nation Elders on reserves in Canada. The themes emerging from the reviews and contextual analysis are depicted in the following three sections.

1. Understanding the landscape: wellness, chronic health conditions, injury, and disability among First Nation Elders who live on reserves in Canada
2. Wheeled mobility use among First Nation Elders who live on reserves and in Canada
3. Barriers to wheeled mobility use on reserves in Canada.

Results

1. Understanding the landscape: wellness, chronic health conditions, injury, and disability among First Nation Elders who live on reserves in Canada.

According to the Truth and Reconciliation Commission (TRC) in order to be more effective in improving health outcomes, non-Indigenous health professionals must develop a better

understanding of the health issues facing Canada's Indigenous People and the legacy of residential school [11]. Understanding the landscape of First Nations Health in Canada is also important in order to better understand the present-day health concerns that affect the need for WM.

Indigenous knowledge is not a uniform concept across all First Nations in Canada, but for most First Nations people there is a shared belief in a connection with the natural world [3]. First Nations people use the concept of wellness, and wellness is a very complex and multi layered philosophy where human beings are connected to the natural world through many different levels of understanding [3]. This approach to health and wellness is based on seeking balance, achieving balance and maintaining balance [3].

According to the First Nations Regional Health Survey (RHS) 62.2% of First Nation adults report being diagnosed with a minimum of one chronic health condition, and by the age of 60 approximately half of First Nation adults are diagnosed with four or more chronic health conditions [3]. The prevalence of chronic health conditions and co-morbid chronic health conditions increases with age, and the prevalence for the majority of chronic health conditions was higher among women [3]. The most common chronic health conditions reported by First Nations adults are high blood pressure (21.8%), arthritis (19.9%), allergies (18.0%), chronic back pain (16.2%), and diabetes (16.2%) [3]. First Nations people living in First Nation communities are at higher risk of developing chronic health conditions because many variables predictive of good health are lacking such as education, paid employment, access to health care, personal health practices, as well as dealing with a lack of freedom from discrimination [3].

A lower proportion of First Nation adults with a chronic health condition reported feeling balanced physically (69.1% vs. 80.4%), emotionally (70.7% vs. 77.7%), and mentally (73.6% vs.

78.7%), and a higher proportion of First Nation adults with a chronic health condition reported moderate to high levels of depression (34.4% vs. 20.8%), reported suicide ideation (24.3% vs. 17.7% and reported suicide attempts (14.9% vs. 9.5%) compared to those without a chronic health condition [3]. A higher proportion of First Nation adults who attended residential schools reported having been diagnosed with at least one chronic health condition compared to those who did not attend residential school (76.1% vs. 59%) [3].

First Nations people living on reserve experience a disproportionate amount of injury compared to the general Canadian population, and account for more than half of all the potential life years lost which is more than all other causes combined [3][2]. Falls and trips were the most frequently identified cause of injury (35.2%), followed by overextension or strenuous movement (12.9%), accidental contact with another person or animal (11.0%), motor vehicle accidents (9.9%) and assault (domestic or family and other combined) 10.9%. Falls and trips were more often reported as the cause of injury among older adults [3]. The most common location for the occurrence of injury was in the home (41.8%)[3]. The RHS asked respondents if alcohol or marijuana or other substances had an influence on their injuries. Fewer First Nation adults 60 years and over cited substances as cause of injury [3].

The percentage of First Nation adults reporting disabilities increases with age, among those aged 55 and older more than half (50.5%) reported having an activity limitation [3]. Like injury, the prevalence of disability has been shown to be greater among First Nations people than the general Canadian population. First Nation adults with disabilities also have worse outcomes than those without disabilities in terms of formal education attainment, income, employment, and health [9].

By the age of 60 approximately half of First Nation Elders report being diagnosed with 4 or more chronic health conditions, compared to 25 % of seniors 65-79 years of age and 37% of seniors over 80 in the general Canadian population [12].

There is a disparity between Indigenous and non-Indigenous senior rates of chronic health conditions, injury and disability. It is concerning that little research is available on the WM needs of Elders living on reserves even though they experience higher levels of injury, disability and chronic health conditions which are all associated with reduced mobility.

Extensive research is required on: the prevention of non-communicable diseases and injury; whether WM needs are currently being met; whether the devices Elders currently have are being maintained; what the barriers to accessibility on reserve are; and how well these devices are supporting the active participation of First Nation Elders in their communities.

2. Wheeled mobility use among First Nation Elders who live on reserves in Canada

In Canada, 1.2 million people need or use mobility aids to participate in their community or society. Health Canada provides eligible First Nation's and Inuit Canadian's with coverage for a specified range of medically necessary health-related goods and services when not covered through private insurance plans or provincial/ territorial health & social programs. This program is called Non-Inured Health Benefits (NIHB), and includes a specified range of medical supplies and equipment (MS&E) [13].

The MS&E benefit list comprises seven benefits including: general MS&E; audiology; orthotics and custom footwear; oxygen equipment and supplies; pressure garments; pressure orthotics; prosthetics; and respiratory equipment and supplies [13]. Mobility aids such as walking aids; walking aids accessories, wheelchairs, wheelchair cushions and wheelchair parts are covered under the general benefit [13]. Many items require prior approval where the provider

must contact the Health Canada regional office to initiate the process. The general MS&E prior approval form must be completed. MS&E covered-clients must obtain a prescription from a prescriber recognized by NIHB Program for MS&E items such as wheelchairs and walkers [14].

The Non-Insured Health Benefits (NIHB) Program annual report for 2013/2014 states that the seniors population (65 and over) has been slowly increasing as a proportion of the total NIHB client population [14]. In 2004/05 seniors represented 5.5% of the overall NIHB population; however, most recently in 2013/2014 seniors accounted for 7.0% [14]. The report stated that this demographic trend will contribute to cost pressures on NIHB Program [14]. The report also stated that in 2013/14 the total NIHB expenditures were \$1,026.4 million. Pharmacy costs, which include Medical Supplies and Equipment (MS&E) such as wheelchairs, represented the largest proportion at \$416.2 Million [14]. Medical Supplies and Equipment accounted for 7.1% or \$29.4 million of the pharmacy benefit costs [14].

The Assistive Device Program (ADP) provides consumer centered support and funding to Ontario residents who have long-term physical disabilities and provide access to assistive devices based on the individual's needs [15]. The devices that ADP covers are intended to allow people with disabilities to increase their independence [15]. Any Ontario resident who has a valid Ontario Health card issued in their name and has a physical disability of six months or longer is eligible for the program. Equipment cannot be required exclusively for sports, work or school, and ADP does not pay for equipment available under the Workplace Safety and Insurance Board or to Group A veterans for their pensioned benefits [15].

The process for ADP coverage is similar to that of the NIHB Program where a medical specialist or physician provides a diagnosis, and the devices must be authorized by a qualified health care professional registered with the program [15]. The program will help pay up to 75%

of the cost but only equipment that is purchased from vendors registered with the Assistive Devices Program [15]

The following data summarizes the number of wheelchairs and/or walkers with wheels paid by the NIHB program for First Nation and Inuit individuals aged 65 years and older from April 1, 2015 to March 31 2016. This data does not include /should not be interpreted as a reflection of the prevalence of use of mobility aids across the eligible population. NIHB clients may also receive wheelchairs or walkers with wheels from elsewhere. This data was retrieved from the NIHB's Program's Health Information and Claims Processing Services (HICPS) system, and indicates that between 1707 clients were funded for walkers and wheelchairs for a total of \$1, 206,744 (Health Canada Non-Insured Health Benefits (HC NIHB), personal communication, August 30, 2016).

That's 1231 walkers for \$325, 249 and 632 wheelchairs at \$881,495. The highest number of wheelchairs and walkers were funded in Saskatchewan (398), Ontario (343), Alberta (261), Quebec (86), Nunavut (65), Atlantic (46) NWT (44), and Yukon (19). More walkers with wheels were purchased than without wheels (957 compared to 268), and more manual wheelchairs were purchased than power wheelchairs (574 compared to 35) (HC NIHB, personal communication, August 30, 2016).

The Canadian Longitudinal Study on Aging (CLSA) is a large national, long-term study that will follow approximately 50,000 people between the age of 45 and 85 for at least 20 years [16]. Biological, medical, psychological, social, lifestyle and economic factors to understand how they have an impact in both maintaining health and the development of disease and disability as people age. The CLSA excluded residents in the three territories and some remote

regions, persons living on federal First Nation reserves and other First Nation settlements in the provinces. [16].

The literature available demonstrates that the information available regarding wheeled mobility (WM) use on reserves in Canada is very limited. The only information available on the quantity of First Nations people using WM is from the NIHB and this only includes the people who used this specific program. More inclusive research on WM use among First Nation Elders on reserves is necessary in order to determine how many Elders need WM devices, how many Elders have WM devices, if they have appropriate devices, how they accessed their devices and barriers to use.

3. Barriers to wheeled mobility use on reserves and in Canada

Although there have not been any specific studies that review WM use on reserves we know that First Nation, Inuit and Metis seniors are more likely than younger generations to live in rural and remote communities where it is more challenging and expensive to provide care [2]. Most seniors must travel to urban areas for anything beyond basic care, which is very disruptive to their lives [2]. Elders often do not understand information given to them about their health conditions and many do not have documents such as birth certificates which are required to obtain a health card [2]. Barriers to WM use on reserve should be reviewed because community and cultural participation is important for the health of First Nations people.

Participation refers to 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 the affordance to do, and is not prevented from doing so by the world in which the person lives and wishes to participate [17]. Participating in self-defined meaningful activities can enhance an individual's sense of competence and well-being, both of which are essential for healthy

emotional, psychological, and skills-based development. Community participation encompasses accessing community spaces, activities, social relationships, and is more closely related to life satisfaction than illness or impairment for people with disabilities [17].

A study by Ripat et al. concluded that the existence of snow, ice and cold temperatures in winter months in some locations create additional challenges especially for WM users. Barriers to WM use in winter months include cold temperatures, ice and snow covered roads and sidewalks, frozen wheelchair system components, reduced wheelchair battery life, decreased manual dexterity and strength for operating controls, and risk of thermal injury [17]. There is a lack of research exploring the details and processes of winter weather barriers inherent to WM and policy related barriers.

While it could be argued that participation levels change for everyone in the winter, the results from this study confirm a large variation in participation between seasons in wheeled mobility device users as 42% of the sample changed their outing frequency from 3 to 7 times per week to less than 3 times per week. The authors state that this magnitude of change is discerning considering the evidence that links activity, socialization and mental and physical health [17].

As mentioned previously only one article yielded information on the design of wheelchairs and it focused on First Nations adults who have Spinal Cord Injuries and live on reserves. This article found that while participants with power wheelchairs identified having greater independence mobilizing between houses and on reserve terrain than those using manual wheelchairs-issues were highlighted about restricted access indoors due to the size of the chair [10]. Those who had other medical conditions and or who experienced the effects of aging raised serious concerns. On the basis of the results from this study it appears that when First Nations people with spinal cord injury are discharged home they often experience a lack of access to

appropriate services, difficulty having their homes assessed for wheelchair accessibility, and they are often denied the chance of experiencing functional independence [10].

A poorly designed wheelchair can contribute to secondary injuries, such as carpal tunnel syndrome and injury to the shoulder resulting from repeated, forceful movement required by the upper extremities during wheelchair propulsion [18]. A poorly designed power chair can limit access of the user to the environment if the wheelchair design and features are not matched to the needs of the user [18]. A person with severe arthritis may no longer have the hand function or shoulder range of motion to propel a manual wheelchair. A study by Winkler et al suggests that those who are less able to advocate for themselves are less likely to receive better-quality wheelchairs [18]. Those who received better quality adjustable power wheelchairs were more likely to have better social function [18].

Although only one study on the subject of WM use on reserve was yielded and although it was not specific to Elders it did detail several barriers to WM use and areas for future research. Aside from the barriers listed we can see from other literature that there is potential for secondary injuries if people are not using the appropriate design of wheelchair. Given the importance of community and cultural participation for the health of First Nations Elders and their communities, more research is needed to look into WM use on reserves in Canada.

Discussion

The Truth and Reconciliation Commission (TRC) recognizes that there are troubling gaps in health outcomes between Indigenous and non-Indigenous Canadians and obtaining precise information on the state of health of Indigenous people in Canada is difficult [11]. The Canadian government has not provided a comprehensive list of well-being indicators comparing

Indigenous and Non Indigenous populations, which means that these issues receive less publicity, media and political attention [11].

The TRC's Call to Action 19 states:

We call upon the Federal government, in consultation with Aboriginal peoples to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess to long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services (p.2-3)

The TRC defines reconciliation as an on going process of establishing and maintaining respectful relationships. A critical part of this process involves repairing damaged trust by making apologies, providing individual and collective reparations, and following through with concrete actions that demonstrate real societal change [11]. Closing the gap in health outcomes will come about only as part of a comprehensive strategy of change [11]

This analysis is useful because it demonstrates that there is a gap in the availability of WM literature between Indigenous and non-Indigenous Canadians. The first aim of this study was to examine the body of knowledge concerning the need for WM among Elders who live on reserves in Canada. Only one article on the subject of WM on reserves was yielded and it was not specific to Elders. Literature on the current health status of Indigenous adults and Elders on

reserves in Canada demonstrates a high need for WM on reserves because there are much higher levels of chronic illness, injury and disability. High rates of chronic illness, injury and disability often mean that WM needs are frequently evolving resulting in the need for new devices more regularly.

The literature demonstrates that Canada has over one million wheelchair users but we don't know how many of these users are First Nation Elders. The only numbers available are from NIHB and organizations that provide WM, but these only tell us the number of devices accessed through these specific organizations. Longitudinal surveys often do not include First Nations people and studies should be culturally relevant. Background literature tells us that there isn't enough health research being done with Elders because research tends to focus on youth. There is a need for more research with Indigenous Elders because they are among the most vulnerable populations in Canada. The literature also tells us that active participation in community and culture is necessary for the positive health outcomes of First Nation Elder's and their communities.

The second aim of this literature review was to search literature on information about whether current WM in use by Elders on reserves meets users needs and supports their active participation. As mentioned only one study was found that discussed WM on reserves, which was specific to First Nations people with SCI's. The article discussed barriers and challenges to WM on reserve which included homes being in major need of repair, homes often not modified for accessibility, challenges negotiating rough reserve terrain, lack of adequate transportation, difficulties participating in cultural ceremonies and isolation due to harsh winter weather. We cannot deduce whether WM is currently meeting the needs of First Nation Elders on reserve due

to a lack of available literature. We do know that there are many barriers due to the remoteness of reserves, and that programs and services can be confusing and complex.

There is an extraordinary need for more research that focuses on the unique WM needs of First Nation Elders living on reserves in Canada where there are higher rates of chronic illness, injury and disability. More research is specifically required to: study the prevention of injury and illness for First Nation Elders who live on reserve; improve products, delivery and service; reduce barriers and review timely and appropriate home assessment and modifications including geographical barriers; assess secondary injuries; include wheeled mobility users in the accessibility planning of their communities; focus on the social environment, research that focuses on all aspect of Elder health including cultural participation, and finally research should go beyond the impact at the level of the user and capture the perspectives of key individuals such as caregivers.

The overall quality of research needs to be improved by gaining the perspectives of First Nations peoples cultures and settings. Research must also follow the principles of ownership, control, access and possession (OCAP) as the communities set them out. Qualitative, quantitative and integrated approaches need to be conducted because each has strengths and limitations. Qualitative approaches should be used to enquire and discuss the need, use of, and satisfaction with WM devices and services. Acceptance and personal adjustment of becoming a WM user, self-perceptions attitudes and beliefs. Using an interdisciplinary approach in studies with Indigenous populations is beneficial because this creates a space for the participants to be involved in the project, this collaborative perspective is also in line with necessity of community engaged research.

It is apparent that the need for WM is greater among underserved Indigenous communities; yet research remains slow to respond to the physical health needs and WM limitations among First Nation Elder populations on reserve.

Conclusion

The body of knowledge in regard to WM use among First Nation Elders living on reserves in Canada is non-existent. The literature reviewed indicates that chronic disease, injury and disability rates are higher among First Nation adults, that participation in society remains a greater challenge on reserves for those who use WM due to the lack of modification to homes for accessibility, lack of access to appropriate services, challenges negotiating reserve terrain, isolation due to harsh winter weather, lack of adequate transportation, difficulty participating in cultural ceremonies required for the balance of health of individuals and communities.

There is a need for further WM research that incorporates an interdisciplinary approach that includes the stakeholders as part of the team in order to decrease barriers and promote facilitators for participation in cultural events.

Declaration of Interest Statement

The study was completed as part of the fulfilment of the dissertation requirements for the author's degree of Master of Science at the University of Ottawa funded by the University of Ottawa. The authors report no conflicts of interests. The author alone is responsible for the content and writing of this article.

Geolocation Information

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Chapter 3: Thesis Proposal

First Nation seniors using wheeled mobility:

An exploration of cultural participation and health

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The following thesis proposal was approved by the University of Ottawa on February 5th, 2017 (Appendix A)

Literature Review

The Canadian Aboriginal Population and Aging

According to the National Household Survey (NHS) Canada has more than one million four hundred thousand people who identify themselves as Aboriginal, which represents 4.3% of the total Canadian population (Statistics Canada, 2011). The Aboriginal population increased by over 200,000 people (20.1%) between 2006 and 2011, compared to 5.2% for the non-Aboriginal population (Statistics Canada, 2011).

