

The relationship between social participation and wheelchair breakdowns in people with spinal cord injury

Sara Múnera Orozco^{1,2}, Maria Luisa Toro³, Lynn Worobey^{2,4}, Michael L. Boninger^{1,2,4}, Rory A. Cooper^{1,2}, Jonathan Pearlman^{1,2}.

1 Department of Rehabilitation Science and Technology, University of Pittsburgh, Pittsburgh, PA

2 Human Engineering Research Labs, VA Pittsburgh Healthcare system

Rehabilitation Science and Technology, University of Pittsburgh

3 Programa de Fisioterapia, Facultad de Salud, Universidad CES, Medellín, Colombia.

4 Department of Physical Medicine and Rehabilitation, University of Pittsburgh, Pittsburgh, PA

ABSTRACT

People with spinal cord injuries use wheelchairs to participate in different roles and activities; however, the relationship between wheelchair breakdowns and social participation has yet to be explored. With this study, we aim to further understand this relationship. A sample of 178 wheelchair users was recruited as part of a larger study and asked about breakdowns in the previous six months. They also completed PROMIS questionnaires examining social participation. There were no significant relationships between wheelchair breakdowns and social participation for this sample. Nevertheless, wheelchair breakdowns are a prevalent issue and negative consequences are frequently reported. Further research is needed to understand how wheelchair breakdowns impact social participation of wheelchair users as well as other quality of life factors.

BACKGROUND

According to the World Health Organization, 15% of the world population has a disability and 1% needs a wheelchair (World Health Organization, 2008b). In the United States, it is estimated that there are 3.6 million adults who use a wheelchair (Brault, 2012). Social participation is a fundamental right of every human being (Layton & Steel, 2015), and access to a proper wheelchair is the first step in accomplishing this for many individuals who cannot ambulate independently (Chen et al., 2011; United Nations, 2006; World Health Organization, 2008a). For wheelchair users, multiple factors are associated with community and social participation, including wheelchair skills, comfort, and durability (Smith, Sakakibara, & Miller, 2014).

Wheelchair breakdowns have negative consequences, such as leaving users injured or stranded (Chen et al., 2011), reducing mobility (Worobey, Oyster, Nemunaitis, Cooper, & Boninger, 2012), and decreasing quality of life (Bourret, Bernick, Cott, & Kontos, 2002). Based on this evidence, it seems logical that wheelchair breakdowns would be associated with social participation.

Breakdowns and repairs are common for wheelchair users. According to Worobey et al, 52.6% of wheelchair users completed repairs in a six-month period. This number has been increasing over time (McClure et al., 2009; Worobey et al., 2012), and 32.3% of wheelchair users experienced at least one adverse consequence as a result of the associated breakdown (Worobey et al., 2012).

The topic of wheelchair breakdowns and their consequences is increasingly represented in research; nevertheless, to our knowledge, the relationship between wheelchair breakdowns and social participation has not been studied. There are two possible relationships between these two issues. Due to an increase in the use of wheelchairs, a higher social participation could be tied to more breakdowns. On the other hand, an increase of breakdowns could lead to a lower social participation, because users would prefer not to be active in the community if they cannot rely on their wheelchairs. The relationship between breakdowns and social participation was more broadly explored rather than hypothesizing if the relationship is in a certain direction.

METHODS

Subjects and Testing Setup

A multi-center descriptive study was conducted based on cross-sectional data. Participants were recruited from four Model System Centers for Spinal Cord Injury as part of a larger study on the impact of a wheelchair skills or maintenance training programs.

Approval of the Institutional Review Board was obtained prior to the start of the study. After informed consent was obtained, participants answered a demographics questionnaire that asked about breakdowns and need for repairs in the previous six months on each part of the wheelchair, as well as general information such as age, gender, and level of injury. 15 wheelchair components, 11 of which were relevant to both manual and power wheelchair users and four additional that were relevant to only power wheelchair users (see table 2) were specifically addressed. Participants were also asked to state if there was

a consequence due to that breakdown, and if a repair was attempted or completed.

