

# **A MODEL OF PARTICIPATION IN COMMUNITY-BASED, DISCRETIONARY ACTIVITIES BY PEOPLE WHO USE WHEELCHAIRS**

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## **ABSTRACT**

This cross-sectional research analyzed an existing data set of 302 wheelchair users to identify the psychosocial predictors of participation in community-based, discretionary activities. Two defining elements of participation were studied: the extent of participation and satisfaction with participation. Descriptive analyses of the participants' demographic information and portions of four assessments were completed first. Regression analyses were then used to systematically eliminate potential covariates until the significant psychosocial covariates of the extent of and satisfaction with participation were identified. Perceived control over one's life and perceived reintegration to social function were found to predict the extent of participation. Perceived control also predicted satisfaction with participation as did the participant's general mental health.

## **INTRODUCTION**

This research used an existing data set to identify the social and psychological characteristics of wheelchair users that predict participation in community-based, discretionary activities. Discretionary activities are those that occur by choice, outside of work, chores, and self-care. Taking into account physical, environmental, and demographic contributors, this research examined the social and psychological characteristics of wheelchair users as predictors of participation in discretionary activities outside home.

The United Nations Convention of the Rights of Persons with Disabilities (the Convention) recognizes that discrimination against a person on the basis of a disability is a "violation of the inherent dignity and worth of the person" (United Nations General Assembly,

2006). The Convention is based, in part, on the principle of full and effective participation and inclusion in society. Research on participation is complex and this study is based on many theoretical models including Maslow's hierarchy of needs (levels of love and belonging and self-esteem), Oldenburg, King et al, Nosek and Fuhrer, and the International Classification of Functioning, Disability and Health (ICF) (Oldenburg, 1997; King, et al, 2003; (Nosek & Fuhrer, 1992; Jette, Haley, & Kooyoomjian, 2003; World Health Organization, 2001; Harris, 2007; Rimmer, 2006).

Many wheelchair users are limited in their participation in activities in their communities. The vast majority of wheelchair users (at least 93%) report a limitation in their ability to perform or participate in desired activities (Kaye, Kang, & LaPlante, 2002). Up to this point, little research has addressed the impact of psychosocial functioning on wheelchair users' participation in community-based activities focusing instead on the physical aspects of performing skills and participating in activities. Additionally, little research regarding wheelchair users addresses activities that are done by choice, in one's free time focusing instead on obligatory activities such as self-care and work. The need for this study was based on three main reasons: 1) limitations in physical rehabilitation programs and the education of physical rehabilitation professionals, 2) a focus in research on physical factors relating to wheelchairs and wheelchair use as a proxy for participation, and 3) the complicated nature of studying and explaining participation.

## **METHODS**

Data were analyzed using SPSS-PC for Windows Release 20.0. Upon receipt, the data set was examined for missing data using procedures described by the instrument authors to address missing data, as appropriate.

Descriptive analysis was performed on the participants' demographic information.

Three variables were derived from the The Participation Survey/Mobility (PARTS/M): Extent, Satisfaction, and Importance (Gray, D. B., Hollingsworth, H. H., Stark, S. L., & Morgan, K. A., 2006). Four variables were derived from the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36): Vitality, Social Function, General Mental Health, and Emotional Role Function (McHorney, C. A., War Jr, J. E., Lu, J. F. R., & Sherbourne, C. D., 1994). One variable, Perceived Control Over One's Life, was derived from The Personal Independence Profile (PIP) and one variable, Perception of Reintegration to Social Activities, was derived from the Reintegration to Normal Living Index (RNLI) (Nosek, M. A., Fuhrer, M. J., & Howland, C. A. 1992; Wood-Dauphinee, S., Opzoomer, M., Williams, J., Marchand, B., & Spitzer, W., 1988). The label for each of these variables came directly from the subscale name. Each variable was calculated using the appropriate instrument's scoring system.

Factor analysis, used to compute the coefficients of a principal component score for importance, determined that importance was comprised of two categories which I named cerebral importance (related to socializing, religious activities, and community activities) and dynamic importance (related to leisure activities, taking a vacation, and active recreational activities). Factor analysis determined that satisfaction was comprised of a single category.

Data analysis on the extent of participation and satisfaction with participation were performed separately following the same series of steps. First, the significant medical and demographic covariates were identified through discussions with this researcher's mentor and with experts in the field of physical rehabilitation. The list of factors was compared with the items in the data base and it was determined that the data base contained sufficient demographic and medical information to perform these analyses. Demographic and medical factors were investigated using regression analysis to determine the significant predictors of extent and satisfaction. Because the importance of each activity studied was thought to be a determinant of participation, the activity's importance scores were then

included in the regression analysis along with the significant demographic and medical covariates. This was necessary to determine the role that the importance of the activities played in predicting the extent of participation after controlling for the covariates.

