

*A Case Study Comparing Activity and Participation Measurement in Two Subjects*

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ABSTRACT

This case study compares the differences between complementary methodologies that measure activity and participation in two subjects who use wheeled mobility devices. Data collection consisted of 1) a self-report participation measure for people with mobility disabilities - the Community Participation and Perceived Receptivity Survey (CPPRS) - and 2) a passive instrumentation data-gathering methodology that includes a global positioning system (GPS) data logger, followed by a prompted recall interview (PRI) to confirm GPS data location and query activity purpose. Many of the destination types (e.g., grocery stores) named in the CPPRS were confirmed by GPS/PRI data. Issues affecting subject responses in both methods included ambiguous categories and researcher assumptions about the nature of activity. Differences between self-report and instrumentation data are discussed as they impact understanding activity and community participation among wheeled mobility users and the development of self-report participation instruments.

KEYWORDS: wheeled mobility; participation; outcomes; GPS, self-reports

BACKGROUND

The measurement of activity and participation has emerged in recent years as a key area of outcomes research [1-5]. Most self-report measures of participation are intended for use across all disability populations e.g., [6-8] or else target a specific population, such as the elderly [9]. Participation is generally assessed in terms of the effectiveness and/or ease with which activities of daily living and social roles are performed.

There are numerous problems associated with the application of these measures among people who use wheeled mobility devices – not the least of which is how assistive technology (AT) is assessed (or not) and scored [10]. The CPPRS is a recent measure that was developed exclusively for people with mobility disabilities. Instead of querying social roles and basic activities, it examines mobility-related participation in terms of common monthly and yearly destinations.

<Table 1 Goes Here >

For each location the CPPRS asks the frequency of visits, assistance and mobility device used, pain and fatigue experienced, overall accessibility, transportation mode, social attitudes, importance, choice, and satisfaction. In addition, it evaluates the impact of environmental barriers and facilitators that make each location accessible or inaccessible.

A complementary methodology to measure participation among wheeled mobility users was developed at the Center for Assistive Technology and Environmental Access (CATEA) at the Georgia Institute of Technology[11, 12]. It uses 1) activity monitoring technologies to provide independent, quantitative data, and 2) a prompted recall interview (PRI) through which researchers may corroborate or probe more extensively into recorded activities and participatory behaviors. The Wheelchair Activity Monitoring Instrument (WhAMI) is attached to a subject's wheelchair and consists of wheel revolution counters, seat occupancy sensors, position sensors, and global positioning systems (GPS) to track wheeled mobility use. After a subject's wheelchair has been de-instrumented, a prompted recall interview (PRI) is administered with 48 to 72 hours in order to probe more deeply into the contexts of an individual's movements.

This case study will compare results between the CPPRS and the WhAMI in two subjects as they impact an understanding of their activities and community participation. Differences in reported data

from both the self-report measure and instrumentation data will be discussed in terms of the strengths and weaknesses of each method, researcher assumptions, and the development of future self report measures of participation.

## METHODOLOGY

Research conducted at CATEA between 2004 and 2006 examined the relationship among tilt-in-space wheelchair users, activity and participation, health, and quality of life outcomes. Thirty subjects' wheelchairs were instrumented with a data logger and sensors that included wheel counters, seat occupancy sensors, tilt sensors, and a GPS unit for a two-week period. A prompted recall interview (PRI) was administered within 48 to 72 hours after chairs were de-instrumented to determine the activity purpose at recorded destinations, subjects' mode of travel, and travel companions. Within two weeks following instrumentation, subjects were also asked to complete the CPPRS via web or phone interview.

Two out of 30 total subjects were selected for case study analysis. These subjects were selected based on the high quality of the instrumentation, PRI, and CPPRS data. Data from the CPPRS were compared to data derived from the two-week instrumentation period and the PRI.

## RESULTS

Subject A is a 57 year old African-American man with quadriplegia from a spinal cord injury in 2002. He has used a tilt-in-space wheelchair for approximately 4.5 years. The subject lives in a multi-level, single family home in a middle class suburb approximately 22 miles from Atlanta with his wife and adult son. The basement level of his home has been adapted for wheelchair use including an accessible bathroom and entrance. There are no sidewalks in his neighborhood and stores and services are too distant to be directly accessible by wheelchair.

GPS data showed that he took approximately 29 trips (including return trips to the home) over the 14 days that his wheelchair was instrumented. The prompted recall interview revealed that he had an adapted van that either his wife or a friend drove on all trips. During these two weeks he visited the 9 locations identified in Table 2:

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Following the prompted recall interview, the subject completed the CPPRS. He indicated those locations that were most important and estimated how frequently he visited them in the past month. These results are summarized in Table 3.

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Because subjects' travels were captured for a two week period and the CPPRS requested estimates of visit frequency for the past month or year, comparison in the accuracy of frequency estimates was difficult. However, the GPS/PRI confirmed much of the CPPRS location data. Many locations captured by GPS data and prompted recall interview were consistent with those reported in the CPPRS. For example, Shepherd Center is an acute rehabilitation hospital in which the subject receives some of his health care. Gwinnett Center Arena is a 'sports arena' and Target is a popular 'large store'. These locations were documented in both the GPS and CPPRS data. However, where GPS data recorded 6 trips to Shepherd during the two weeks his wheelchair was instrumented, the subject estimated he made only 4 trips to the doctor over an entire year. It is possible that the subject received a wide range of health services at Shepherd, and that he did not conceive all his visits to Shepherd as being medical. Therefore, he may not have reported them as visits to "doctors' offices."

