TITLE: MEASURING PARTICIPATION AMONG WHEELED MOBILITY USERS

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Introduction

It is well established that people with mobility disabilities confront increased challenges to participation in daily activities. Although wheelchair users comprise less than one-quarter of mobility device users in the USA, the need for measurement of activity and participation transcends the size of this population. This is because, first, wheelchair users are more likely to be limited in everyday activities than other mobility device users. More than 90% of wheelchair users report activity limitations and only 14.7% are able to complete all of their activities of daily living (ADL) mobility tasks. Second, prevalence of wheelchair use has doubled in the last decade and is growing rapidly [1].

Lack of participation in home and community activities is the result of many factors, both intrinsic and extrinsic to the person. As researchers, we lack fundamental knowledge regarding the needs and problems that wheeled mobility device users confront while performing everyday tasks within their homes and communities [2]. There is also a lack of consensus among disability researchers on how to measure participation, both conceptually and methodologically [3, 4].

This paper describes a methodology to measure activity and participation among wheeled mobility users that is being developed at The Center for Assistive Technology and Environmental Access (CATEA) at the Georgia Institute of Technology. Designed to supplement traditional self-report instruments, it consists of the adaptation of passive, sensor-based techniques in order to monitor and document in-home and community movements of people with mobility disabilities. Through prompted recall interviews researchers query subjects' activities and participation in terms of their recorded movements and probe for the physical and social environmental barriers they routinely experience in everyday life. This is a descriptive methodology that imposes minimal burden on subjects while systematically gathering objective data on daily movements and activities.

Background

The importance of activity and participation is reflected in its inclusion in the recently revised International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This taxonomy attempts to capture the range of factors that may impact a person's experience of disability [5]. Participation and activity are one of four interrelated domains that together comprise peoples' experience of disability as described within the ICF. Activity is defined as "the execution of a task or action by an individual" whereas participation is defined more broadly as "involvement in a life situation." Two additional domains include medical descriptors of body structures and functions. The fourth domain identifies contextual factors both within the individual (personal factors) and outside the individual (environmental factors) which may impact activity and participation.

In addition, the ICF notes two essential characteristics of activity and participation. The first is *performance* ("what an individual does in his or her current environment"), and the second is *capacity* ("the ability to execute a task or an action"). *Capacity* is most often determined through clinical measurements of basic functional activities such as reach. *Performance* is usually evaluated through self report of activities in the context of a person's natural environment. It is most often associated with participatory behaviors reflected in social or occupational roles.

This is a key distinction for researchers. For example, a person may demonstrate the capacity for reach in a clinical environment using a mobility device, but be unable to reach an item on a kitchen countertop (performance), either because of the placement of the item or the height of the countertop. For rehabilitation purposes, it is important to discern between the functional capacity inherent within an individual and those features in the everyday environment which hinder or facilitate their performance of an activity.

Self Report Instruments

The most common method of measuring activity and participation to date is through self-report instruments. Although there are numerous issues that affect the quality and accuracy of self-report data in general [6, 7], they continue to provide the most time-efficient quantitative assessment tools for use across large populations. The past two decades have seen the development of numerous participation measures designed for multiple disability populations, e.g., [8-14]. Some strive to reflect normative values of society [8]; others employ a subjective, person-perceived approach [9, 12, 15], while one measure attempts to combine both [14]. However, with the exception of the Late-Life Function and Disability Instrument, none attempt to capture the distinction between capacity and performance in the measurement of activity and participation [10].

Despite these developments, most instruments are inadequate for measuring the effects of assistive technologies (AT) on peoples' activities in their homes and communities. First, with the exception of two instruments [9, 11], none consider the role of AT as it facilitates or hinders participation. This trend is consistent with results of a recent review of 100 instruments commonly used in rehabilitation research [16]. The authors argue that even when AT use is captured, it tends to lower overall scores. Contrary to the aims of AT service providers, this suggests that using technological aids reflects a negative rehabilitation score. In addition, scoring procedures are inconsistent across measures, reflecting ambivalence and lack of clarity regarding the role of AT in rehabilitation goals.

