

Exploring Winter Community Participation Among Wheelchair Users: An Online Focus Group

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ABSTRACT. The aim of this qualitative study was to gain an understanding of what people who use wheeled mobility devices (WMDs; e.g., manual and power wheelchairs, and scooters) identify as environmental barriers to community participation in cold weather climates, and to explore recommendations to overcome environmental barriers to community participation. Researchers conducted an online asynchronous focus group that spanned seven days, with eight individuals who use WMDs. Each day, participants were asked to respond to a moderator-provided question, and to engage with one another around the topic area. The researchers analyzed the verbatim data using an inductive content-analysis approach. Four categories emerged from the data: (1) winter barriers to community participation; (2) life resumes in spring and summer; (3) change requires awareness, education, and advocacy; and (4) winter participation is a right. Participants confirmed that it is a collective responsibility to ensure that WMD users are able to participate in the community throughout the seasons.

KEYWORDS. Environment, Focus group, Participation, Wheelchair, Winter

INTRODUCTION

Occupational therapists have long considered how the interactive relationship between people, their environments, and their occupations influences the performance and participation in occupations that are deemed important, desired, or necessary (Law et al., 1996). Participation is defined by the World Health Organization (2002) as “involvement in a life situation” (p. 10), including involvement in community, social, and civic realms. However, participation is more complex than solely the extent of involvement; rather, the subjective aspects and nature of involvement are also crucial to consider (Law, 2002). In a qualitative study of 63

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people with disabilities, values such as choice, meaningful engagement, social connection, inclusion, access, and opportunity were highlighted as key participation values (Hammel et al., 2008). Researchers have identified a number of positive outcomes associated with social and community participation among people with disabilities, including improved subjective ratings of quality of life, independence, sense of belonging, and overall health (Datillo et al., 2008; Levasseur et al., 2004; Milner & Kelly, 2009).

Yet, when compared to people without disabilities, users of wheeled mobility devices (WMD) face many environmental barriers to community participation. The environmental barriers most frequently reported by users of WMD include: social barriers such as negative societal responses (Wee & Paterson, 2009); physical barriers such as lack of or poorly maintained ramps (Brandt et al., 2004; Chaves et al., 2004; Wee & Paterson, 2009), natural environment barriers (Lysack et al., 2007; Whiteneck et al., 2004), and uneven travel surfaces (Barker et al., 2006); and institutional barriers such as lack of accessible parking (Wee & Paterson, 2009), lack of public transportation (Wee & Paterson, 2009), and lack of enforcement of regulations on community accessibility (Hammel et al., 2006). In contrast, the environmental facilitators most frequently reported by individuals who use WMD are the positive attributes of the same environmental barriers listed above (Brandt et al., 2004; Wee & Paterson, 2009), demonstrating how the environment can serve as either a barrier or facilitator to community participation.

Inclement weather, specifically winter weather conditions, can create additional environmental barriers (Ripat et al., 2010; Wee & Paterson, 2009) that, in some geographic locations, can extend for a substantial portion of the year. In winter, WMD users have reported additional physical and technology barriers such as lack of traction on snow and ice (Lemaire et al., 2010), sidewalks and surfaces not adequately cleared of snow and ice (Joshi, 2014; Lindsay & Yantzi, 2014; Ripat et al., 2015; Shirado et al., 1995), poor grip and difficulty pushing wheelchair rims/tires due to snow, ice, and the cold (Lemaire et al., 2010; Ripat et al., 2015), and lower battery capacity in power wheelchairs (Wee & Paterson, 2009). Winter has also been reported to negatively affect the physical health (Shirado et al., 1995) and emotional health (Lindsay & Yantzi, 2014; Ripat et al., 2015) of WMD users.

The World Federation of Occupational Therapists (2006) highlighted the role that occupational therapists can take in addressing occupational injustices in a key principle outlined in their position statement on Human Rights: "People have the right to be supported to participate in occupation and, through engaging in occupation, to be included and valued as members of their family, community and society" (p. 1). Based on their expertise in identifying and addressing environmental barriers to community participation, occupational therapists have an opportunity to seek ways to eliminate the barriers that limit community access. However, much of the focus to date has been on the built environment, with less attention paid to barriers that exist in the natural environment. While some winter-specific issues have been raised in the few studies that have addressed the experiences of WMD users in the winter, there is a need for more research to better understand "the nature and the extent" (Law, 2002, p. 641) of community participation experiences of WMD throughout the winter. Thus, the purpose of this study was to identify environmental barriers WMD users face when participating in the community in cold

weather climates, and to explore WMD users' recommendations to overcome these barriers. It is important to understand what winter environmental barriers exist and what strategies can be implemented so WMD users are able to participate in the community throughout the seasons.