The subject also indicated in the CPPRS that, although visiting family and friends was important, their homes' inaccessibility prevented him from visiting them in the past month. In this instance, the

CPPRS was especially sensitive to a lack of participation in activities and destinations a subject may have wanted to participate in, but could not.

In another example, the subject noted in the CPPRS that gas stations and restaurants were unimportant destinations. However, GPS data showed that the subject visited 1 restaurant and 2 gas stations during the 2 week instrumentation period. One possible explanation for his rating these visits as personally unimportant, is that his behavior was influenced by the wishes of his wife to dine out one evening, and the gasoline requirements of his van, respectively. This underscores the impact of family members and, more generally, the environmental context in which people live, on peoples' activities and participation.

Another interesting GPS destination was the Regional Youth Detention Center where the subject volunteers to help troubled youth as part of his church ministry. In the CPPRS the subject described himself as retired and denied volunteer work. Yet, the PRI revealed this to be important to his sense of participation in the community. He described it as "my way of making a contribution."

Subject B is a 42 year old African-American man with quadriplegia who was 6 years post spinal cord injury at the time of his instrumentation. He has used a tilt-in-space wheelchair for approximately 3 years. He lives in a semi-attached apartment within an older suburb approximately 6 miles from downtown Atlanta. His home is completely accessible in terms of entering and exiting, bathroom, and moving between rooms. He lives alone and relies on Paratransit for all travel outside his immediate neighborhood.

GPS data showed that he took approximately 99 trips (including return trips home) over the 14 days of instrumentation. These trips were primarily in his wheelchair in his immediate community.

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CPPRS data indicated that the most important and frequented locations included grocery stores, pharmacies, restaurants, family and friends, public parks, shopping malls, doctor's office and DME providers (Table 5).

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Again, GPS data confirmed some CPPRS locations. For example, GPS data showed 3 visits to a convenience store (which also sells groceries), dining in a restaurant approximately every other day, and visiting his doctor once at Shepherd Center.

A notable feature of Subject B's recorded trips was the lack of a specific destination. On these trips he wheeled around his home and immediate neighborhood. These were categorized by CATEA research staff as "no destination" trips. The purposes of these trips were diffuse and not destination-specific. Purposes ranged from sitting in the sun, to seeing if any neighbors or friends were outside to chat with, to wheeling for the pleasure of mobility. Duration of "no destination" trips ranged from a few minutes to more than an hour.

There was no equivalent category in the CPPRS for this type of activity. However, upon review of the CPPRS data for this subject, it was noted that he reported visiting public parks approximately 104 times a year. The park named as the one he visited most frequently is very close to his home where most "no destination" trips occurred. It is possible that the subject chose the category of "public parks" in the CPPRS because it was the nearest park to his home and because it was the most approximate representation of these "no destination" trips in terms of their recreational and social purpose.

## DISCUSSION

Both the CPPRS, as a self report measure, and the GPS/PRI methodology offer complementary strengths in the measurement of activity and participation. They are unique among participation measurement approaches in that they offer a mobility disability- and device-specific method with which

to examine activity and participation. In addition, both are grounded in the assumption that mobility is essential in order to accomplish tasks and participate within a community. Wheeled mobility devices and other modes of transportation are examined as they provide transition from one destination to another and enable participation in activities both in the home and community.

In these two subjects, GPS and CPPRS data roughly approximated each other in terms of types of locations visited. However, estimates of CPPRS accuracy of activities were difficult to determine because activities were queried over different time periods (e.g., 2 weeks, 1 month, 12 months).

The CPPRS was better able to elicit those destinations subjects wanted to visit, but were unable to reach due to environmental barriers such as an inaccessible entrance (as in Subject A's case). In contrast, GPS data was better able to establish the specific locations visited and the purpose(s) of individual trips. Both subjects demonstrated the limitation inherent in self-report and researcher categories that contain, for example, assumptions regarding the connection between destination and activity (as in Subject B's recreational wheeling during his "no destination" trips).

In addition, the disjuncture between the self report and prompted recall responses regarding Subject A's volunteer activities indicates an ambiguity inherent in many self-report categories [13, 14]. For example, the household chores one performs as part of a social role and for which one does not receive a wage may not be viewed as "work" by a respondent. However, a personal aide who receives an hourly wage for performing these same chores may self identify as "employed." Similarly, volunteering contains multiple possible meanings and purposes, ranging from gaining experience for career development, to expressing one's personal values in a tangible way, to extending one's social network[15]. For Subject A, "volunteer" may have carried associated meanings inconsistent with how he regarded his ministry work. The inherent ambiguity of such self-report categories may deter subjects from accurately reporting their activities.

Data from these two subjects illustrate some of the challenges of accurately reflecting the activity and participation of people who use wheeled mobility devices. Self-reports will continue to be developed as outcome measures of activity and participation; they continue to provide the most time-efficient, quantitative assessment tools for use across large populations. However, an objective data collection system offers the opportunity, not only to accurately document travel patterns, but to probe activity purpose and wheelchair use without imposing preconceived societal categories or expectations. This method provides valuable normative data about activities, travel, wheelchair use which, in turn, may help inform and refine categories of self-report participation measures.

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