In order to measure the impact of wheeled mobility device use on activity and participation among its users, researchers need to design instruments that first, assume the potential positive effects of AT use in the performance of everyday activities and participation. Second, instruments need to be device-specific. That is, activities and participatory behavior need to be examined with reference to device use in everyday life.

Among self-reports, only the Community Participation and Perceived Receptivity Survey (CPPRS) targets mobility-specific characteristics that can be directly linked to the activities and participation of people who use wheeled mobility devices [11]. Instead of querying social roles and basic activities, it examines mobility-related participation in terms of common destinations, such as grocery stores, homes of family and friends, pharmacies, etc. For each location it queries the frequency of visits, assistance used, mobility device use, pain and fatigue, overall accessibility, transportation, social attitudes and the importance and satisfaction of these destinations. In addition, it evaluates the impact of environmental barriers and facilitators that make each location accessible or not.

From a mobility-specific point of view, the CPPRS articulates an innovative basis for measuring participation. It is grounded in the assumption that mobility is essential in order to accomplish tasks and participate within the community. Device use is examined as it provides a transition from one destination to another. The mobility-specific characteristics of this transition can be linked directly to participation in activities that are associated with a specific destination.

Wheelchair Activity Monitoring System (WhAMI)

The WhAMI methodology both extends the destination-based basis of activity and participation measurement and overcomes many limitations of current self report participation measures by being device-specific for wheeled mobility users. Monitoring people's daily activities through passive sensor-based techniques - such as accelerometer-based physical activity monitors - has been used to record accurate levels of physical activity over long periods of time for ambulatory populations [17-19]. However, prior to the ongoing study at Georgia Institute of Technology application to wheeled mobility devices had not been systematically applied. Only one study had measured the average speed, distance, and frequency of wheelchair users [20].

Global positioning systems (GPS) previously have been used in transportation and travel studies [21-24]. These projects demonstrate the ability of GPS to accurately capture distance, frequency, duration, and pattern of travel activity [22, 25] and its potential to capture mobility activities of people with disabilities who rely on wheelchairs and other mobility aids. However, limited work has been reported on the activity of wheelchair users [20] and the only current project combining technology-based activity monitoring with participation measures is ongoing at Georgia Tech [26, 27].

When joined with a prompted recall interview WhAMI obviates the accuracy problems associated with self-report measures. For example, when used with an ambulatory population GPS data tend to be highly accurate in reporting the number and length of trips - more so than self-report measures [21, 25, 28]. In addition, by having this data at hand prior to the interview, it is no longer necessary to ask subjects to estimate the frequency of past activities. Rather, the time saved can be used to query more extensively into the participatory and environmental context of activities, thus minimizing subject burden and maximizing accuracy of frequency reports.

As an example of the application of this methodology researchers at Georgia Tech instrumented 37 power upright or power tilt-in-space (TIS) with WhAMI. A convenience sample of full time wheelchair users aged 18-60 was recruited over a two-year period from Shepherd Center, an acute rehabilitation hospital in Atlanta, Georgia. Subjects signed informed consent forms prior to beginning their participation in this study. In addition to WhAMI, a series of self-report measures were administered following de-instrumentation of subjects' wheelchairs. These included measures of general health (SF-8), the CPPRS, a study-specific survey regarding device use in the home, and a prompted recall interview.

WhAMI instrumentation included a wheel revolution counter, seat occupancy sensor, seat position sensor and GPS receiver. Wheelchair data were recorded in two second epochs. Data logged included the sum of wheel counts over the epoch, the state of occupancy as a binary value and the position of the seat at the end of the epoch. The GPS receiver was attached to the wheelchairs and collected geolocation data at five second intervals.

