Chapter 6
Measuring the Effectiveness of Assistive Technology on Active Aging: Capturing the Perspectives of Users

Jeffrey Jutai and Kenneth Southall

6.1 Introduction

The United States' Assistive Technology Act (1998) defines assistive or adaptive technology as "…any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (SEC. 3. DEFINITIONS AND RULE subsection 3). This chapter uses the term mobility assistive technology (MAT) to describe a category that includes both assistive devices (applied to or directly manipulated by a person—e.g., a cane, walker, or wheelchair) and special equipment (attachments to the original structure of the physical environment—e.g., grab bars in the bathroom) that are designed to improve mobility.

It is helpful to distinguish the effects of medical and assistive technologies since the latter are especially important in supporting active aging (Jutai et al., 2009a). Medical technologies are more narrowly defined and are designed for assessment and intervention at the level of physical health and healing or, in the language of the International Classification of Functioning, Disability and Health (ICF), *body function and structures* (World Health Organization [WHO], 2001).

J. Jutai, Ph.D., C.Psych. (✉)
Interdisciplinary School of Health Sciences, University of Ottawa, 25 University Street, Ottawa, ON, Canada K1N EN5
e-mail: jjutai@uottawa.ca

K. Southall, Ph.D.
Institut Raymond-Dewar Centre de recherche interdisciplinaire en réadaptation, 3600 rue Berri, Montréal, PQ, Canada H2L 4G9
e-mail: southall.kenneth@gmail.com

A. Sixsmith and G. Gutman (eds.), *Technologies for Active Aging*, International Perspectives on Aging, DOI 10.1007/978-1-4419-8348-0_6,

Medical devices are not designed to directly and appreciably improve quality of life (QoL) and well-being. These improvements are much more influenced by MAT which helps individuals to engage in life activities and participate in society. Assistive technology provides a platform to support active aging as defined by the WHO. The challenge, however, is to demonstrate the efficacy of particular devices.

6.2 Challenges for Outcomes Measurement

According to the ICF (WHO, 2001), participation refers to the involvement of an individual in a real-life situation. A participation restriction is experienced when, for example, a person has difficulty attending educational classes or other learning activities or engaging in social activities with family, friends, neighbors, or groups. Very commonly, these difficulties result from diminished mobility that occurs naturally with aging or from illness or injury experienced while aging, and many forms of rehabilitation are available to accommodate them. Participation measures, particularly those that measure subjective participation, provide important information for individuals working in the field of rehabilitation since they assess how the individual is doing in the community, which some would argue, is the ultimate rehabilitation outcome. In fact, participation has been termed the most meaningful outcome of rehabilitation (Cicerone, 2004); however, it is probably also the most challenging to measure since there are many things that contribute to a person's level of participation (Dijkers, 2010).

6.3 Does Mobility Assistive Technology Enhance Participation?

This question is more difficult to answer than one might expect. Historically, it was assumed that beneficial effects of assistive technology on participation must be obvious and easily observable, but since they often are not, there is a dearth of studies showing positive outcomes (Fuhrer, Jutai, Scherer, & DeRuyter, 2003). Most existing health and rehabilitation studies have one of three limitations (a) assistive technology impact is not even considered, (b) where it is, there is a failure to recognize that use of assistive technology lowers the functional impact score, and/or (c) the impact is not attributed to specific assistive devices (Rust & Smith, 2005). A review of 20+ years of published assistive technology outcomes research (Lenker, Scherer, Fuhrer, Jutai, & DeRuyter, 2005) revealed several trends in outcome measurement. Device usage and usability accounted for almost 70 % of the dependent variables appearing in the literature, while outcome domains such as functional level, participation, and quality of life accounted for less than 30 %. Of 212 outcome variables used in 82 reviewed articles, 79 % ($N = 168$) were measured using non-standardized, study-specific measurement tools with scant reporting of the psychometric properties of the tools used.

As a result of the field's approach to measurement, the assistive technology outcomes research literature is vulnerable to one of three fundamental flaws (a) genuine treatment effects may be undetected because of measures that have weak reliability; (b) tools lacking validity may result in systematic underestimation, overestimation, or misrepresentation of treatment effects; or (c) the impacts of MAT in outcome domains of interest are simply not measured.