METHODS

Design

A qualitative description study design (Sandelowski, 2010) was selected because the researchers were seeking a nuanced understanding of WMD users' experiences regarding community participation and winter barriers, the strategies they employ to overcome those barriers, and the recommendations they had for improving winter community participation. Qualitative description is an approach to qualitative inquiry that focuses on exploring and describing the views and experiences people have with a particular phenomenon in rich detail, and is useful for contributing evidence towards issues that are commonly experienced (Stanley, 2015). In order to gain this understanding, an asynchronous online focus group was used to gather data. In this study, an asynchronous online focus group was viewed as having several advantages over a traditional focus group. Advantages included time for more in-depth and reflective responses from participants (Turney & Pocknee, 2008), greater participant anonymity (Turney & Pocknee, 2008), increased convenience in terms of participating from any location at any time (Krueger & Casey, 2009), and automatic capture of discussion data (Tates et al., 2009). Closed- and open-ended questions (Table 1) were developed based upon the existing literature, and the results of a completed pilot study conducted with two users of WMD.

Procedures

The Health Research Ethics Board at the University of Manitoba approved this study and written informed consent was received from each participant prior to the start of the online focus group. The online focus group was open for seven consecutive days, has 24 hour/day password protected access, and was hosted on WordPress.comTM. A moderator posted a new set of questions daily for the participants to discuss, and encouraged additional thoughts and reflections. Participants were asked to respond to the daily questions, to one another, and/or to previous days' questions throughout the entire week. On the final day, participants were asked to reflect on their own answers and the answers of others, and to post any additional comments that may not have been addressed by the topic questions. All participants received an honorarium at the conclusion of the study.

Participants were included in this study if he or she: (a) was an adult WMD (manual wheelchair, power wheelchair, and/or scooter) user for at least 12 months, (b) was a Manitoba resident, (c) had Internet and computer access, (d) had adequate written literacy skills, and (e) was willing to respond to questions, six out of seven days, posted by the moderator. Participants were recruited through posters distributed at approximately 20 community-based organizations that provided services to people who use WMD. Each organization shared study information using

TABLE 1. Online Focus Group Questions**Day 1: Introduction**

Please tell us how long and where you have lived in Manitoba, and about your favorite hobby.

Day 2: Wheeled Mobility and Community Participation

What types of wheeled mobility devices do you use, and which devices do you use most often in the winter?

How often do you use your wheeled mobility devices outdoors in the winter?

What are your favorite things to do/places to visit in the community during the winter?

Day 3: Wheeled Mobility and Participation Facilitators

When using your wheeled mobility device outdoors in the winter, what factors make participating in the community safer and easier?

Do you receive any help from family, friends, or other services when going to places in your community? If yes, please provide examples.

Day 4: Wheeled Mobility and Winter Participation Challenges

Please identify the five main challenges that you encounter while using your wheeled mobility device outdoors in the winter.

Are you able to use your wheeled mobility device outdoors and participate in the community the way you want to? Please provide examples.

Day 5: Solutions to Winter Participation Challenges

Please share one solution to one challenge you encounter while using your wheeled mobility device outdoors in winter.

What strategies do you personally use to manage these challenges?

Day 6: How to Implement Change

What would need to change in order to make it easier to participate in the community during the winter?

Who do you see as being responsible for making these changes?

Who should the study recommendations be shared with?

Day 7: Reflection and Additional Comments

Please reflect on your comments over the past six days and the comments of the other participants and add any additional comments that you think are important.

their established mechanisms for sharing information with members (e.g., post on their website, poster hung up in main office). Each potential participant was asked to confirm eligibility for the study through an email exchange with the second author and the focus group was initiated once eight participants had been recruited.

Data Management and Analysis

All discussion board data were automatically saved on the website. At the end of the study period, all data were copied and pasted into a word-processing document. The researchers engaged in an inductive content-analysis process (Thomas, 2003) where they independently reviewed the transcript and used shorthand phrases or words to code the data. They then met to review the coding framework. After discussion and agreement on the coding, the codes were organized into topics, similar topics were clustered together, and major topics were identified and collapsed into categories. To enhance trustworthiness, participants were sent a summary of the results and asked to comment on whether the findings accurately represented their discussion. Five participants responded to the request for comments and minor changes were subsequently made to ensure clarity of the results.

