

Function and Feelings: Assessing Psychosocial Outcomes for Assistive Technologies

Jeffrey W. Jutai^{1,2}¹Interdisciplinary School of Health Sciences, University of Ottawa, Ottawa, Canada²Bruyère Research Institute, Ottawa, Canada**Abstract:**

Purpose. The aim of this paper is to highlight the achievements and limitations of research on assessing the outcomes of assistive technology interventions for enhancing function and wellbeing.

Method. The research evidence for the impact of assistive technologies on psychosocial outcomes is examined. Several approaches to improving the quality of outcomes research pertaining to assistive technologies are described. They include acknowledging that assistive technologies are complex health interventions, the importance of grounding research in well-developed conceptual frameworks and theories, and the need for measurement tools that are accessible and easy to use.

Results and Conclusions. There have been significant advances in approaches to assessing psychosocial outcomes for assistive technologies. Several promising measurement tools have been developed; however, fulfilling the promise of psychosocial assessment has been difficult because of slow adoption of measurement tools by researchers and health care professionals. More effective methods for knowledge translation are needed.

Key Words: Assistive technology, outcomes research, psychosocial outcomes, quality of life, wellbeing

1. Psychosocial outcomes for assistive technologies

1-1 Conceptual framework

Assistive technologies are tools that enhance the independent functioning of individuals who have physical limitations or disabilities. They include products such as wheelchairs, low vision aids, prosthetic limbs, and environmental control devices. Without their assistive technology devices, the many individuals with disabilities and chronic conditions in the world today would have severe restrictions on their ability to perform life activities and participate in society.

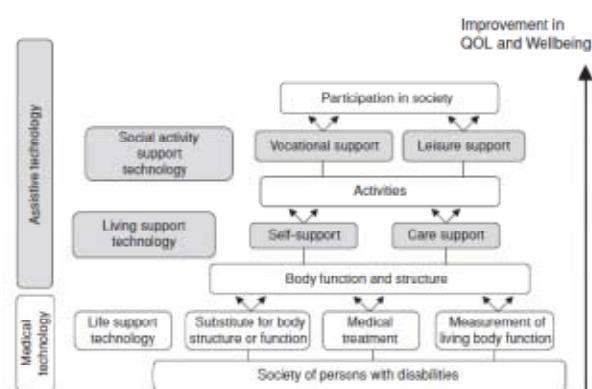


Fig. 1 Conceptual framework for relating technology to improvement in quality of life and wellbeing. *Source:* adapted from Ohnabe, 2006.

It is helpful to distinguish the effects of medical and assistive technologies since the latter are especially important in supporting function (Figure 1; Jutai et al., 2009). 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, 2001). Medical devices are not designed to directly and appreciably improve quality of life (QoL) and wellbeing. These improvements are much more influenced by assistive technology (AT) which helps

individuals to engage in life activities and participate in society. Assistive technology provides a platform to support health and wellbeing as defined by the WHO.

Well-being and related constructs of quality of life and psychological functioning are part of a constellation that makes up the human experience with technology and so may be inseparable. There is no universally accepted definition of *quality of life* (QoL) but some approaches to definition lend themselves to measuring the impact of technology better than others. In our research on the impact of assistive devices for individuals who have a physical or sensory disability (Jutai et al., 2009), we have adopted the position that QoL refers to the degree to which a person enjoys the important possibilities of his/her life. This is a definition that speaks directly to the themes of this conference because it compels us to focus on the most important goals for technology in supporting human existence. In defining *wellbeing*, we refer to the degree to which individuals have positive appraisals and feelings about their lives, considered altogether or in terms of particular domains, such as health and recreation (Fuhrer, 2000). Research has examined how devices make users feel more competent, confident, and motivated to exploit life's possibilities (Jutai, 1999; Jutai and Day, 2002). Assumptions about these constructs and how they are affected by technology include that they (1) are complex and multidimensional; (2) are dynamic, changing over time and over a person's life; (3) arise from the individual's interaction with his/her environment; and (4) are experienced differently from person to person, but have the same components for everyone (Jutai, 1999). Approaches to outcome measurement should be faithful to these assumptions. The relationship of technology to function and wellbeing is difficult to measure but not impossible (Fuhrer et al., 2003; Jutai et al., 2005).