PROMIS instruments on ability to participate in social roles, satisfaction with participation in roles and activities, and social isolation were also collected (PROMIS, 2014a, 2014b, 2015a). These instruments are part of the social health domain framework and are a computerized adaptive test in which participant responses guide the system's choice of subsequent items (PROMIS, 2015b).

Data Processing

From the sample of 178 subjects, three were excluded from the analysis due to missing data. The level of SCI was divided into quadriplegia and paraplegia (Maynard et al., 1997). The number of breakdowns was dichotomized to breakdown or no breakdown. Statistical tests were done using SPSS version 22, and the level of significance was set at 0.05. A logistic regression with social participation, ability to participate, and social isolation, as independent variables and the dichotomous variable of breakdown as the dependent variable was used.

RESULTS

Data from a total of 175 wheelchair users were analyzed. The mean age of the participants was 45.5 ± 14.1. Table 1 contains the demographic characteristics of the participants. For this sample, 74.3% (n=130) reported a breakdown in the last 6 months and 64% completed a repair in the same period of time, suggesting 10% of the wheelchairs breakdowns were unrepaired.

Table 1: Demographic characteristics of the participants

	No. (%) of Subjects	No. of Missing Subjects
Gender		
Male	128 (73.1)	0
Female	47 (26.9)	
Type of wheelchair used		
Manual wheelchair	94 (53.7)	0
Power wheelchair	79 (45.1)	
Power assist wheelchair	2 (1.1)	
Level of injury		
Paraplegia	92 (52.6)	8
Tetraplegia	75 (42.6)	
Occupational status		
Working	35 (20.0)	0
Homemaker	1 (0.6)	
Retired	26 (14.9)	
Student	14 (8.0)	
Unemployed	57 (32.6)	
Other	42 (24.0)	

The mean number of breakdowns in the last six months was 3.2± 4.1. Table 2 shows the frequency and percentage of breakdowns for each part of the wheelchair. 21.5% of the users reported an adverse event after a breakdown. For this sample, power wheelchair users experience more breakdowns than manual wheelchair users (p= 0.003).

The mean for the PROMIS questionnaires was the following: Ability to participate 50.8±8.2. Satisfaction with participation in social roles 50.3±8.5. Social isolation 46.73 ± 8.07.

The regression analysis did not yield significant results. There was no relationship between breakdowns and social participation, and none of the independent variables predicted the dependent variable (p=0.489).

DISCUSSION

While PROMIS questionnaires focus on the challenges the user experiences when performing regular activities at home and work, and engaging in social relationships, there are factors that may be related to wheelchair breakdowns that are not reported with these questionnaires such as the quality and reliability of the wheelchair, the level of activity as it relates to distance traveled, the weather conditions and terrain where it was used, and the maintenance performed (Toro, Garcia, Ojeda, Dausey, & Pearlman, 2012).

The results of the PROMIS questionnaires for this sample are similar to the results for the general population (PROMIS Health Organization and PROMIS Cooperative Group, 2011).

This study shows a breakdown incidence of 74.3% and a mean of 3.2 breakdowns in a period of six months with 21.5% users experiencing consequences. The most frequent causes of wheelchair breakdowns were due to worn out tires or tubes (17.1%) and loose positioning supports (16.4%). This information is especially relevant so that users can regularly inspect these components.

The data on this study supports previous research stating that power wheelchair experience more breakdowns than manual wheelchair users (Gaal, Rebholtz, Hotchkiss, & Pfaelzer, 1997).

The results of this study indicate that 64% of wheelchair users completed repairs in the last six months; previous studies have reported this number to be between 26% and 44.8%. (Fitzgerald et al., 2005; McClure et al., 2009) Although the questions asked in this study were slightly different than in these previous studies, it does suggest a possible increase in the repair rate of wheelchairs over time, which is concerning for the safety and quality of life of wheelchair users.