According to Statistics Canada someone who identifies him or herself as being Aboriginal is First Nation, Metis or Inuit (Statistics Canada, 2011). Of the total Aboriginal population 851,560 identify themselves as First Nations, which represents 60.8 % of the Aboriginal population in Canada; whereas, Metis comprise 33% and Inuit 4% of the total Aboriginal Population (Statistics Canada, 2011).

In 2011 the largest Aboriginal population in Canada lived in Ontario (301,425), which represents 21.5% of the total Aboriginal population (Statistics Canada, 2011). The largest First Nations population was also recorded as being in Ontario where 23.6% (201,000) of all First Nation people said they lived (Statistics Canada, 2011). Therefore 201,000 of the 301,425 Aboriginal people in Ontario are First Nations. In Ontario 37.0% of First Nation people with registered Indian Status lived on a reserve (Statistics Canada, 2011). One in four Ontario First Nations is a small remote community, accessible only by air year round or by ice road in the winter (Government of Canada, 2014). Ontario has more remote First Nation reserves than any other region in Canada (Government of Canada, 2014).

Statistics Canada described the Aboriginal population as being young due to higher fertility rates and shorter life expectancy (Statistics Canada, 2011). Aboriginal children aged 14 and under in Canada represented 28.0% of the total Aboriginal population; whereas, non-Aboriginal children aged 14 and under in Canada represented 16.5% of the non-Aboriginal population (Statistics Canada, 2011). Seniors made up a lower proportion of the total Aboriginal population where approximately 6% of the total Aboriginal population (82,690) were seniors aged 65 and over, which is less than half of the proportion (14.2%) of seniors in the non-Aboriginal population (Statistics Canada, 2011).

Because Aboriginal people are comprised of a young population compared to non-Aboriginal people, research is often focused on Aboriginal Youth (Health Council of Canada, 2013). This Thesis, by contrast will investigate the processes, barriers, and facilitators that impact cultural participation for FN seniors who use wheeled mobility and live on reserves in Ontario.

The term elder is used in some communities to describe all seniors, and in other communities the term Elder is used to identify someone who is recognized and respected in their community for their wisdom and cultural knowledge (Health Council of Canada, 2013). For the purpose of this thesis the terms senior and elder will be used interchangeably to identify First Nation people over the age of 65. Some organizations and health care providers offer senior services to Aboriginal people aged 55 and over due to earlier onset of chronic conditions and lower life expectancy (Health Council of Canada, 2013).

According to the Health Council of Canada seniors are an important part of healing efforts because many retain knowledge of their language and cultural traditions (Health Council

of Canada, 2013). This quote as cited by Statistics Canada (2006) describes how knowledge is passed on and carried forward:

The ancient wisdom, the traditions, rituals, languages and cultural values were passed on and carried forward. In this process, a primary role was played by the Elders, the Old Ones, the Grandmothers and Grandfathers. As individuals especially knowledgeable and experienced in the culture, they were seen as those most closely in touch with the philosophical teachings of life lived in harmony with the Creator and creation (p.221).

In 2013 the Health Council released a report on Improving health care for First Nations, Inuit, and Metis seniors. The report stated that there is growing concern because not enough attention is being paid to the health care needs of Aboriginal seniors in either research or public policy (Health Council of Canada, 2013).

Health History

The disparities in the health status of the Aboriginal people can be linked to the beginning of the colonization period. Aboriginal leaders sought agreements with representatives of the British Crown in order to address the worsening health status of their people, brought on by “new” infectious diseases and poverty (Health Council of Canada, 2005). Treaty 6 (1876) Treaty 8 (1899) treaty 10 (1906) and treaty 11 (1921) were signed by the federal government stating that the crown would provide health care to the First Nations people to reimburse them for the use of their land and resources (Health Canada, 2005). First Nation people view health care as a treaty right which was confirmed in a treaty signing process; therefore, legally binding via the federal government to this day (Health Council of Canada, 2005).

First Nation people went to live on the land set aside for them by the crown. These land bases are known as reserves and still exist to this day (Health Council of Canada, 2005). As a result of being restricted to a limited land base, resources such as food and clothing materials normally obtained by hunting, trapping and fishing quickly shrunk reducing opportunities to trade and barter (Health Council of Canada, 2005). As access and availability of these resources declined, so did lifestyle livelihood and diet affecting the health status and well-being of Aboriginal people (Health Council of Canada, 2005).

Many other postcolonial events have contributed to the present day health status of Aboriginal people. Many First Nations, Inuit and Metis children were taken from their families and placed in residential schools. At least 35% of Aboriginal adults over the age of 45 attended a residential school for an average of six years (Health Council of Canada, 2005). Over 11,000 First Nation status children were taken from their homes between 1960 and 1990, and 70% were adopted into non-Aboriginal homes. This is referred to as the sixties scoop which carried on and became known as the Millennium scoop. As a result of being socialized and acculturated many of these adoptees face cultural and identity confusion (Ontario Ministry Of Children and Youth Services, n.d).

In 1978, a new policy was put forward by the federal government to encourage more involvement of Aboriginal people in the planning and delivery of health care services within their communities (Health Council of Canada, 2005). First Nation people anticipated that this meant they would have full control of health services, but for the federal government this only meant administrative control (Health Council of Canada, 2005).

Health Canada has been responsible for providing health care services to First Nation and Inuit populations who live on reserve (Health Canada, 2015). The First Nations and Inuit Health

Branch (FNIHB) of Health Canada carry out public health services with exception to those communities that have opted for transfer of health services, which does not include Ontario (Health Canada, 2015).

Current Health Status of Canada's Most Vulnerable

The most recent report by the Health Council of Canada describes First Nation Inuit, and Metis seniors as being among the most vulnerable people in Canada because a significantly larger proportion of these seniors live on low incomes, in poor health, with multiple chronic conditions and disabilities compared to the larger Canadian population (Health Council of Canada, 2013). The Health requirements of Aboriginal seniors are magnified by determinants of health such as poverty, poor housing, racism, language barriers, and cultural differences (Health Council of Canada, 2013).

First Nation, Inuit and Metis seniors are more likely than younger generations to live in rural and remote communities where it is more challenging and expensive to provide care (Health Council of Canada, 2013). Most seniors must travel to urban areas for anything beyond basic care, which is very disruptive to their lives (Health Council of Canada, 2013). The government covers medical travel for status First Nation and Inuit populations. In 2013/14 the Non-Insured Health Benefits Medical Transportation costs were \$352.0 million (34.3%) of the total NIHB expenditures (Health Canada, 2015). Being that many Aboriginal seniors do not have the same level of care as non-Aboriginal Canadians, health conditions often become more severe; therefore, increasing the amount of care needed (Health Council of Canada, 2013).

First Nation, Inuit, and Metis seniors reported many common health experiences such as lack of nutrition, shortage of housing, overcrowding, inability to adapt homes for medical equipment or to accommodate disabilities as well as difficulty covering the costs to heat their

homes (Health Council of Canada, 2013). Many participants discussed financial, emotional, physical neglect and abuse. In small communities with few economic opportunities a senior who receives Old Age Security may be the only family member with a reliable income. Being that sharing is a core value in many Aboriginal cultures many seniors will share even if it means they cant take care of their own needs (Health Council of Canada, 2013).

The lasting effects of colonization and residential schools has left many seniors socially isolated, and has left whole communities affected by post-traumatic stress disorder (Health Council of Canada, 2013). Seniors may also feel more isolated because many of the young people are leaving the communities in order to obtain an education and are not returning (Health Council of Canada, 2013). Seniors often do not fully understand information given about their health conditions, and many do not have documents such as birth certificates, which are required to obtain a health card (Health Council of Canada, 2013). More research is required with First Nation seniors living on reserves in order to eliminate the disparities between First Nation, Inuit, Metis population and the non-Aboriginal Populations.

Coverage for Medical Supplies & Equipment

Mobility difficulties are especially prevalent among First Nation seniors where 45% of person over the age of 85, and 8 % of seniors aged 65-74 cannot walk and require mechanical support such as a wheelchair (Statistics Canada, 2006).

The Non-Insured Health Benefits (NIHB) Program annual report for 2013/2014 states that the seniors population (65 and over) has been slowly increasing as a proportion of the total NIHB client population (Health Canada, 2015). In 2004/05 seniors represented 5.5% of the overall NIHB population; however, most recently in 2013/2014 seniors accounted for 7.0%. (Health Canada, 2015). The report stated that this demographic trend will contribute to cost

pressures on NIHB Program (Health Canada, 2015). The total number of seniors (65 and over) in Ontario that represent the NIHB population in 2013/14 was 19,726 people, which was much higher than any other provinces in Canada (Health Canada, 2015).

The report stated that in 2013/14 the total NIHB expenditures were \$1,026.4 million. Pharmacy costs, which include Medical Supplies and Equipment (MS&E) such as wheelchairs, represented the largest proportion at \$416.2 Million (Health Canada, 2015). NIHB covers 25% of the cost Of MS&E equipment. Of the \$416.2 million \$78,000 was spent by the Ontario NIHB population (Health Canada, 2015). Medical Supplies and Equipment accounted for 7.1% or \$29.4 million of the pharmacy benefit costs (Health Canada, 2015).

MS&E covered-clients must obtain a prescription from a prescriber recognized by NIHB Program for MS&E items such as Wheelchairs and Walkers. Clients must obtain a prescription from a prescriber recognized by NIHB, and the prescription must be filled at an approved provider (Health Canada, 2015). Walking Aids accounted for 9.6% of the claims for NIHB Medical Equipment (Health Canada, 2015).

The Assistive Device Program (ADP) provides consumer centered support and funding to Ontario residents who have long-term physical disabilities and provide access to assistive devices based on the individual's needs (Ontario Ministry of Health and Long-Term Care, 2014). The devices that ADP covers are intended to allow people with disabilities to increase their independence (Ontario Ministry of Health and Long-Term Care, 2014).

Any Ontario resident who has a valid Ontario Health card issued in their name and has a physical disability of six months or longer is eligible for the program. Equipment cannot be required exclusively for sports, work or school, and ADP does not pay for equipment available under the Workplace Safety and Insurance Board or to Group A veterans for their pensioned

benefits (Ontario Ministry of Health and Long-Term Care, 2014).

The process for ADP coverage is similar to that of the NIHB Program where a medical specialist or physician provides a diagnosis, and the devices must be authorized by a qualified health care professional registered with the program (Ontario Ministry of Health and Long-Term Care, 2014). The program will help pay up to 75% of the cost but only equipment that is purchased from vendors registered with the Assistive Devices Program (Ontario Ministry of Health and Long-Term Care, 2014).

In most cases, the client pays a share of the cost at time of purchase and the vendor bills ADP the balance. There are many sources of funding for the client's share of the cost including: Clients, voluntary/charitable organizations e.g. March of Dimes, The Easter Seals Society, Kiwanis, Lions Clubs, social assistance, Department of Veteran Affairs, insurance companies relatives, friends (Ontario Ministry of Health and Long-Term Care, 2014).

First Nation Health Philosophy

The concept of health is complex and its basic tenants are explained through the medicine wheel, as illustrated in *Fig. 1*, the medicine wheel is divided into four sections that represent the four directions: North, East, South and West (Wilson, 2003). According to beliefs, the four elements of life, the physical, emotional, mental and spiritual are represented in the four directions of the medicine wheel. All four elements are intricately woven together, and interact to support a strong and healthy person (Wilson, 2003). The balance between all four elements is essential for maintaining and supporting good health (as cited in Wilson, 2003, p. 87). Balance expands beyond the individual, meaning that good health also requires that an individual live in harmony with others, their community, and the spirit worlds (as cited in Wilson, 2003, p.87).

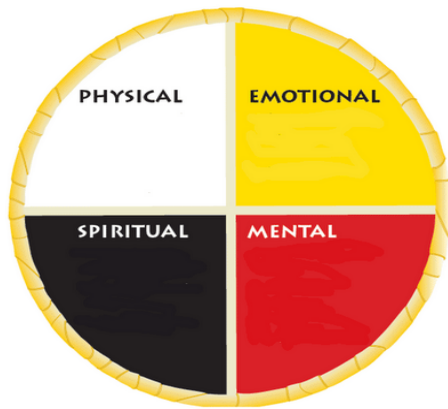


Figure 1. Medicine Wheel. This figure illustrates the belief that the four elements of life, the physical (North), emotional (East), mental (South) and spiritual (West) are represented in the four directions of the medicine wheel.

To be a healthy individual one must strive to go beyond physical health and achieve balance between all aspects of life. If one element within the wheel is neglected or receives too much attention then health suffers in all four areas (as cited in Wilson, 2003, p.87). Current research overlooks the complex ways in which the link between cultural participation and health is manifested simultaneously in physical, symbolic, cultural and neocolonial relationships to the land on a daily basis (as cited in Wilson, 2003, p. 91).

The activities in which individuals participate in their everyday lives are important for physical, emotional, mental and spiritual health. This is why its important to investigate what the processes, barriers and facilitators are that impact cultural participation for First Nation seniors who use wheeled mobility and live on reserves in Ontario.

Summary

There are more than 600 First Nation Bands in Canada, and over 60 Aboriginal languages. Statistics Canada describes this as an indication of the diversity of First Nation people across Canada (Statistics Canada, 2011). The largest number of First Nation Canadians lives in Ontario. Ontario has more reserves than any other regions in Canada, and 1 in 4 of these reserves are remote communities only accessible by air or ice road in winter. Mobility difficulties are especially prevalent among First Nation seniors, and First Nation seniors are more likely to live in remote communities where providing care is more challenging. Research tends to focus on Aboriginal youth. Current research also overlooks the importance between the activities in which individuals participate and their health.

First Nation elders are considered the most important part of healing efforts because they retain the knowledge of their language and cultural traditions. More research must focus on the processes, barriers and facilitator that impact cultural participation for First Nation seniors who use wheeled mobility and live on reserves in Ontario. The senior population over 65 is increasing in proportion to the total NIHB client population and it is increasingly important to reduce the health gap between First Nations and non-Aboriginal Canadians.

Rationale

This thesis will focus on First Nation seniors because they are Canada's most vulnerable population. A majority of First Nation seniors live on remote reserves on low incomes, in poor health, with multiple chronic conditions and disabilities, which are magnified by poor housing,

racism, language barriers and cultural differences. Participants using wheeled mobility were chosen in order to gain a first-hand understanding of how culture and health are linked. Current research overlooks the links between physical, emotional spiritual and mental aspects of life that are necessary in obtaining optimal health for First Nation elders.

First Nation seniors have retained knowledge of their language and cultural traditions, and they're lack of presence or participation can be a cultural misfortune to entire communities. Cultural supports are critically important to maintaining the health and well-being of seniors and their communities. There is insufficiently literature on the impact of wheelchair use, and its relation on cultural participation and health for First Nation seniors living on remote reserves in Northern Ontario. This qualitative study is designed to develop a greater understanding of how the experiences of First Nation elders, who use wheeled mobility and live on remote reserves, relate with culture, individual health, and the health of communities. Current research often overlooks the complex ways that cultural participation and health are linked and how health is manifested simultaneously in physical, symbolic, cultural and neocolonial relationships to the land on a daily basis.

There are many gaps existing to properly determine the health of Aboriginal peoples in Canada, especially in comparison to the availability of health information on the general Canadian population (Health Council of Canada, 2005). The data that exists is inadequate and does not accurately reflect the health of Aboriginal people in Canada (Health Council of Canada, 2005). Many First Nation communities refuse to participate in any statistical gathering activities for political, historical and cultural reasons (Health Council of Canada, 2005). There remains a scarcity of information necessary to measure and compare the health status of the Canadian First

Nations population to that of the general Canadian population. Data needs to be collected in order to contribute to health service, planning and delivery (Health Council of Canada, 2005).

There is less research being conducted with the senior populations because it is a much smaller population compared to its younger population. The number of Aboriginal seniors is increasing and more research is necessary. This Thesis will investigate the processes, barriers and facilitators that impact cultural participation for First Nation seniors who use WM and live on reserves in Ontario.

Methods

Research Design

In this study, a qualitative approach will be used to explore the processes, barriers and facilitators that impact cultural participation for First Nation Seniors who use wheeled mobility and live on reserves in Ontario. A qualitative analysis of semi-structured interviews with open-ended questions will be conducted with 8-10 participants in two different communities in Ontario. A phenomenological approach will be used in order to meet the objectives of this study. Grounded theory will not be used since the aim is not to go beyond description of experience. Ethnography, narrative studies and case studies will not be used because these methods would not capture a collective of experiences. A phenomenological study will strengthen our understanding of First Nation seniors experience with cultural participation, as well as perceived facilitators and barriers that impact cultural participation.

An interdisciplinary approach will be used in order to fully address this research question. It is a complex question, which will require collaboration within the health science disciplines as well as across major disciplinary boundaries.

