

Increasing the winter community participation of older adult wheelchair users

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Participation has been defined by the World Health Organization as “involvement in a life situation” and includes involvement in community, social, and civic realms.<sup>1</sup> The concept of participation is more complex than simply considering the extent to one does or does not engage in a prescribed activity, rather it also has qualitative attributes that relate to the nature and self-perceived meaning of participation.<sup>2</sup> Research has supported the association between community participation among people with disabilities, and outcomes such as higher subjective ratings of quality of life and independence, improved sense of belonging, and positive self-perception of health.<sup>3-5</sup>

In Canada, 1.2 million people use mobility aids, such as wheelchairs, as a means to participate and engage in meaningful occupations within their community.<sup>6</sup> Furthermore, the prevalence of mobility issues reported increases as people age, with approximately one-quarter of Manitobans age 75 or over reporting mobility issues.<sup>7</sup> However, users of wheeled mobility devices (WMD) face numerous environmental barriers to community participation including barriers such as limited access to accessible public transportation,<sup>8</sup> lack of or poorly maintained ramps,<sup>8-11</sup> lack of accessible parking,<sup>8</sup> negative societal attitudes,<sup>8</sup> and lack of enforcement of accessibility regulations.<sup>12</sup>

One environmental barrier that WMD users in Manitoba acutely experience is winter weather. In a web-based survey of 99 Manitoban WMD users,<sup>13</sup> 80% of respondents reported needing additional help for home maintenance, transportation, and community access in the winter; however 57% reported not receiving that needed help. Respondents reported that limited community participation in winter led to feelings of loneliness, isolation, fear, and anxiety. Forty-two percent of respondents reported reducing their community participation frequency from almost daily in summer, to once or twice a week (or less) in winter; this finding was associated with older adult WMD users and those who lack access to family/friends for transportation. These results are particularly concerning, given a recent systematic review of community-dwelling older adults that provides strong evidence to support the positive impact of involvement in social, recreational, spiritual, and physical activity on health and quality of life.<sup>14</sup>

Though we are beginning to gain an understanding of participation barriers specific to WMD users in the winter, few studies have sought to address these barriers through the development of new technology or adapting environmental features.<sup>15-17</sup> The five environmental domains identified by International Classification of Functioning, Health and Disability (ICF)<sup>18</sup> (i.e., technological, natural, physical, social/attitudinal, and policy) interact with a person with a health condition to either promote or limit activity and participation. Targeted interventions directed toward one or more of those domains may be an effective way of addressing reduced winter community participation. The purpose of this study is ***to examine whether intervention strategies targeted at the level of the environment can successfully promote the community participation experiences of community-dwelling older adult Manitobans who use WMD in the winter.*** The findings of this pilot study will help determine the feasibility of, and guide the development of, a proposal targeted at conducting a larger scale study.

## Method

**Overview** Using a single-subject design, five older adult WMD users will each select three community-based participation goals to work on throughout the winter months. Each participant will work with an occupational therapist to receive individually-focused interventions aimed at increasing community participation. A client-centred outcome measure will be used to set initial goals, and to measure change in performance and satisfaction with performance.

**Detailed Description** Given the subjective nature of participation the experience of participating, community-based interventions should consider the individual nature of participation occupations and strive to engage individuals in occupations considered meaningful to them.<sup>14</sup> This study will use an Interrupted Time Series Design (ITS), a quasi-experimental single-subject design suitable for evaluating the effectiveness of individually-designed interventions.<sup>19</sup> Using ITS, each participant serves as his/her

own control, multiple baseline measurements are taken, and multiple measures of the targeted outcome are collected throughout the study trajectory.<sup>20</sup>

### Participants

This application is a pilot study, and thus feasibility of the research approach will be examined by recruiting five older adult Manitobans who are wheelchair users. Participants will be recruited through collaboration with one or more of the five Winnipeg Regional Health Authority ACCESS Centres and other health resource centres for seniors including Active Living Coalition for Older Adults (ALCOA), Age and Opportunity, Creative Retirement Manitoba, Healthy Aging Resource Team (HART) and the Independent Living Resource Centre (ILRC). Posters will be used to recruit participants. Participants will be screened for inclusion by the occupational therapist using the Geriatric Depression Scale-Short Form<sup>21</sup> (GDS-SF) and the Montreal Cognitive Assessment<sup>22</sup> (MOCA). Inclusion criteria include: age 70 or older, user of a manual or power wheelchair or scooter for outdoor mobility, self-identifies a reduction in community participation throughout the winter months, community-dwelling, GDS-SF score of 5 or less, MOCA score >26, and lives within the perimeter of Winnipeg. If the score on the GDS-SF is >5 (indicating mild depression), the individual will not be included in the study and with permission of the individual, the occupational therapist will telephone the individual's physician and suggest further assessment.