We have published frameworks for research that are significantly advanced over previously published formulations (Demers et al., 2009; Fuhrer et al., 2003; Jutai et al., 2005;

Scherer et al., 2007). They are richly detailed in accounting for the most influential sources of variation in AT outcomes, as identified in classification systems such as the ICF. They have invited the application of promising innovations in longitudinal data analysis to more sensitively examine the dynamic processes for assistive technology device (ATD) procurement, utilization, and outcome. Rather than being merely descriptive, they have provided a sound structure for rigorous hypothesis testing and evaluation of extant instruments, to support measurable growth in the knowledge base in this area. These developments have laid a firm foundation for the meaningful measurement of the impact that various ATDs and services have on the lives of people who have disabilities.

1-2 Research evidence

Answering the question, *Does assistive technology work?*, is difficult. In large part this is due to the limitations of existing health and rehabilitation outcome measures, the preponderance of which has one of three limitations: (a) AT impact is not at all considered; (b) use of AT lowers the functional impact score; or (c) the impact is not attributed to specific AT devices (Rust & Smith, 2005). These limitations are reflected in the AT outcomes research literature. Our review of 20+ years of published AT outcomes research (Lenker et al., 2005) revealed several measurement trends. Device usage and usability accounted for almost 70% of the dependent variables appearing in the literature. Outcome domains such as functional level, participation, and quality of life accounted for less than 30% of reported outcome variables. Of 212 outcome variables reported in 82 reviewed articles, 79% (N=168) of the variables were measured using non-standardized, study-specific measurement tools. Among these studies, there was scant reporting of the psychometric properties of the measurement tools used. As a result of the field's approach to measurement, the AT 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 AT in outcome domains of interest are simply not measured (Jutai, 2011).

Other limitations of measurement tools include narrowly defined outcomes domains, lack of comparability of results across instruments, and unacceptable tradeoffs between instrument precision and practical implementation. Additionally, many measurement tools cannot be used across the variety of settings in which physical rehabilitation services are provided, nor along the continuum of care (Jutai & Southall, 2012).

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. In the proposed Taxonomy of Assistive Device Outcomes (Jutai et al., 2005), the impacts of AT on caregiving relate to objective and subjective assessments of the nature and amount of effort involved in providing care for the AT user. Assistive technology outcome studies have paid scant attention to the impacts of that technology on users' caregivers. To appreciate the full impact of

AT intervention on particular activities, one must understand how both users and caregivers are affected. In a related vein, the current literature provides little information about the benefits of providing AT interventions in the home, especially as they impact on caregivers (Mortenson et al., 2012).

2. Improving the quality of outcomes research

Assistive technology devices readily qualify as "complex health interventions" to which the structural framework for hypothesis-driven experimental work outlined in Figure 2 applies.

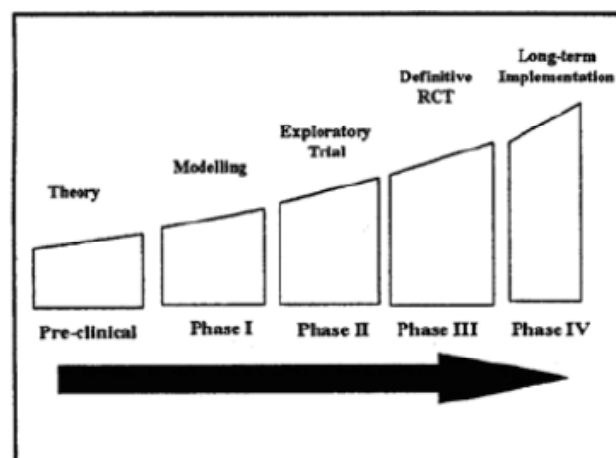


Fig. 2 Structural framework for development and evaluation of randomized controlled trials for complex health interventions

The measurement of QoL impact is considered to be very important in the management of AT outcomes (Minkel, 1996; Scherer, 1996). Emphasis on collecting data from the patient's perspective parallels a shift in theoretical premises in the field of rehabilitative technology, from a medical assessment model to a client-centered perspective (Oldridge, 1996; Scherer, 1996). The task of examining the impact of AT on QoL represents a considerable and unique challenge compared to measuring the other important outcome domains, including clinical results, functional status, satisfaction, and cost, because it focuses on the individual's subjective experiences. As such, it is subject to multiple personal, technological and environmental influences.

To measure the QoL impact of assistive technology in a standardized, objective and measurable fashion requires specifically designed tools. One such tool, the Psychosocial Impact of Assistive Devices Scale (PIADS) (Day & Jutai, 1996) is available to the English- and French-speaking communities in Canada (Demers et al., 2002). The PIADS is an assessment tool which has been shown to reliably predict the adoption of AT. The scale has a good reputation in Canada and the USA and has been shown to reliably predict the successful use of AT (Jutai et al., 2003, 2006; Saladin & Hansmann, 2008).

AT 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 (Jutai & Southall, 2012).