The myth of the solitary scientist in search of truth is a romantic notion whose continued existence serves as the major barrier to progress in bringing the collective weight of the sciences to bear on the problems of human kind. And the idea that all scientific progress takes place within the boundaries of current disciplines is historically invalid and currently counter-productive” (Kahn & Prager, 1994).

During the process of writing and organizing this thesis proposal collaboration has begun with my supervisor Jeff Jutai (PhD), Director and Full Professor in the faculty of Health Sciences and co-lead member of the Research Management Committee for AGE-WELL, Canada's technology and aging network, and also my Thesis Advisory Committee members Frantz-Hubert Sully and Wendy Gifford (PhD). Frantz working as a policy analyst for Health Canada, and Wendy is an Assistant Professor at the Ottawa University School of Nursing, and senior Research Associate at St-Elizabeth Health Care.

Marts described interdisciplinary research as, “a cooperative effort by a team of investigators, each expert in the use of different methods and concepts, who have joined in an organized program to attack a challenging problem” (Marts, 2002). Using an interdisciplinary approach fits well with First Nations belief in circular thinking, where it is believed that change can come from within a circle of people sitting together, sharing ideas and agreeing on actions that are beneficial for the individual and the community.

This study will follow First Nation principles of OCAP. Meaning that First Nations control data collection processes in their communities.

- First Nations own, protect and control how information is used.

- The right of First Nation communities to own, control, access and possess information about their peoples is necessarily tied to self-determination and to the preservation and development of culture.

Research Questions

What are processes, barriers, and facilitators that impact cultural participation for First Nation Seniors who use wheeled mobility and live on reserves in Ontario?

Research Objectives

- To understand better how the experiences of First Nation seniors who use wheeled mobility and live on reserves in Ontario have changed since becoming a wheeled mobility user.
- To explore the barriers and facilitators that impact participation, and how the participants view this as affecting their health and the health of their communities.
- To identify perspectives on how participation might be improved.

Research Site

Emails have been sent to all reserves in Ontario. I will not be working at Neskataga due to the current suicide crisis the community has closed its doors. I am filling out ethics approval for Six Nations and waiting to hear back from Curve Lake and Akwasasne. Curve Lake is presetting my project to council this week.

Sample and Recruitment

In this study participants will be recruited purposively. Inclusion criteria are that the participants must be First Nation and live on a reserve in Ontario. They must be aged 55 and older and use

wheeled mobility. Approximately 8-10 participants will be recruited from two different communities.

Data Collection and Analysis.

Semi-Structured interviews will be conducted with 8-10 participants in two different communities, or until data saturation is reached. Narrative data from the transcribed interviews will be analyzed and field notes will also be taken. Field notes will be taken to reflect the thoughts, ideas and feelings on the interviews and initially on the guide structure and any changes made to the guide.

Ethics

This proposal will be submitted to the Health Sciences and Sciences Research Ethics Board (REB) at the University of Ottawa. Applications for initial review must be submitted to the Ethics Office during the first three business days of the month. The REB will evaluate the application during the same month it is submitted. The REBs comments and feedback are compiled and sent to the researchers via email between 5 to 7 weeks. If resubmission is not required an Ethics Certificate will be issued via email. Once the Ethics certificate is received recruitment and data collection may begin. Ethics approval applies for one year.

The Tri-County Policy Statement guided ethical considerations for this study: *Ethical Conduct for research Involving Humans* (Government of Canada, 2015). With particular reference to Chapter 9 Research Involving the First Nations, Inuit and Metis Peoples of Canada.

Expected Results

This study will provide useful insights into the main cultural concerns that confront First Nation Elders, who use wheeled mobility and live on reserves in Ontario.

From this study we expect to find barriers and facilitators to the cultural participation of First nation seniors using WM. We expect to find results that will encompass the physical, emotional, mental and spiritual elements represented by the medicine wheel. It will also examine how these resolutions can be managed to assist individuals and communities to enhance the success of cultural participation in order to promote health.

This project will be useful for health practitioners, individuals and communities in recognizing any barriers or facilitations in order to help First Nation seniors participate in cultural events necessary to improve health. Increasing cultural participation for First Nation seniors is not only important for the individuals overall health but also for the health of the community because First Nations seniors are key holders to the language and culture required for healing.

Limitations

The sample sizes will be small. The researchers perspectives can be subjective, for example the researchers thoughts might affect the data coding process and effect major categories. Researcher bias is also a possible limitation. The length of time the participant has been using wheeled mobility may also affect their lived experiences in relation to health.

Timeline

Task	Year 1				
	Nov/ Dec	Jan/ Feb	Mar/ Apr	May/ Jun	Jul/ Aug
Proposal					
Proposal Submission					
REB Approval					
Develop Interview					
Data Collection					
Annual Progress					
TAC Meeting					
Data Analysis					
Thesis Write -up					
Annual Progress					
Thesis Submission					
Thesis Defense					
Task	Year 2				
	Sept/ Oct	Nov/ Dec	Jan/ Feb	Mar/ Apr	May/ Jun
Proposal					
Proposal Submission					
REB Approval					
Develop Interview					
Data Collection					
Annual Progress					
TAC Meeting					
Data Analysis					
Thesis Write -up					
Annual Progress					
Thesis Submission					
Thesis Defense					

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Chapter 4: Qualitative Study

First Nation Elders who use wheeled mobility:

An exploration of culture and health

This chapter is based upon an unpolished manuscript formatted for submission to the Journal of
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First Nation Elders who use wheeled mobility: an exploration of culture and health.

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First Nation Elders who use wheeled mobility: an exploration of culture and health.**Abstract****Purpose**

The purpose of this study was to gain an understanding of the importance of Elder cultural participation, perceptions of the effects of participation on health, how cultural participation has changed since becoming a wheeled mobility user, the barriers to participation, and thoughts on how participation can be improved for First Nation Elders who use wheeled mobility and live on reserves in Canada.

Method

A qualitative design with an interpretive phenomenological approach guided by Hermeneutic phenomenology was used. The research participants were Elder wheeled mobility users who live on reserve in Canada. Data were collected using a demographic form and a semi-structured interview.

Results

Eight themes were extracted from the interviews: (1) Participation in cultural ceremonies, (2) Participants perceptions of the usefulness of their device, (3) Ability to access the outdoors safely and independently, (4) Transportation to and from the events (5) Exterior paths of travel to and from cultural events, (6) Accessibility at the events (7) Stigma (8) and Burden.

Conclusion

The findings demonstrate that policy changes are required regarding the allocation of funding to ensure that Elders have safe access to outdoors, to provide adequate transportation to and from cultural events, to create accessible paths of travel to and

from cultural events, to increase accessibility at the events, and to increase education in order to reduce stigma.

Implications for Rehabilitation

- Expectations and social norms surrounding wheeled mobility use create stigma, which encourages the implementation of wheeled mobility awareness programs.
- Power wheelchairs may enhance participation and feelings of independence by overcoming reserve terrain and encouraging participation in the social and cultural elements of the community.
- Transportation that is properly equipped for Elders and their wheeled mobility devices is essential to participation in the cultural elements of the community.

Keywords: Wheelchairs, walkers with wheels, community, culture, health

Introduction

Wheeled mobility (WM) continues to make up the greatest portion of assistive devices in use in Canada where there are currently over one million (1,186,800) wheelchair users [1].

Independence in mobility is one of the most significant determinants of quality of life for individuals with disabilities [2], 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 [3].

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” [4]. Participating in self-defined, meaningful activities can enhance sense of competence and well-being [5]. 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 less activities than people without disabilities [6].

It remains an even greater challenge on Canadian reserves and in northern communities because an increasing number of First Nation adults are reporting that they’re homes are in major need of repair, homes are often not modified for accessibility, lack of access to appropriate services, challenges negotiating reserve terrain, lack of adequate transportation, difficulty participating in cultural ceremonies, and isolation due to harsh winter weather [7].

Understanding WM use among First Nation Elders is important because as the Regional Health Survey (RHS) demonstrates a healthy person is one who maintains balance with their environment [8]. According to the RHS, First Nations adults who report being more involved in the cultural elements of their community report more spiritual, mental, emotional and physical balance [8]. The presence of Elders in community is important because many Elders retain the knowledge of their language and cultural traditions, which are an important part of healing efforts [9]. 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 [8].

There is an unprecedented need for research that examines WM use that incorporates First Nations theories of wellness, and that encourages the continuation of and participation in traditional culture. First Nation leadership, youth, community members and Elders have made it clear that culture must not only guide work, it must be understood as an important social determinant of health [10]. Culture as a foundation means that Indigenous knowledge and culture should be the base for current policies, strategies and frameworks [10].

The researcher sought to gain an understanding of the importance of Elder cultural participation, perceptions of participation on health, how cultural participation has changed since becoming a WM user, the barriers to participation, and thoughts on how participation can be improved for First Nation Elders who use WM and live on reserves in Canada. To the best of my knowledge there have not been any published studies examining WM use among Elder First Nation populations.

Method

Research design

This study adopted an interpretive phenomenological approach guided by Hermeneutic phenomenology [11] since it aims to describe lived experiences. The researcher aimed at equalizing 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, and through a critically reflexive research process.

This project is also interdisciplinary in nature and engaged the perspectives of community members, Chief and Council, long-term care employees, a senior policy analyst from Health 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, physiotherapists and policy analysts. Participants were recruited and interviewed until new data no longer emerged and data saturation was reached for each community.

Ethics approval was obtained from the University of Ottawa's Health Sciences and Sciences Research Ethics Board (Appendix B), from Six Nations Council (Appendix C), and from the Mohawk Council of Akwesasne (Appendix D). Research agreements were negotiated with the Mohawk Council of Akwesasne (Appendix E), and Six Nations Council (Appendix F). Ownership, Control, Access, and Possession (OCAP) were incorporated into each agreement as seen necessary by each community.

Procedure

The researcher sought to gain an understanding of the importance of Elder participation and perceived effects of participation on health, how cultural participation has changed since becoming a WM user, barriers to participation, and how participation can be improved. 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 researcher (Appendix G).

Volunteers were taken on a first come/first serve basis. The researcher followed up by telephone or email to schedule interviews. Written consents (Appendix H) were obtained from the Elders prior to conducting the interviews. The author assured the Elders that their participation was voluntary and that they could withdrawal from the study at any time without penalty. The confidentiality of their contribution was also guaranteed. The demographic forms (Appendix I) and interviews (Appendix J) were conducted in the homes of the participants, lasting one hour or less and were audio-taped if agreed by the participant for later transcription.

All participants agreed to be audio-taped. A tobacco offering was given to the Elders to say thank-you for sharing their experiences and knowledge.

Participants

Eighteen participants were recruited into the study based on the following inclusion criteria: must be aged 55 and older, be First Nations, live on a reserve in Canada, comprehend and converse in English, use a wheelchair or walker with wheels (for at least one year but not since birth). 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

Prior to the interview demographic information was collected which included participants age, gender, current living arrangement, when they started using WM, and what type of device(s) they are currently using. A semi-structured interview was developed based on available literature and with help from an interdisciplinary team who have extensive experience working with First Nations populations.

The interview consisted of 20 questions surrounding barriers and processes to attending cultural events, including how participation levels have changed since becoming a WM user, the importance of Elder participation, and perceived effects that participation has on health, ending with questions on how cultural participation can be improved. The interview was re-examined following the first two interviews and no major changes were necessary. Throughout the interview field notes were taken to capture methodological and theoretical insights in the data, and to record expressions and gestures made by the participants. The field notes were later

incorporated into the transcribed texts. The interview process and potential biases were discussed with the research team.

Data Analysis

The researcher transcribed the interviews and field verbatim and NVIVO was used to help organize, analyze, and find insights into the data. Thematic coding and categorization was employed, all data relevant to each theme was examined. The researcher reviewed and compared the data to the themes to ensure that codes and data were not missed. A hybrid approach was used because some codes were determined deductively based on the interview guide, while themes emerged inductively from the data.

The researcher completed the data analysis in three steps: once for each community and once together to look for common themes or best practice opportunities. The findings were organized around eight broad themes. The first two themes are based on the Elders perceptions of the usefulness of their device(s), and on the importance of cultural participation on health. The following six themes represents barriers to cultural participation.

Using an interpretive phenomenological approach guided by Hermeneutic phenomenology was the most appropriate approach to data analysis because it helped the researcher to gain rich contextual data to reveal aspects of human experience that are rarely described or accounted for. Bracketing was not used because Hermeneutic phenomenology does not require researchers to bracket their own preconceptions or theories during the process because it is acknowledged that people are inextricably situated in our worlds [12].

Participation in cultural ceremonies

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 Tota's (Grandma's) are and that all the Tota's are their teachers. Participants said that by sharing knowledge and teaching youth about their identity they will learn the importance of respecting others and give them back the self-respect that's been taken from them. Participants also said that this would increase family pride and give the youth something to look forward to: something to believe in

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 (WMUS2).

Many participants spoke of culture as a foundation for health and that the Elders play a central role in providing cultural leadership to their communities

I try to share as much as I can with youth as best I can in a wheelchair.... you have to take time for your culture because this is who you are. It's going to help you later in life when you start asking philosophical questions. All the answers you're looking for in life is based on your culture. Every culture supplies that for the people that are in it. We had a unique culture survival where our culture was desecrated and we're trying to hold

on. This is the outcome we have right now... the solution to our social problems is family pride and a lot of people don't know their family. Leadership I try to look at teaching leadership (WMUS8).

“It's important so we can keep our ways...It's for the Elders to be out there because the young people don't really know. The Elders are there to show them what to do” (WMUS4).

Several participants spoke specifically about how their leadership can help the youth regain the self-respect that has been taken from them. The participants associated increased self-respect with more positive health outcomes

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. Also I always tell my little guys, they give me a hug and I say ' I love you'. I want them to hear what I believe. That's the way they will learn. The young folks in the community see that and maybe they will change their ways and there's always hope (WMUS9).

“I'm trying to teach the kids respect to give back that respect it's gone” (WMUA1).

“For one thing respect and you got to work together. You and I meet and well I’ll try and teach you what I know and your going to teach me what you know. You can learn everyday” (WMUA5).

One participant 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 grand children are participating in there so it’s good I almost cried it’s just...(WMUA1).

Participants also said that cultural participation is important for their own health and well-being. Some participants said that it’s important to get fresh air and to spend time with nature

“It’s important to get fresh air. We should get fresh air” (WMUS6).

For my own peace of mind and to be with nature. When you grow up around here your used to trees you know, and seeing and hearing the birds, hearing the trees talk. Were used to the animals, were used to the air. You’re used to the animals. Talking to the animals and listening to what they are saying. You watch for things and the animals can show you a lot. I miss that (WMUS1).

Several participants spoke specifically about their experiences with depression and loneliness due to lack of 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 (WMUA3).

"I've got too much time to think and it makes me feel lonely" (WMUS2).

"My mental state because I'm just sitting here" (WMUS3).

One participant discussed how lack of participation affects both his mental health and his diabetes

"Depressing. You go from the TV to the fridge and eat too much. That has its own drawbacks especially with sugar...I also experience depression" (WMUS8).

One participant does not use her walker with wheels due to environmental barriers and the difficulty of getting her device in and out of her car. Her levels of participation have not changed since becoming a WM user and she describes what she thinks it would be like if she didn't participate

“It’s like ummm I can’t do that either and its if you let it you could get really depressed and if you just stay in your apartment or your home and didn’t get out I can’t even imagine, you would just be depressed” (WMUS5).

One participant mentioned the effects of weight gain after becoming a WM user, and how people react to her weight gain

“ I gained 100 lbs. when I started using the wheelchair. Yeah. Yeah everyone says oh my god WMUA8 what did you eat. I said you try being in a wheelchair for 7.5 years and see how you keep your shape” (WMUA8).

When the participants were asked what cultural activities they find meaningful, a majority of participants said Pow-wow’s, Longhouse, basket making, quilting, travelling to other reserves to learn about other cultures and Lacrosse. Participants also said that cultural events are not the only space for the transmission of culture. The community in general is seen as a place where culture can be transmitted, and that this knowledge does not have to be taught explicitly: it can be learned just by being together

“ I learned by watching. It goes in your head...same with the Mohawk language. You don’t teach them. Your talking in Mohawk and they’ll learn. You don’t have to teach it to them you talk and they’ll learn” (WMUA6).

You don't need any structure just somewhere for us to gather...just be there...and once the older people start talking and reminiscing then you start catching the ear of all these young kids and that's what needs to happen, inter- mingling or whatever (WMUS2).

One participant described basket making as a cultural activity and said that she learned by watching

I grew up with it. My mother used to make baskets and she don't have to teach me. I look at it and...yes nobody taught me how to make baskets. My mother was making basket. I would see her (WMUA6).

A couple of participants gave specific examples of how they could share some of their skills with the younger generation

"I would think if they had a place where a person could go in. Shop or equipment or what not...we could teach the young people how to do carpentry" (WMUS6).

"Working in the greenhouse together, learning how to do canning and stuff like that...classes on making bannock...I don't know what they are going to do if we don't have stores for them to go and buy stuff and they don't know how to cook from scratch" (WMUS5).

