Assessing the Influence of Wheelchair Technology on Perception of Participation in Spinal Cord Injury

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ABSTRACT. Chaves ES, Boninger ML, Cooper R, Fitzgerald SG, Gray DB, Cooper RA. Assessing the influence of wheelchair technology on perception of participation in spinal cord injury. Arch Phys Med Rehabil 2004;85:1854-8.

Objective: To investigate factors related to the wheelchair, impairment, and environment that affect perception of participation of persons with spinal cord injury (SCI) in activities performed in 3 settings: in the home, in the community, and during transportation.

Design: Cross-sectional study.

Setting: Research centers and a specialized assistive technology (AT) clinic in Pittsburgh (Pitt). Research centers and community-based rehabilitation technology suppliers in Saint Louis (SL).

Participants: Seventy wheelchair users with SCI.

Interventions: Subjects from Pitt and SL completed a written survey of AT usage in daily activities.

Main Outcome Measures: Subjects were asked 5 questions within each setting (home, community, transportation) related to their perceived reason for functional limitations.

Results: The wheelchair was the most commonly cited factor limiting participation, followed by physical impairment and physical environment. Twenty-one percent of subjects with paraplegia reported pain as a limiting factor for their transportation use, significantly more (P=.047) than subjects with tetraplegia (3%). A trend (P=.099) was seen toward a higher percentage of subjects with tetraplegia (tetraplegia, 7%; paraplegia, 3%) reporting lack of equipment as a limiting factor for use of transportation. Differences were also seen across sites.

Conclusions: The wheelchair was the most commonly cited limiting factor, followed by physical impairment and physical environment. The wheelchair is the most important mobility device used by persons with SCI and the one that users most associate with barriers.

Key Words: Activities of daily living; Outcomes research; Rehabilitation; Spinal cord injuries; Wheelchairs.

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0003-9993/04/8511-8891\$30.00/0 doi:10.1016/j.apmr.2004.03.033 THE OCCURRENCE OF A spinal cord injury (SCI) leads to an enormous change in an individual's lifestyle. Limitations related to mobility can become critical, affecting ability to participate in nearly all activities of daily living.¹ Quality of life and perception of life satisfaction have also been shown to be affected.².³ Treischmann⁴ has suggested what a person with SCI must do to avoid deterioration of his/her health. Initially, the person should be involved in self-care and health care activities. Second, he/she should maintain appropriate participation in productive activities. Participation is defined as the extent of a person's involvement in life situations in relation to impairments, activities, health condition, and contextual factors.⁵

Assistive technology (AT) has been used by people with disabilities to facilitate the return to as many preinjury activities as possible.^{6,7} People with SCI rely on AT, and especially their wheelchair, to engage in many of life's activities. Wheelchairs are used to enhance function, to improve independence, and to enable a person to successfully live at home and in the community.^{6,7} On the other hand, a wheelchair may be perceived as negatively impacting a person's life if it does not enable him/her to participate fully in social and community activities.⁸

The combination of AT and environmental interventions affects participation. The International Classification of Function and Disability (ICF) has proposed a paradigm that considers the environment and AT in the determination of disability. The central theme of this new approach to studying disability is that, although medical indicators are necessary, they are not sufficient for developing complete explanations of disability. A person's functioning and disability is conceived as a dynamic interaction between impairments and environment. This new paradigm has great potential for demonstrating the role of wheelchairs in affecting disability and, ultimately, a person's participation.

Little empirical work has been done to assess the effects of wheelchair interventions on consumers. Research has focused on a narrow range of activities and has ignored the role of wheelchairs.²⁻¹⁰ Most literature on wheelchairs is focused around issues of design, consumer preferences, use, disuse, abandonment, cost, and policy.¹¹⁻¹³ What is not known is how wheelchairs and related factors of a physical disability affect overall participation. There is also a need for outcomes research in service provision and activities that support the wheelchairs service provision system.⁷ Hence, the user's assessment of daily participation as well as wheelchair provision needs to be considered to identify gaps in activity involvement by people with SCI.