Subjects' wheelchairs were instrumented with WhAMI for 2 weeks, and upon removal, post-processing of the data was done with custom code (GeoStats Inc, Atlanta, GA) and in-house using custom Matlab code. Using this data, mobility bouts were calculated. A mobility bout was defined as a bout of movement initiated when a subject travels a minimum of 2 feet within four seconds and continues until the subject travels less than 2.5 feet over 14 seconds. This allowed for natural hesitations in movement but identified pauses meant to accomplish tasks as ends of bouts.

Power wheelchair users in this study traveled less than wheelchair users previously reported [20]. Physical activity literature reports that healthy ambulatory adults walk between 1.5 and 2.7 miles daily [18, 29, 30]. The wheelchair users in this study wheeled less than their ambulatory counterparts. We will attempt to determine the causes of this discrepancy once a complete data set is obtained. Data indicated that subjects used many small bouts of movement, averaging 100 bouts per day. This result supports the concept that mobility for people who use *wheelchairs may function mostly* as *transitions between activities or spaces*. Thus, an overall daily distance may not be the most effective measure of mobility without detailed bout or frequency information.

GPS Prompted Recall Interview. GPS data were overlaid onto Geographic Information System (GIS) information. Maps were created depicting travel and destinations and were incorporated into web-based GPS Recall interviews. The locations of habitual destinations, collected from the subjects during instrumentation, were added to the maps (i.e. Shepherd Center and Home in Figure 1) to provide landmarks for the prompted recall interview.

A prompted recall interview was administered to subjects within 48-72 hours of de-instrumentation of the wheelchair. Subjects were queried for the name of destination and type of activity conducted there. Activities were classified as 1) Work or School, 2) Daily Living Task (e.g., grocery shopping), 3) Social (e.g., attending church or having dinner with friends), 4) Entertainment, Recreation, Leisure (e.g., attending a concert, baseball game, or visiting a park), 5) Travel. When destinations were unclear subjects were prompted to recall with the cross streets identified using the GPS/GIS data (Fig1). In addition, subjects were queried about mobility aid(s) used at each destination, traveling companions, and mode of transportation

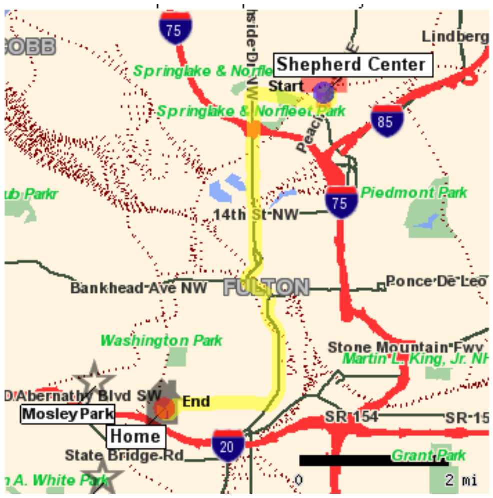

Figure 1: An example of GPS data showing a subject's trip between Shepherd Center and his home.

Analyses were performed based on definitions of trips and bouts of mobility. A trip was defined as travel between two destinations. Completion of a trip was defined as a 2 minute stop. A tour was defined as a round trip to and from home, including all trips and destinations therein. Parameters were calculated from data to determine answers to the following: number of trips within the community, distance traveled outside the home, number and types of activities conducted at destinations.

The analyses described here combine quantitative data and prompted recall information to describe wheelchair use at destinations based on activity type (Table 1). Two subjects are highlighted in Table 1. Although Subject B visits fewer places on the average day than Subject A, the majority of his wheelchair use takes place out of the home. Figure 2 geographically illustrates Subject C's activity patterns as reflected in the time spent at each destination and by activity type. Such graphic representations of subjects' participatory behavior can link different combinations of quantitative and prompted recall variables. For example, activity type and destination can be linked to number of hours spent at various destinations per day to determine relative temporal or spatial intensity of various activities per day. In turn, such maps can be linked across a range of variables (e.g., type of disability, number of mobility aides, income, age, or gender) in order to examine broad patterns of activity and participation.