Table 2: Frequency and percentage of breakdowns.

	Total number of breakdowns	Percentage of breakdowns
Worn out tire or tube in any wheel	70	17.11 %
Broken wheel axle	12	2.93 %
Loose wheel or casters	26	6.36 %
Broken caster assembly	10	2.44 %
Broken wheel or caster bearings	28	6.85 %
Broken wheelchair frame	10	2.44 %
Loose positioning support	40	16.38 %
Worn out positioning support	40	9.78 %
Worn out seating components	30	9.78 %
Broken seating components	8	7.33 %
Suspension elements	16	0.98 %
Broken controller box	25	5.87 %
Loose controller box	12	4.65 %
Battery that would not hold charge	14	3.42 %
Broken power seat function	68	3.67 %

Even though no relationship between social participation and wheelchair breakdowns was found, it is clear that breakdowns and adverse events have an impact on wheelchair users (Chen et al., 2011; Kirby, Ackroyd-Stolarz, Brown, Kirkland, & MacLeod, 1994). Thus, the PROMIS questionnaires for the social health domain may not be sensitive to this relationship, and a different indicator or a data collection approach more targeted at the consequences of the breakdown on participation may need to be used or developed.

Future Work

Social participation is a central concept in rehabilitation, and while extremely important for everyone, it is even more so for wheelchair users (Baum, 2011). Further research is needed in order to understand the causes of wheelchair breakdowns and its relationship to social participation. This may include developing more sensitive objective and subjective instruments that can capture the activity level of the user and the consequences of a breakdown on social participation.

Limitations

The sample was recruited as part of a larger study on wheelchair training on skills and maintenance; thus, it is possible that this sample was biased. It may have been more likely for individuals with wheelchair breakdowns to participate in this study when compared with individuals who had never experienced a breakdown on their wheelchairs.

Users were not asked if they were performing routine maintenance; they were only asked about repairs to specific problems of their wheelchairs, which could impact the breakdown rate. The inspection of the wheelchair and some basic maintenance activities such as filling the tires with air can improve the performance of the wheelchair and affect the number of breakdowns.

CONCLUSIONS

For this sample of the population, no relationship was found between social participation and whether a wheelchair breakdown occurred. This study did reveal, however, that wheelchair breakdowns are common among wheelchair users and highlights the need for an intervention to reduce breakdowns, such as regular maintenance or more reliable wheelchairs.

ACKNOWLEDGMENTS

This paper was part of the Collaboration on Mobility Training (COMIT) study and was funded by the National Institute on Disability and Rehabilitation Research (NIDILRR). The primary author gratefully acknowledges Fulbright for supporting her studies and research at the University of Pittsburgh.

REFERENCES

- Baum, C. M. (2011). Fulfilling the Promise: Supporting Participation in Daily Life. *Archives of Physical Medicine and Rehabilitation*, 92, 169–175. <http://doi.org/10.1016/j.apmr.2010.12.010>
- Bourret, E. M., Bernick, L. G., Cott, C. a., & Kontos, P. C. (2002). The meaning of mobility for residents and staff in long-term care facilities. *Journal of Advanced Nursing*, 37(4), 338–345. <http://doi.org/10.1046/j.1365-2648.2002.02104.x>
- Brault, M. W. (2012). *Americans with disabilities: 2010*. Washington, DC.
- Chen, W. Y., Jang, Y., Wang, J. Der, Huang, W. N., Chang, C. C., Mao, H. F., & Wang, Y. H. (2011). Wheelchair-related accidents: relationship with wheelchair-using behavior in active community wheelchair users. *Archives of Physical Medicine and Rehabilitation*, 92(6), 892–898. <http://doi.org/10.1016/j.apmr.2011.01.008>
- Fitzgerald, S. G., Collins, D. M., Cooper, R. A., Tolerico,