Although participants detailed the importance of community and cultural participation on their health and the health of their communities they also expressed an overall decrease in participation in relation to their WM devices. It was stated that Elders would be able to attend community and cultural events if appropriate accessibility existed

“ I can’t get out that much. I don’t go that often. I’d rather stay home. It’s hard with the bathroom if you don’t know where you’re going. I don’t have much help”
(WMUA6).

I was one who loved to walk. I would walk in the snow, walk in the rain, I loved to go out and walk. Even when I was pregnant I was out there walking walk walk walk walk. Yeah I had to slow everything down. It gets depressing because you’re stuck in one position (WMUA8).

“It’s really important. I don’t get out very much but when I do I have to have help. I can’t do it on my own. If they had good accessibility I wouldn’t have to”
(WMUS10).

Several participants said they stopped participating all together since becoming a WM user

I would like to go if I was more mobile. I manage my ability right. Some people say I wish I could go. It’s not like that. I manage my ability just like I manage my food intake.

I have to manage my ability. If working in the shop is more important than I'll do that (WMUA2).

“I don't do nothing...I used to go to the Pow-wow but since I'm in a wheelchair it's hard. It's important but I just don't participate. I don't like going anywhere” (WMUA3).

One participant shared her memory of gardening and said that she was no longer able to garden once she started using her walker with wheels

I used to sit in a chair and just move like that. It was just a small garden but it was something for me to do. I always had a huge garden but when I was alone I just put the vegetables I really liked. I took care of it everyday. I used to do all my canning and go in the woods and pick berries, like blueberries then you make jam. Yeah I couldn't do it anymore. I missed it. I missed being out there and I missed having the stuff (WMUA5).

The same participant said she participates less in community and cultural activities because she doesn't like to ask for help and likes to be independent

“ I don't know. I truly hate to ask anyone to do anything for me. What I cannot do I let it go...I've always been like that, very independent” (WMUA5).

One participant said that he only gets out for doctors appointments. He no longer attends community or cultural events and doesn't move around within his home. In the morning he goes from his bed to a lazy boy chair in his living room and stays there until bedtime

Well I don't have much of a life because I can't get out because I'm disabled. I can't walk at all. I sit here (in lazy boy chair) from when I get up in the morning around 9:30 am and I sit here until 11pm. I can't move around to do anything (WMUS4).

Two participants said they still participate as much as they did before. Both of these participants are of the few who still drive, and the second participant does not use the walker with wheels that was prescribed to her

Getting around with a walker doesn't stop me. I manage to go down the stairs there. They are supposed to put in a ramp to make it easier. I'm not getting any younger (laughs). I work out a system how to get around with it. For every hurdle there's a way...I manage that pretty good. To go down the steps I take a hold of it lock the wheels, take a hold of the top and bring it out (Flicking and down motion) and down the steps (WMUS6).

“ I'm actually too busy. I could be less busy. I think but there's so much to do in the community” (WMUS5).

Two participants said it doesn't bother them that they can't participate. The first participant has a progressive disease and was aware early on that he would one day not be able to walk

I'm so used to being home all the time. I kind of prepared my mind that I would be home all the time. I tried not to go all over so I wouldn't miss anything. The way I am now I don't miss anything. I prepared my mind (WMUS4).

"It doesn't bother me. There are some things I like to go to, but I realize there are limitations for me. If I can I go but if I can't I just don't" (WMUS9).

Participant's perceptions of the usefulness of their current wheeled mobility device

A majority of participants related positively to the usefulness of their device(s)

"If you don't use that your 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" (WMUA1).

"Yes definitely because sometimes I get dizzy or lightheaded and if I didn't have this (walker) to keep stable I'd be on the ground" (WMUS2).

“My daughter always tells me...dad use that walker all the time. You might fall and break the other hip...It's useful yeah. I can get around most places with it”

(WMUS6).

When talking about the usefulness of their devices several participants talked about safety in particular

“Its useful I feel safer with it. Your a lot safer and freer to do what you want”

(WMUS5).

“ Well I feel safer with it. That's one thing I'm always sore so that takes some of the pressure off my back. So I use my walker all the time” (WMUA5).

One participant said that he feels safer with his walker, but that he takes a cane on outings instead. When he was asked why he doesn't take his walker with wheels he said it's easier to transport a cane

“Oh yeah more secure with the walker. Always more secure with that not with a cane.

I'm not that good. Well as soon as I get home I go grab old Betsy their (laughs) ”

(WMUS3).

Five participants have motorized wheelchairs, which they describe as providing more independence because they can overcome rough reserve terrain and gain access to areas that they can't access with a manual chair or walker with wheels

I got approved for that chair so I could go outside and enjoy life...I thought ok and I use it to go and sit outside at my sister's. We have functions and events over there, so I was able to go there by myself, go as I please... It gave me a sense of freedom because I could go get my own milk...you know freedom. Our family is buried back there. I couldn't go back there before but now that I have that wheelchair I can go back there and visit the graves (WMUS1).

"It works well on grass and rocks. Yeah I can do just about anything with it"
(WMUS7).

" I drive around and go to the neighbors...around outside, look around. That way I can go where I want to go, shift the gears and go " (WMUS4).

"I have one of those power chairs and I can zip around with it" (WMUS2).

One participant talked about how she thought the motorized wheelchair would give her more independence but because everything is so spread out on the reserve she's afraid of running out of battery

“I got a riding one. I thought I would be more independent but things are just too far. I’m afraid of running out of battery ” (WMUS10).

Although participants find the motorized wheelchair the best for overcoming reserve terrain and increasing independence participants explained that these devices can not be used at cultural events because they have no way to transport them

I couldn’t really do that in town...it weighs about almost 300 lbs. You couldn’t do it. I think it comes apart for stronger people that can pick it up and put it in the car, but she (wife) isn't strong enough for that (WMUS4).

“I have that electric chair that would be awesome at the Pow-wow. I could do what I want...if you could get it there. I could use that” WMUS1

Although this participant has not had the opportunity to use her motorized device at a cultural event she described how useful it would be by relating it to an experience she had at another event.

My other 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. I don’t have a vehicle of my own to get to these things. It was awesome because like I said I didn’t have to depend on someone else to push me. This great big crowd all through the streets and its hard for this (gestures to manual chair she

is sitting in) and smaller ones 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.

One participant said that she considers her manual wheelchair as an advantage because she can transport it

I see a lot of people out they have those motorized wheelchairs. I don't have one but in order for you to go some place with that its fine in the community, but if you want to in town you have to put it in the car and you cant it doesn't fold up as where a wheelchair will. That's the advantage of a manual wheelchair (WMUA9).

Most participants did not have difficulty accessing their device (s) and had them in a timely manner

“ Got in two days. Really fast. The only thing was they didn't teach me how to use it. They could have at least taught me how to put the breaks on” (WMUA5).

“It was done here (LTC) ...mine was brand new 400 and some dollars it costs all together. It didn't cost me nothing I was very fortunate” (WMUS3).

“I got it through the physio. Probably about geepers 3 months. Then I had to go to Brantford and pick it out and everything” (WMUS5).

It was easy to get them. I guess we get them through NIHB. I think they paid for some of that. It depends what situation your in. Sometimes um at a younger age it goes by your age. If your disabled then you get that government disability program ODSB then I think you can get paid for it but I don't know how it works now everything keeps on changing. They pay so much then Indian Affairs pays another percentage ...I think there's another program called ADP (Assistive Device Program). That's only up to age 65. Yeah that's how I got my electric one they paid $\frac{3}{4}$ and Indian Affairs paid the other portion (WMUS4).

Some participants brought up that not everyone knows how to go about getting WM and that the process can be quite complicated

Accessibility to the equipment, not everybody meets the criteria...see this thing here this is a beautiful chair (walker), my husband got it in the dump at work. All he had to do was buy a new wheel for \$40. And it was in the dump. I lucked out on that one because not everyone qualifies for the different programs. Not everyone knows how to go about getting it, I don't think they want to go through the red tape too many forms (WMUS2).

One of the workers (Home Support) had a smaller one I could sit in and I was comfortable, so I inquired about buying it but they had one and they loaned it to me (WMUS4).

Some participants expressed difficulty in obtaining a second device when health circumstances changed

“ You have to wait for 5 years or more before they give you another one. If you’ve already got a walker you can’t go back for a wheelchair they don’t understand that with me I’m complex care” (WMUS1).

The biggest thing is that it isn’t going to last forever (wheelchair). You as a user I think people should listen to you. As good as it was maybe it’s time to get a new one...you call this woman and she comes. I’m waiting on a new one and it’s been over a year and I haven’t got it yet (WMUS9).

Although most participants find their device useful many also said that the design of their device 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 ” (WMUA2).

“ I think a rubber tire would be a lot better...rubber tire would be softer. I don't know if they make rubber tire walkers but you see wheelchairs have that” (WMUS3).

Although participants found their devices useful some also said that they could use more maintenance

“ Have them fix the breaks it's too hard and you wont go. Should grease up the tire and check it once and awhile” (WMUA6).

“ I'm glad it didn't happen when I was sitting on it but the cross there it came off. What the heck is that something kind of gave” (WMUS1)?

Ability to access the outdoors safely and independently

Eight participants do not have the ability to get out of their residences independently. Five of these participants have make shift ramps that are not up to code

I had to build that ramp because there was nobody to help me. When I came back from the hospital I needed a ramp to get into the house so I had to come up with \$50/month for a fold up steel ramp. It was \$50 a month and the agencies were coming around. I was like holy I just got out. There were so many people here it was hard to know who was doing what. One agency said they were going to pay for that but they never did it so I got in trouble... I told them to take it back because I can't afford it...housing came in and said we have to build it out this way and that way for it to be up to code. Well I never had

the money for that, so my son in law built it. It needs repairs because someone with 4-wheel drive came up and drove up over my ramp (WMUS8).

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 (WMUS1).

One participant lives on ground level in a senior's apartment but there is no automatic door and she can't get through with her walker, which is one of the reasons she doesn't use her walker even though she needs 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 (WMUS5).

One participant has been waiting 4 years for a lift because her application wasn't followed through on

"I wish I could build something because this house is so high. That's what I'm waiting for. They are supposed to get me a lift. I can't even climb my own stairs" (WMUS2).

Another participant has been waiting a year for a ramp and was told he has to hire a contractor and pay for it himself

Well when I first broke my hip they said they would get me a ramp but you know politics. Goes from one person to another person and then they kind of left it up to me to find a contractor. I don't know a contractor around that does that kind of work (WMUS6).

Of those participants who currently have safe access to outdoors some had access right away while others had to wait

Yes it was already here, so I think it was two weeks before my release that they filled out papers for someone to come in and make sure I had a ramp and that I had proper lighting...it's a loaner while I use it but when I'm done with it they take it back. Its uh what do they call it...temporary (WMUA3).

I applied for the disability thing so they put that door in my bedroom to go outside on the ramp. They built the ramp it all came with that disability thing. Its permanent if there's a problem with it I just call Home Support and they have guys that come over (WMUA4).

“It wasn’t very long. I think I told the doctor about it and he requested it and maybe within a week we had a ramp” (WMUA5).

One participant waited a year and half for a ramp to be built. In the meantime her granddaughter had to carry her in and out

“ She used to have to pick me up and bring me in and out. Yeah and she hurt herself a couple of times” (WMUS10).

When the participant was asked how long they had to do that for she said

“About a year and a half. We had to wait for funding; they had run out of funding. You know how it is” (WMUS10).

Some participants expressed difficulty when ramps are not cleared of snow, except one participant who has her ramp in the garage

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 (WMUA3).

Transportation to and from cultural events

Transportation was seen as the largest barrier to community and cultural participation where 15 participants said that transportation was a direct barrier to their participation to community and cultural events. The three participants who didn't find transportation to be a barrier are also the only three who still drive

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 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. Yeah yeah it's not like in the city or you can go stand on the street and catch a bus ...not here (WMUA1).

Transportation I think is the biggest hindrance for Elders...if there was transportation available where you didn't have to bother somebody else. You know what times it comes through and you know what time you can get home. On the American side they used to bring their bus on the island and you could get to their events but they stopped because whoever their driver was didn't like to report at the Canadian customs but I don't know why they didn't put it back on because you don't have to report now (WMUA3).

Participants mentioned that long-term care facilities have transportation for their residents but this transportation can't be used by anyone else

I know Tssionkwonsho:te takes their patients for outings every now and then. They have a bus, sometimes they go shopping... there's nothing for everyone else. Maybe that would be something useful or even giving an incentive to a person who drives Elders around (WMUA2).

Many participants discussed several options for transportation to and from medical appointments, for shopping, or to get a haircut but that there isn't any transportation available to go to community and cultural activities

There's medical transportation but you have to have somebody go with you. Maybe for insurance I don't know... here in Snye they have little golf carts. They go around the streets. If I can't get a motorized wheelchair I might think about investing in something like that. The only thing is that I'd have to leave my wheelchair somewhere or else have someone put it in the back and take it out. The breeze in my face and my hair. I never felt like that. I was in a nursing home for 7.5 years and I never once felt that way. This was exciting (WMUA8).

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 (WMUS1).

The only time I have help is through the medical transportation they are a great service. I try to get more people to use it cause if you don't use it you lose it. I use it all the time when I go to doctor's appointments. I like it because I don't have to get out of here (wheelchair) because I fell once getting out of my chair into a truck. That's a great service (WMUS8).

There's a place you call and they will take you out but they take you there and dump you there. Like if I want to go to Polytech they wont take me inside. I don't use that very often...I have to have someone help me all the time (WMUS9).

We got a van here. A long-term health care van. I just jump right in there, well I don't jump in they put me in and we go to wherever we got to go. You can use it sometimes if you want to go to the bank and cash a cheque or something. Yeah you can get them to take you if you want to go for a haircut (WMUS4)

There's a taxi service but you have to make arrangements two days ahead of time so they will take you to your doctor's appointments and take you shopping but not to the bingo or go socialize...a lot of times I had to walk with my walker to the Tri-District Elders Centre. I couldn't find anyone to take me...it was tiring I had to stop about 10 times (WMUA3).

Due to a lack of public transportation for people with disabilities participants have to find rides. They often expressed experiencing difficulties getting in and out of various vehicles

My son usually takes me but now it's getting hard to get in the van. We went to Costco in November...I says to my son I'm going to have a hard time getting back in, he said we would just take our time. We did but I could feel myself going backwards. I told him he had to grab my back and he also has the wheelchair there so if I fall I'll land in the wheelchair, but that's the last time I go in (WMUA4).

“That's another thing. When you get in the car you have to have someone help you step in the car. Its high-up and your no good and I had my knee operation”
(WMUA6).

“Well sees how I can't get into a vehicle that well, I have to be cheesy on the people who can take me, so I can get into their car and they can pick up my wheelchair. I can fit in my daughters little car...Big trucks or vans ...it took four people to get me into the front seat of that truck. That was the last time I went. It made me feel awful”
(WMUA8).

“Sometimes it's difficult for me and then some days it's not too bad. But what I do is bump my legs sometimes. I've always got bruises on my legs from getting in and out”
(WMUS9).

“I have family but they either have a high truck or small cars that I can't fit my...(WMUS1).

This participant still drives but has a hard time getting in and out of his vehicle and it is a regular occurrence for him to fall onto the ground

That's why I take a flip usually every two weeks or so. I'm still in there trying. Last time I fell near the car and I use the door handle and I pull myself up. About a week and a half ago. Fell out front there. I grab for the back door handle. It's a new car and it came right off. The handle came with me (WMUS7).

Several participants talked about difficulties with transporting their devices

Sometimes when you travel...like when the last time we went I took my walker then thank God people would help me too because we get a shuttle, so when you get a shuttle you got pick it (walker with wheels) up put it in the bus. Kind of hard for me but I lucked out and somebody would help me. A man or whatever and take it off of there. I need help. I can't be by myself to move around (WMUA1).

There's a bar you have to take the back off then you have to take the seat to fold it up. So and so isn't going to stand there and take it all apart. I didn't know that's what I was getting. It's custom made for me because I'm so fat. I got tired of hearing the lady say it only goes up to 350 lbs. and blah blah blah same shit different day (WMUA4).

"I used to fold it and grab it in the middle here and put it in the trunk but I'm not able to do it now" (WMUA7).

“Ok you know it’s not just me...do you have room for me my chair and my son”

(WMUS1).

One participant described one scenario that helps her transport her walker with wheels

You can use the car and we put the thing in the trunk and then we got a spongy jumper...bungee cord and I tie it together so it’s easier to pick it up and put it in the trunk, get it there and take it out. It’s a nuisance but when it helps you walk then you appreciate it just the same (WMUA1).

When asked about transportation to and from cultural events, several participants said that transportation is expensive and gave the example of the cost of getting to and from medical appointments and not always being able to fit through the doors once they got there

It takes a lot to live up here. All the driving you have to do. To get to the doctor and back that’s \$20 every time you go to Cornwall. I had to go three times in one week. There’s medical transportation but I have to have someone with me in the car to go into the doctors with you (WMUA8).