TABLE 2 Focus Group Participants

Participant	Gender	Type of Outdoor Mobility Used in Winter	Years Used
Sidekick	Female	Manual wheelchair	44
Muzix	Female	Power and manual wheelchair	17
Snowtired	Male	Power wheelchair	8
Worksahobby	Male	Manual wheelchair	13
Jets96	Male	Scooter and walker	18
Babs	Female	Manual wheelchair	14
Survivor	Male	Power wheelchair	10
One2one	Female	Manual wheelchair	1

RESULTS

Eight participants took part in the online focus group (Table 2). Participants used various WMD for outdoor winter mobility. Most lived in one major urban center; one participant resided approximately 100 kilometers (60 miles) outside of the urban center. Participants posted a total of 105 comments/responses throughout the week (individual participants ranged from 2 to 37 comments) with all but one participant posting daily. While asynchronous in nature, participants engaged with one another's thoughts and opinions as illustrated by the following exchange (ellipses indicate content removed by authors to reduce length):

Worksahobby (February 24, 2014, at 8:17 am):

Manual wheelchair (rigid). It's how I get around year-round. I use it outdoors as little as possible. 99% of the time when I am outside in the winter it is to get from the closest possible accessible parking spot to the entrance of whatever building I am going into Favourite things to do in the community during the winter? Almost nothing. I hibernate. I go to church less often, I try to get groceries less than once a week. I'll try to have coffee with friends on occasion, but honestly, I become a bit of a hermit Favourite places to visit? Anywhere with attached parking is fine with me, or any place with good accessible parking and diligent snow clearing policies I sound pretty negative, but I really hate snow.

Muzix (February 24, 2014, at 1:52 pm):

Worksahobby that's not being negative, it's just the way it is for most of us. ~cheers

Sidekick (February 24, 2014, at 4:51 pm):

Worksahobby . . . I love your honesty! I fully agree! My husband and I are also very much homebodies and to be honest, could care less if we have company! LOL . . . winter is that way here for us as well . . . in our community, it is hard to get around PERIOD because of poor snow clearing or just inaccessible entrances . . . so it's easier to stay home and play on computer or direct my staff . . . so I love your commentary! Very well put. . . !

Overall, our findings confirmed that winter barriers negatively impact community participation among WMD users. Participants shared a commonality of mo-

bility challenges and experiences, in winter, as one participant wrote, “the problem of mobility in winter is the same for all of these using wheelchairs, scooters, [and] walkers” (Sidekick). Participants proposed that the situation would not improve without public awareness, education, and the development of alliances and actions. Participants viewed winter community participation as a right extended to all citizens but, due to winter barriers, WMD users are not able to enjoy this right to the same extent as the rest of society.

Winter Barriers to Community Participation

Reported winter barriers fell into three types: weather, policies, and attitudes. Participants reported weather-related barriers such as snow, ice, slush, cold temperatures. Snow was the most frequently reported barrier particularly when not cleared properly from sidewalks and curb cuts. Participants highlighted how snow might create an inconvenience for some citizens, but created substantial barriers to WMD users: “The mound [of snow] may be easily stepped over, but might as well be the Great Wall of China to someone with mobility limitations” (Snowtired).

Participants reported barriers related to snow-clearing, sidewalk, and street maintenance policies, and policies developed by publicly funded accessible transportation services. Participants commented that community participation became more difficult, or even impossible, when sidewalks, curb cuts, streets, parking lots, parking spaces, and bus stops were not properly cleared of snow, not cleared in a timely manner, or when frozen ruts and high snow banks prevented ability to access community locations. As Worksahobby posted, “I pretty much assume that all city sidewalks are off-limits to me and my manual chair in the winter due to snow and ice.” Accessible transportation policies were viewed as problematic, leaving limited or no transportation options for those who did not have their own vehicle or access to other public transportation means. For example, one participant wrote: “Inflexible booking rules make [accessible public transportation] so difficult to use for attending events or even shopping that many people prefer to just stay home most of the winter and save community involvement for the summer months” (Snowtired).

Attitudinal barriers were raised, such as pedestrians who did not accommodate WMD users on sidewalks, and snow-clearing operators and city inspectors who may not be aware of accessibility principles. As Jets96 wrote, “No matter the barrier, the attitude of the people around you can be the biggest to overcome.”

As a result of winter barriers, participants identified safety concerns related to their health and well being. Health concerns included the risk of frostbite or hypothermia. Poorly cleared sidewalks resulted in participants getting stuck in the snow for prolonged periods of time, the necessity of wheeling their wheelchair on the street with vehicular traffic due to sidewalks that were not cleared of snow, and tipping over on the sidewalk or street because of frozen ruts.