### Measures

The **Canadian Occupational Performance Measure**<sup>23</sup> (COPM) is a client-centered outcome measure designed to detect changes in performance and satisfaction in occupations that the individual has self-identified as being important and difficult to perform. The COPM has well-established psychometric properties and will be used as the primary outcome measure and will be used to set treatment goals, determine baseline stability, and detect change in performance of, and satisfaction with, the goals.

The **Activity Card Sort**<sup>24</sup> (ACS) uses a Q-sort methodology where photographs of people performing various activities are sorted into categories that the participant indicates interest in performing. The ACS will be used to identify valued instrumental, leisure and social activities that the person has performed in the past and/or desires to participate in in the future and will guide the formation of goals on the COPM. The **WHO-DAS 2.0**<sup>25</sup> is a generic self-report health status measure, linked to the concepts of health and disability outlined in the ICF and intended to identify limitations in six domains, including self-care, and community and social functioning experienced over the past 30 days. The WHO-DAS 2.0 is responsive to change, has excellent internal consistency, established content validity, and high convergent validity. The WHO-DAS 2.0 will be used to identify changes in overall health status that occur through the study. Follow-up **semi-structured interviews** will be conducted at the end of the intervention phase, to gain the perspective of each participant of the experience and personal value of working to increase winter community participation. Interview questions will address barriers and supports to participating in self-identified occupations and impact on sense of inclusion and engagement in the community.

### Procedure (repeated for each of 5 participants, entered concurrently into study)

Recruit/screen for inclusion ACS; COPM goal-setting phase WHO-DAS 2.0	Week 0	Occupational therapist will conduct initial assessment to establish goals using the ACS and COPM.
COPM baseline measurements (2x/week)	Weeks 1-4	Minimum 24 data points required to conduct statistical analysis <sup>19</sup>
Intervention related to goal 1 (e.g. attend weekly spiritual services at local place of worship) Continue with baseline measurements (2x/week) for goals 2 and 3	Weeks 5-7	A sample intervention for goal 3 might include working with participant to: identify appropriate neighborhood grocery store suitable for mobility/accessibility needs (e.g.

Intervention for goal 2 (e.g. participate in wheelchair yoga class 1x/week) Continue with baseline measurements (2x/week) for goal 3	Weeks 8-10	store that has scooter and basket available for customer use), determine regular transportation means and travel route, prepare weekly grocery list, learn to use debit card to pay for groceries.
Intervention for goal 3 (e.g. weekly grocery shopping at local grocery store)	Weeks 11-13	
Follow up phase (COPM/WHO-DAS) Follow-up interview (week 16 only)	Weeks 16 and week 20	Research assistant conducts follow up interviews and administer follow-up COPM and WHO-DAS 2.0

### Analysis

COPM data will be plotted and visually inspected to gain an understanding of the timing and nature of any change. Statistical analysis will be conducted using the celeration line and C statistic<sup>19</sup>, where the proportion of data points above and below the line is calculated and compared to a probability table to determine statistical significance. Repeated measures ANOVA will be used to identify change on the six domains of the WHO-DAS 2.0. Guided by an Interpretive Descriptive approach<sup>26</sup>, qualitative interviews will be transcribed verbatim and directed content analysis<sup>27</sup> used to gain a descriptive and interpretive understanding of clinically relevant issues and suggestions for future study.

### Importance and Relevance to Aging

Approximately one-third of Manitobans aged 65 or over reported emotional and social loneliness and older adults reported a decline in leisure activity participation with increasing age.<sup>7</sup> Older adult WMD users in Manitoba bear a disproportionate burden in the winter – when aging, mobility limitations, and weather coincide to create conditions not conducive to community participation. A recent systematic review identified strong evidence to support the use of occupation and client-centred interventions in maintaining instrumental activities of daily living abilities of community-dwelling older adults.<sup>28</sup> However, evidence is required to identify whether, and how, we can use individually-focused interventions at the level of the environment to improve or maintain the community participation experiences of community-dwelling older adults who use WMD,<sup>28</sup> particularly in the winter.

### Qualifications and Strategic New Direction

My program of research focuses on understanding the intersection between assistive technology users and their environments. I primarily use client-centered approaches to inquiry, specifically qualitative methods, photovoice, case study, and mixed methods. While aging has not been a particular focus in past research, findings from a recent survey that I conducted<sup>13</sup> indicated a disproportionate burden placed on older adults who are WMD users in terms of limitations in community participation in winter. I view this application as an important opportunity to explore innovative ways of addressing those challenges.

### Publications and Future Applications

One peer-reviewed publication and a minimum of two professional presentations on this research will result from this study. While the sample size of five will not provide evidence of a treatment effect, the findings can be used to determine sample size required for a larger scale study proposal targeted at the Canadian Institutes of Health Research. This study will form a key component of a larger program of research focused on improving winter community participation among people with disabilities.

### Timeline

Hire research assistant and OT; Submit HREB	July –August 2015
Recruit/Baseline phase	November – December 2015
Intervention (to occur over mid-winter)	January - March 2016
Follow up	Complete by April 2016

Data analysis	Complete by July 2016
Presentations/publications	May –September 2016

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