Development of An Outcome Measure Tool for Wheelchair Seating & Mobility Interventions: A Work in Progress

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This study is being conducted at the Rehabilitation Engineering Research Center on Wheeled Mobility and Seating at the University of Pittsburgh, and is funded by the National Institute on Disability and Rehabilitation Research.
Clinicians who provide wheelchair seating and mobility interventions are faced with a need for evidence-based outcomes. Evidence-based outcomes are needed to allow consumers to have a means of measuring the effectiveness of seating-mobility technology to meet their needs, and for funding sources to have an objective means of determining the costs and benefits of seating-mobility technology.
Quantitative indicators and functional status rating tools that document the effectiveness of seating-mobility interventions are a requirement in service delivery, and serve as a basis for research in the field of assistive technology. Service providers often develop their own clinical rating scales to document consumer status in their practices, but neglect to test their reliability or validity, nor do they have the time, skills or support of administration to participate in research or outcomes data collection as part of usual care.
The medical model focuses on the functional capabilities of consumers within the scope of their disease or disorder as opposed to considering what consumers want to do, where they want to do it, and what they need to allow them to do it. Functional status rating tools that measure consumers’ performance in activities that are meaningful to them allow service providers to detect changes in functional status based on perceived quality of life rather than the consumers’ ability to perform activities.
The purpose of this study is to systematically develop a new outcome measure that is concise and easy to administer by service providers, and has the ability to evaluate functional changes associated with seating-mobility interventions as perceived by the consumer.
The development of the outcome measure is designed to occur in three phases over a 5 year period. For Phase 1, we selected and evaluated existing functional measurement instruments with factors relevant to wheelchair users such as function, quality of life, and satisfaction. We also conducted videotaped interviews with 20 manual and power wheelchair users, and developed the initial items for the new outcome measure, titled Functional Evaluation in a Wheelchair or FEW. Phase 1 was completed and the findings will be presented.
For Phase 2 of the study we are currently examining the test-retest reliability of the FEW.
The objective for Phase 3 is to conduct clinical trials to determine if the FEW is capable of detecting changes in function following acquisition of new seating-mobility technology.
Inclusion Criteria

- Phase 1 (n = 30)
  - Manual/power wheelchair user with a progressive or non-progressive condition
- Phase 2 (n = 30)
  - Manual/power wheelchair user with a non-progressive condition
- Phase 3 (n = 40)
  - Manual/power wheelchair user with a non-progressive condition and receiving a new intervention

Phase 2 participants are eligible to participate in Phase 3, provided they meet the other eligibility criterion. Consumers with progressive conditions will not be recruited for Phase 2 and Phase 3 to eliminate change in function as a confounder in the development of the tool. However, the design of the FEW allows it to be applied to both populations.

Minimal cognitive and language status will be determined by the participant’s capacity to cognitively and linguistically respond to questions posed in the questionnaire.
Participants were recruited from the Three Rivers Center for Independent Living, local advocacy groups, and from a roster of individuals who had previously participated in focus groups and mobility research at the RERC, and agreed to be contacted for future research projects. 20 consumers agreed to participate in Phase 1.
Primary diagnoses
- Spinal cord injury \( (n = 5) \)
- Cerebral palsy \( (n = 4) \)
- Spina bifida \( (n = 3) \)
- Polio \( (n = 3) \)
- Multiple sclerosis \( (n = 2) \)
- Arthrogryposis, muscular dystrophy, and congenital limb anomaly \( (n = 1) \)

These were the primary diagnoses of the Phase 1 participants.
The average consumer was a wheelchair user for 27.9 years, and currently owned 2.1 wheelchairs or personal mobility devices. The length of time consumers had their current seating system ranged from 1 day to 20 years, and 1 day to 6 years for their current mobility system. Seventeen consumers had a professional involved in the decision making process in obtaining their current seating-mobility system, inclusive of an equipment supplier and manufacturer, a physician, occupational and physical therapists, and a seating-mobility service providers.
After evaluating existing functional measurement instruments to provide guidance in the development and scoring of the FEW, trained interviewers administered the Canadian Occupational Performance Measure. The COPM has consumers prioritize the importance of reported tasks or activities into three categories:

(1) Self-care (i.e. personal care, functional mobility, and community management)
(2) Productivity (i.e. paid/unpaid work, household management, and play/school)
(3) Leisure (i.e. quiet recreation, active recreation, and socialization)

The scaling system consists of 1 = highest priority to 10 = lowest priority.
The modified version of the COPM developed for use in this study asked consumers to report the importance of self-care, productivity, and leisure tasks or activities relating to function in their seating-mobility system, and included a detailed demographic section regarding the consumers current seating-mobility system, and the service delivery process involved with obtaining that system.

