



**Elizabeth M. Hannold, PhD;**  
*Coauthors not pictured:* Jini M.  
**Hanjian, PhD; Meggan M. Jordan,**  
**MA; Mary Joan Roach, PhD; and**  
**Craig A. Velozo, PhD**

## Using veterans' perspectives to enhance rehabilitation outcome measures: Value of qualitative methods

Innovative rehabilitation interventions and technologies aimed at recovery of walking show great promise and are receiving considerable support from the Department of Veterans Affairs (VA) Rehabilitation Research and Development (RR&D) Service. For example, functional electrical stimulation (FES) improves gait component execution and knee flexion coordination for patients with chronic stroke [1]. Locomotor training (LT) using partial body-weight support with a treadmill and manual assistance improves gait speed in persons with chronic stroke and mild to moderate stroke severity [2]. LT with a driven-gait orthosis improves gait velocity, endurance, and functional performance in ambulatory persons with chronic, incomplete spinal cord injury (SCI) [3]. In general, clinical measures are the standard for documentation of the outcomes of these innovative treatments. Typical clinical measures include walking speed [4], the Walking Index for SCI II [5], the Berg Balance Scale [6], and the Dynamic Gait Index [7].

A weakness of these existing clinical outcome measures is that the majority were generated with little input from veterans. Although valuable to scientists and clinicians, presently used laboratory and clinically generated rehabilitation measures may fail to capture outcomes that individuals recovering from disability view as most meaningful [4]. For example, a recent case study of a veteran with an incomplete SCI who was participating in manually assisted LT reported activities of daily living and role/social participation as important areas of change [8]. The participant often identified a renewed ability to engage in personally meaningful tasks, aside from gait changes, as a highly valued treatment outcome. This editorial (1) examines the challenge of developing veteran-centered outcome measures that are useful for the rehabilitation process and meaningful for the veteran and (2) discusses the role of qualitative methodologies in the development of outcome measures based on the veterans' perspective.

Disability scholars have frequently criticized scientists without disabilities who are conducting disability-related research [9–10]. These scholars charge that, in the absence of personal disability experience, scientists without disabilities may be insensitive to the full spectrum of disability experiences. Like much of the general population, scientists may incorrectly assume that disability and its consequences are always unfavorable experiences and fail to recognize any positive aspects of the disability experience—a tendency called “catastrophizing” [11]. Disability scholars claim that this bias may lead scientists to inaccurately assume and judge the abilities, needs, and priorities of people with disabilities [11–12].

When discussing challenges associated with the knowledge translation of rehabilitation research findings, Sherwood raises the question [13], Who are the ultimate beneficiaries of rehabilitation and disability research? Sherwood

further notes that “. . . people with disabilities do not seek generalizable information, but information that specifically relates to them” [13]. We maintain that scientists and individuals participating in rehabilitation will benefit from more veteran-centered outcome measures. Tapping into the experiences of individuals with disabilities as part of the measurement development process establishes a valuable partnership that can empower both parties. Scientists will benefit from measures that capture the true needs, abilities, priorities, and quality-of-life outcomes that are meaningful to rehabilitation participants. This challenge has led us to propose using qualitative methodology based on grounded theory [14] to study veterans’ experiences of emerging gait interventions.

The Rehabilitation Outcomes Research Center-Research Enhancement Award Program (RORC-REAP) and Brain Rehabilitation Research Center in Gainesville, Florida, and the FES Center in Cleveland, Ohio, were funded by a VA RR&D Collaborative Center grant to generate veteran-centered outcomes associated with state-of-the-art gait interventions. This collaborative effort involves an extensive qualitative examination of the experiences of veterans participating in one of three interventions: manually assisted LT, robotic LT, or FES gait training. In-depth interviews and ethnographic video diaries are being conducted with 20 veterans (10 with stroke and 10 with SCI) at the beginning, middle, and end of the respective interventions, yielding a total of 60 interviews and 60 video diaries. Through these interviews and video diaries, participants are free to express their experiences related to these gait interventions. Data from interviews and video diaries are then systematically coded to identify prominent themes and relationships.

Our initial data reveal numerous overarching themes that will be the foundation for the generation of outcome measures important to the veterans participating in the rehabilitation interventions. One theme that our data to date have highlighted as important to the veterans is the quality of their walking. Initial findings suggest that participants are very concerned with changing a gait that “flops” into a gait that is “smoother” and looks more “normal.” They also talk about gait improvement in terms of

“walking more correctly” and “increasing walking distances in their community.” Another element of walking quality is building their endurance. The participants see endurance as a necessary component so that they can “walk without a cane for longer distances,” “walk safely” to avoid falls or collisions, and “walk comfortably” to increase the distance they can walk. A second theme for these veterans is the social and community aspects of a less-than-normal gait. Participants’ goals include walking well enough “to go to the mall and shop,” “cook for her family,” “go fishing,” and “go out to social events with friends and family.” One participant said that his goal was to enjoy life again, which to him meant a “full enough recovery so that he was able to think about other things other than how to walk.” Additionally, participants are acutely aware that they are seen by friends, family, and society as “disabled” and “different” and they greatly value the ability to walk in a near-normal fashion. For many participants, having a near-normal gait reflects the quality of their walk and the quality of their life.

