

Preferences for Recovery of Walking Function in Incomplete Spinal Cord Injured (SCI) Consumers at 1, 2 and 5 Years Post Injury

Patricia Ditunno, PhD¹; Mary Patrick, RN²; John Ditunno, MD²

¹University of the Sciences in Philadelphia, Philadelphia, PA

²Regional Spinal Cord Injury Center of the Delaware Valley, Thomas Jefferson University, Philadelphia, PA

ABSTRACT

Objective: To illustrate preferences for the recovery of function longitudinally and cross-sectionally at 1, 2 and 5 years post injury in consumers with incomplete spinal cord injury (SCI).

Design: Direct observation of a constrained consensus building process longitudinally with the same individuals in a repeated measure design at 1, 2, and 5 years post injury and cross-sectionally with different individuals at the same time periods.

Participants: A modified version of Stineman's Features Trade-Off Consensus Building tool was utilized to assess consumer preference for recovery among 14 functional status items of the modified Functional Independence Measure (MFIM), comparing walking to the other dimensions of the motor functional domains of the FIM. The method involved trading levels of independence (resources) across different items (features). The longitudinal panel consisted of 5 incomplete SCI individuals at 1-year post injury and 3 of the same individuals again at 2 and 5 years post injury. Three other panels consisted of different SCI individuals cross-sectionally at 1, 2 and 5 years post injury. Concentric pie charts (CPC) were used to illustrate preferences.

Results: Preferences for walking recovery in incomplete SCI consumers remain equal to bowel and bladder recovery at 1, 2 and 5 years post injury and remains constant for some individuals over the first 5 years post injury.

Conclusion: These results confirm that walking function is equal in preference to bowel and bladder function for incomplete subjects with SCI over 1 to 5 years.

Support: This project was supported in part by NIDRR, grant #H133N00023

INTRODUCTION

Consumer preference needs careful study to determine the importance of mobility to persons with spinal cord injury. Consumer preference and satisfaction are important and essential components of the new paradigm defined and described in the Long Range Plan of the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education¹. While numerous studies^{2,3,4} have addressed the domains of quality of life among persons with spinal cord injury, only a few studies^{5,6,7} have directly asked people with SCI to indicate what specific improvements in function are most meaningful to their quality of life. Stineman⁸ recently reported a discrepancy between consumers and clinicians rating of dimensions of disability. This study not only showed differences, but also facilitated a discussion between consumers and clinicians. An adaptation of Stineman's methodology was developed for this study. The purpose of the study was to examine longitudinal and cross-sectional preferences for recovery of walking function in incomplete SCI consumers at one, two and five years post injury.

METHODS

The Features Game developed by Stineman to demonstrate consumer/staff preferences for recovery was applied to spinal cord injury. Consumer/staff preference for walking was compared to the other dimensions of a modified Functional Independence Measure (MFIM), which separated walking and wheelchair mobility. Thus, six items of self-care, two items of sphincter control, and six items of mobility (wheelchair, walking, stairs, and chair, tub and toilet transfers) comprised the MFIM.

The study involved the direct observation of a constrained consensus building process. A panel of five individuals with incomplete spinal cord injury (2 tetraplegia, 3 paraplegia) was assessed at one year post injury and three of the same individuals again at two and five years post injury. In addition, different cross-sectional groups were assessed at one (2 tetraplegia, 1 paraplegia), two (3 tetraplegia, 2 paraplegia) and five (4 tetraplegia, 1 paraplegia) years post injury.

The objective of the Features Game is to establish the relative value of alternative functional status states. The features being traded were the 14 MFIM. Resource trade-off was the imagined level of independence achieved among the various tasks. The game uses the nominal group process⁹ that is clearly integrated with concepts from economic utility analysis¹⁰. This process assures that each panelist has equal opportunity for input.

The game involves a continuous two-step process of building imagined recovery patterns until all stages are completed. The specific steps to form each stage are as follows:

- Step 1 The Free Movement Phase
 - Step 2 Zero-Sum Exchange with Individual Discussions and Voting
- Steps 1 and 2 are repeated until the five interim stages are defined.