The overall aim of this study was to investigate factors related to the wheelchair, impairment, and environment that affect the perception of participation of persons with SCI in activities performed in 3 settings: in the home, in the community, and during transportation. The specific aims were:

Table 1: Subjects' Demographic Information

	Mean Age ± SD	Average Time Postinjury	Gende	r, n (%)	Level of In	jury,* n (%)	Type of Whe	elchair, n (%)
Study Groups	(y)	± SD (y)	Men	Women	Tetra	Para	Manual	Power
All participants (N=70)	41±10	14±9	55 (77)	15 (21)	29 (41)	38 (54)	54 (77)	16 (23)
Pitt (n=37)	42±11	16±9	30 (81)	7 (18)	13 (35)	21 (56)	32 (87)	5 (13)
SL (n=33)	39±9	12±10	25 (76)	8 (24)	16 (49)	17 (51)	22 (67)	11 (33)

Abbreviations: Para, paraplegia; SD, standard deviation; Tetra, tetraplegia.

- To determine wheelchair and related factors that people with SCI rank as the most limiting for participation in the 3 settings.
- 2. To compare the perceived wheelchair and related limiting factors on participation between persons with tetraplegia and paraplegia for activities in all 3 settings. It was hypothesized that fewer factors limited participation for persons with paraplegia than those with tetraplegia for activities in all 3 settings.
- 3. To investigate whether differences exist based on location: Pittsburgh (Pitt) and Saint Louis (SL). Differences may result from geography, method of recruitment, and method of wheelchair service delivery.

METHODS

Participants

Seventy people with SCI who used wheelchairs for mobility provided written informed consent. All participants had been discharged from rehabilitation for at least 1 year and had to live in a community setting. Demographic information is listed in table 1. Institutional review board approval was obtained at each site before initiation of the study. Pitt subjects were recruited through research centers and through a comprehensive AT clinic that uses a client-centered multidisciplinary team approach. SL subjects were recruited from research centers and rehabilitation centers. In both locations, subjects were recruited via flyer or were approached by clinical study coordinators, who asked whether they were interested in participating.

Questionnaire

We used the Participation Survey/Mobility (PARTS/M) questionnaire in this study. The PARTS/M was specifically designed to define participation in the same manner as the ICF.¹⁴ The PARTS/M is composed of 25 major life activities. For this study, only 3 activities were analyzed: (1) moving around inside the home, which includes getting out of the bed,

getting out of the chair, and going from room to room or getting to another floor (eg, the basement); (2) leaving the home, which includes going out into the community (eg, go shopping, go to doctor, get into a vehicle); and (3) transportation, which involves accessing and using different forms of transportation. Subjects were asked 5 questions within each setting related to their perceived reason for functional limitations (tables 2, 3).

Although not specific to SCI, previous work on the PARTS/M involving 108 polio survivors showed internal consistency values for the *P* evaluative scores ranging from .39 to .77, with most values over .65.¹⁴ The test-retest values were more than .87 for the specific mobility questions used in this study. Comparison of the cross-population similarities and differences are currently under way.¹⁴

According to the PARTS/M, subject responses were divided into 2 categories: (1) participation limitations, defined as health-related factors that interfere with the ability to do activities (eg, wheelchair, physical impairment, wheelchair seating, pain, fatigue, illness), and (2) access limitations, defined as non-health-related issues that interfere with the opportunity to participate in activities (eg, wheelchair, physical environment, wheelchair seating, lack of assistance, lack of equipment, social attitudes, self-concept, family attitudes). These specific definitions are written into the first page of the questionnaire and were read by each subject. As consistent with the PARTS/M, the wheelchair and wheelchair seating were cited as part of participation limitation, because they are used to compensate for health conditions (ie, inability to walk). For example, manual wheelchairs for most individuals limit distance traveled, whereas power wheelchairs that do not go through gravel and sand limit participation in those environments.

Statistical Analysis

SPSS software^a was used to calculate frequencies of perceived limitations. The frequency of perceived reasons for limitation in activities performed at home, in the community,

Table 2: Factors That Limit Participation in Activities in the Home, in the Community, and During Transportation

Factors	Is your participation in moving around your home limited by	Is your participation in leaving your home limited by	Is your participation in using transportation limited by
Wheelchair	69	64	61
Physical impairment	41	36	39
Wheelchair seating	16	14	16
Pain	11	13	14
Fatigue	6	11	9
Illness	3	6	3
No limitation	19	23	20

NOTE. Values are percentage of participants.

^{*}Data on level of injury was unavailable for 3 subjects.