Other limitations of measurement tools include narrowly defined outcome domains, lack of comparability of results across instruments, and unacceptable trade-offs between instrument precision and practical implementation. Additionally, many measurement tools cannot be used across the variety of settings in which rehabilitation services are provided, nor along the continuum of care (Jette & Haley, 2005; Jutai, 1999; Jutai, Ladak, Schuller, Naumann, & Wright, 1996; Lenker et al., 2005; Seale & Turner-Smith, 2003). The available pool of traditional measures, in other words, is inadequate to measure outcomes of use of mobility assistive technologies. New tools and techniques are needed. MAT outcomes, including impact on participation as defined by the ICF (WHO, 2001), must be understood and measured within the context of personal choices and activity-level factors. The inherent complexities of this model can only be measured efficiently using dynamic assessment techniques, such as computer adaptive testing (CAT) built on item response theory (IRT) approaches (Gershon, Heinemann, & Fisher, 2006). Input from diverse stakeholder groups is required to form a conceptual basis of MAT outcomes and to assure relevance across a range of disabling conditions. Our research program, described below, addresses these challenges.

6.4 Assistive Technology Outcomes Profile for Mobility

The Assistive Technology Outcomes Profile for Mobility (ATOP/M) is based on state-of-the-art applications of IRT and CAT and designed for evaluating the impact on activities and participation of increased mobility resulting from the use of MATs. With the ATOP/M, the impact can be attributed to specific assistive devices. With CAT, the respondent's ability level relative to a norm group can be iteratively estimated during the testing process and items can be selected based on their current ability estimate. Thus, respondents will receive few items that are very easy or very hard for them. This tailored item selection can result in reduced standard errors and greater precision with only a handful of properly selected items.

The targeted populations for the ATOP/M are adults who have a mobility disability, as defined by the ICF (WHO, 2001) that limits their ability to move from place to place independent of any form of assistance. The ATOP/M is applicable to all relevant conditions that produce this disability and to all settings in which mobility devices may be used, including transfers to/from mobility devices.

An important feature of our research is that it has been very sensitive to the perspectives of MAT users. The ATOP/M includes information that users believe would assist them in better adopting and using an outcomes measure. It presents items in ways that users find understandable and sensible.

6.5 Materials and Methods

The first step in developing the instrument was to assemble an item pool. A total of 148 items were drawn from the Patient-Reported Outcomes Measurement Information System (PROMIS, 2008), the Community Participation Indicators (CPI, v. 4) from the Rehabilitation Research and Training Center (A. Heinemann, personal communication, January 21, 2008), and over a dozen other instruments (Jutai et al., 2009b). Items were mapped to the ICF to ensure adequate coverage of relevant domains. Gaps in content were identified, and items were added from the other instruments. Nine focus groups were then conducted in the USA and Canada with multiple stakeholder groups to identify additional items that were needed and to refine item wording and response format (Hammel et al., 2012). The participants included 45 mobility device users, 10 caregivers of device users, and 10 individuals involved in delivering mobility device services. MAT users had a wide range of diagnoses, including cerebral palsy, multiple sclerosis, spinal cord injury, acquired brain injury, stroke, and amputation. Mobility devices used included canes (quad, single point, side), walkers (wheeled, side), wheelchairs (manual and powered), scooters, prosthetic legs, and crutches. The focus group discussions were analyzed thematically. Items were subjected to binning and winnowing by an expert panel and then cognitively tested with 20 device users.

The ATOP/M pool was field tested in a web-based survey of MAT users to calibrate items. A total of 1,037 subjects were recruited from a national data registry. Sample characteristics were as follows: the age range was 16–95 years, 41 % were male and 81 % were white. Canes (32 %), power (18 %) and manual (13 %) wheelchairs, and walkers (14 %) were the most commonly used devices. Users had a wide range of conditions responsible for their mobility difficulties, including cerebral palsy, multiple sclerosis, spinal cord injury, acquired brain injury, stroke, and amputation. Examples of ATOP/M items are presented below.

Rasch analyses were conducted to create full-length and short-form instruments, and an item bank for CAT applications was developed. The criterion for determining the reliability of the measures, separation reliability, was a value of 0.80, a value that distinguishes at least three distinct strata of respondents (high, average, and low) and a relatively wide range of task frequency (expected to be at least 4 log-odd units) for the items. The internal validity of the scale was assessed using fit statistics. External validity was assessed by comparing the ATOP/M domain and subdomain measures for groups of respondents who differed in the type of assistive device they used. External validity was assessed by comparing the ATOP domain and subdomain measures for groups of respondents who differed in the type of assistive device they used.