The preference stages developed by each panel are illustrated by concentric pie charts consisting of slices profiling panelists preferences for functional achievement in the 14 MFIM (Figures 1 and 2).

RESULTS

Consumers with incomplete spinal cord injury advanced walking to complete independence by Stage 4. Walking was as important as bowel and bladder function

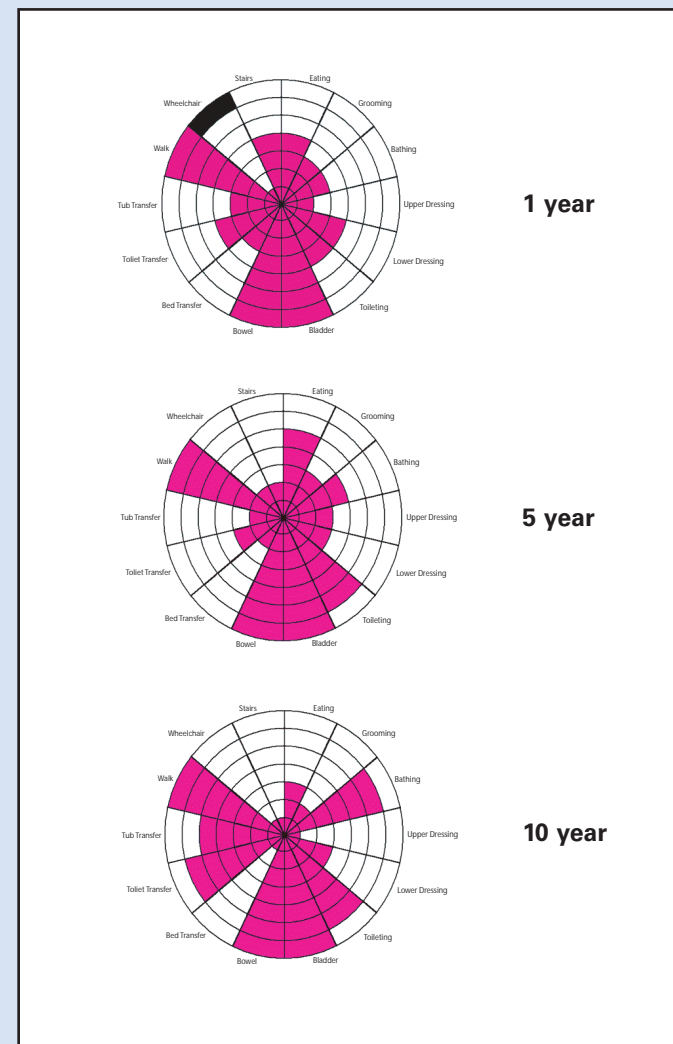


Figure 1. Concentric pie charts depicting stage 4 for the same incomplete SCI consumers longitudinally at years 1, 2, and 5 post injury