Table 3: Factors That Limit Access to Community and Transportation

Factors	Is your access to leaving your home to go out into the community limited by	Is your access to using transportation limited by
Wheelchair	53	67
Physical environment	47	41
Lack of assistance	19	9
Wheelchair seating	14	13
Limited finances	NA	16
Social attitudes	9	7
Lack of equipment	7	3
Self-concept	7	3
Family attitudes	1	1
No limitation	14	20

NOTE. Values are percentage of participants.

Abbreviation: NA, not applicable.

and during transportation was used to calculate the percentage that each factor was perceived as a limitation. Percentages were reported both for subjects with paraplegia and tetraplegia. The differences between the perceived reasons for limitation at the Pitt and SL sites were examined for each task using a chi-square test or Fisher exact test, as appropriate. Differences between perceived reasons for limitations to complete a task for subjects with paraplegia and tetraplegia were analyzed using a chi-square test. To assess group differences between the 2 clinical settings, demographic characteristics (gender, injury level, type of wheelchair) were compared using a chi-square test. The significance level was set a priori at less than .05. In addition, we report trends where the *P* value was less than .10. No correction was made for the multiple statistical comparisons because of the relatively small sample size.

RESULTS

All Participants

The wheelchair was most often cited as limiting participation in each of the 3 settings, followed by physical impairment and environment. Table 2 illustrates the relative percentages of perceived participation limitations for all respondents. Table 3 illustrates the relative percentages of perceived access limitations for all participants.

Level of Injury

Thirty-eight subjects (95%) with paraplegia used manual wheelchairs, and 29 subjects (55%) with tetraplegia used power wheelchairs. Subjects with paraplegia (21%) reported pain as a perceived limiting factor for their transportation use significantly more (P=.047) than people with tetraplegia (3%). A trend (P=.099) was seen toward a higher percentage of subjects with tetraplegia (tetraplegia, 7%; paraplegia, 3%) reporting lack of equipment as a limiting factor for use of transportation.

Study Location

Demographics. The only significant demographic difference found between Pitt and SL was type of wheelchair used (P < .05). A greater number of subjects in Pitt (87%) used manual wheelchairs, and a larger number of subjects from SL (33%) used power wheelchairs. All participants (100%) with paraplegia in Pitt used manual wheelchairs, whereas 69% of participants with tetraplegia used manual wheelchairs. Eightyeight percent of respondents with paraplegia in SL used manual

wheelchairs, whereas 44% of subjects with tetraplegia used manual wheelchairs.

Participation limitation. For activities in the home, there was a trend toward a higher percentage of SL participants (SL, 18%; Pitt, 5%; P=.094) indicating pain as a perceived limiting factor. For leaving the home, a higher percentage of subjects from SL reported wheelchair seating as a perceived limiting factor (SL, 24%; Pitt, 5%; P=.025); whereas for transportation, SL subjects trended toward being more likely to report fatigue as a limiting factor (SL, 15%; Pitt, 3%; P=.061).

Access limitation. Data showed a significant difference in 3 of the 9 perceived limiting factors for leaving one's home. SL subjects were more likely to indicate that wheelchair seating (SL, 24%; Pitt, 5%; P=.028), social attitudes (SL, 18%; Pitt, 0%; P=.007), and self-concept (SL, 15%; Pitt, 0%; P=.015) were limiting factors. For factors affecting transportation, a greater number of participants from SL reported social attitudes (SL, 15%; Pitt, 0%; P=.017) as a limiting factor.

DISCUSSION

The data indicate patients perceived that the main cause of limited participation inside the home, outside the home, and during transportation was the wheelchair. The wheelchair is most likely the most important mobility technology, but it is also the device most associated with barriers. According to Post et al,¹⁵ there are significant complaints about wheelchairs among subjects with SCI. Manual wheelchairs are often considered heavy and difficult to maneuver. The dimensions of the mobility device base will affect how the wheelchair can negotiate through tight spaces. Similarly, Mann et al⁸ found that 26% of the problems associated with a wheelchair were related to the physical characteristics of the wheelchair (too heavy to push, too wide to use inside the home). In a real sense, a wheelchair is an extension of the user's body. Therefore, it is critical that any wheelchair must match the user's current expectations, preferences, physical needs, and functional requirements based on his/her interactions with the environment.16