I remember I had to urologist and we had to wait till the people ahead of me had their appointments get them out and had too sit and wait for two hours to get in that one room. Because the door wasn’t big enough for me. I was so pissed. I had to wait in the waiting

room but they kept taking these people, taking these people but I kept watching that. I was so pissed. We had to wait till everyone got in there because there's no room for me. We couldn't get in that room. I had to wait until it was empty. I had the same thing happen to me in Cornwall...they called my name and I couldn't get through the door. I said 'I can't get through this door' they said 'oh no'. So I had to make another appointment there at the hospital. I had to go back. You have to be skinny even in a wheelchair. See these are the problems I have (WMUA8).

Another participant talked about no longer being able to work due to her disabilities and how this in abled her to afford a vehicle

"I can't afford it. I had a bush beast...its like a regular car but its not insured or doesn't have plates on it. So you're just running here. That's what you have to resort too"
(WMUS1).

When participants were asked what would make it easier for them to attend, a majority of participants said transportation would be the biggest facilitator

A little bus. Because even for the Elders when we get together they can't go because they got no car and I don't know today is different nobody wants to go around and pick up anybody. So it would be to coordinate a bus driver and have a little bus. We were talking about getting a little bus at the Elders but that's a very expensive venture. So then we really have to go out and what do you call that...make money to pay for all that stuff. The

insurance plus the payment of the bus then insurance will be high because you're carrying other people (WMUA1).

Transportation. Transportation. I've heard them talking about bus lines...but it wouldn't work because the people down here don't consider um jobs down here to be real jobs. 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 Oshwegen 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 (WMUS2).

“ 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” (WMUS1).

Exterior paths of travel

Participants who used walkers with wheels or manual wheelchairs experienced challenges negotiating uneven terrain, and a general lack of pavement and sidewalks, which they said is a barrier to community and cultural events

What street what sidewalk? If they had incentives or a program to help build a walkway to join our small village, but usually Council wants to do everything big. We want to make a park where everyone can walk like Cornwall. They want to mirror

Cornwall. We want to have bike trails like Cornwall. I mean it's great but what about mobility around the yard or local neighborhood (WMUA2).

“The sidewalks aren't even. When somebody is pushing you or you go yourself here's the sidewalk then this one is crooked then BOMP you fall out of your chair”
(WMUS1).

“Sometimes the sidewalk is too close especially with a wheelchair. You got to have room for your wheelchair to get in there by the door. You know a little bit narrow?”
(WMUS9).

“ I think mostly its getting to a sidewalk you know is the whole thing. It's very deferent here everything isn't paved. Our parking lot isn't paved” (WMUS5).

Participants said that even when there is a sidewalk sometimes they have trouble getting onto it because they don't have a curb cut

“Sometimes when you travel and we go somewhere they don't have a slant ”
(WMUA1).

“Walking with a walker is terrible here...because the curbs are all lifted and you've got to pay attention or you could flip the cart yourself. The sidewalks are all heaved from the frost” (WMUS3).

Have things accessible...we went to something 3 or 4 years ago about how can we make things more accessible, or how accessible is Six Nations. Even the community hall that they had the session in...you couldn't get in there because there's a lip. The parking to the curb is supposed to be easy but there's a big lip. I had to go backwards to help me push myself back and kind of jump up. They kind of fixed it now (WMUS1).

One participant said that even when there is a curb cut in the sidewalk it's often really far from parking, ramps and doors

Even when there's a low-grade thing you can walk up but it's way over here and you have to walk really far to get to it. If you have to lift the thing up and over it gets to be cumbersome (WMUS2).

Several participants said that potholes and uneven ground make it really difficult to manoeuver with a wheelchair or walker with wheels

Yes grass is what's worse...the biggest obstacle for being in a regular wheelchair is black rock. Yeah because we cant afford to pave...you know I got black rock that way and this way...when you move to a new house its black rock up the driveway then I'm SOL again (WMUS1).

There's no real good access when your trying to go across pebbles and stuff like that's a big deal when you're in a wheelchair. They might be pebbles but they are big to you when you have to go through it and when there's a lot you just kind of get dragged right down (WMUS8).

Some participants talked about the importance of accessible ramps. They explained that even when there are ramps available they can be very difficult to access.

“If it's not a ramp it's hard. That's why I can't go out that much...there's trouble” (WMUA6).

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 (WMUS1).

“ The disabled parking is here to get up the sidewalk is way over here. You get out of your car the sidewalk is like this where the disabled parking is so to get to the incline you have to go half way down the sidewalk” (WMUS5).

“That's one of the things I pointed out to the board is clear and enforceable disabled parking. When I say enforceable I mean were supposed to be respectful. Like I

can't remember myself when I was healthy I never parked in those places. You know I always said wait till it's your turn" (WMUS8).

One participant talked about how he moved his garden from the backyard closer to the front door, so that his mother who also uses a walker with wheels could access it

You can sit here and it's the warmest place in the summer. It can go up to 20 degrees here so my mom likes to sit out here... anyway all this will be plants here and here and those benches will go here so she can get through with her walker. It's still a bit rough but she can pick strawberries if she wants. Everything is close (WMUA2).

Accessibility at the events

Participants were asked if they experienced any challenges accessing community and cultural events while using a walker with wheels or wheelchair. Many participants talked about their experiences negotiating grass and uneven terrain

Pebbles are a big thing when you're in a wheelchair. I like to go to Longhouse but it's kind of hard. Yeah to get me across the lawn. They usually have Pow-wows in a field and it's hard to get a wheelchair across the field. I used to go but that's the main reason (WMUS8).

I go to Pow-wows. I like to hang out there. I took my walker there but it's a little hard to push around but it's better than nothing...well its bumpy and somebody takes you.

They help me (WMUA1).

It's like a lot of yard or grounds. The grounds aren't walker friendly. Grass isn't right.

Even steps you have to walk up the steps and carry your walker and I can see the difficulty because I'm getting older (WMUA2).

I used to go to the Pow-wow but since I'm in a wheelchair it's hard. Potholes and ground wasn't level. Even if I used the walker when I went" (WMUA4).

I like to go to the Pow-wow but its 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 (WMUA8).

Its not level and with them pushing me I get stuck so I used to sit on the picnic table watch them dance but it gets uncomfortable...or to go the bathroom. I just stay home I'm more at ease that way (WMUA4).

One participant talked about how he moved his garden from the backyard closer to the front door, so that his mother who also uses a walker with wheels could access it

You can sit here and it's the warmest place in the summer. It can go up to 20 degrees here so my mom likes to sit out here... anyway all this will be plants here and here and those benches will go here so she can get through with her walker. It's still a bit rough but she can pick strawberries if she wants. Everything is close (WMUA2).

Participants said that it's helpful when someone takes them down to the Pow-wow on a four-wheeler. They said that it really helps them get over some of the rough reserve terrain

“Well they have golf carts over there” (WMUA4).

You know once I'm down there I'm Okay I'll go look around and they have a lot of vendors so you take your time. I take my time anyway and I sit for a few minutes and go on to the next one so I'm not going straight though. If I was going straight through then I would have a problem but going slow and just nonchalantly. I have no trouble with that (WMUA1).

Many participants also brought up some issues with access while attending Longhouse. Some participants said that the benches are too high and too hard, and some participants said that there isn't enough space for their device, and one participants said the kids like to play with her walker with wheels but she needs it to be accessible when she needs it at the last moment

Well you go to a Longhouse but I haven't been going because it takes too long and I can't sit sit sit on the hard benches at the Longhouse. Yeah so I don't go to ceremonies

because of that. I get all stiff...and if you put a walker and then your taking up another space. I just felt its better for me to stay home (WMUA1).

The benches are high. I haven't been there in about 40 years (WMUS4).

I never got a chance to renew my vows this year but I usually go but when I take my walker I have a hard time hanging on to it because the kids want to play with it. They want to sit and ride around in it, so the last time I went I took my cane and because even the walker took a lot of space and with the amount of people. I can fold it up but I need it at the last minute I like to grab it and take off with it (WMUA3).

Some participants also said they have a difficult time attending Longhouse because they can't fit through the door

"There's no way to get in there. There's room but I'll go if there's a family funeral. I don't bother with other stuff because it's too hard" (WMUS7).

"I never went to Longhouse in probably about 40 years because I barely been getting around and its kind of harder to go...you can't get in the doorway" (WMUS4).

Several participants said that parking and ramps can make accessibility difficult at the Longhouse

Most of the time yeah except for cultural events likes Longhouses. There are no disabled parking at Longhouse mainly because you're supposed to respect that and help. The Mohawk longhouse was built with a ramp so there is no problem there but they also have big stones (WMUS8).

There's a ramp in the women's door. You come up the side of the building and you go in but its awful hard getting out of there. The door is only as wide as the wheelchair. And uh usually in the walkway there's a lot of people so if your coming down in and out with the wheelchair or walker its awful hard to move over to the side (WMUA3).

“There's a ramp but its not that good the ground moves and its not too safe”
(WMUS4).

Several participants don't attend Longhouse due to inaccessible bathrooms

“Its like the old days outhouse” (WMUS7).

“That's one of the things that stops me. I can't get into the bathrooms there. I can't get in. ...Can we get something more appropriate for us to participate? I don't go because of that. It's the main reason. How will I go to the bathroom” (WMUS8)?

They have ramps and there is room. The only thing is that where I go they have outdoor toilets. They should fix that so it's accessible for people that can't. When you get older sometimes you can't raise your leg high enough to step up (WMUS9).

“Yes that's why and nobody wants to help and it's hard. I'd rather stay home. It's hard with the bathroom if you don't know where your going...it's not always for wheelchairs” (WMUA6).

One participant said she doesn't have a problem attending Longhouse

“ I attend Longhouse...there are quite a few here...5 or 6 and there's a ramp...and they have indoor bathrooms” (WMUS10).

Participants also talked about the Elders Centre. Some participants said that the bathroom door is too heavy and that it's difficult to get your meal due to lack of space

Going to the bathroom, the door is so heavy...I says that door is way too heavy for even the Elders without wheelchairs or anything like that to push but I says imagine how hard it is to a person with a walker or wheelchair (WMUA3).

Where they have their meal...it's like an island so when they put the food people with wheelchairs and walkers have a hard time getting around because when your tying to

fill your plate while trying to hang on to something to walk with the space is very limited. When you go in for your food. It's very tight quarters (WMUA3).

Many participants talked about how well the Elders center is set up for accessibility

When you go there you push the automatic door going in and you can also use...there's a lot of spaces between the tables and that so you can easily move around. There's no stairs (WMUA3).

"The Elders center there's nothing high it's kind of low easy to get in"
(WMUA1).

And I belong to a bunch of Elders and what were doing is trying to get all the cultural stuff and the language and we meet once a month. It's a social outing. We have a meal at lunch but were trying to get everything preserved for the people. Ceremonies, dances whatever...we put it on a computer. So it will be there for them. Different stories. Sometimes we pick a topic and talk about that...they have facilities there (Polytech). They have an elevator too (WMUS9).

One participant talked about Lacrosse being a cultural event because it is the creator's game and he explained how his experience attending Lacrosse games has changed since becoming a WM user

I get a ride in a truck. I get help down the ramp what have you. I have two boys and two girls and there's an area, there's a ramp and out in front there's a spot where I can sit. Is there a drawback? Yes I can't go and sit over here where I would like to sit because when I could walk I'd be sitting in a different spot. I'd be sitting more like in between both sides on the fan side of things. That's where my family sat because I sit by myself now (WMUS8).

Participants 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 (WMUA3).

"Younger people are on the go go go. They are watching their watch-I gotta hurry. They have their day timed" (WMUS10).

Overall half of participants said that weather is a barrier to community and cultural participation. Several participants reported that there are fewer opportunities for people to mobilize with their devices in winter, which leads to limited activity engagement, isolation, and loneliness

“ 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” (WMUA6).

Again it depends on snow...I can’t even imagine trying to get around in the snow with something like that. As it is you’re worried about falling anyway...that’s one thing you don’t want to do is fall. I’ve been really lucky though so you know trying to push one of those the snow (WMUS5).

“ Trying to get around and I’m worried about falling” (WMUS5).

“Yes but like I say most times if your going out in the snow someone is with you so there is help to get over the bad stuff“ (WMUA1).

Participants also said that there are several barriers in the spring such as rain and mud

“ It never fails it always rains. So I don’t go anywhere” (WMUA4).

“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 4 wheels. Coming home from an event like that I have to have a towel and wipe it off which takes a lot of time” (WMUS8).

Some participants talked about the summer heat as a barrier to participation

They can't take us (long-term care residents) if it's too hot outside... When it's too hot out it's hard to take some of them to events (LTC)...I can go stand under a tree but they can't move that good. So its constant taking people over there from here to there.

Staffing is very bad here (WMUS3).

“Well that's why I got a riding one. I thought I would be more independent but things are just too far. I'm afraid of running out of battery” (WMSU10).

Participants also talked about some things they think will improve access at the cultural ceremonies. Handicap parking was said to be a facilitator especially if it's near ramps and automatic doors. Bathrooms were often mentioned and participants said that it would be beneficial to either have handicap bathrooms with bars on the walls for balance or family bathrooms so someone can go in with them or help them. It was also noted that having an extra device to use outdoors would increase participation because the Elders would not have to track mud and snow inside their homes.

Stigma

During the interviews several participants 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” (WMUA6).

When this participant 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 (WMUA6).

When she was asked how this makes her feel she said

“ I feel like going away somewhere” (WMAU6).

Another participant talked about how other people think she is pitiful because she uses a wheelchair

“ ‘Oh you poor pitiful thing’ ‘poor pitiful thing’ I don’t want to be thought of that way” (WMUA8).

Some participants 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 (WMUS2).

“ I’m not bad with a cane on my good days but I’d rather have my walker but people look at you” (WMUS3).

One participant had her ramp built in the garage so that other people wouldn’t know she needs one to get in and out of her house. One benefit that was discussed is that it never needs to be cleared of snow

“They were going to put it outside. I said no put it in the garage. There’s enough room there...because I didn’t want everyone to know that’s how I get out. I’m vein I guess” (WMUS9).

Another participant talked about her experience with her friends not wanting to use WM devices because they worry about what others will think

Nope, nope, nope in fact it's when my friends can't walk... I don't know what it is but they will not use it and I asked them ‘why why don't you want to?’ ‘I don't want everybody to see me using that’. ‘Oh my God but it helps you, helps you do what you want to do’. When it was real bad I could hardly walk. I go in the stores with it get in the wheelchair and my sister would drive me around or I’d push myself and go do what I wanted. Stand up look at whatever and sit back down and I was able to still do what I wanted. If you don't use that you're not doing nothing, so you can at least...no no no no they refuse (WMUA1).

The same participant explained why she doesn't 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 (WMUA1).

One participant suggested that educating the public about mobility would help reduce stigma and increase participation

Just the stigma that people put on you. I used to be out and about and everybody knew who I was. But now its like 'look at her, poor her' I don't like that. I just feel small. Like less. When you see someone in a wheelchair you start feeling sorry for them or like they are less than you. They do less than you. I don't really know what it is but I don't like that...People just have to be educated to realize that the woman over there needs a walker, but her inability to move or walk doesn't affect her mind ... I think education is needed to stop the stereotyping that's what mainly stops me from going out (WMUS2).

Several participants said that more education is needed when it comes to WM

More mobility conscious people. How do you change things, how do you accommodate the people that are not as mobile...you have to have people who are trained to think

that way. It eventually catches on. You have to make it popular to be conscious of mobility (WMUA2).

Burden

Burden as a barrier of participation was another theme that emerged during the interviews

“ I don’t want to be a burden to anyone and that’s how I feel. They tell me not to feel that way” (WMUA4).

“ One thing I don’t like is to hold people up. You know I don’t like to be a burden” (WMUS10).

One participant spoke about burden as a barrier and said she wouldn’t have to 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 (WMUS1).

One participant said that she felt like a burden to others when they would see that she uses a walker with wheels

“ The reason I did that (stopped using her walker with wheels) was because whenever I asked someone to take me anywhere as soon as they seen my walker they would of sort of roll they’re eyes” (WMUS5).

Discussion

The purpose of this study was to gain a better understanding of the importance of Elder cultural participation, the perceived effects of participation on health, how participation has changed since becoming a WM user, barriers to participation and how participation levels can be improved for First Nation Elders who use WM and live on reserve.

Using an interdisciplinary approach allowed the author to utilize the perspectives and expertise from a broad foundation in order to prepare and disseminate findings for use across real life context. Having community members as part of the interdisciplinary team ensured that the information derived from the study would be culturally appropriate and therefore usable.

The findings from this study are consistent with the Health Council of Canada’s report *Canada’s most vulnerable: Improving health care for First Nations, Inuit, and Metis seniors* because the Elders talked about the importance of their presence in community and at cultural events. The Elders explained younger generations have been disconnected from their culture and that culture needs to be transmitted in order to improve health. The findings from this study regarding the importance of cultural participation on the health of the community are consistent with the data from the *Regional Health Survey* where increased participation in culture is associated with positive health outcomes [8].

The findings are also consistent with the study conducted by Wearmouth & Wielandt because the Elders related positively to their devices but found several barriers to using them. In

this study the participants also brought up barriers such as weather, transportation, challenges negotiating reserve terrain, difficulty participating in cultural ceremonies. These findings were also consistent with the National Organization of Disability 's *Harris Survey* because the Elders said that they participate less often specifically due to barriers in using WM. Some findings that emerged were the barriers of burden and stigma. Many Elders said that they do not participate because they feel like a burdens to others. They explained that they feel like a burden in relation to needing transportation for themselves and their 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 due to 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.