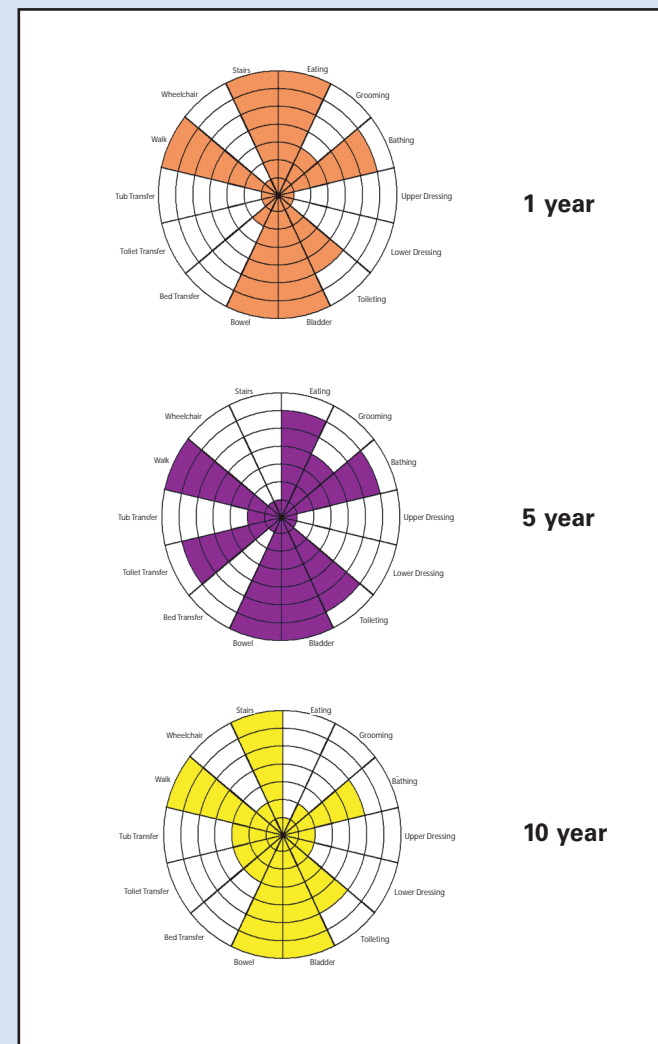


Figure 2. Concentric pie chart depicting Stage 4 for different groups of incomplete SCI consumers cross-sectionally at years 1, 2, and 5 post injury.

DISCUSSION

This study further suggests that walking is as important as the recovery of bowel and bladder function among incomplete subjects with SCI and remains constant in the same panel longitudinally at one, two and five years post injury and with different panels cross-sectionally at the same time points. It has been well documented that recovery of bowel and bladder is primary in preference for recovery¹¹. However, this study gives new insight into the importance of recovery of walking among consumers with incomplete spinal cord injury.

REFERENCES

1. National Institute on Disability and Rehabilitation Research (NIDRR) - Notice of Proposed Long Range Plan Fiscal Years 2005 - 2009, Federal Register Volume 70, No. 143/ Wednesday, July 27, 2005.
2. Tate, DG, Kalpakjian, CZA., Forchheimer, MB. Quality of life in individuals with spinal cord injury. *Arch Phys Med Rehabil* 2002; **83** (2 suppl): S18-25.
3. Manns, PJ, Chad, KE. Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury. *Qual Health Res* 2001; **11**, 795-811.
4. Dijkers, MPJM, Whiteneck, G, El-Jaroudi, R. Measures of social outcomes in disability research. *Arch Phys Med Rehabil* 2000; **81** (suppl 2): S63-80.
5. Anderson K. Targeting Recovery: Priorities of the Spinal Cord-Injured Population. *J Neurotrauma* 2004; **21**: 1371-83.
6. Donnelly C, Eng JJ, Hall J, Alford L, Giachino R, Norton K, Kerr DS. Client-centered assessment and the identification of meaningful treatment goals for individuals with a spinal cord injury. *Spinal Cord* 2004; **42**: 302-7.
7. Estores IM. The consumer's perspective and the professional literature: What do persons with spinal cord injury want? *J Rehabil Res Dev* 2003; **40**: 93-98.
8. Stineman MG, Maislin G, Nosek M, Fiedler R, Granger CV. Comparing consumer and clinician values for alternative functional states: application of a new feature trade-off consensus-building tool. *Arch Phys Med Rehabil* 1998; **79**(12):1522-1529.
9. Van de Ven AH, Delbecq AL. The nominal group as a research instrument for exploratory health studies. *Am J Public Health* 1972; **62**(3):337-342.
10. Samuelson PA. Foundation of economic analysis. Cambridge, MA: Harvard University Press, 1947.
11. Marino RJ, Ditunno JF, Donovan W, Maynard F. Neurological recovery after traumatic spinal cord injury: data from the Model Spinal Cord Injury Systems. *Arch Phys Med Rehabil* 1999; **80**: 1391-1396.