- M., Kelleher, A., Hunt, P., ... Cooper, R. (2005). Issues in maintenance and repairs of wheelchairs: A pilot study. *Journal of Rehabilitation Research & Development*, 42(6), 853–862.
<http://doi.org/10.1682/JRRD.2004.10.0130>
- Gaal, R. P., Rebholtz, N., Hotchkiss, R. D., & Pfaelzer, P. F. (1997). Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *Journal of Rehabilitation Research and Development*, 34(1), 58–71.
- Kirby, R. L., Ackroyd-Stolarz, S., Brown, M., Kirkland, S., & MacLeod, D. (1994). Wheelchair related accidents caused by tips and falls among noninstitutionalized users of manually propelled wheelchairs in Nova Scotia. *American Journal of Physical Medicine & Rehabilitation*, 73(5), 330–319.
- Layton, N., & Steel, E. (2015). “An Environment Built to Include Rather than Exclude Me”: Creating Inclusive Environments for Human Well-Being. *International Journal of Environmental Research and Public Health*, 12, 11146–11162.
<http://doi.org/10.3390/ijerph120911146>
- Maynard, F. M., Bracken, M. B., Graham, C., Ditunno, J. F., Donovan, W. H., Ducker, T. B., ... Young, W. (1997). International Standards for Neurological and Functional Classification of Spinal Cord Injury. *Spinal Cord*, 35(5), 266–274.
<http://doi.org/10.1038/sj.sc.3100432>
- McClure, L. A., Boninger, M. L., Oyster, M. L., Williams, S., Houlihan, B., Lieberman, J. A., & Cooper, R. A. (2009). Wheelchair Repairs, Breakdown, and Adverse Consequences for People With Traumatic Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*, 90, 2034–2038.
<http://doi.org/10.1016/j.apmr.2009.07.020>
- PROMIS. (2014a). *A brief guide to the PROMIS Satisfaction with Social Roles and Activities instruments* :
- PROMIS. (2014b). *Ability to participate in social roles and activities*.
- PROMIS. (2015a). *A brief guide to the PROMIS Social Isolation instruments* :
- PROMIS. (2015b). Domain Frameworks. PROMIS Adult self-reported health. Retrieved February 8, 2016, from <http://www.nihpromis.org/measures/domainframework1>
- PROMIS Health Organization and PROMIS Cooperative Group. (2011). PROMIS Instrument-Level Statistics Including Gender, Educational Level, Age Bracket, Clinical, and Levels of Self-rated General Health Subgroups. Retrieved February 8, 2016, from http://www.nihpromis.org/Documents/PROMIS_Age_Gender_Comorbidty.pdf
- Smith, E. M., Sakakibara, B. M., & Miller, W. C. (2014). A review of factors influencing participation in social and community activities for wheelchair users. *Disability and Rehabilitation. Assistive Technology*, 3107(December), 1–14.
<http://doi.org/10.3109/17483107.2014.989420>
- Toro, M. L., Garcia, Y., Ojeda, A. M., Dausey, D., & Pearlman, J. (2012). Quantitative Exploratory Evaluation of the Frequency, Causes and Consequences of Rehabilitation Wheelchair Breakdowns delivered at a Paediatric Clinic in Mexico. *Disability, CBR & Inclusive Development*, 23(3), 48–64. <http://doi.org/10.5463/dcid.v23i3.167>
- United Nations. (2006). *Convention on the rights of persons with disabilities and optional protocol*. New York, NY: United Nations. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- World Health Organization. (2008a). *Guidelines on the provision of manual wheelchairs in less-resourced settings*. Switzerland.
- World Health Organization. (2008b). *The world health report*.
- Worobey, L., Oyster, M., Nemunaitis, G., Cooper, R., & Boninger, M. L. (2012). Increases in wheelchair breakdowns, repairs, and adverse consequences for people with traumatic spinal cord injury. *American Journal of Physical Medicine & Rehabilitation / Association of Academic Physiatrists*, 91(6), 463–469.