A majority of participants said that Elders have an important role that directly affects the health of the community. This role involves leadership and the transmission of culture to younger generations. The Elders in this study said that knowing your culture is important for health because it provides youth with identity, respect, and gives them something to believe in. This information is consistent with a study conducted by Levesque and Li where First Nations participants discussed the importance of maintaining their traditions and culture as a health promoting strategy. These participants were also more likely to report engaging in practices that aim at promoting the health of their families, their communities and the environment [13].

Participants also said that participation in community and culture is important for their own health because they explained that getting fresh air, spending time with nature and taking part is important for their health. They said that lack of participation increases loneliness, feelings of depression, negatively affects eating habits and weight.

This study focused on cultural participation, but after a few interviews it became clear that the community is also considered an important space for the transmission of culture and that the most important thing is to be together with other community members in a natural setting. It was explained that culture doesn't need to be explicitly taught in order to be transmitted. Overall participants reported a decrease in participation since becoming WM users and several participants stopped participating all together. Two participants, who are two out of the three that still drive, said that their participation levels have not changed at all.

Most participants did not associate a decrease in participation with their mobility device because most participants found their devices useful. Participants found that barriers to using their device(s) makes it difficult to attend community or cultural events. A majority of participants said they found it fairly easy to access their devices although some participants waited considerable amounts of time for replacement devices. Some participants said that they only have access to one device every 5 years which they said isn't always enough given that many Elders have several evolving chronic illnesses. 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.

Some participants said that the design of their WM devices needs to be changed in order to be more suitable for rough reserve terrain and others discussed the need for regular more maintenance of their devices. All of the participants who have motorized wheelchairs find their devices useful for overcoming reserve terrain and for providing autonomy and independence; however, participants expressed that they can't use their motorized devices in community or cultural events because they have no way to transport them.

A little under half of participants do not have the ability to exit their home independently and safely, which makes it difficult to attend community and cultural events. Several participants had long wait times for ramps and others had them right away. Some participants described needing to be carried in and out of their homes and that their family members have sustained several injuries in doing so. One participant expressed concern that the only way she can eat is to trust someone with her bankcard to go and get her groceries. Those participants who were not able to access funding and cannot afford ramps have had to resort to building makeshift ramps that are not up to code. Several of the participants said they can't access their ramps in winter because they are covered in snow.

Transportation was the largest barrier to participation. Participants gave several examples of transportation that is available for medical appointments, shopping, banking or getting a hair cut, but expressed that there isn't any transportation services available for social or cultural events. Participants said they have to rely on friends and family in order to participate, which can be difficult because people are so busy.

Participants expressed a desire to have transportation so they can access these events independently, as well as transport their devices. Participants also made it clear that transportation services have to be geared toward people on reserve and need to be affordable for Elders. The only participants who didn't discuss transportation as a barrier are still driving their own vehicles. The rest of participants experienced isolation and lack of independence. Lack of transportation was said to create situations where Elders either aren't participating or that when they do participate they often aren't using the devices that have been prescribed. Some participants are walking long distances by themselves to get to events.

A majority of participants discussed difficulties with exterior paths of travel to and from community and cultural events. Many discussed difficulty navigating curbs and sidewalks. Many said that there are barely any sidewalks and when there are sidewalks they often aren't inclined for wheelchairs and walkers. Participants expressed a need for more people in wheelchairs to be guiding the design of accessible spaces, and that more focus is needed on mobility around the local neighborhood.

Many participants talked about barriers at the events themselves. Many talked about uneven ground, potholes and a general lack of pavement. Mud, grass and rocks were described as very difficult to navigate in manual chairs or with walkers with wheels. Some participants talked about doors that aren't wide enough, not having enough space between doors, lack of accessible bathrooms, and lack of space to maneuver in with their WM devices.

Participants reported experiencing accessibility concerns at the events due rough reserve terrain, parking that is too far from ramps, lack of ramps, doors that aren't wide enough and inaccessible bathrooms. Participants also said that there are added barriers during spring and summer months mainly due to rain, mud and heat. Participants said that winter is difficult because it's hard to maneuver in the snow and they are afraid of falling. This lack of mobilization in winter was described as creating increased isolation, depression and loneliness.

These facts are consistent with a study conducted by Ripat, Brown and Ethan where they reviewed barriers to wheelchair use in winter. The authors state that although it could be argued that participation patterns change for the entire population in winter their results confirm a large variation in participation between seasons in WM users where 42% changed their frequency from 3 to 7 times per week to less than 3 times per week in the winter. Reasons for reduced participation included getting stuck in the snow, difficulty with ramps, tires slipping on ice, cold

hands while operating controls of pushing tires, some reported frozen batteries, electronics, seat cushions, and back rests [14].

Two themes emerged during this study and include stigma and burden. Both were described as direct barriers to participation. Participants expressed not wanting to go out because they feel that others perceive them as less valuable. Other participants said they don't like to go out because they feel like a burden to others because they need help physically or have to depend on them for transportation.

Aside from needing more studies on the barriers to culture for First Nations Elders who use WM this study also demonstrates a need for technological advancements such as designing WM devices specific for overcoming reserve terrain. Other advancements could include designing components to help with barriers of WM use in winter months such as heated seats, back rests, and temperature controlled batteries, low cost heating for ramps, and technology to assist Elders to get in and out of regular vehicles.

An evaluation of scientific rigor for this study demonstrated that credibility was obtained by the researcher as prolonged engagement in the research setting occurred and trust and rapport were established. Triangulation is not relevant for phenomenological studies based on interviews to elicit understanding of lived experiences conducted with specific groups of participants by a single researcher [15]. Although peer debriefing is not required with Hermeneutic phenomenology [15] my thesis advisory committee supported and challenged me. Records of these supports and challenges have been kept as part of the audit trail. Dependability was achieved through records of all stages of the research and all decisions were recorded as well as the thinking behind them- a full audit trail is available. The findings are not meant to be transferable because First Nation communities have different languages, cultures, beliefs and

funding and policy. Confirmability was achieved through reflectivity on behavioral and emotional responses and these were also kept as part of the audit trail.

Limitations

There were several limitations to this study. Although the focus of this study was WM, many participants had other health conditions that might impact their participation levels. The study reviewed change in participation but not actual participation levels. Member checking was not conducted with participants after the interviews and the results are not meant to be generalizable. Member checking was not completed due to lack of sufficient time.

Member checking can be a lengthy process since experiences are always changing and reinterpretation could be ongoing [16]. The findings were however sent for validation from leadership of the participation communities. Although the focus of this study was on

Clinical implications

The findings from this study indicate the need to build collaborative relationships and interdisciplinary teams with First Nation Elders in order to provide them with appropriate WM for their unique accessibility needs, as well as a need for health professional education aimed at providing culturally competent care that is informed by culturally competent research programs and policies.

Conclusion

This phenomenological 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. The

participants in this study are faced with: unsafe access to outdoors; lack of adequate transportation; lack of accessible exterior paths of travel; difficulties negotiating reserve terrain, accessibility concerns at community and cultural events; issues with stigma and feeling like a burden.

This study has underscored the additional difficulties this population experience in trying to access community and cultural events. Many participants 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 to ensure that Elders have safe access to outdoors, to provide adequate transportation to and from cultural events, to create accessible paths of travel to and from cultural events, to increase accessibility at the events, and to increase education in order to reduce stigma.

Disclosure of interest

The study was completed as part of the fulfilment of the dissertation requirements for the author's degree of Master of Science at the University of Ottawa funded by the University of Ottawa. The author reports no conflicts of interests. The author alone is responsible for the content and writing of this article.

Geolocation Information

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Chapter 5 Conclusion: Integrated Discussion

Thesis Summary

Introduction

The overall aim of this thesis was to explore the experiences of First Nation Elders who use WM on reserve, and more specifically their access to cultural ceremonies and events. Chapter 1 provided a background on the population of interest and gives context to the need for research in this area. This chapter also outlined the research questions and objectives that guided this research. Chapter 2 was structured as a manuscript and addressed the first main objective of this thesis. Chapter 3 provided a copy of the approved thesis proposal for this project. Chapter 4 was structured as a manuscript, which addressed the second main objective of this thesis. Chapter 5 provides an integrated discussion of the findings from the literature review and the qualitative study within the broader context of Elder WM use on reserve and highlights the implication for assistive technology, aging and rehabilitation.

Summary of Thesis Findings

Literature Review

A literature review was conducted to examine the body of knowledge concerning the need for WM, whether WM currently meets the users needs and supports the active participation of First Nation Elders who live on reserves in Canada, to review the scope and gaps in the literature and to identify areas for future research. Zero results were yielded; however, grey literature

demonstrates increased levels of injury, disability and chronic health conditions, which are all associated with reduced mobility.

The review of the literature demonstrates that there is a gap in the availability of WM literature between Indigenous and non-Indigenous Canadians. The only data available on WM use are from NIHB and organizations that provide WM but these numbers only tell us the number of devices accessed through these specific organizations. Longitudinal surveys often do not include First Nations people and studies are often not culturally relevant. The literature also tells us that active participation in community and culture is necessary for the positive health outcomes of First Nation Elder's and their communities.

There is an extraordinary need for more research that focuses on the unique WM needs of First Nation Elders living on reserves in Canada where there are higher rates of chronic illness, injury and disability. More research is specifically required to: study the prevention of injury and illness for First Nation Elders who live on reserve; improve products, delivery and service; reduce barriers and review timely and appropriate home assessment and modifications including geographical barriers; assess secondary injuries; the benefits of WM users being involved in accessibility planning in their communities; focus on the social environment, research that focuses on all aspect of Elder health including cultural participation, and finally research should go beyond the impact at the level of the user and capture the perspectives of key individuals such as caregivers.

The overall quality of research needs to be improved by gaining the perspectives of First Nations cultures and settings. Research must also follow the principles of ownership, control, access and possession (OCAP) as the communities set them out. Qualitative, quantitative and integrated approaches need to be conducted because each has strengths and limitations.

Qualitative approaches should be used to enquire and discuss the need, use of, and satisfaction with WM devices and services. Acceptance and personal adjustment of becoming a WM user, self-perceptions attitudes and beliefs are another area that needs be researched.

Using an interdisciplinary approach in studies with Indigenous populations is beneficial because this creates a space where many levels of expertise including the stakeholders can come together and is involved in the project. It is apparent that the need for WM is greater among underserved Indigenous communities; yet research remains slow to respond to the physical health needs and WM limitations among First Nation Elder populations on reserve.

Qualitative Phenomenological Study

A phenomenological study was conducted to explore the lived experiences of First Nation Elders. Eighteen participants (12 females and 6 males) participated in a short demographic form followed by a semi-structured interview. The interviews and field notes demonstrate that Elders play an important role in the community, which includes leadership and the transmission of culture.

Eight themes emerged: (1) Participation in cultural ceremonies, (2) Participants perceptions of the usefulness of their device, (3) Ability to access the outdoors safely and independently, (4) Transportation to and from the events (5) Exterior paths of travel to and from cultural events, (6) Accessibility at the events (7) Stigma and (8) Burden. Facilitators to WM use in accessing cultural participation were discussed and a majority of participants said that transportation would be the largest facilitator to cultural participation.

The findings are consistent with the study conducted by Warmouth & Wielandt because the study demonstrated that WM use remains an even greater challenge on reserves in Canada

because an increasing number of First Nation adults are reporting that they're homes are in major need of repair, homes are often not modified for accessibility, concerns with the unpredictability of weather, there are challenges negotiating reserve terrain, lack of adequate transportation, difficulty participating in cultural ceremonies, and isolation due to harsh winter weather [1]. These findings were also consistent with the National Organization of Disability 's *Harris Survey* because the Elders said that they participate less often specifically due to barriers in using WM [2].

The findings from this study are consistent with the Health Council of Canada's report *Canada's most vulnerable: Improving health care for First Nations, Inuit, and Metis seniors* and the *Regional Health Survey* because the Elders talked about the importance of their presence in community and at cultural events for the transmission of culture to younger generations, as well as the importance of cultural participation on the health of the community [3][4].

Overall participants reported a decrease in participation since becoming WM users and several participants stopped participating all together. Most participants did not associate a decrease in participation with their mobility device because most participants found their devices useful. Participants found that barriers to using their device(s) make it difficult to attend community or cultural events.

Many participants do not have the ability to exit their home independently and safely, which makes it difficult to attend community and cultural events. Several participants had long wait times for ramps and others had them right away. Some participants described needing to be carried in and out of their homes and that their family members have sustained several injuries in doing so. Those participants who were not able to access funding and cannot afford ramps have

had to resort to building make shift ramps that are not up to code. Several of the participants said they can't access they're ramps in winter because they are covered in snow.

Transportation was the largest barrier to participation. Participants gave several examples of transportation that is available for medical appointments, shopping, banking or getting a hair cut, but expressed that there isn't any transportation services available for social or cultural events. Participants said they have to rely on friends and family in order to participate, which can be difficult because people are so busy.

Participants expressed a desire to have transportation so they can access these events independently, as well as transport their devices. Participants also made it clear that transportation services have to be geared toward people on reserve and need to be affordable for Elders. The only participants who didn't discuss transportation as a barrier are still driving their own vehicles. The remainder of the participants experienced isolation and lack of independence. Lack of transportation was said to create situations where Elders either aren't participating or that when they do participate they often aren't using the devices that have been prescribed. Some participants are walking long distances by themselves to get to events.

A majority of participants discussed difficulties with exterior paths of travel to and from community and cultural events, and many participants talked about barriers at the events themselves. Many talked about uneven ground, potholes and a general lack of pavement. Mud, grass and rocks were described as very difficult to navigate in manual chairs or with walkers with wheels, parking that is too far from ramps, lack of ramps, doors that aren't wide enough and inaccessible bathrooms. Participants also said that there are added barriers during spring and summer months mainly to due rain, mud and heat. Participants said that winter is difficult

because it's hard to maneuver in the snow and they are afraid of falling. This lack of mobilization in winter was described as creating increased isolation, depression and loneliness.

These facts are consistent with a study conducted by Ripat, Brown and Ethan where they reviewed barriers to wheelchair use in winter. The authors state that although it could be argued that participation patterns change for the entire population in winter their results confirm a large variation in participation between seasons in WM users where 42% changed their frequency from 3 to 7 times per week to less than 3 times per week in the winter. Reasons for reduced participation included getting stuck in the snow, difficulty with ramps, tires slipping on ice, cold hands while operating controls of pushing tires, some reported frozen batteries, electronics, seat cushions, and back rests [5].

Two themes emerged during this study and include stigma and burden. Both were described as direct barriers to participation. Participants expressed not wanting to go out because they feel that others perceive them as less valuable. Other participants said they don't like to go out because they feel like a burden to others because they need help physically or have to depend on them for transportation.

We cannot deduce whether WM is currently meeting the needs of First Nation Elders on reserve due to a lack of available literature. We do know that there are many barriers due to the remoteness of reserves, and that programs and services can be confusing and complex.

Aside from needing more studies on the barriers to culture for First Nations Elders who use WM this study also demonstrates a need for technological advancements such as designing WM devices specific for overcoming reserve terrain. Other advancements could include designing components to help with barriers of WM use in winter months such as heated seats,

back rests, and temperature controlled batteries, low cost heating for ramps, and technology to assist Elders to get in and out of regular vehicles.

Conclusion

The literature review demonstrated that the body of knowledge in regard to WM use among First Nation Elders living on reserves in Canada is non-existent. The grey literature reviewed indicates that chronic disease, injury and disability rates are higher among First Nation adults, that participation in society remains a greater challenge on reserves for those who use WM due to the lack of modification to homes for accessibility, lack of access to appropriate services, challenges negotiating reserve terrain, isolation due to harsh winter weather, lack of adequate transportation, difficulty participating in cultural ceremonies required for the balance of health of individuals and communities.

This research has demonstrated that the Elders interviewed consider culture a determinant of health, and that their participation in community and cultural events is important for the health of the community because they are the leaders and knowledge keepers of the culture needed to be transmitted to younger generations. This research demonstrates that culture must be used as a foundation for health protocols and policies, that WM is most likely higher on reserve due to higher disability, injury and chronic health that barriers to WM urgently need to be reduced and participation needs to be increased.

There is a need for further WM research that incorporates an interdisciplinary and collaborative approach in order to decrease barriers and promote facilitators for participation in community and cultural events. Aside from needing more studies on the barriers to culture for First Nations Elders who use WM this study also demonstrates a need for technological advancements such as designing WM devices specific for overcoming reserve terrain. Other

advancements could include designing components to help with barriers of WM use in winter months such as heated seats, back rests, and temperature controlled batteries, low cost heating for ramps, and technology to assist Elders to get in and out of regular vehicles.