## RESULTS

Data from 302 participants were analyzed. The mean age was 49.42 years (SD 15.66; range 17- 83 years, skewness 0.033, kurtosis -.65), 44.7% were male and 55.3% were female; 88.1% were white; 90% had at least a high school education or GED; 42.7% of the participants were married or part of an unmarried couple and 18.8% were separated, divorced, or widowed; and 17.9% reported having children living at home. Participants' reported a wide range of incomes with 44.4% reporting their annual income to be less than \$25,000. The participants reported living in a variety of housing situations. The mean amount of time the participants reported living at their current location was 16.07 years (SD, 14.22; range <1 - >61 years). Participants reported using both private and public transportation within their communities.

All participants were wheelchair users; 49% reported using a manual wheelchair only, 17.2% reported using a power wheelchair only, and 8.6% reported using a scooter only; 20.9% reported using both a manual and power wheelchair, 4% reported using both a manual wheelchair and a scooter, and 0.3% reported using both a power wheelchair and a scooter. However, participants' reasons for using multiple devices were not included in the data set.

The participants presented with various diagnoses requiring the use of a wheelchair for community mobility; 29.8% with spinal cord injury, 19.9% with multiple sclerosis, 22.5% with cerebral palsy, 21.9% with polio, and 6% with stroke. Participants reported the onset of their diagnosis as ranging from < 1 year to > 79 years. These data demonstrate normality with the exception of years since onset of the diagnosis of multiple sclerosis which is kurtotic (kurtosis is 3.52) due to the presence of one outlier. When this participant is removed from

the data set, the distribution is normal (skewness = 0.823, kurtosis = -0.075).

Five variables were predictive of the extent of participation: a diagnosis of cerebral palsy, dynamic importance, cerebral importance, perceived control, and perception of reintegration to social function. The diagnosis of cerebral palsy, general mental health, perceived control, and the extent of participation predicted satisfaction with participation.

## **DISCUSSION**

The following variables were eliminated as predictors of the extent of participation when importance was added to the model: years in the present living arrangement, education to grades 6-8 and 12 (or GED), and having a primary diagnosis of stroke. A diagnosis of cerebral palsy was the only medical or demographic covariate that remained a positive predictor of the extent of participation.

I expected that people who recently began using their wheelchairs would participate to a lesser extent than those who had used their wheelchairs for longer lengths of time because they needed time to acclimate to their condition and new status as wheelchair users. In this study, length of time since the diagnosis resulting in wheelchair use did not predict either extent of or satisfaction with participation.

The study data set included information about how much help participants required in hours per week. It also identified the caregivers. Neither the amount of help nor the identity of the caregiver predicted participation. Future studies should also account for the types of tasks for which assistance is needed such as personal versus household care. It is plausible to think that people who need assistance of a more personal nature, such as, for example, for dressing or feeding, would have more difficulty participating in discretionary activities than those who need help with less personal tasks like writing checks to pay bills or shopping for groceries. Conversely, however, it is also plausible that people who use more assistance might conserve energy for desired activities and therefore be more able to participate in discretionary activities.

Similarly broad arguments can be made regarding the people who provide assistance. It is equally plausible that a person may be more active if his or her assistant is a relative or a stranger dependent on the relationship they develop, the ease with which the wheelchair user can ask for help, and the strength with which (s)he makes his/her needs known. In this study, the amount of assistance used and the source of the assistance were not found to be significant predictors of participation. It may be however, if different questions were asked, the findings might show that assistance actually does predict participation.

The only medical or demographic covariate that predicted either the extent of participation or satisfaction with participation was a diagnosis of cerebral palsy leading to wheelchair use. Cerebral palsy predicted both a high frequency (extent) of participation as well as high satisfaction with participation. It is not obvious why this diagnosis would predict participation while other diagnoses leading to wheelchair use do not. It may be that growing up with a disability or as a wheelchair user impacts participation but this is not clear, especially since the length of time since the onset of the disabling condition was not found to predict either extent or satisfaction.

This study demonstrated that both cerebral importance and dynamic importance are significant positive predictors of the extent of participation. In order to understand the role of importance, it is necessary to study the concept in greater detail. Future research needs to address the characteristics that make an activity important to an individual, such as whether it is the activity itself or the interaction with other people. It would also be necessary to determine the reasons that people do not participate in activities they identify as important. There may be other factors that influence a person's participation in certain discretionary activities. This study was not sensitive enough to determine, for example, whether a person who thought a given activity was important or not is based on other factors like access to the activity's location or finances needed to participate.

There are several limitations to this study including the homogeneity in terms of race of the participants. The five medical conditions that led participants in this study to

use wheelchairs were spinal cord injury, stroke, cerebral palsy, polio, and multiple sclerosis. Four of the five diagnoses were fairly evenly represented in the participant pool (19.9%-29.8%) but only 6% of the participants were diagnosed with stroke as the condition leading to wheelchair use. It is not clear from the recruitment strategies why so few people who had strokes were recruited or agreed to participate. While having had a stroke did not predict participation in this study, so small a sample may not be representative of the population of people who had strokes in the areas from which participants were recruited. Additional research including more stroke survivors may reveal other important findings. Additionally, the data set did not include information about where the participants lived. It would have been interesting to know if there were differences or similarities between experiences of people in urban, suburban and rural settings.

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