

# Capturing perspectives

*J. JUTAI (Convener). Measuring the effectiveness of assistive technology in community and home environments: Capturing the perspectives of users and caregivers. Gerontechnology 2010;9(2):116; doi:10.4017/gt.2010.09.02.054.00* **Participants:** *J. JUTAI (CANADA), L. DEMERS (CANADA), B. MORTENSON (CANADA), and F. DERUYTER (USA).* **ISSUE** Assistive technology (AT) is purported to enhance the user's activities and participation, and thereby relieve burdens of care and promote caregiver health. The speakers will describe improvements in conceptualization and measurement of these intended benefits. **CONTENT** The papers will describe related efforts to measure the outcomes of assistive device use in community and home environments, and empirical research using these new tools. Issues for the design of instruments, from conceptualization to field implementation, will be discussed with respect to their implications for delivery of AT service. Limitations of existing health and rehabilitation outcome measures will be addressed, including: (i) technology impact is not at all considered; (ii) use of technology lowers the functional impact score; or (iii) the impact is not attributed to specific devices. **STRUCTURE** Jeff Jutai will describe a conceptual framework for self-report measurement of assistive device outcomes that is consistent with the International Classification of Functioning, Disability and Health. He will present findings from a study to develop an instrument based on state-of-the-science applications of item response theory (IRT) and computerized adaptive testing (CAT). Louise Demers will analyze the key factors for understanding AT outcomes experienced by caregivers within the context of a general stress model of caregiving. Ben Mortenson will present findings from a study which evaluated the effects of a formalized approach to AT provision on (i) users' performance of self-selected activities and (ii) their caregivers' sense of physical and emotional burden. Frank DeRuyter will present various tools to capture and manage AT outcome data which will include portable/mobile devices, alternative data-capture technologies, web-based interfaces and data management and reporting tools. Following the individual presentations, Jeff Jutai will lead an open discussion focusing on key next steps needed to improve AT outcomes measures and increase their use. **CONCLUSION** AT is best understood as a complex health intervention which requires a systematic approach to establishing its outcomes. Significant advances in measurement have been achieved, but substantial challenges remain for research design and barriers to implementation in the field. A paradigm shift is needed to move the field away from informal clinic and hospital-based assessments, toward standardized instrumentation for assessing community and home environments.

**Keywords:** assistive device, assistive technology, caregiving, adaptive testing  
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*J. JUTAI, M. FUHRER, R. BODE, A. HEINEMANN, L. DEMERS, J. LENKER, F. DERUYTER. A computerized adaptive testing approach to measuring the impact of mobility devices on activities and participation. Gerontechnology 2010;9(2):116-117; doi:10.4017/gt.2010.09.02.055.00* Despite their widespread use, the effectiveness of mobility assistive technology devices (ATDs) is unknown. Most existing health and rehabilitation outcome measures do not consider the impact of assistive technology in measuring functional ability or, if they do, the use of an ATD lowers a person's score. Additionally, impacts of ATDs are not specifically attributed to their use<sup>1</sup>. The Assistive Technology Outcomes Profile for Mobility (ATOP/M), is designed to measure the impact of mobility ATDs in areas that are identified in the CATOR taxonomy as representing both

the subjective vantage on ATD outcomes<sup>2</sup> and a desired subjectification of ATD effectiveness as defined in the International Classification of Functioning, Disability and Health (ICF) framework<sup>3</sup>. The ATOP/M is applicable to all relevant etiologies for conditions that produce mobility disabilities, and to all settings in which mobility devices may be used. **Method** The ATOP/M was developed in a sequence of phases that consisted of reviewing extant instruments and conducting focus groups to create an item pool, surveying 1,037 individuals with mobility difficulties to calibrate items, and performing Rasch and item response theory (IRT) based analyses to create full-length, and short form, instruments and an item bank for computer adaptive testing (CAT) applications. The ATOP/M item pool was created using items drawn from the PROMIS<sup>4</sup>, CPI<sup>5</sup>, and over a dozen other instruments. Focus groups were held in the USA and Canada, with multiple stakeholder groups, to identify additional items and to refine item wording and response format. Users of ATDs had a wide range of diagnoses, including cerebral palsy, multiple sclerosis, spinal cord injury, acquired brain injury, stroke, and amputation. The data were analyzed thematically. The item pool was then subjected to binning and winnowing. **Results & Discussion** The full-length ATOP/M consists of 68 items distributed across four domains of activity and participation: Physical Performance, Instrumental Activities of Daily Living, Social Role Performance, and Discretionary Social Performance. The standardized stem, "Are you able to...", was adopted for all items. A standardized set of response options was also adopted: 'Without any difficulty; With a little difficulty; With some difficulty; With much difficulty; Unable to do'. A 'Not Applicable' option was included in each domain, with the exception of the Physical Performance domain. The ATOP/M yields two scores, one reflecting respondents' mobility level while using an ATD, the other reflecting their capability without it. A 7-item short form was developed for each of the four domains. 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.

