

LETTER TO THE EDITOR

Who wants to walk? Preferences for recovery after SCI: a longitudinal and cross-sectional study

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We have read with great interest the descriptive study by Ditunno *et al.*¹ evaluating preferences for recovery in SCI patients. Using a modified version of the features-resources trade-off game and a modified version of the functional independence measure, this challenging study evaluated the preference of patients with spinal cord injury (SCI) for the restoration of walking. The authors conclude that, regardless of the severity of injury, time of injury and age at the time of injury, the priority of walking is high among the patients with SCI and professionals.

We agree that the 'features game' is a very sophisticated and effective tool to assess preferences for recovery. This was proven a decade ago by coauthor Dr Stineman.² Despite application of this strong instrument, several concerns raised with regard to the study design and validity of study's outcomes.

As the modified functional independence measure comprises four main functional entities, which are self-care, sphincter control, transfers and locomotion, we observed an overlap of functional outcomes within the 14 selected items. For instance, three transfer independency items were included: toilet transfers, tub transfers and chair/bed transfers. Physical effort to complete these transfers are almost equal in paraplegic patients. Once patients with SCI are able to perform tub transfers, they certainly can perform other types of transfers. In contrast, the three locomotion items, which are wheelchair, walking and stairs independence, clearly show improving grades of ambulatory capacity and performances.

Unfortunately, possible explanations for why bowel and bladder independency scored higher priority than walking have not been discussed. Incontinence is a topic that is likely to make both care providers and patients socially uncomfortable. The body has been 'privatized' in our social life.^{3,4} This could also be the reason why toilet transfers score relatively high within the functional entity transfers, see Figures 2 and 3 in Ditunno *et al.*¹ This significant socially uncomfortable issue stresses the importance of emotional affection in choosing preferences for recovery. However, as the bowel care is indirectly a part of functional entity transfers, this in turn might act as a confounder within this entity.

Therefore, we believe that, except for functional independence measure items concerning functional entity sphincter control, dilemmas faced within the features game lack face validity. We propose to use a broader description of functional entities without overlapping items as outcome measures in

future research concerning the patients' recovery preferences. In addition, it would be more interesting to know whether the recovery preferences would be the same in a more realistic setting than authors applied research condition 'maximal personal and economic freedom'. After all, realistic approaches in models will increase the external validity.

Another interesting aspect, the authors unfortunately did not discuss, is the possible influence of patients' estimation of (long-term) neurological and functional recovery. It is well known that approximately 5% of patients with complete SCI recover ambulatory function. Schönherr *et al.*⁵ reported that the correct predictions were most often found regarding the mobility of patients with complete lesions. Ditunno *et al.*,¹ however, report a stage 4 preference for independent walking with device in patients with complete SCI. This stresses the importance of patient education in the (sub)acute care setting. This in turn will result in more realistic rehabilitation targets and preferences.

Another comment concerns the description and number of eligible patients. The authors did not describe essential baseline parameters in detail. No information concerning American Spinal Injury Association (ASIA)/ International Spinal Cord Society (ISCoS) neurological standard scale (AIS) or level of SCI (tetra- or paraplegic) is presented. As incomplete paraplegic patients do have normal strength in the upper extremities, they focus on the recovery preferences concerning the lower extremities. For this reason, the recovery preferences concerning the functional independence measure self-care items might be underestimated and vice versa.

At last, in the discussion, the authors write: 'While survey research may sample large populations, it often loses specificity of results.' That is true, however, choosing one panel consisting of only five patients with complete SCI, might in turn lose the sensitivity of results. We agree with the authors that the generalization of their study results must be done cautiously and confirmation of their findings in multiple centres is desirable.

Despite raised questions, we praise the efforts that have been made by Ditunno *et al.*¹ This study stresses the importance of implementing patient-related recovery priorities in the development of future rehabilitation programs. In future research programs, however, the use of appropriately defined outcome measures with adequate face validity is mandatory.

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