

Research Paper

Starting a new conversation: Engaging Veterans with spinal cord injury in discussions of what function means to them, the barriers/facilitators they encounter, and the adaptations they use to optimize function

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Abstract

Background: Assessments of function in persons with spinal cord injury (SCI) often utilize pre-defined constructs and measures without consideration of patient context, including how patients define function and what matters to them.

Objectives/hypothesis: We utilized photovoice to understand how individuals define function, facilitators and barriers to function, and adaptations to support functioning.

Methods: Veterans with SCI were provided with cameras and guidelines to take photographs of things that: (1) help with functioning, (2) are barriers to function, and (3) represent adaptations used to support functioning. Interviews to discuss photographs followed and were audio-recorded, transcribed, and analyzed using grounded-thematic coding. Nvivo 8 was used to store and organize data.

Results: Participants ($n = 9$) were male (89%), Caucasian (67%), had paraplegia (75%), averaged 64 years of age, and were injured, on average, for 22 years. Function was described in several ways: the concept of ‘normalcy,’ aspects of daily living, and ability to be independent. Facilitators included: helpful tools, physical therapy/therapists, transportation, and caregivers. Barriers included: wheelchair-related issues and interior/exterior barriers both in the community and in the hospital. Examples of adaptations included: traditional examples like ramps, and also creative examples like the use of rubber bands on a can to help with grip.

Conclusion(s): Patient-perspectives elicited in-depth information that expanded the common definition of function by highlighting the concept of “normality,” facilitators and barriers to function, and adaptations to optimize function. These insights emphasize function within a patient-context, emphasizing a holistic definition of function that can be used to develop personalized, patient-driven care plans. Published by Elsevier Inc.

Keywords: Spinal cord injury; Function; Photovoice

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Background

Sustaining a spinal cord injury (SCI) can have a major impact on physical, cognitive, and emotional function.¹ Corresponding adjustments to lifestyle are typically described as moderate to extremely severe.¹ Persons with SCI, their families/caregivers, and their health care providers are concerned about impacts on function and challenges that might be encountered due to poor or reduced functioning.² A study of individuals with both new and existing injuries found significant decreases in perceived physical and cognitive function, which sustained over time in those with existing injury.¹

Rehabilitation medicine is focused on optimizing function and health in individuals with disabilities.³ Commonly used measures to assess function in the clinical setting include the Functional Independence Measure (FIM) and the Spinal Cord Independence Measure (SCIM).^{4,5} The FIM has been found to be a valid and reliable tool for persons with SCI and includes assessment of physical and cognitive abilities.^{6,7} The SCIM (and newer SCIM II), a functional independence scale, focuses on areas of functional importance for persons with SCI and is weighted according to clinical relevance with respect to overall function.⁸ Recent literature, however, suggests that SCI research would benefit from comprehensive, precise, and sensitive functional measures⁹ and from utilizing approaches to defining function that complement the existing ‘static’ measures which contain pre-selected items defining function in a narrow range.¹⁰

A key concern of using existing measures (e.g., FIM) as the only source for characterizing function is the lack of involvement of persons with SCI in defining aspects of function.¹¹ These outcomes are insufficient when considered alone because they do not capture the perspectives and values of individuals with SCI in an open-ended way^{12,13} and highlight a gap in current definitions of function. Andres and colleagues (2003) took steps to address this gap by defining activity and selecting measures of activity from the patient viewpoint.¹⁴ This resulted in the creation of the Activity Measure for Post-acute Care (AM-PAC)¹⁴ which is administered in a structured interview format and designed to define functional activity from the patient perspective in three domains: (1) physical and movement, (2) personal and instrumental, and (3) applied cognition.

In more recent efforts, studies have utilized patient-reported outcomes resulting in recommendations to expand traditional definitions and assessments of domains that individuals perceive as important to their function.^{9,10} Inclusion of these individual perspectives in the development of a holistic definition of function that accounts for areas that are important to them is critical to SCI care and research. A potentially promising way to do this is use of participatory research methods. Photovoice is a participatory research method that has been used in a

variety of ways in the health care setting, including in the area of disability and rehabilitation, to gather insights of persons with disabilities and promote engagement in research.^{15,16} Ripat and Woodgate (2012) utilized photovoice in a study of persons with SCI to understand how assistive technologies contributed to self-perceived participation and to refine existing definitions of assistive technology (AT), which resulted in an expanded definition of AT.¹⁷ In another study, photovoice was used to explore barriers and facilitators that impact community participation in persons with SCI.¹⁸ The insights offered by these studies may serve as important components for refining the way in which some aspects of functioning are defined.

The purpose of this study was to use photovoice, to examine ‘unrestricted’ perspectives (open-ended, visual and narrative freedom) of persons with SCI including definitions of function and optimal functioning, as well as the facilitators, barriers, and adaptations they utilize to assist with function.

Methods

Study design/setting

A convenience sample of Veterans with SCI was recruited via flyers posted at the Edward Hines Jr. VA Hospital SCI Unit and distributed by SCI providers working on the unit. Recruitment occurred concurrently with data collection over a period of 5 months. This study was approved by the Hines VA Institutional Review Board.

Data collection

Participants attended an informational session at which time they: provided informed consent, completed a short demographic survey, received a digital camera, a memory card, an envelope to return the memory card after photos were taken, and instructions for camera use and study participation. Participants were asked to take 25–30 photographs using the following verbatim prompts: take pictures of (1) things that help you function the way you want to, (2) things that are barriers to you functioning the way that you want to, and (3) the adaptations you make so you can do the things you want to do.

After 4 weeks, those who returned a memory card were invited to participate in a 30–60-min, one-on-one follow-up interview to discuss the photographs from their perspectives. The interviews were audio-recorded and transcribed verbatim for analyses. After completing the interview, participants were given the digital camera and a new memory card to keep along with ten dollars as a token of appreciation for their time and efforts.

Inductive coding was used on an initial set of transcripts ($n = 5$) by three qualitative researchers (JH, KL, SB) to develop a thematic coding structure which was then applied

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