## References

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*L. DEMERS, M.J. FUHRER, J. JUTAI, J. LENKER, F. DERUYTER. A conceptual framework for integrating caregivers' perspective in the provision of assistive technology. Gerontechnology 2010;9(2):117-118; doi:10.4017/gt.2010.09.02.056.00* Both assistive technology (AT) and human assistance are used by people with disabilities to enhance their functioning<sup>1,2</sup>. From both a clinical and policy viewpoint, a principal justification for providing AT to people with disabilities is that it reduces their dependence on human assistance. However, there is scant research evidence to support this assertion in the context of community-living environments<sup>3</sup>. This lack of data can be partially attributed to the absence of a fully formed conceptual framework. The goal of the current study was to develop and content-validate a conceptual framework for understanding the impacts of care recipients' use of AT, on the lives of their caregivers. We hypothesized that AT affects the quality of caregiving and thus, the caregivers' quality of life. **Method** The present study included four stages that blended qualitative and quantitative ap-

proaches. First, a list of potential, key outcome variables, relevant to the caregivers of AT users, was generated from a review of existing literature and semi-structured interviews with 19 caregivers. Second, the research team analyzed, regrouped, and partitioned the variables into components and subcomponents, using a conceptual mapping approach. Third, the components and subcomponents were anchored in a general framework of caregiving<sup>4</sup>. Finally, four rehabilitation experts were engaged to evaluate the conceptual framework and assess the degree of consensus on its structure and contents. **Results & Discussion** An important result of this study, is the identification of a complex set of variables that need to be considered when examining the experience of caregivers of AT users or potential users. The proposed conceptual framework considers the interactions among four categories of factors: (i) stressors; (ii) caregiver outcomes; (iii) moderating factors; and (iv) mediating factors. Stressors, whether primary or secondary, are the predominant determinants of caregiver outcomes along with caregivers' personal resources acting as mediators. By itself, a recipients' use of AT is not sufficient to explain caregivers' outcomes in terms of quality of life, psychological health factors, physical health, and participation. Our results suggest instead that, AT use comes into play subtly and indirectly as a key moderating factor. This does not diminish the importance of AT for caregivers. Recipients' use of AT has the potential to influence a number of prominent stressors, such as forms of assistance, number of tasks, and the physical effort that is involved. Viewed as a whole, this work demonstrates that the AT experience of caregivers has many facets that merit the attention of outcomes researchers.

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W. MORTENSON, L. DEMERS, M. J. FUHRER, F. DERUYTER, J. LENKER, J. JUTAI. *Impact of an assistive technology intervention on users and their caregivers: Initial findings. Gerontechnology* 2010;9(2):118-119; doi:10.4017/gt.2010.09.02.057.00 Mobility is a broad concept that encompasses participation in society, physical activity and carrying out instrumental activities of daily living. Mobility assistive technology (AT), which includes devices such as wheelchairs, bathroom grab bars and dressing aids, facilitates users' day-to-day activities and social participation and may decrease their dependence on human assistance. Although some research has reported beneficial outcomes of AT use, few studies have used experimental designs and the results are often difficult to interpret because the AT interventions are vaguely described. As a result, the benefits of AT use are incompletely portrayed. The present study was undertaken to evaluate the efficacy of a formalized approach to AT provision that is inclusive of AT users and their caregivers. Its objectives are to: (i) increase AT users' performance and satisfaction with performance on dyad-selected activities and (ii) decrease their caregivers' sense of physical and emotional burden. **Method** This semi-crossover study is a randomized clinical trial that will include 72 dyads comprised of (i) older individuals (aged >65) with physical impairments that restrict their mobility or ability to perform activities of daily living, and (ii) their informal caregivers who provide more than 2 hours of care per week. The intervention includes (i) detailed home assessment; (ii) identification of problematic activity by the user-caregiver dyad; (iii) negotiation of a personal AT plan with both caregiver and AT user; and (iv) implementation of this plan, which may include device provision and training and/or home modifications. The intervention was iteratively developed in consultation with clinicians, users