While most participants reported going out as little as possible, they discussed strategies they used to cope with winter barriers such as receiving help from others (family, friends, and attendants), going out as little as possible, taking extra safety precautions, and contacting the City and local officials to report concerns. Sidekick expressed a need to always be accompanied by “friends or assistance in order to

travel safely outside in the winter months . . . just to ensure that we get where we are wanting to go and safely.”

Life Resumes in Spring and Summer

In winter, participants reported they engaged in the community less often than in other seasons. The places participants reported they went to in winter were mainly indoors and places of necessity, such as medical appointments or grocery shopping. When participants were asked if they were able to use their WMD outdoors and participate in the community the way they wanted to, the consensus was no, and participants used words like *shut-in*, *hermit*, *hibernate*, and *homebody*, to describe their lack of community participation in winter. However, participants reported they resumed their activities in the spring, for example Babs posted: “Most of us just can’t wait till the snow is gone so we can get out and enjoy the activities in our community.” The emotional toll that limited community participation had on participants was best described by Muzix, “By the time spring rolls around I’m like a lion that has been caged in. FREEDOM to wheel is in my blood.”

Change Requires Awareness, Education, and Advocacy

Recommendations addressed public awareness and education. Participants felt that change would not happen until, as Sidekick posted, “someone who is in charge actually has to face a mobility challenge.” Recommendations included educating the public, government employees, and contractors on principles of accessibility, integrating accessibility education into the school system, and creating public awareness about the issues WMD users face in the winter. Overall, education was highlighted as a key recommendation, as Snowtired expressed, “Education, starting with the very young is a good way to go. The rewards may not be felt by our generation, but this is how a society moves ahead.”

Some participants viewed advocacy as a strategy that could help reduce winter barriers and improve community participation for WMD users. Individual advocacy suggestions included persistency in contacting municipal and provincial government officials, and becoming a member of a disability organization charged with advocating on behalf of people with disabilities. Half of the participants reported being involved in individual or group advocacy efforts that addressed their community participation rights. However, the success of these efforts was perceived as questionable, as participants most often felt their complaints had not been heard or addressed. Others expressed that they had not advocated for their rights; Muzix posted “Before this study was offered to me, I never viewed or voiced the challenges or struggles to anyone.” Coalition advocacy was also suggested since other groups, such as older adults, face similar mobility issues as WMD users. Jets96 posted, “Seniors’ groups should be approached for their input. We face similar barriers and challenges.”

Participants generated specific policy improvement and by-law recommendations for snow-clearing and general street maintenance and the creation of better communication systems for expressing their concerns to responsible civic employees. Specific accessible public transportation recommendations were proposed to improve access to and expand available services. Participants also recommended WMD modifications by wheelchair manufacturers to improve the use of their

WMD in winter. As Sidekick described, “Wheelchair manufacturers aren’t thinking about winter months in Canada! They make them only for pavement and sunny days.” Participants recommended development of wheelchairs that could better handle the winter climate, such as a WMD with tires with better traction and heated seats. Participating in the focus group provided participants with hope for change, best expressed by Worksahobby, “I hope the information provided here finds its way into the right hands, helps educate some people with the power to make a difference, and brings some understanding to the plight those with mobility issues face during the winter.”

Winter Participation as a Right

Overall, participants viewed winter participation as a right that should be extended to all citizens: “City councils, governments need to understand that tax dollars need to be spent on making sure ALL [citizens] can have access” (Sidekick). Participants established that they wanted to be able to enjoy the community in the way other citizens could, with access to sidewalks, streets, and building entrances throughout the seasons. As Snowtired posted:

Winter means being virtually a shut in, keeping us from enjoying the “winter events” others do and take for granted . . . we are not asking for special privileges or treatment, we just want to do as others do. It is difficult to have a rich, productive life when 5 months of the year we are trapped in our homes.

Viewing the issue from the lens of universal access was seen as one way of addressing the needs of all, as expressed by Survivor: “If snow was cleaned and sidewalks properly maintained, it would make life easier for everyone—furniture movers, people with child strollers, etc. I don’t think the people would complain.”

DISCUSSION

Our findings support the limited research available on WMD users’ winter community participation where snow, ice, and cold temperatures create barriers (Lindsay & Yantzi, 2014; Wee & Paterson, 2009). Our study also identified policy barriers regarding snow-clearing, and sidewalk and street maintenance similar to those reported in research in other geographic locations (Lindsay & Yantzi, 2014). Finally, our study found attitudinal barriers that extended from government officials to the general public, similar to the findings of Barker et al. (2006). Overall, this study confirms that elements of the environment, including the natural environment, supports, services, policies, and WMDs (World Health Organization, 2002) can alternatively serve as a barrier or facilitator to community participation.