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Appendices

Appendix A

Thesis Proposal Approval



Appendix B

University of Ottawa Ethical Approval



Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Jeffrey W.	Jutai	Health Sciences / Others	Principal Investigator
Lindsay	Croxall	Health Sciences / Others	Student Researcher

File Number: H06-16-43

Type of Project: Master's Thesis

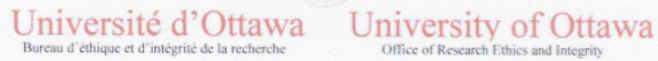
Title: First Nations Seniors using Wheeled Mobility: An Exploration of Cultural Participation and Health

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
08/15/2016	08/14/2017	Approved

Special Conditions / Comments:

This certificate is valid for recruitment and data collection to start within the Six Nations and Akwesasne communities.

ELDERS WHO USE WHEELED MOBILITY



This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <http://www.research.uottawa.ca/ethics/forms.html>

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <http://www.research.uottawa.ca/ethics/forms.html>

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Riana Marcotte
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix C

Six Nations Ethical Approval

ELDERS WHO USE WHEELED MOBILITY

Appendix C

Six Nations Ethical Approval



**GENERAL COUNCIL
MOTION MEMORANDUM**

TO: Teresa Longboat, Ethics Committee Secretary
Chief and Council
Dayle Bomberry, Senior Administrative Officer

Cc: Shirley Johnson, Administrative Coordinator
Rebecca McComber, Admin. Assistant to Director of Finance

FROM: Carol Martin

DATE: May 25, 2016

MEETING DATE: May 24, 2016

RESOLUTION NO: GC#331/05/24/2016

Moved by Melba Thomas and seconded by Robert Johnson that the Six Nations Elected Council approve the Ethics application submitted by Lindsay Croxall titled "First Nations Seniors/Elders, Who Use Wheelchair Mobility: An Exploration of Culture and Health."

ALL IN FAVOUR

CARRIED

SIX NATIONS COUNCIL

Carol Martin
Council Secretary

Appendix D

Mohawk Council of Akwesasne Ethical Approval

ELDERS WHO USE WHEELED MOBILITY

Appendix D

Mohawk Council of Akwesasne Ethical Approval

MOHAWK COUNCIL OF AKWESASNE

Sustaining our inherent rights, facing challenges together to build a strong and healthy future.



Office of Grand Chief

Ohiari:ha/June 17, 2016

Lindsay Croxall

RE: Permission to talk to Elders

Wa'tkwanonhwera:ton/Greetings.

This letter confirms that Mohawk Council of Akwesasne has given approval to the project entitled, "First Nation Elders who use Wheeled Mobility: An Exploration of Culture and Health". This Project will be conducted by Lindsay Croxall. Lindsay will be interviewing elders from our community to get information for her Thesis.

Lindsay is a Master's student in the Interdisciplinary Health Sciences Program at the University of Ottawa and supervised by Professor Jeffrey Jutai. Upon approval by the University of Ottawa of Lindsay's thesis the Mohawk Council is requesting two copies of her Master's thesis for our records and research.

Should you require any further information, please contact District Chief Louise Thompson at Mohawk Government office at 613-575-2348 ext. 2256.

Sken:nen/In Peace,
Mohawk Council of Akwesasne

Abram Benedict
Grand Chief

AKWESASNE-LAND WHERE THE PARTRIDGE DRUMS
 ADMINISTRATION OFFICES 613-575-2250 WWW.AKWESASNE.CA BOX 579 CORNWALL, ONTARIO K6H-5T3 MOHAWK GOVERNMENT OFFICES 613-575-2348

Appendix E**Mohawk Council of Akwesasne Research Agreement**

THIS AGREEMENT made this ____ day of September 2016.

Between:

Lindsay Croxall,
University of Ottawa

(“hereinafter referred to as “the researcher”)

and

Mohawk Council of Akwesasne
P.O. Box 579
Cornwall, Ontario
K6H 5T3 (hereinafter referred to as “Council”).

WHEREAS:

The researcher has been granted funds by the University of Ottawa to undertake a research project entitled “*First Nation Elders who use Wheeled Mobility: An Exploration of Culture and Health*” which forms part of the researcher’s Master Thesis; and

The researcher indicates that the purpose of the project is to explore the processes, barriers, and facilitators that impact cultural participation for First Nation Elders who use wheelchairs and walkers with wheels and who live on-reserve in the Mohawk territory in Ontario and Quebec; and

The specific aims of the project are to gain an understanding of how cultural experiences have changed since becoming a wheeled mobility (wheelchair/walker with wheels) user; and to explore the barriers and facilitators that impact participation and how this is viewed as affecting individual health and the health of the community; and

The Council, on behalf of the Mohawks of Akwesasne, will benefit by gaining a best practice guide, which will identify how cultural participation, and health might be improved;

NOW THEREFORE THIS AGREEMENT WITNESSES that in consideration of the mutual covenants and agreements herein and subject to the terms and conditions in this agreement, the parties agree as follows:

Term of Agreement:

1. This Agreement shall begin on the date it is signed by both parties and shall end on September 1st, 2017 unless otherwise terminated earlier in accordance with provisions in this agreement.

Research Methods:

2. The methods to be used to carry out the research shall include completion by participants of a demographic form, undergoing a consent process and the signing of a consent form, and taking part in an interview conducted by the researcher. This process will take approximately one hour per participant.

Community Concerns and Feedback:

3. The development of this project is based on sincere communication between the Council and the researcher. All efforts will be made to incorporate and address local concerns and recommendations raised by Council at each step of the project. At the end of the project, the researcher will hold and facilitate a meeting with the participants at which the results of the research project and analysis thereof will be shared.

Collection, sharing, use, distribution, storage and ownership of data:

4. Data shall include personal identifiers of participants including but not limited to gender, age, address, disability, and all participant responses to the interview, the manipulation and aggregate results of such data are considered data and shall be subject to the terms of this agreement.
5. The data collected is confidential and no name or other personal identifier shall be attached to a record.
6. Data collected in its aggregate form is the property of the Mohawks of Akwesasne and shall not be stored, released, reused, shared, or divulged to any person without the consent of Council except as specified in this agreement.

Data Kept for Five (5) Years By Researcher & University

7. Two copies of the data including electronic data will be conserved for five (5) years from the end of the researcher's Masters' Thesis (September 2017) and will be secured and stored by my supervisor and myself. The researcher's copy will be locked in a safe in her home where only the researcher has the key and the second copy will be kept by the researcher's Supervisor locked in a cabinet in his lab at St-Vincent hospital, Assistive Research Lab, 45 Empress Avenue, Ottawa Ontario, K1R.
8. We agree that the data will be destroyed after 5 years.

Final Reports

9. Two copies of the Final Reports containing the data, results and analysis will be distributed to Council.
10. The researcher will be available to answer questions and assist Council should Council decide to use the data for different purposes.

Informed Consent of individual Participants:

11. The interviewer will obtain the informed, written consent of each participant. A copy of the consent form will be left with the participant indicating how to contact the researcher for additional information.

Protecting Identity of Participants:

12. The participant's identity, interviews and demographic forms are confidential. In no instance will the name of a participant be attached to a record. A generic identifier number or code will be assigned to each participant file.

Project Progress:

13. Project progress will be communicated to Council and the Community in the following manner:
 - a. One email per month to Grand Chief Abram Benedict and to Chief Louise Thompson.
 - b. A follow up meeting with the Participants to explain the data findings/results.
 - c. A copy of the researcher's Final Masters' Thesis will be sent to Mohawk Council of Akwesasne, to the attention of Grand Chief Abram Benedict for approval. Once approved it will be submitted to Ottawa University via the thesis defence process.

Communication with the media:

14. The researcher agrees that no communication will be made with the media unless the prior, written consent of the Council has been sought and given.

Funding

15. The researcher has received funding and other forms of support for this research project from the University of Ottawa. The researcher may apply for any upcoming funding opportunities. Any funding relationships and details about these relationships will be discussed with Council.
16. Any funding received and details about the funding of such as disclosure, limitations, and reporting responsibilities will be discussed with and approved by Council prior to such disclosure or other action taking place.
17. The researcher and Council agree that Mohawk Council of Akwesasne is not contractually obligated to deliver cash or other equitable financial assistance for this project.

Benefits

18. The researcher wishes to use this research project for the researcher's own benefit in order to complete my Masters' Thesis.
19. The Masters' Thesis process will involve the researcher:
 - a. Presenting my project in a poster session at the University of Ottawa
 - b. Making scientific presentations and publishing articles after discussion with Council.
 - c. Elders and Council will be thanked and acknowledged for their advisory role and contributions.
20. The benefits likely to be gained by the community through this research project are:
 - a. The Mohawks Council of Akwesasne will receive a best practise guide based on the information obtained.
 - b. The Mohawks Council of Akwesasne will gain a relationship with an ethical researcher.
 - c. Access to data owned by the Mohawks of Akwesasne for future use/reference.

Commitments of the Parties

21. The Mohawk Council of Akwesasne's commitment to the researchers is to:
 - a. Recommend capable and reliable community members to participate in, collaborate or to be employed in this project.
 - b. Remain informed about the progress of the project, and help in leading the project toward meaningful results.
 - c. Provide constructive feedback and suggestions to researcher on the Final Masters' Thesis within 5-10 business days of receiving it in order to allow the Researcher sufficient time for amendment, as appropriate.
22. The researchers' main commitment to the community of Akwesasne is to:
 - a. Provide regular reports to Council about the progress of the project in a clear, plain language, specific, and timely manner.
 - b. Act as a resource to Council on project related questions.
 - c. Share project results and analysis with participants and community members in plain language
23. The researcher agrees to interrupt the research project in the following circumstances:
 - a. If Council decides to withdraw their participation.

ELDERS WHO USE WHEELED MOBILITY

Signed this 13 day of September, 2016

by:

[Redacted Signature]
Lindsay Croxall: Researcher

[Redacted Signature]
Witness

[Redacted Signature]
Grand Chief Abram Benedict
Mohawk Council of Akwesasne

[Redacted Signature]
Witness

[Redacted Signature]
Chief Louise Thomps...
Mohawk Council of Akwesasne

[Redacted Signature]
Witness

Appendix F**Six Nations Research Agreement**

THIS AGREEMENT made this ____ day of October 2016.

Between:

Lindsay Croxall,
University of Ottawa

(hereinafter referred to as “the Researcher”)

and

Six Nations Elected Council
1695 Chiefswood Rd
Ohsweken, Ontario
N0A 1M0

(hereinafter referred to as “Council”)

(The Researcher and Council collectively hereinafter referred to as the “Parties”)

WHEREAS the Researcher has been granted funds by the University of Ottawa to undertake a research project entitled “*First Nation Elders who use Wheeled Mobility: An Exploration of Culture and Health*” which forms part of the Researcher’s Master Thesis;

AND WHEREAS the Researcher has requested and received permission from the Six Nations Council Research Ethics Committee to conduct this research within the Six Nations Territory;

AND WHEREAS the Researcher indicates that the purpose of the project is to explore the processes, barriers, and facilitators that impact cultural participation for First Nation Elders who use wheelchairs and walkers with wheels and who live on-reserve in the Six Nations Territory;

AND WHEREAS the specific aims of the project are to gain an understanding of how cultural experiences have changed since becoming a wheeled mobility (wheelchair/walker with wheels) user; and to explore the barriers and facilitators that impact participation and how this is viewed as affecting individual health and the health of the community;

AND WHEREAS the Researcher shall take all reasonable precautions and actions to protect and preserve the integrity of Indigenous Knowledge garnered as a result of research activities conducted with Six Nations members;

AND WHEREAS Council is the governing body of the Six Nations of the Grand River Territory (“the Territory”) and performs the functions of a government for the Territory.

AND WHEREAS the Council, on behalf of the Six Nations, will benefit by gaining a best practice guide which will identify how cultural participation and health might be improved;

NOW THEREFORE in regard of the foregoing premises, and other valuable consideration, the Parties hereto for themselves, their respective successors and assigns mutually covenant and agree with each other, as hereinafter follows:

1. AGREEMENT

- 1.1 This is a contract entered into freely by the Parties, hereinafter referred to as the “*Agreement*”, and it, as well as any schedules appended hereto, shall constitute and serve as a single instrument as the whole Agreement.
- 1.2 This Agreement is the Parties commitment and mutual understanding in respect to:
 - a) clearly defining the roles, responsibilities and relationship of both Parties; and
 - b) the terms and conditions for the conducting of research by the Researcher in the Territory.

2. GENERAL

- 2.1 This Agreement and any appended Schedules constitute the entire agreement between the Parties. No future modification, supplement, amendment, or waiver of this Agreement shall be binding or effective unless agreed to by both Parties in writing.
- 2.2 The division of this Agreement into sections and the insertion of headings are for convenience of reference only and shall not affect the construction or interpretation of the Agreement.
- 2.3 All accounting and financial terms used herein shall be interpreted and applied in accordance with generally accepted accounting principles that have been established in Canada.
- 2.4 This Agreement, and any actions or decisions arising from it shall be conducted in a manner that is in compliance with applicable law, rules, and regulations.
- 2.5 If any action is required to be taken pursuant to this Agreement on or by a specified date which is not a business day, then such action shall be deemed timely and valid if taken on or before the business day immediately following the specified date.

3. FORCE MAJEURE

- 3.1 Notwithstanding anything contained in this Agreement, neither Party shall be liable for any failure or delay on its part to perform any of the terms, conditions or obligations of this Agreement to the extent that such failure or delay is the result of a cause beyond its reasonable control, including such things as availability of material, equipment, utilities, services, an act of God, a fire, an act of public enemy, an act of Her Majesty in her sovereign capacity, laws, a flood, a quarantine restriction, an epidemic, a labour dispute, a riot or civil commotion, vandalism, malicious mischief, or other similar cause beyond its control and not avoidable by reasonable foresight and which occurs without the fault or negligence of the Party seeking relief. The Party being delayed shall be entitled to extend the time for fulfillment of such obligation by a time equal to the duration of such delay and the other Parties shall not be entitled to any compensation for any loss or inconvenience occasioned thereby. The Party delayed shall, however, use its best efforts to fulfill the obligation(s) in question as soon as reasonably possible.

3.2 In the event a Force Majeure occurs at any point in the course of the duration of this Agreement either Party may seek amendments hereto or otherwise obtain assistance for the performance of this Agreement.

4. SEVERABILITY

4.1 If any provision of this Agreement is deemed invalid, illegal, or unenforceable by a court of competent jurisdiction the remaining provisions of the Agreement shall continue in full force and effect and the invalid or unenforceable provision will be deemed modified so that it is valid and enforceable to the maximum extent permitted by applicable law; moreover the Parties agree to remedy any such issues as soon as is reasonably possible so that the objectives and intent of this Agreement can be met.

5. RESPONSIBILITIES OF COUNCIL

5.1 Council shall:

- (a) Ensure that the Researcher is informed of any issues relevant to the conduct of their research project;
- (b) Ensure that any Traditional Indigenous Knowledge that is learned or otherwise acquired during the course of the research that is not germane to the focus of the Research Project or its conclusions is reported immediately, in writing, to the Indigenous Knowledge Center. The Indigenous Knowledge Center shall serve as steward of the information preserving it for posterity in perpetuity.
- (c) Respond on a timely basis to all communication received from the Researcher with respect to this Agreement; And
- (d) Monitor the progress of the Research Project to ensure it is conducted in compliance with Council policy, in accordance with this Agreement, and in adherence with applicable law.

6. RESPONSIBILITIES OF RESEARCHER

6.1 The Researcher is responsible to conduct the Research Project, as approved by the Six Nations Council Research Ethics Committee, in accordance with this Agreement.

6.2 The Researcher shall:

- (a) Avoid any Conflict of Interest in the performance of this Agreement; and
- (b) Immediately provide Council with information regarding any real or perceived Conflict of Interest that arises during the course of this Agreement and what steps will be taken to resolve the Conflict.

6.3 The Researcher shall not assign, subcontract, delegate, or otherwise transfer its rights and obligations herein without the prior written consent of Council.

6.4 The Researcher shall conduct the Research Project in compliance with the Application (Six Nations Council Research Ethics Committee Protocol) as submitted to Council, subject to any conditions imposed on the approval of research project, and appended hereto as *APPENDIX I*.

6.5 The Researcher shall not disclose, nor permit to be disclosed, to any person any information obtained by virtue of the Research Project and this Agreement other than as approved by the Research Ethics Committee within the Application.

- 6.6 The Researcher agrees that neither communication, nor correspondence shall be made with the media unless the prior, written consent of the Council has been sought and granted.
- 6.7 The Researcher at its sole cost and expense shall collect, maintain, store, and secure all data obtained from the Research Project in compliance with the Application as approved and appended hereto, as well as generally accepted standards.
- 6.8 The Researcher shall make all reasonable effort to incorporate and address any local concerns and recommendations raised by Council throughout the conduct of research in the Territory.
- 6.9 The Researcher shall submit Two (2) copies of the final thesis report, as submitted to the Researcher's institution, which shall include: the data, results, and analysis to the Six Nations Research Ethics Committee. One (1) copy each shall be furnished to the Six Nations Public Library and the Indigenous Knowledge Center at Six Nations Polytech. Furthermore, the Researcher shall submit One (1) Best Practice Report that shall propose suggestions for enhancing accessibility and promoting participatory opportunities for mobility impaired citizens at community and cultural events as outlined by the Researcher within the Application.
- 6.10 Traditional Indigenous Knowledge that may be learned or otherwise acquired during the course of the research that is not germane to the focus of the Research Project or its conclusions shall be reported immediately, in writing, to the Research Ethics Administrative Coordinator.
- 6.11 The Researcher shall provide monthly updates regarding the status of the Research Project to the Administrative Coordinator of the Six Nations Council Research Ethics Committee.
- 6.12 The Researcher shall adhere to all applicable laws, including federal, provincial, and Council laws.