Based on consumer ranking of the items in each category, a reverse ranking system of 10 = highest priority to 1 = lowest priority was used to assign a weighted value to each item across all responses. The frequency of item responses and weighted values assigned by the consumers were then multiplied to yield a weighted rank order (WRO) value for each item. Consumers were paid $25.00 upon completion of the interview.
Data from the interviews yielded a total of 154 items across the three COPM categories. All items were then sorted based on shared characteristics into 21 categories derived from literature searches and review of other functional measurement instruments. Next, all items from the original 21 categories were reallocated to 10 categories for the purpose of creating an outcome measure that is concise and easy to administer, and reflects factors viewed by consumers as most affecting function in their seating-mobility system.
The final 10 FEW categories were:
Accessing task surfaces
Transfers
Transportation-accessibility
Natural barriers
Accessories
Transportation-securement
Human-machine interface
Architectural barriers
Transportation-portability
Reach
Method

Phase 1 participants validated the 10 FEW categories (n = 17)

Scaling system

- 10 = highest priority to 1 = lowest priority

Consumers self-administered the FEW, Beta Version, 1.0

Data analyses were conducted using SPSS

Approximately 6 months after completion of the interviews, 17 of the 20 Phase 1 participants responded to a questionnaire asking them to prioritize the importance of the 10 FEW categories relating to function as a seating-mobility system user. A scaling system of 10 = highest priority to 1 = lowest priority was used. We also had them complete the 1st version of the FEW for themselves, and provide feedback about the wording and content of the items, the scoring system, and to report aspects of seating and wheelchair mobility that are important to them, but not included in the FEW, Beta Version 1.0. Data analyses were conducted using SPSS.
Results

My wheelchair allows me to operate it easily:
(e.g., do what I want it to)

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<tr>
<th>Completely agree</th>
<th>Mostly agree</th>
<th>Slightly agree</th>
<th>Slightly disagree</th>
<th>Mostly disagree</th>
<th>Completely disagree</th>
<th>Does not apply to me</th>
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<tr>
<td>X</td>
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Based on the 10 FEW categories, items for the new outcome measure were developed. The FEW, Beta Version 1.0 consists of 10 questions in the format displayed on the slide in front of you. When the Phase 1 participants self-administered the FEW, the scoring system consisted of a 6 point scale of 6 = completely agree to 1 = completely disagree. We have now modified the scoring system to include the choice of ‘does not apply to me’.
When the items from the 21 categories were reallocated to 10 categories, the data indicated that accessing task surfaces, architectural barriers, and reach were the highest priority for seating mobility system users.
Transportation accessibility, transportation securement, and transportation portability were the lowest priority for seating mobility system users.
Consumer validation of the 10 FEW categories indicated seating-mobility system users ranked architectural barriers (mean 7.00), transfers (mean 7.00), and accessing task surfaces (mean 6.41) as the highest priority.
Transportation-securement (mean 4.88), natural barriers (mean 4.18), and accessories (mean 4.00) as the lowest priority.
Based on responses on the self-administered FEW Beta Version 1.0, more consumers agreed they were able to operate their wheelchair, transfer from surface to surface, and access public transportation.
However, consumers were less positive regarding the securement of their wheelchair during transportation, accessing to various task surfaces, and getting around outdoors in their wheelchair.
The results of Phase 1 indicated consumers have unmet needs in their current seating-mobility systems that affect their quality of life and occupational performance in the areas of self-care, productivity, and leisure. Our data also showed consumers responses changed when they were asked to prioritize the importance of the FEW categories for wheelchair users in general versus themselves. This variation was demonstrated, for example, for the human-machine interface, in which consumers viewed this FEW category as a low priority for seating-mobility system users, but as the highest priority individually on the FEW, Beta Version 1.0. These findings provided support for the validity of the FEW as a dynamic indicator of function for consumers using seating-mobility technology. Additionally, the results of Phase 1 demonstrated a need to further study and evaluate the goals and abilities of consumers concerning provision of the most appropriate technology to improve or maintain function.
The FEW is expected to benefit consumers by ascertaining the level of functional change as a result of receiving the most appropriate technology. Secondly, a validated outcome measurement tool will enable service providers to demonstrate the efficacy of seating-mobility interventions, and help validate the cost effectiveness and functional value of seating-mobility interventions to consumers and third-party payers.
Thank you for your attention!

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