

LETTER TO THE EDITOR

Reply to JJ van Middendorp, AJF Hosman and H van de Meent's letter

Spinal Cord (2009) 47, 347–348; doi:10.1038/sc.2008.131;
published online 25 November 2008

We thank Dr van Middendorp and colleagues for their comments because it provides us the opportunity to clarify important issues and include additional information.

Dr van Middendorp and colleagues' letter confuses the *ontogeny of disability recovery* and the *meaning of disability recovery*. They note correctly that physical efforts to complete toilet transfers, tub transfers and chair to bed transfers are fairly comparable, but walking and stair climbing are progressively more difficult. This is consistent with hierarchical patterns of likely recovery such as those present in the empirically derived functional independence staging system.¹ Recovery patterns are observable, predictable and reflect therapist-measured assessments of how well a person is able to perform specific tasks. Patterns of recovery follow an ontology beginning with activities requiring the least, and ending with items requiring the most complex motor and perceptual capacities within a domain.² When a therapist records that a man with tetraplegia requires moderate assistance to transfer from a bed to a chair, this quantifies the level of physical assistance required from a second person, but says nothing about the meaning of needing that assistance to the man who needs it or to the person who provides it.

The game³ uncovers recovery preferences, which are a completely different concept from ontology. Recovery preferences are formed through recovery choice pathways,⁴ which reflect the embodied⁵ value-laden *meanings of disability* as driven by the individual's life contexts, self concepts, beliefs, culture and experiences. Functional independence measure (FIM) items arranged into domains by meaning are not necessarily grouped in the same ways as FIM items arranged into domains by ontology.⁶ When creating domains of meaning, people use various strategies that differ dramatically. Some link activities performed in sequence, such as toilet transfers with toileting (from the activities of daily living (ADL) and mobility domains, respectively). Others link activities causally, such as eating with bowel and bladder (from the ADL and sphincter management domains, respectively). Orders of recovery preference do not necessarily reflect the ontological order. In addition, recovering the ability to transfer onto a toilet is often considered as much more important than the ability to transfer from bed to chair, even though these skills require fairly comparable motor activities.

Dr van Middendorp and colleagues' comments about bowel and bladder more appropriately reflect the meaning. People nearly universally assign these activities very high recovery preferences. For the reasons stated, recovery of bowel and bladder functions is almost always preferred over recovery of walking. Nonetheless, assessing the importance of bowel and bladder functions *per se* was not considered the main objective of the analysis. Utilities from the games in our study allowed a comparison of the perceived importance of each of the individual 14 items to any one of the remaining 13 items. The objective was to compare the relative importance of being able to walk as opposed to using a wheelchair, making the comparison of these utilities primary. This supported the point that walking, as a therapeutic objective, should not be abandoned too quickly in spinal cord injury rehabilitation.

Dr van Middendorp and colleagues' questions the face validity of the features game as applied. They propose to use a 'broader description of functional entities without overlapping items as outcome measures'. The feature game is designed to use any set of functions. We would encourage and welcome the application of any ordered sets of items that researchers deem appropriate. The question of 'overlap', as it relates to the domains of meaning, is puzzling. Clearly, as argued, toilet transfer ability is a prerequisite to (linked to) bowel care, and some component of its meaning results from this linkage. Both items taken together yield a 'broader functional entity' associated with bathroom use, but each carries distinct meanings. Consistent with the 'privatization argument' cited, the value-laden consequences of requiring help getting on and off the toilet may seem less than needing someone to wipe and clean the perianal area and are clearly distinct.

The degree to which the selected guiding principle matches the study objectives determines the face validity and meaning of the resulting recovery choice of pathways. The particular guiding principle, 'maximal personal and economic freedom', reflects the social model of disability. It was selected recognizing that spinal cord injury patients are typically young in the prime of life, and focused on maximizing personal productivity. Any number of guiding principles might be applied to drive the move selection. There are also different ways to set up the game board. The setup that we applied anchored the procedure by having patients 'imagine' a total state of disability across all activities. In a 'more realistic' setup, the initial board would be configured to reflect the patient's current functional status for each activity. The resulting recovery choice pathway would then express how he or she would want to

Table 1 ASIA impairment scale (AIS) and neurological level at admission

c-SCI	i-SCI-long-1y, i-SCI-long-2y, i-SCI-long-5y	i-SCI-cross1y	i-SCI-cross2y	i-SCI-cross5y	i-SCI < 50	i-SCI > 50
C4 A	C5 B	C4 C	C5 C	C4 B	C4 B	C3 B
C5A	C6 B	C4 C	T9 C	C4 C	C5 B	C4 C
T2 A	T8 B	C5 D	C4 D	C4 C	L1 B	C7 D
T6 A	L3 B		C5 D	C5 C	C4 C	
T11 A	L2 C		T12 D	C5 D	C4 D	

Abbreviations: c-SCI, complete SCI; i-SCI-long-1y, 2y, 5y, incomplete SCI longitudinally at 1, 2 and 5 years; i-SCI-Cross-1y, 2y, 5y, incomplete SCI cross-sectionally at 1, 2 and 5 years; i-SCI < 50, incomplete SCI less than 50 years old; i-SCI > 50, incomplete SCI over 50 years old; SCI, spinal cord injury.

recover from that initial status. This 'realistic approach' might be clinically valuable, but it is open only to a single player, and utilities are not comparable across players, as patients would start at different levels based on their status.

Dr van Middendorp and colleagues correctly identify that the prognosis for walking in complete subjects is poor based on a recent review of spontaneous recovery.⁷ This again deals with the realistic prediction as compared with meaning. Although it is true that we included only one panel consisting of five complete subjects, the primary purpose of the analysis was to examine walking preferences in incomplete subjects.

Finally, a Table 1 that details the American Spinal Injury Association (ASIA) Impairment Scale (AIS) and neurological level for each of the panels is included.

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