This qualitative study of persons undergoing innovative gait training is the first of two phases in the development of veteran-centered outcome measures. The second phase involves the generation of self-report items for each of the major themes identified through the qualitative analysis. Based on an Item Response Theory (IRT) framework, pools of 20 to 50 self-report items are being created that reflect different amounts of each theme. For example, for the “goals” theme, simpler goals include walking without a flop and walking safely, while more challenging goals include walking in a shopping mall and “back to normal.” These item pools will be the foundation for short-form instruments (~10 items) and computer adaptive measures with limited items (6–15) in order to direct only the most relevant items to a respondent.

Despite rising scientific interest in the development of therapies incorporating new interventions, few studies have examined the impact of such therapies from the veterans’ perspective. Clearly, veterans with walking disabilities are the ultimate stakeholders in these interventions and their perspectives will only strengthen the tools for measuring therapeutic progress. Our preliminary veteran-generated data

suggest that a measure that considers recovery of function, such as changes in role participation, may be very appropriate. Qualitative methodologies can be useful in the development of outcome measures based on the veterans' perspective. Combining qualitative findings with IRT-based instrument development may ensure that, together with state-of-the-art interventions, we develop state-of-the-art outcomes measures. Our initial qualitative findings reveal the veterans' developing understanding of their disabilities and the value that the veterans place on the rehabilitation interventions. Qualitative methodologies will most likely play a critical role in the development of rehabilitation outcome measures relevant to recovering veterans, and by extension, ensure that VA rehabilitation care is both high-quality and patient-centered.

## ACKNOWLEDGMENTS

This material was based on work supported by the RR&D project "Veteran-centered outcomes using qualitative and quantitative methods" (grant O4052X, Principal Investigator Craig A. Velozo, PhD).

## REFERENCES

- Daly JJ, Roenigk KL, Butler KM, Gansen JL, Fredrickson E, Marsolais EB, Rogers J, Ruff RL. Response of sagittal plane gait kinematics to weight-supported treadmill training and functional neuromuscular stimulation following stroke. *J Rehabil Res Dev.* 2004;41(6A):807–20. [PMID: 15685469]
  - Plummer P, Behrman AL, Duncan PW, Spigel P, Saracino D, Martin J, Fox E, Thigpen M, Kautz SA. Effects of stroke severity and training duration on locomotor recovery after stroke: A pilot study. *Neurorehabil Neural Repair.* 2007;21(2):137–51. [PMID: 17312089]
  - Wirz M, Zemon DH, Rupp R, Scheel A, Colombo G, Dietz V, Hornby TG. Effectiveness of automated locomotor training in patients with chronic incomplete spinal cord injury: A multicenter trial. *Arch Phys Med Rehabil.* 2005;86(4):672–80. [PMID: 15827916]
  - Schmid A, Duncan PW, Studenski S, Lai SM, Richards L, Perera S, Wu SS. Improvements in speed-based gait classifications are meaningful. *Stroke.* 2007;38(7):2096–2100. [PMID: 17510461]
  - Dittuno PL, Dittuno JF Jr. Walking Index for Spinal Cord Injury (WISCI II): Scale revision. *Spinal Cord.* 2001;39(12):654–56. [PMID: 11781863]
  - Berg KO, Wood-Dauphinee SL, Williams JI, Maki B. Measuring balance in the elderly: Validation of an instrument. *Can J Public Health.* 1992;83 Suppl 2: S7–11. [PMID: 1468055]
  - Chiu YP, Fritz SL, Light KE, Velozo CA. Use of item response analysis to investigate measurement properties and clinical validity of data for the Dynamic Gait Index. *Phys Ther.* 2006;86(6):778–87. [PMID: 16737403]
  - Behrman AL, Lawless-Dixon AR, Davis SB, Bowden MG, Nair P, Phadke C, Hannold EM, Plummer P, Harkema SJ. Locomotor training progression and outcomes after incomplete spinal cord injury. *Phys Ther.* 2005;85(12):1356–71. [PMID: 16305274]
  - Luborsky MR. The process of self-report of impairment in clinical research. *Soc Sci Med.* 1995;40(11): 1447–59. [PMID: 7667650]
  - Sim J. Physical disability, stigma, and rehabilitation. *Physiother Can.* 1990;42(5):232–38.
  - Smart J. Disability, society, and the individual. Gaithersburg (MD): Aspen; 2001.
  - Brown M, Gordon WA. Empowerment in measurement: "Muscle," "voice," and subjective quality of life as a gold standard. *Arch Phys Med Rehabil.* 2004;85(4 Suppl 2):S13–20. [PMID: 15083418]
  - Sherwood AM. Knowledge translation: A mandate for Federal research agencies. *J Rehabil Res Dev.* 2007;44(3):vii–x.
  - Lincoln YS, Guba EG. Naturalistic inquiry. Beverly Hills (CA): Sage Publications; 1985.
- Elizabeth M. Hannold, PhD;<sup>1</sup> Jini M. Hanjian, PhD;<sup>1\*</sup> Meggan M. Jordan, MA;<sup>1</sup> Mary Joan Roach, PhD;<sup>2</sup> Craig A. Velozo, PhD<sup>1,3</sup>**  
<sup>1</sup>RORC-REAP, North Florida/South Georgia Veterans Health System, Gainesville, FL;  
<sup>2</sup>Department of Physical Medicine and Rehabilitation, and Center for Health Research Policy at MetroHealth Medical Center, Cleveland, OH;  
<sup>3</sup>Department of Occupational Therapy, College of Public Health and Health Professions, University of Florida, Gainesville, FL  
 \*Email: [Jini.Hanjian@va.gov](mailto:Jini.Hanjian@va.gov)  
 DOI: 10.1682/JRRD.2007.10.0170