It is interesting to note that subjects identified their wheelchair as more limiting to participation than their impairment. In other words, lower-limb paralysis did not keep them from going up a curb, their wheelchair did. It is possible that at some point after their injury, people with SCI accept their impairment as part of themselves and no longer see it as the main cause of limitations. Subjects instead see inadequate technology as the factor preventing them from doing more. The wheelchair not being able to go up the curb becomes the source of frustration, not the physical impairment. This is likely a healthy adaptation to injury. According to ICF, the functioning of people with impairments is affected by technology and environment as much as by specific anatomic and physiologic deficits.⁵

The second most limiting cause of decreased participation in the 3 settings was the physical environment and physical impairment. The physical environment can determine what tasks need to be performed and can impact the individual's ability to live independently.^{17,18} Richards et al¹⁹ reported that environmental access increases the likelihood that a person with SCI will engage in a variety of meaningful activities. In the study by Harrison and Kuric,²⁰ subjects with SCI identified ramps, wider doors, and wheelchair lifts as equipment that would make their homes completely accessible. People who had assistance available or who lived in wheelchair-accessible homes were more likely to use their wheelchair. However, people with lower income levels were less likely to have their homes modified.²¹ Dudgeon and Massagli²² also illustrated the importance of having an accessible environment in a school setting. They highlighted that barriers within school environments do not directly affect academic achievements among students with SCI, rather barriers discourage socialization and community participation.

Our study findings indicate that wheelchair seating was perceived as the third main cause of limited participation in the 3 settings, as well as the fourth access-limiting factor for leaving the home and transportation use. Mann et al⁸ reported that 41% of wheelchair problems are related to the fit between the user and the wheelchair (eg, uncomfortable to sit in). The lack of specific training for wheelchair prescription and fitting by suppliers and clinicians may have caused this finding. Experts indicated that most clinicians do not receive any specific training for prescribing wheelchairs.²³ Only a very small number of therapy or residency training programs dedicate more than a few hours to training students in the proper selection and use of AT, especially wheelchairs.²³

A greater number of persons with paraplegia reported pain as a transportation-limiting factor than did persons with tetraplegia. This may be explained by the fact that 95% of the subjects with paraplegia used manual wheelchairs, which require more effort to load and unload in and out of a vehicle. Another possible reason may be related to transfers in and out of the vehicle seat. Pain and injury of the upper extremities are experienced by as many as 70% of manual wheelchair users²⁴ and represent a form of overuse.²⁵ Persons with tetraplegia indicated that the lack of equipment is a limiting factor in transportation use. This may be due to difficulties in transporting a power wheelchair. Accessible transportation increases the likelihood that people with SCI will participate in the community.¹⁷

Our findings showed that the wheelchair and related factors were less limiting for Pitt subjects than for SL subjects. The data also revealed that a greater number of individuals from Pitt used manual wheelchairs, whereas a higher number of people from SL used power wheelchairs. It is possible that the differences between the 2 sites result from the differences in the 2 populations. Although an attempt was made to recruit in the same fashion at both institutions, differences in recruitment likely led to different populations examined. Unfortunately, our sample size was not large enough to allow us to control for this statistically. Other reasons that may explain differences between the 2 sites include the presence of a specialized wheelchair clinic in Pittsburgh. It is possible that such a clinic provided chairs better matched to the user and environment and

that this was responsible for the differences. To determine definitively whether a specialized wheelchair clinic makes a difference, a controlled longitudinal study is needed. Another important finding indicated that a greater number of subjects from SL indicated social attitudes and self-concept as an obstacle to participation in the community and transportation use. It is difficult to understand why these differences exist; however, Pierce²⁶ found that the public lacks understanding of the life of people with disabilities and that the attitudes of others can have an impact on activity performance. Therefore, consideration of social attitudes is essential when wheelchairs are prescribed.

It was identified through this study that wheelchairs and related factors impact daily participation of persons with SCI. Unfortunately, we do not have any data on the direct cause of those reported limiting factors. Finding the cause of the problems of each factor identified in this study would be useful to help us understand the limitations that people with SCI face in their daily routines. Studies are needed that investigate the impact of the seating interventions and related factors on changes in daily participation of a person with SCI. In addition, studies comparing a specialized wheelchair clinic to other forms of receiving a wheelchair evaluation are needed. Such studies could be used to advocate for social policy change in support of the provision of wheelchairs and in support of clinical practice guidelines.