The full-length ATOP/M consists of 68 items distributed across two domains, each having two subdomains: Activities (Physical Performance and Instrumental Activities of Daily Living) and Participation (Social Role Performance and Discretionary Social Participation). The naming of the domains and subdomains is consistent with the taxonomy published by the PROMIS project (Cella et al., 2010;

Hahn et al., 2010). The Activities domain is defined as one's ability to carry out various activities that require physical capability, ranging from self-care (activities of daily living) to more vigorous activities that require increasing degrees of mobility. The ATOP/M items have a *capability* stem and a corresponding *capability* set of response items (e.g., "Are you able to…normally, without any difficulty, with a little difficulty, with some difficulty, with much difficulty, unable to do") and are given in the present tense. The Activities domain has two related subdomains: Physical Performance (mobility and lower extremity function) and ability to carry out Instrumental Activities of Daily Living. The Participation domain is defined as involvement in one's usual social roles in life's situations and activities. It includes two subdomains that describe *social roles* such as work and family responsibilities and more *discretionary social activities* such as leisure activity and relationships with friends.

Respondents are asked to answer each item under two different conditions—with device and without device. The instructions are presented as follows:

With device

For the following questions, you will be asked to think about how you usually do the activity, *with the use of a device*. This device can be the primary one that you identified during the previous part of the interview or any of the secondary mobility devices you identified.

Without device

You will now be asked to answer the same series of questions but this time thinking about your ability to do the activity *without* any *device*.

The following are example items.

Activities

Physical Performance: Are you able to get around your neighborhood or town?
Instrumental Activities of Daily Living: Are you able to do yard work like raking leaves, weeding, or pushing a lawn mower?

Participation

Discretionary Social Participation: Are you able to participate in active recreational activities?
Social Role Performance: Are you able to go to classes or participate in learning activities?

The ATOP/M yields two scores, one reflecting respondents' mobility level while using a device and the other reflecting their capability without it. As anticipated, the domain and subdomain measures were lower when respondents rated task difficulty when not using the device than when using the device. All item banks had acceptable reliability, were essentially unidimensional, and had acceptable model fit for most items. Evidence of validity was found in significant differences for persons using canes or scooters compared with those using manual or power wheelchairs (i.e., the unaided performance of wheelchair users was poorer than that of cane and scooter users).

Some of the items proposed by the focus groups did not survive the psychometric analyses. Although they had meaningful content for users, scores on these items did not have distributions and other statistical properties that were adequate for scale construction. These items concerned the effect of MAT on helping people to manage their disability:

Are you able to… use different options for getting around?
Are you able to… get support from other people who have disabilities to help you manage your disability?
Are you able to… get the services you need to better manage your disability?
Are you able to… get the information you need to better manage your disability?
Are you able to… use the Internet to find information that you need to better manage your disability?

In proposing these items for the ATOP/M, focus group members described how being effective at management meant that they could use their MAT to participate in the face of significant challenges in their physical and social environments. In comparison, individuals who could not manage well reported that they abandoned MAT or gave up choice and control in life participation (Hammel et al., 2012). Some focus group participants described using many different types of MAT, conceptualizing them as sets or integrated solutions. They pointed to a need to evaluate MAT outcomes in a way consistent with this reality rather than focusing on a single piece of technology.

6.6 Discussion

The ATOP/M comprises items that reflect activities and participation in areas that are important to users of mobility assistive devices. Items cover a wide range of functional ability and reflect most categories of the ICF framework. The instrument has excellent person and item reliability and no significant ceiling and floor effects. The ATOP/M has been translated into Canadian-French, and its validity is being further examined in several Canadian studies. A similar approach to instrument research and development is under way in Europe and has shown promising results (Brandt, Kreiner & Iwarsson, 2010; Brandt et al., 2008). It includes items derived from the ICF framework and has used Rasch analysis for scale construction.