Our research has also revealed that ATD users have some expectations for the impact of assistive technology that are not easily measured. Assistive technology outcome assessment should consider approaches that combine questionnaires with other methods for obtaining end-user perspectives on participation (Jutai & Southall, 2012).

3. Adoption of approaches to outcome assessment

While the field of assistive technology has in general been lacking specific instruments relating to outcomes measurement, there are a few standardized/non-standardized instruments available along with several new instruments currently under development. For those existing instruments, each requires paper/pencil completion resulting in significant effort and resources for entry into a central database and subsequent data analysis. The collection and capture of outcomes data should be at the point of service and could be greatly facilitated through the utilization of web-based interfaces and/or platform independent portable devices for direct outcomes data entry. In addition, the management and reporting of AT outcome data could also be organized through web-based interfaces. We have made several proof-of-concept and beta-testing efforts to demonstrate feasibility and functionality of improved AT outcome data capture, management and reporting tools (Figure 3; DeRuyter et al., 2010).

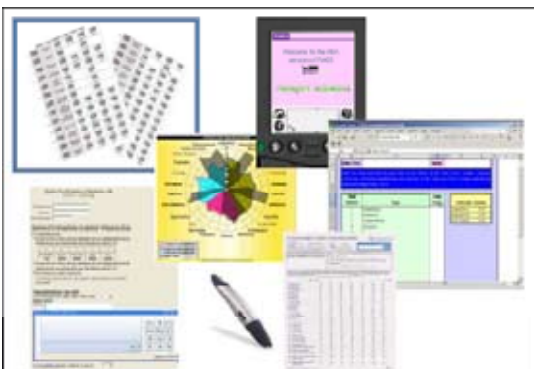


Fig. 3 AT outcome data collection tools

It is imperative to invest in improving the evidence base for the effectiveness of AT. Another approach is to encourage significant development in international collaboration on guidelines and standards for AT outcome measurement. We have established a working collaboration with international colleagues to research and develop translations for the PIADS.

Currently, there is no international scale to assess the impact of ATs, although we have begun to translate the PIADS scale due to the pressing need for this type of outcome measure. The many important advantages to having AT outcome measurement instruments, such as the PIADS, available in different world languages include: (1) increased opportunities for international scientific collaboration in AT research and advancement of AT knowledge base; and (2) improved accessibility of AT outcome

research, and thereby the potential benefits from its results, to populations of persons with disabilities worldwide. The topic is very timely given the significant interest worldwide in developing international standards relating to AT, and recent developments in emerging global consensus on the role of AT in promoting health and well being (Lenker & Jutai, 2002). Also, recent demographic trends identify a need for having available measurement instruments in languages other than English, to accommodate the large linguistically and culturally diverse populations of AT users in North America. Internationally-translated and evaluated PIADS questionnaires will also allow developers of AT to develop devices which have greater uptake and will therefore benefit the companies making AT, as well as the users. The questionnaire can be used to evaluate the different features of technology that are preferred by users of all ages from many culturally diverse groups. This will ensure that “one size fits nobody” technology is identified and rejected in favour of technology which is preferred by people with a wide range of backgrounds and needs. International translations of the PIADS questionnaire will also allow purchasers of AT to recognize which technology is preferred by users and therefore, with a higher adoption rate, more people will benefit.

4. Conclusions and Recommendations

Few doubt the general proposition that AT has the potential to enhance users’ functioning, and in the process, to allow them to be less dependent on the assistance of others. However, for a variety of stakeholders, that generality needs to be buttressed by systematic evidence applicable to defined users and specific types of AT. A more in-depth perspective of the multiple outcomes that people with disabilities and their caregivers obtain from an AT intervention would enable service providers to derive recommendations that are adapted to their concerns.

Without research and resultant improvements in measurement tools, consumers are denied access to highest quality AT outcomes research and, therefore, the benefits to their quality of life and wellbeing that might come from this research.

References

- (1) Day H, Jutai J. Measuring the psychosocial impact of assistive devices: The PIADS. *Canadian Journal of Rehabilitation*, vol. 9, no. 3, pp. 159-168, 1996.
- (2) Demers L, Fuhrer MJ, Jutai J, Lenker J, Depa M, De Ruyter F. A conceptual framework of outcomes for caregivers of assistive technology users. *Am J Phys Med Rehabil*, vol. 88, pp. 645–658, 2009.
- (3) Demers L, Monette M, Descent M, Jutai J, & Wolfson, C. The Psychosocial Impact of Assistive Devices Scale (PIADS): Translation and preliminary psychometric evaluation of a Canadian-French version. *Quality of Life Research*, vol. 11, pp. 583-592, 2002.
- (4) DeRuyter F, Fuhrer MJ, Demers L, Lenker J, Jutai J. Assistive Technology Outcome Data Capture,