CONCLUSIONS

The outcome of wheelchair use and related factors that affect perceived participation at home, in the community, and during transportation were identified among wheelchair users. The wheelchair was the most commonly cited limiting factor, followed by physical impairment and physical environment. The wheelchair is most likely the most important mobility device of persons with SCI, yet it is also most associated with barriers. Providing a wheelchair that fits well and is simple to operate without addressing environmental access may limit the potential benefits of the equipment. Similarly, an accessible environment is of no benefit if the equipment is difficult for the user to operate.

References

- Noreau L, Fougeyrollas P. Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. Disabil Rehabil 2000;22:170-80.
- Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Predictors of life satisfaction: a spinal cord injury cohort study. Arch Phys Med Rehabil 2002;83:555-61.
- Leduc B, Lepage Y. Health-related quality of life after spinal cord injury. Disabil Rehabil 2002;24:196-202.
- Treischmann RB. Spinal cord injuries: psychological, social and vocational rehabilitation. 2nd ed. New York: Demos; 1988.
- World Health Organization. International classification of functioning, disability, and health. Geneva: WHO; 2001.
- Scherer M, Cushman L. Measuring subjective quality of life following spinal cord injury: a validation study of assistive technology device predisposition assessment. Disabil Rehabil 2001; 23:387-93.
- Smith RO. Measuring the outcomes of assistive technology: challenge and innovation. Assist Technol 1996;8:71-81.
- Mann WC, Hurren D, Charvat B. Problems with wheelchair experienced by frail elders. Technol Disabil 1996;5:101-11.
- Hammel J, Lai J, Heller T. The impact of assistive technology and environmental interventions on function and living situation status with people who are ageing with developmental disabilities. Disabil Rehabil 2002;24:93-105.
- Anderson C, Krajci K, Vogel L. Community integration among adults with spinal cord injuries sustained as children or adolescents. Dev Med Child Neurol 2003;45:129-34.

- Kittel A, Marco A, Stewart H. Factors influencing the decision to abandon manual wheelchairs for three individuals with a spinal cord injury. Disabil Rehabil 2002;24:106-14.
- 12. Phillips B, Zhao H. Predictors of assistive technology abandonment. Assist Technol 1993;5:36-45.
- Donovan WH, Carter RE, Wilkerson MA. Profile of denials of durable medical equipment for SCI patients by third party payers. Am J Phys Med 1987;66:238-43.
- Hollingsworth HH, Gray DB, Morgan KA. Participation and environment measurement system: PARTS and FABS. Paper presented at: The American Public Health Association Annual Meeting; 2002 November; Philadelphia (PA).
- Post MW, Asbeck F, Dijk AJ, Schrijvers AJ. Services for spinal cord injured: availability and satisfaction. Spinal Cord 1997;35: 109-15
- Batavia M, Batavia A, Friendmans R. Changing chairs: anticipating problems in prescribing wheelchair. Disabil Rehabil 2001;23: 539-48
- Gray D, Gould M, Bickenbach JE. Environmental barriers and disability. J Architectural Plann Res 2003;20:29-37.
- Rogers J, Holm M. Task performance of older adults and low assistive technology devices. Int J Technol Aging 1991;4:93-106.

- Richards JS, Bombardier CH, Tate D, et al. Access to the environment and life satisfaction after spinal cord injury. Arch Phys Med Rehabil 1999;80:1501-6.
- Harrison C, Kuric J. Community reintegration of SCI persons: problems and perceptions. SCI Nurs 1989;6(3):44-7.
- Hoenig H, Pieper C, Zolkewitz M, Schenkman M, Branch L. Wheelchair users are not necessarily wheelchair bound. J Am Geriatr Soc 2002;50:645-54.
- 22. Dudgeon B, Massagli T. Educational participation of children with spinal cord injury. Am J Occup Ther 1996;51:553-61.
- 23. Cooper R. Wheelchair users are not necessarily wheelchair bound [editorial]. J Am Geriatr Soc 2002;50:771-2.
- Davidoff G, Werner R, Warning W. Compressive mononeuropathies of the upper extremity in chronic paraplegia. Paraplegia 1991;29:17-24.
- Nichols PJ, Norman PA, Ennis JR. Wheelchair user's shoulder? Shoulder pain in patients with spinal cord lesions. Scand J Rehabil Med 1979;11:29-32.
- Pierce LL. Barriers to access: frustrations of people who use a wheelchair for full-time mobility. Rehabil Nurs 1998;23:120-5.

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a. SPSS Inc, 233 S Wacker Dr, 11th Fl, Chicago, IL 60606.