The development of the ATOP/M revealed that end-users have some expectations for the impact of mobility assistive technology that are not easily measured. Assistive technology outcome assessment tool developers should consider ways to address these expectations. It is also useful to employ a variety of methodologies. For example, visual qualitative methodologies are increasingly being employed to investigate issues related to health care (e.g., Riley & Manias, 2004), and these has been successfully used with older adults (Lockett, Willis, & Edwards, 2005; Magilvy, Congdon, Nelson, & Craig, 1992). One such method, which we are currently using to better understand user perspectives, is called Photovoice. Photovoice

is a technique used by researchers and community members to represent their community (Wang & Burris, 1997) and to assess needs and study health promotion topics (Wang, 1999). In this technique, cameras are provided to elderly MAT users who are then asked to take photographs that portray, illustrate, symbolize, or represent their lives. Researchers meet with the photographers to discuss the meanings of the images that were captured, to understand life as seen by the photographers (Hurworth, 2003). The purpose of asking participants to collect photographs is not to recreate or to illustrate empirical truths or *reality*; rather, photographs are primarily used as a medium of communication between researcher and participant about the impact of MAT. The use of photographs facilitates the involvement of elderly research participants and makes them feel more comfortable discussing issues that may be socially stigmatizing. Although the photographs may not contain new information per se, they may inspire alternate meaning-making concerning participation that may otherwise remain dormant in a face-to-face interview (Prosser & Schwartz, 2004).

The broader context for assistive technology and active aging includes recognizing when the need is not for functional assistance but for policy change. Many of the factors that influence device adoption and use are directly or indirectly associated with stigma. Assistive technology use may potentially draw unwanted attention to the user, resulting in embarrassment and fear of being identified as "disabled" (Kaplan, Grynbaum, Rusk, Anastasia, & Gassler, 1966; Kochkin, 2007; Mann, Hurren, & Tomita, 1993). Cultural considerations such as societal attitudes about disability and the value placed on integrating individuals who use assistive technology into society play a critical role in device adoption and use (Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007). MAT may be a very helpful prophylactic intervention for some elders who are experiencing a decline in physical capability. Why should they wait until after they have had a serious fall, and related injury, before adopting MAT? Measuring the effectiveness of assistive technology on active aging should include the impact of public perceptions of device use on the behaviors of elders.

6.7 Conclusions

The ATOP/M is a conceptually grounded instrument for measuring the outcomes of mobility device use. The advances represented in this instrument are a clarified conceptual model and precise measurement of outcomes by adaptively administering only questions that retrieve maximum information from the device user, thus minimizing respondent burden. While the ATOP/M successfully measures the performance of activities and participation that are important and meaningful to MAT end-users, it does not address all MAT-related issues that are a concern to end-users and may impact active aging. MAT users appear to prioritize a broader range of functional activity, participation, and social/societal outcomes than is typically captured in questionnaires. This suggests the need for a tool or an item pool that

includes this range of outcomes and considers differentially weighting the value and importance of items.

MAT users appear to distinguish functional activity and participation from the broader societal impact and value associated with active aging. New and imaginative approaches to outcomes measurement are needed.

References

Brandt, A., Kreiner, S., & Iwarsson, S. (2010). Mobility-related participation and user satisfaction: construct validity in the context of powered wheelchair use. *Disability and Rehabilitation: Assistive Technology, 5*(5), 305–313.

Brandt, Å., Löfqvist, C., Jónsdottir, I., Sund, T., Salminen, A.-L., Werngren-Elgström, M., et al. (2008). Towards an instrument targeting mobility-related participation: Nordic cross-national reliability. *Journal of Rehabilitation Medicine, 40*, 766–772.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., et al. (2010). The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology, 63*, 1179–1194.

Cicerone, K. D. (2004). Participation as an outcome of traumatic brain injury rehabilitation. *The Journal of Head Trauma Rehabilitation, 19*(6), 494–501.

Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: an overview. *Archives of Physical Medicine and Rehabilitation, 91*(9), S1–S76.

Fuhrer, M. J., Jutai, J. W., Scherer, M. J., & DeRuyter, F. (2003). A framework for the conceptual modeling of assistive technology outcomes. *Disability and Rehabilitation, 25*, 1243–1251.

Gershon, R., Heinemann, A. W., & Fisher, W. P. (2006). Development and application of the orthotics and prosthetics user survey: applications and opportunities for health care quality improvement. *Journal of Prosthetics & Orthotics, 18*, 80–85.

Hahn, E. A., DeVellis, R. F., Bode, R. K., Garcia, S. F., Castel, L. D., Eisen, S. V., et al. (2010). Measuring social health in the patient-reported outcomes measurement information system (PROMIS): item bank development and testing. *Quality of Life Research, 19*, 1035–1044.