Community participation among participants in this study was restricted during the winter. Participants found it easier to stay indoors rather than try to overcome environmental barriers. Other studies have found that decreased winter community participation leads to WMD users feeling socially isolated (Lemaire et al., 2010; Lindsay & Yantzi, 2014). While participants in our study felt forced to stay indoors and alter their community participation patterns, they did not use words like lonely or depressed, emotions expressed by participants who used WMD in another winter study (Lindsay & Yantzi, 2014). This may have occurred because

all participants were either married, had a significant other, or had family, friends, or attendant staff for support. Social supports may have been a mitigating factor for social isolation in this study and further research regarding the impact of social supports or networks on reducing social isolation among WMD users in the winter is warranted.

While “full and effective participation and inclusion in society” and “accessibility” are identified as key guiding principles asserted by the United Nations Convention on the Rights of Persons with Disabilities (2006, Article 3), winter issues that impede effective participation, inclusion, and accessibility have not been specifically identified as barriers to exercising this right. Our research supported that participants identified winter community participation as a right for all citizens; this right was associated with having access to public sidewalks and streets in a safe and accessible manner. There are a few noteworthy efforts to address winter access, for example, Li et al. (2013) identified the need to address alternate curb ramp designs and Morales et al. (2014) engaged in research around possible design solutions to improve winter accessibility of sidewalks. However, the results of this study point to the need to take a multi-pronged approach to addressing winter barriers that include changes to the built environment, policy review with consideration of specific winter challenges, and the need to develop winter-specific technology. As occupational therapists, we are experts at identifying and providing solutions for environmental barriers to participation for our clients (Townsend & Polatajko, 2007), however we need to pay special attention to how client needs may differ across the seasons.

Participants in this study felt that public education, awareness, and developing coalition alliances were crucial to the public and key stakeholders truly understanding how winter barriers impact WMD users’ community participation. Occupational therapists can play an important role as change agents and advocates at community and population-based levels in supporting these efforts. For example, multi-component disability awareness programs targeted at school-aged children have been shown to be effective in developing positive attitudes towards peers with disabilities (Lindsay & Edwards, 2013). Through their role in school-based settings, occupational therapists are well positioned to address inclusionary attitudes (Wener et al., 2009) and could take an expanded role in educating children about broader community accessibility and participation. Bringing community members and policy-makers together to address issues of importance for persons with disabilities is another role for occupational therapists. For instance, in a participatory research project addressing winter walkability for older adults and people with disabilities, stakeholders were brought together to examine issues and advise civic policy-makers (Ripat et al., 2010). Using accessibility audit tools to highlight environmental barriers to community participation may be another way that occupational therapists can promote broader societal awareness and ultimately generate opportunities for advocacy activities to ameliorate identified barriers (Ripat et al., 2008).

Limitations and Future Research

This study recruited participants who were active users of their WMD, and drew the sample from only one particular region; thus, the results may not be transferable

to all WMD users. However, it is clear from this small study that issues exist and likely are widespread. Therefore, there is a need for more research on the impact of winter and climate on WMD users and community participation at a more extensive level including individuals who are less active in the community, older adults, those with chronic conditions, and those who live in rural areas where services are less available.

While we only ran one focus group, we believe the asynchronous nature of the group running over the course of seven days with daily contributions from most participants yielded rich and thoughtful data. Other areas for research could include exploring the impact of coalition advocacy and a public education campaign on improving winter community participation. Finally, WMD manufacturers should explore opportunities for developing WMDs suitable for winter climates.

CONCLUSIONS

Participants in this study confirmed that community participation is a right and that users of WMD are entitled to enjoy this right as fully as the rest of society year round. It is vital that all key stakeholders take an active role in addressing policies and creating action plans to reduce winter barriers since, unless actions are taken to address the issues faced, users of WMD will continue to be denied the opportunity to enjoy this right. Ultimately, we need to address these issues so WMD users can safely participate in their communities and enjoy life across the seasons.

The profession of occupational therapy is being challenged to use existing and developing knowledge and influence to address societal-based issues that prevent groups of people from their right to full and inclusive participation (Hammell, 2015). While our domain of practice has often started at the individual client level, occupational therapists are encouraged to think and act broadly to address the barriers to occupation that occur at community and societal levels (Hammell & Iwama, 2012; WFOT, 2006). In doing so, our profession can contribute to improved community access and occupational participation that ultimately can benefit all citizens (van Bruggen, 2010).

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