Table 1

		DESTINATIONS			WHEELCHAIR USE		
	activity type	**# unique destinations (avg / day)**	**# visits / day**	**# hrs spent there /day**	**% time spent wheeling**	**# bouts of mobility**	**distance wheeled (feet)**
Subject A	**Undefined**	0.08	0.08	0.5	0	0	0
	Work/School	0.46	0.54	4.1	9	22	435
	Daily Living Task	0.85	0.85	0.7	13	33	709
	Entertainment	0.15	0.15	0.3	1	2	60
	Social	0.08	0.08	0.3	2	6	103
	Home	1	1.77	15.9	11	19	821
	Total	2.62	3.46	21.8	37	81	2128
Subject B	**Undefined**	0	0	0	0	0	0
	Work/School	0	0	0	0	0	0
	Daily Living Task	0.31	0.31	0.2	21	35	1681
	Entertainment	0	0	0	0	0	0
	Social	0.31	0.38	0.4	18	30	1487
	Home	0.77	1.31	16.5	2	3	199
	Total	1.38	2	17	41	68	3367

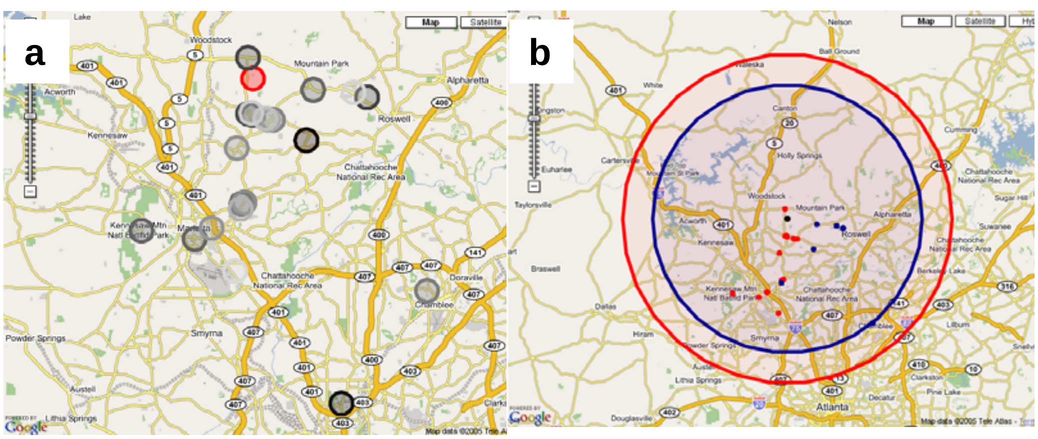

Figure 2: Subject C's activity patterns are represented geographically a) by the time spent at each destination. (red=home, black = short time → white = long time) and b) by activity type (black=home, red = daily living tasks, blue = entertainment, radius of large circle is the farthest distance traveled for that purpose).

Potential Applications of WhAMI

The development of WhAMI will significantly add to our understanding and measurement of activity and participation, both in the home and community, among wheeled mobility device users. As a methodology, it is intended to be a flexible and versatile research tool that can be adapted for various research projects that examine mobility and mobility aids. Its innovativeness lies in the ability to investigate what constitutes participation or "involvement" - not just in terms of destinations achieved or pre-formed categories of activities and social roles – but within the specific contexts of people's travels. It also offers the potential to query complex mobility patterns and activities among people who use a variety of mobility aids.

This integrated methodology also links activity *performance* - as captured within a subject's natural environment - to *capacity* as measured within a controlled clinical environment. As an example, functional outcomes studies, which seek to measure the impact of an intervention, rely exclusively on either self-report or measurements taken in a clinical setting. WhAMI can provide objective data against which clinical measurements can be compared in order to chart progress toward individual rehabilitation goals. Moreover, because this methodology is *descriptive,* it can be used to articulate more succinct categories of activity and participation within the ICF as they reflect wheeled mobility use. WhAMI can contribute valuable normative data about activity and participation that, in turn, may inform the basis of increasingly sensitive and accurate self-report measures.

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