7 RESPONSIBILITIES OF BOTH PARTIES

- 7.1 Both Parties shall ensure that a defined relationship between the Parties exists and is maintained between both parties.
- 7.2 Both Parties shall act with good faith and fair dealing in performance of this Agreement.
- 7.3 Both Parties shall communicate sincerely in order to address and accommodate any obstacles that may arise during the conduct of the research project.
- 7.4 Both Parties agree that Council is not under any obligation to provide any financial or in-kind support to the Researcher for the conduct of the Research Project.
- 7.5 Either Party shall provide this Agreement to any Six Nations member if requested, and shall not charge any fee in excess of the cost for the copying of the document.

8 INDEMNIFICATION

- 8.1 The Researcher shall indemnify and save harmless Council from and against all losses, claims, damages, actions, causes of action, costs, and expenses or liabilities that may arise directly or indirectly out of any act, omission, delay, or negligence on the part of the Researcher in carrying out this Agreement, or any agreement that is entered into as a

result of this Agreement. Such indemnity shall survive the termination or expiry of this Agreement for matters that occurred prior to the termination of this Agreement.

9. TERMINATION

9.1 Either party may at any time, for any reason, terminate this Agreement by providing 30 days written notice to the other Party. During the 30 days the Parties may attempt to negotiate a mutually agreeable resolution to prevent termination of this Agreement.

9.2 Council may terminate this Agreement immediately if, in the opinion of Council, the Researcher has:

- a) Knowingly provided false or misleading information in any communication with Council;
- b) breached any material provision of this Agreement including, but not limited to, failing to abide by parameters set out in approved Application; or
- c) discontinued or is unable to complete its research project.

9.2 Upon Termination of this Agreement or upon Council's request at any other time, the Researcher shall deliver to Council all of Council's property.

10 TERM

10.1 This Agreement shall commence on the 20th day of September, 2016, or on the date upon which it becomes duly executed; and shall conclude on the 1st day of September, 2017, or upon Termination by either Party.

10.2 Prior to expiration of this Agreement both Parties may agree in writing to extend the term of this Agreement for up to a year, providing such extension has a clear date of conclusion.

11 AMENDMENTS

11.1 The Parties shall have the right to modify the provisions of this Agreement at any time by mutually agreeing to the proposed amendment.

11.2 All amendments to this Agreement shall be made in writing and executed by both Parties.

12 DISPUTES

12.1 All disputes and negotiations will be conducted in good faith in an attempt to reach an agreement that is acceptable to both Parties.

12.2 In the event that either party is of the opinion that a dispute exists between them regarding the interpretation of a provision of this Agreement or the obligation of a party under this Agreement, that party will give the other party written notice setting out

- a) that the party giving notice wishes to undertake the dispute resolution process provided for in this section; and
- b) a concise summary of the matter in dispute

12.3 The Researcher and Council shall meet within five (5) business days of the day the notice was given under subsection 12.2.

- (a) Any dispute that cannot be resolved shall result in immediate termination of this Agreement.

13 NOTICE

13.1 Wherever in this Agreement notice is required or permitted to be given by either Party such notice shall be in writing and shall be deemed to be received if delivered by hand or prepaid courier to the Party for whom it is intended or forwarded by fax to the Parties' respective addresses as follows:

Six Nations Elected Council
1695 Chiefswood Rd.
P.O. Box 5000
Ohsweken, Ontario N0A 1M0

Phone: (519) 445-2201
Fax: (519) 445-4208
Email: ajoseph@sixnations.ca
Attn: Andrew Wm Joseph

Lindsay Croxall
University of Ottawa
Faculty of Health Science: Interdisciplinary Health

Phone:
Fax:
Email:

13.2 The addresses above may be changed from time to time by either Party giving notice as described above.

13.3 Notice shall be deemed to be given on the day delivered if delivered by postal service or electronic mail, or on the following business day if delivered by fax. If notice is delivered on a non-business day it shall be deemed to have been delivered on the first business day immediately following the non-business day on which notice was delivered.

14 AUTHORIZATION

In acknowledgement and assent to the terms and conditions set out herein the Parties affix their signatures hereto, duly executing this Agreement.

APPENDICES

1. Six Nations Council Research Ethics Committee Protocol (May 3, 2016)
2. Six Nations Research Ethics Committee motion **EC#3-05/17/2016** Six Nations Council Resolutions **GC#331-05/24/2016** and **GC#332-05/24/2016**

APPENDIX 1

Six Nations Council Research Ethics Committee Protocol (**RE16-004[C]**) appended here
as approved by RECtee

*APPENDIX 2***(I) EC#3-05/17/2016:**

“Moved by Lois Bomberry and Seconded by Christine Shawana that the Research Ethics Committee recommends to Six Nations Elected Council to approve Lindsay Croxall application to conduct research, titled “First Nations Seniors/Elders Who use Wheelchair mobility: An exploration of Culture and Health”

ALL IN FAVOUR -- CARRIED

(II) GC#331-05/24/2016:

“Moved by Melba Thomas and Seconded by Robert Johnson that the Six Nations Elected Council approve the Ethics application submitted by Lindsay Croxall, titled “First Nations Seniors/Elders Who use Wheelchair mobility: An exploration of Culture and Health”

ALL IN FAVOUR – CARRIED

(III) GC#332-05/24/2016:

“Moved by Melba Thomas and Seconded by Robert Johnson that Six Nations Elected Council Waive Second Reading on SNCR: GC#331-05/24/2016”

ALL IN FAVOUR -- CARRIED

Appendix G

Recruitment Flyer

WHEELED MOBILITY: AGING CULTURE AND HEALTH

Appendix G

Recruitment Flyer



uOttawa



DO YOU OR SOMEONE YOU KNOW
USE A **WHEELCHAIR** OR A
WALKER?

Volunteers are needed for a graduate research study investigating the experiences of people who use wheelchairs or walkers.

To qualify, you must: be aged 55 or older, be First Nations, live on a reserve, speak English, use a wheelchair or a walker with wheels (for at least one year but not since birth).
Volunteers will be taken on a first come/first serve basis.

For more information, please contact:
Lindsay Croxall at:

Lcrox036@uottawa.ca

Appendix H

Information Letter & Consent

This informed consent form is for participants in the Six Nation community who are invited to participate in the research, “First Nation Elders using Wheeled Mobility: An Exploration of Cultural Participation and Health”

This Informed Consent Form has two parts:

- 1. Information Sheet (to share information about the study with you)**
- 2. Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form.

Part I: Introductory Information:

I am Lindsay Croxall; I am a Masters student at the University of Ottawa. I am doing research on the experiences of First Nation seniors/elders who use wheeled mobility in accessing cultural participation. I am going to give you information and invite you to participate in the research. You can talk to someone you feel comfortable with about the research before making a decision to participate. If at any time there is something you don't understand in the consent form, please stop me and I will take the time to explain. If you have any questions please ask me at anytime.

Participant Selection

You are being invited to take part in this research because your experience as a First Nation senior/elder who uses wheeled mobility (such as a wheel chair or walker with wheels) can contribute much to our understanding and knowledge of First Nation cultural participation and health. The specific criteria that made the basis for you taking part in the research, includes, being 55 or older, being First Nation, living on a reserve in Ontario, speaking English (because the interview is in English), and because you've used a wheelchair or walker with wheels for at least one year but not since birth.

[Question to elucidate understanding: Do you know why we are asking you to take part in this study? Do you know what this study is about?]

Voluntary Participation:

Your participation in the research is voluntary and you may refuse to participate without reason or may withdraw yourself and your data from the study, at any time, without penalty.

[Question to elucidate understanding: Do you know that you do not have to take part in this research study, if you do not wish to? Do you have any questions?]

Purpose of the research:

Mobility difficulties are prevalent among First Nation seniors. We want to find out how

Participation can be made easier we believe that you can help by telling us about your experiences. We want to learn about what you think makes it easier or harder to attend cultural events and ceremonies. We also want to learn about how you perceive cultural participation as affecting your health and the health of your community.

Type of research Intervention/Procedures.

This research will involve your participation in an interview with me Lindsay Croxall. I will sit down with you in your home, a friend's home or a community center. If you do not wish to answer questions during the interview, you may say so and I will move on the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except myself [Lindsay Croxall] will have access to the information documented during your interview. The entire interview will be tape-recorded (with your permission), but no one will be identified by name on the tape. The tape will be kept locked in my office. The information recorded is confidential, and no one else except myself [Lindsay Croxall] will have access to the tapes. The interview will take one hour or less.

Risks / Benefits:

There are no known risks involved in participating in this study. During participation you might express some negative opinions or information that causes you to feel some emotional or psychological discomfort. Negative opinions are a normal response that may occur when responding to questions about barriers such as those in the study. Identifying barriers is important so that people in the community and organizational leaders understand the issues that impact your health. There is no immediate direct benefit from taking part in this research, but your participation is likely to help us find out more about how to increase the cultural participation of First Nation seniors, which is important for health. Being that First Nation seniors are the key holders to tradition and language increasing cultural participation is beneficial for the health of the community. Increasing the health of the First nation population will help close the gap between Aboriginal and non-aboriginal health status'.

Compensation / Expenses:

You will not be provided any incentive to take part in the research. However we will provide you with any travel expense if you prefer not to have the interview in your home.

[Question to elucidate understanding: Can you tell me if you have understood correctly the benefits that you will have if you take part in the study? Do you have any other questions?]

Confidentiality

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that I collect from this research project will be kept private.

Data Conservation

Two copies of the data including the electronic data will be conserved and stored for 5 years after completing my thesis (Around September 2017). One copy will be locked in a safe in my office and the other will be locked in a cabinet at my supervisor's lab (St –Vincent Hospital).

Contact Information:

If you have any questions about this study, please contact:

- Lindsay Croxall
- Collect calls will be accepted.
- If you have questions about your rights as a research participant, you may contact:
The Protocol officer for Ethics Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel (613) 562-5387. Email: ethics@uottawa.ca.
- Jeffrey Jutai (supervisor), University of Ottawa, 25 University Street, Ottawa Ontario, K1N 6N5, 613-562-5800 ext. 5254, jjutai@uottawa.ca

Part II: Certificate of Consent

Acceptance: I, _____ (Name of Participant), agree to participate in the above research study conducted by Lindsay Croxall, School of Interdisciplinary Health, Faculty of Health Science, and University of Ottawa.

I consent to audiotaping this interview for research purposes.

Researcher Signature _____

Appendix I**Demographic Form****Name:****Date:****Home Community:****Current Community:****Phone:****Email:****1. What is your gender?**

- Male
- Female
- You don't have an option that applies to me (Please specify) _____

2. What is your ethnic origin?

- First Nation
- Inuit
- Metis
- You don't have an option that applies to me (Please specify) _____

3. Where do you live?

- Apartment
- Assisted living center
- Long-term care facility.
- Single family home
- Supervised group living

- Other. Please specify _____

4. Who do you live with?

- Alone
- With Spouse
- With other family
- With others. Please specify _____

5. What is your previous occupation?

- Employed-part time paid

- Employed-full time paid
- Unemployment
- Volunteer
- Retired
- Student
- Other. Please Specify _____

6. Do you use a wheelchair or walker with wheels? Please check all that apply.

- Wheelchair _____
- Walker with Wheels _____
- Both _____

7. Where do you usually use your wheelchair or walker with wheels? Please check all that apply

- Indoors _____
- Outdoors _____
- Both _____

8. Do you ever have difficulty getting around your home using a wheelchair or walker with wheels?

- Yes _____
- No _____
- If Yes please give details _____

9. Do you ever have difficulty getting around your community using a wheelchair or walker with wheels?

- Yes _____
- No _____
- If Yes please give details: _____

10. Do you ever need someone else's help to get around??

- Yes _____
- No _____

11. If yes, what type of help do you receive? Check all that apply.

- Someone physically helps you to get around
- Someone gives you reminders but does not physically help
- Someone is nearby in case you need help.

12. How long have you been using your wheelchair or walker with wheels?

- Since Birth _____
- Less than One year _____
- More than one year. Indicate the number of years. _____

13. How did you pay for your device?

- Provincial/State assistance
- Self-Pay
- Private Insurance
- NIHB (Non-Insured Health Benefits)
- ADP (Assistive Device Program)
- WSIB (Workplace Safety & Insurance Board)
- Department of Veteran Affairs
- Charitable Organization. Please specify _____
- Other. Please specify _____

**14. Do you use other mobility device other than wheelchairs or walkers with wheels?
(Example Cane)**

Yes _____
No _____

15. If yes, what other assistive device(s) do you use for mobility?

16. Do you use any other kinds of devices? (Example for hearing, or vision)

Yes _____
No _____

17. If yes, what kinds of devices do you use.

Appendix J

Interview Guide:

Opening: Thank-you for taking the time to talk to me today. I will start by giving you some information on how this interview will work.

I want to learn about cultural participation of First Nation seniors/elders who use wheelchairs, or walkers with wheels.

When I say cultural participation I mean taking part in activities such as sweat lodges, Pow-wows, sharing circles, smudging, ceremonies/feasts, gatherings, hunting/fishing, solstice, or any other activities that come to your mind.

I want to learn about what helps people and what stops people whom use wheelchairs and walkers from taking part in these types of activities.

I will be asking you a few questions to learn about your experiences with wheelchair/walker use and then a few questions about what you think makes it hard and what makes it easier to take part in events/ceremonies.

I will also ask you a few questions about how you see your health and the health of your community.

Just a reminder that I will be recording (If agreed) the interview and that the information gathered will be private. I will let you know when I start taping. Please let me know if you want me to turn off the recorder at anytime during the interview.

You can tell me at any time if you want to stop the interview.

I will start with a few questions to get to know you better.

Part I- Introduction

1. I'd like to begin by asking you to tell me little bit about yourself?

Probes: name, age, from, culture/beliefs.

Probes: where living/social and physical supports.

2. How would you describe community life?

Probes: What's going on that's important/how often? What is cultural life like?

3. What do you see as cultural activities?

Probes: Ceremonies, events, celebrations, rituals. Which do you value most. Where are these held?

4. When did you start using a wheelchair/walker?
Probes- what was that like, what changed?

Part II- Cultural Participation and Health

Before and after started using wheelchair/walker

5. Did you take part in cultural activities before you started using your walker/wheelchair?
Probes-Tell me more about that. What types of activities.
6. Did you continue to take part in cultural ceremonies/events after you started using the wheelchair or walker?
Probes- do you feel that you take part less, same, or more (why). Same events or different events.

What makes it easier and what makes it harder?

IF YES:

7. Tell me about what it is like getting to the ceremony/event?
Probes- how do you get there, type of car/truck. Does someone help you? Rough roads/curb cuts?
8. Are the ceremonies /events wheelchair/walker friendly?
Probes-Tell me more about that. How do you feel about that?
9. Please tell me what makes it easier for you to get to the events.
Probes: Type of car, physical and mental support.

IF SAID NO:

10. You mentioned that you no longer take part in cultural events/ceremonies or that you take part less often. Can you tell me more about that?
Probes- Transportation, curb cuts, sidewalks
11. In your opinion are the ceremonies/events wheelchair/walker friendly?
Probe: tell me more about what you find works and what doesn't work.
12. What are the things that make it hard for you to attend in a wheelchair/walker?
Probes- transportation, enough room to move around- rough roads/sidewalks and curbs.

Meaning of Cultural Participation

13. How important is it that you be able to access/get to the event?
Probe- how important is this, in what ways, important to your family?

14. What do you do at these activities?

Probe: What is your role?

15. What does taking part in these events/ceremonies mean for your community.

Probe- how important is this, in what ways.

16. Does participating in cultural activities using a wheelchair or walker have a different meaning for you?

Probes: has it changed how you look at things or feel about things?

Impact of Cultural Participation on Health

17. What effect do you think your cultural participation has on your life?

Probe: Support, health.

18. What impact do you think the cultural participation of seniors has your community?

Probe: Health, connection, support?

Importance of senior/elder participation

19. Are there any reasons that you think it is important for seniors/elders to be taking part in cultural ceremonies/ events?

Probe: Any important reasons for seniors in wheel chairs?

20. What do you think the effects of seniors participation has on the health of the community?

Probe: If they do or don't take part in events and ceremonies.

PART V -WAYS CULTURAL PARTIPATION CAN BE IMPROVED

Ways to improve cultural participation for seniors using wheelchair and walkers.

21. Are there any things that can be done so that you could take part more often?

Probe: who might be involved, where might changed be needed?

22. In what ways would this be good for you?

23. In what ways would this be good for your community?

24. If you could make one wish to make it easier for seniors in wheelchairs/walkers to take part in cultural activities in your community-what would it be?

Part VI- Closing

25. Is there anything I didn't ask in the interview that you would like to talk about?

26. Is there anything that you can think of that would be important to know?

Thank-you, I will now turn off the audio recording.