Hammel, J., Southall, K., Jutai, J., Finlayson, M., Kashindi, G., & Fok, D. (2012). Evaluating use and outcomes of mobility technology: A multiple stakeholder analysis. *Disability and Rehabilitation: Assistive Technology*, Nov 9 [Epub ahead of print].

Hurworth, R. (2003). Photo-interviewing for research. *Social Research Update, 40*, 1–4.

Jette, A. M., & Haley, S. M. (2005). Contemporary measurement techniques for rehabilitation outcomes assessment. *Journal of Rehabilitation Medicine, 37*, 339–345.

Jutai, J. (1999). Quality of life impact of assistive technology. *Rehabilitation Engineering, 14*, 2–7.

Jutai, J. W., Coulson, S., & Russell-Minda, E. (2009a). In Amichai-Hamburger (Ed.), Technology and psychological well-being. Cambridge: Cambridge University Press, pp. 206–226.

Jutai, J. W., Demers, L., DeRuyter, F., Finlayson, M., Fuhrer, M. J., & Hammel, J. (2009b, June). *Assistive technology outcomes profile for mobility (ATOP/M)–item pool development*. New Orleans, LA: Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).

Jutai, J., Ladak, N., Schuller, R., Naumann, S., & Wright, V. (1996). Outcomes measurement of assistive technologies: An institutional perspective. *Assistive Technology, 8*, 110–120.

Kaplan, L. I., Grynbaum, B. B., Rusk, H. A., Anastasia, T., & Gassler, S. (1966). A reappraisal of braces and other mechanical aids in patients with spinal cord dysfunction: Results of a follow-up study. *Archives of Physical Medicine and Rehabilitation, 47*, 393–405.

Kochkin, S. (2007). MarkeTrak VII: Obstacles to adult non-user adoption of hearing aids. *The Hearing Journal, 60*, 24–51.

Lenker, J. A., Scherer, M. J., Fuhrer, M. J., Jutai, J. W., & DeRuyter, F. (2005). Psychometric and administrative properties of measures used in assistive technology device outcomes research. *Assistive Technology, 17*, 7–22.

Lockett, D., Willis, A., & Edwards, N. (2005). Through seniors' eyes: An exploratory qualitative study to identify environmental barriers to and facilitators of walking. *The Canadian Journal of Nursing Research, 37*, 48–65.

Magilvy, J., Congdon, J., Nelson, J., & Craig, C. (1992). Visions of rural aging: Use of photographic method in gerontological research. *The Gerontologist, 32*, 253–257.

Mann, W. C., Hurren, D., & Tomita, M. (1993). Comparison of assistive device use and needs of homebased older persons with different impairments. *The American Journal of Occupational Therapy, 47*, 980–987.

PROMIS Health Organization and PROMIS Cooperative Group. (2008). PROMIS Item Pool v.1.0. Retrieved from http://www.nihpromis.org

Prosser, J., & Schwartz, D. (2004). Photographs within the sociological research process. In S. Hesse-Biber & P. Leavy (Eds.), *Approaches to qualitative research: A reader on theory and practice* (pp. 334–349). New York, NY: Oxford University Press.

Riley, R. G., & Manias, E. (2004). The uses of photography in clinical nursing practice and research: A literature review. *Journal of Advanced Nursing, 48*, 397–405.

Rust, K., & Smith, R. O. (2005). Assistive technology in the measurement of rehabilitation and health outcomes: A review and analysis of instruments. *American Journal of Physical Medicine & Rehabilitation, 84*(10), 780–793.

Scherer, M., Jutai, J., Fuhrer, M., Demers, L., & Deruyter, F. (2007). A framework for modelling the selection of assistive technology devices (ATDs). *Disability and Rehabilitation: Assistive Technology, 2*, 1–8.

Seale, J. K., & Turner-Smith, A. R. (2003). Measuring the impact of assistive technologies on quality of life: can rehabilitation professionals rise to the challenge? In A. J. Carr, I. J. Higginson, & P. G. Robinson (Eds.), *Quality of life*. London: BMJ Books.

United States' Assistive Technology Act (1998). Assistive Technology Act of 1998. Retrieved April 5, 2012 from http://www.section508.gov/508Awareness/html/at1998.html

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health, 8*, 185–192.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*, 369–387.

World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*. Geneva: WHO.