- Management and Reporting Tools. *Gerontechnology*, vol. 9, no. 2, pp. 119-120, 2010.
- (5) Fuhrer MJ. Subjectifying quality of life as a medical rehabilitation outcome. *Disability & Rehabilitation*, vol. 22, pp. 481-489, 2000.
- (6) Fuhrer M, Jutai JW, Scherer MJ, DeRuyter F. A framework for the conceptual modeling of assistive technology outcomes. *Disability & Rehabilitation*, vol. 25, pp. 1243-1251, 2003.
- (7) Jutai J. Quality of life impact of assistive technology. *Rehabilitation Engineering*, vol. 14, pp. 2-7, 1999.
- (8) Jutai JW. End-user participation in developing the Assistive Technology Outcomes Profile for Mobility (ATOP/M). *Everyday technology for independence and care*. GJ Gelderblom et al., Amsterdam, IOS Press, pp. 1026-1032, 2011.
- (9) Jutai J, Day H. Psychosocial impact of assistive devices scale (PIADS). *Technology and Disability*, vol. 14, pp. 107-111, 2002.
- (10) Jutai JW, Southall K. Measuring the Effectiveness of Assistive Technology on Active Aging: Capturing the Perspectives of Users. *Technologies for Active Aging*, Gutman G & Sixsmith A, New York, NY, Springer., 2012 (In Press)
- (11) Jutai JW, Coulson S, Russell-Minda E. Technology and medicine. *Technology and Psychological Wellbeing*, Y.A. Hamburger (ed.), Cambridge, Cambridge University Press, 2009.
- (12) Jutai J, Day H, Woolrich W, Strong G. The predictability of retention and discontinuation of contact lenses. *Optometry*, vol. 74, pp. 299-308, 2003.
- (13) Jutai JW, Fuhrer MJ, Demers L, Scherer MJ, DeRuyter, F. Toward a taxonomy of assistive technology device outcomes. *American Journal of Physical Medicine & Rehabilitation*, vol. 84, pp. 294-302, 2005.
- (14) Jutai J, Fuhrer M, Demers L, Scherer M, DeRuyter F. Psychosocial impact predicts locomotion assistive technology device outcome. RESNA, Atlanta, June 24, 2006.
- (15) Lenker, J.A., & Jutai, J.W. (2002). Assistive technology outcomes research and clinical practice: what role for ICF? 8th North American Collaborating Center Conference on ICF, Toronto, June 2-4.
- (16) Lenker JA, Scherer MJ, Fuhrer MJ, Jutai JW, DeRuyter F. Psychometric and administrative properties of measures used in assistive technology device outcomes research. *Assistive Technology*, vol. 17, no. 1, pp. 7-22, 2005.
- (17) Minkel JL. Assistive technology and outcome measurement: Where do we begin? *Technology & Disability*, vol. 5, pp. 285-288, 1996.
- (18) Mortenson WB, Demers L, Fuhrer MJ, Jutai JW, Lenker J, DeRuyter F. How assistive technology use by individuals with disabilities impacts their caregivers: a systematic review of the research evidence. *Amer. J. Phys. Med. Rehabil.*, 2012 (In Press).
- (19) Ohnabe H. Current trends in rehabilitation engineering in Japan. *Assistive Technology*, vol. 18, pp. 220-232, 2006.
- (20) Oldridge NB. Outcomes measurement: Health-related quality of life. *Assistive Technology*, vol. 8, pp. 82-93, 1996.
- (21) Rust K, Smith RO. Assistive technology in the measurement of rehabilitation and health outcomes: A review and analysis of instruments. *American Journal of Physical Medicine and Rehabilitation*, vol. 84, no.10, pp. 780-793, 2005.
- (22) Saladin SP, Hansmann SE. Psychosocial variables related to the adoption of video relay services among deaf or hard-of-hearing employees at the Texas School for the Deaf. *Assistive Technology*, vol. 20, pp. 36-47, 2008.
- (23) Scherer, M.J. (1996). Outcomes of assistive technology use on quality of life. *Disability & Rehabilitation*, vol. 18, pp. 439-448, 1996.
- (24) Scherer M, Jutai J, Fuhrer M, Demers L, DeRuyter F. A framework for modeling the selection of assistive technology devices (ATDs). *Disability and Rehabilitation: Assistive Technology*, vol.2, no. 1, pp.1-8, 2007.
- (25) World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO, 2001.