and caregivers and then pilot tested with two dyads. Subjects are divided into either an immediate intervention or delayed intervention group. The delayed group commences the intervention 6 weeks after the immediate intervention group. Both groups are evaluated before and after receiving the intervention, and then 16 weeks later to examine long-term effects. The Assessment of Life-Habits<sup>1,2</sup> is being used to measure users' performance and satisfaction with performance. The Caregiver Assistive Technology Outcome Measure<sup>3</sup> is being used to measure caregivers' sense of physical and emotional burden. **Results & Discussion** Pre-post data are currently available for seven dyads. Six of the AT users demonstrated an improvement in performance and performance satisfaction and one user remained unchanged. All of the caregivers indicated decreased physical and psychological burden. Despite the small sample size, all of these changes were statistically significant (Wilcoxon Signed Ranks test,  $p < 0.05$ ). If similarly positive findings are exhibited by the remaining subjects, the study will have significant policy and practice implications for advocates of better funding of AT follow-up services for both users and their informal caregivers.

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**Keywords:** community dwelling, mobility, participation, experiment

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*F. DERUYTER, M. FUHRER, L. DEMERS, J. LENKER, J. JUTAI. Assistive technology outcome data capture, management and reporting tools. Gerontechnology 2010;9(2):119-120;*

*doi:10.4017/gt.2010.09.02.058.00* Assistive technology (AT) has few standardized outcome measures and each involves paper/pencil completion that requires substantial resources for capturing, managing and reporting the data. Optimally, outcomes data collection should be collected in electronic format at the point of service. Among current technologies, web-based interfaces and handheld devices hold the greatest potential for efficient data capture, organization, management, and reporting. This study explored the feasibility of various options. **Method** A variety of devices, technologies, interfaces and strategies were evaluated in three broad areas: portable devices, web-based interfaces, and management or reporting tools. Proof-of-concept and beta-testing was undertaken to demonstrate feasibility and functionality of improving AT outcome data capture, management and reporting. Underlying criteria for successful portable data-capture tools included platform independence, facilitation of direct data entry and ability to address location, software and user independence. Underlying criteria for successful web-based data-capture interfaces included facilitation of direct data entry and ability to manage location, user, platform, and software independence. Underlying criteria for successful data management and reporting included the consolidation, interpretation and display of gathered data. **Results & Discussion** A variety of strategies were evaluated using currently available, standardized and non-standardized, AT outcome instruments. Successful portable and alternative data-capture solutions included: (i) efficiency of porting data (synchronously/asynchronously) into a main data collection repository; (ii) functionality within clinical/administrative environments; and (iii) ability to capitalize on wireless technology. Successful web-based data-capture interfaces solutions included (i) 'in-house reporting' capability, facilitating ease of use throughout a facility; (ii) 'remote reporting' capability for remote locations as well as data entry from varying institutions; (iii) automatic data entry; (iv) functionality within clinical/administrative environments; (v) ability to capitalize on wireless technology; and (vi) ability to observe results and reports in real-time. Successful data management and reporting strategies included (i) clinician and manager acceptance; (ii) ease of data porting; (iii) enhanced user independence; (iv) resolution of remote HIPAA reporting concerns; (v) the incorporation of technologies into other service lines; and (vi) data repository security. Based on

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feedback obtained in trials within controlled test environments as well as beta sites, a plethora of benefits and challenges associated with AT outcome data capture, management and reporting have been collated. These results will be shared and discussed as well as demonstrated through short video-clips.

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