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Disability meanings according to patients and clinicians: imagined recovery choice pathways

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Abstract

Objective—The purpose of this study was to explore how the meaning of disability varies between patients with acute-onset activity limitations and clinicians, and between males and females.

Methods—Seventy-nine patients undergoing inpatient rehabilitation and 93 practicing rehabilitation clinicians in the USA developed personal recovery choice pathways through recovery preference exploration (RPE). Imagining complete dependence in 18 activities as diverse as eating and expression, each individual determined an optimal sequence of recovery. This sequence was used to determine the relative value of each activity compared with the other 17. Three comparisons were made by calculating the mean absolute difference (MAD) in median utilities, including patients versus clinicians, male versus female patients, and male versus female clinicians. The MAD shows the relative magnitude of disparity between each pair.

Results—The MAD value between patients and clinicians was 3.4 times larger and 4.8 times larger than the MAD values between male and female patients and male and female clinicians, respectively.

Conclusions—The much larger difference in recovery preferences between patients and clinicians compared with differences between genders suggests that life contexts of being a patient with disabilities versus a clinician are more potent determinants of activity limitation perspectives than being a man or woman.

Keywords

Activities of daily living; Decision making; Patient-centered care; Patient care team; Quality of life

People with medical conditions and the general public see quality of life (QoL) differently [1]. Health care providers, like the general public, typically estimate the QoL of people with disabling medical conditions as lower than people with those conditions rate the quality of their own lives [2,3]. Many with serious long-standing disabilities are satisfied with life despite their inability to perform activities able-bodied people see as essential [4,5]. Their QoL depends on their opportunities to interact socially, on the quality of their physical environments, and on their reorganization of life goals. Consequently, it is essential to discover the particular activity limitations for which patients see recovery as most essential to QoL and to see how clinician beliefs differ.

The process of patients' seeking adaptation transfers the meaning of activity limitations [6]. This process is largely "ideographic," "unique," personal, and context dependent [7]. For rehabilitation patients with new-onset disabilities, meanings are emergent, resulting from the daily in-hospital experiences of therapy for their activity limitations. Consequently, meanings assigned by patients represent an "insider perspective" of disability expressing what they "feel about their condition or its consequences" (p. 251 WHO ICF) [6,8]. In contrast, clinicians will likely apply a more "nomothetic" or logic-based approach when evaluating the implications of activity limitations. Trained to diagnose and treat through scientific observational standards [9], clinicians tend to conceptually dismantle the body into structures to be measured as objective "exterio-rized signs" [6]. Analyzed as functional assessments devoid of life contexts, disability measurements fail to express peoples' feelings about those conditions and represent an "outsider perspective" of disability [8].

Being male or female, like being a patient or clinician, is a socially constructed life context which shapes how one sees oneself interacting with others [10]. A person's gender might influence recovery preference due to different social constructions of disability for males and females [11]. Previous thematic analyses of recovery choice logic suggest subtle differences, where women often place comparatively greater value in activities such as grooming as important to personal expression and intimacy [12].

In an effort to understand the perceived importance of being able to perform particular activities, we apply recovery preference exploration (RPE) [13,14], a phenomenologically based tool designed to break down disabilities into elements of meaning. This uses partial decentering to help relinquish personal perspectives [15], guiding patients to look at meanings outside their current status and clinicians outside scientific knowledge. Without decentering, patients would logically choose to recover preferentially from limitations they are experiencing and clinicians would select an ontology beginning with activities requiring the least and ending with items requiring the most complex motor and perceptual capabilities [16]. To capture the relative importance of recovering from different activity limitations, it is essential to look beyond personal status or any clinical training, recognizing meanings, status, and ontology as distinct.

We hypothesize that, because of differences in life contexts and circumstances, patterns of recovery preference will differ strikingly between patients undergoing inpatient rehabilitation and clinicians providing them care. Differences in preferences between male and female clinicians and patients will be of smaller magnitude than between patients and clinicians, allowing the pooling of genders. Moreover, the order of activities through which recovery is preferred will not necessarily follow ontology.

Methods

Sample

The RPE procedure was piloted with 20 patients prior to enrolling 102 from an urban inpatient rehabilitation unit in the USA. Patients were selected to represent diverse sociodemographic backgrounds and types of disabling conditions. Only patients with a Functional Independence Measure (FIM™) [17,18] score of supervision (5) or above in comprehension, expression, memory, and problem solving were included because of the cognitive demands of RPE. Data from 23 patients unable to complete the full procedure were excluded. Reasons for noncompletion were inability to imagine complete dependence, lack of understanding of how the procedure worked, or feeling too tired or in too much pain. RPE results from 79 patients were compared with 93 rehabilitation clinicians' RPE results obtained through the clinician version of RPE [19]. All clinicians were actively rotating through inpatient rehabilitation programs. Clinicians were selected to represent a broad range of disciplines including 27 physicians, 5 medical students, 23 nurses, 11 occupational therapists, 1 recreational therapist, 15 physical therapists, 7 neuropsychologists, and 4 social workers. The protocol was approved by the participating hospital's Institutional Review Board. All patients and clinicians signed consent forms in which they agreed to the publication of deidentified qualitative and quantitative information.

RPE

RPE is "a technique intended to reflect the strength of one's preference" [20] for recovery of each item in a list of essential daily activities relative to all other activities specified. The procedure is set up to simulate decision making in the face of uncertain recovery by asking players to select each recovery step as if each selected step might be their last. Players must consider both the relative value of being able to perform each activity, and the meaning of alternative performance levels. The desirability of any one of the many choices at any point will depend on the current imagined state of independence across all activities (i.e., all previous selected choices). The procedure by necessity begins at the same level for all players, allowing comparison of recovery preferences across groups. Imagining complete dependency in all activities, each person plans optimal recovery. The result is a recovery choice pathway that establishes the relative importance of being able to perform each activity compared with each of the other activities in the procedure.

Individuals apply salient real-life experiences and environmental contexts over time as personal frames of reference [21]. The assumption is that particular recovery pathways will shape QoL differently depending on appraisals of past experience, personal values, and life goals. RPE yields utilities that quantify the relative importance of different functional abilities to an individual. Utility values range from 0 to 1 and are widely accepted as an appropriate way to measure health-related QoL [20,22]. In addition to utilities, themes emerge as players explain the logic behind their recovery choices. Emerging themes are applied to explore contextual drivers of meaning [14,23].

Any ordinal set of functional or health status questions can form the basis of RPE. For this study, the FIM™ [17,18] was selected because it is the standard instrument used to assess activity limitation in inpatient rehabilitation in the USA. It includes 18 physical and cognitive and communication activities [24,25]. RPE is played on a game board [12] with the activities listed in a column on the left hand side and performance levels listed along the top (Fig. 1). FIM™ levels were combined to express broad concepts of dysfunction: complete dependence (FIM™ level 1), requires some assistance (FIM™ levels 2, 3, and 4), needs supervision (FIM™ level 5), takes longer/needs a device or safety issues (FIM™ level 6), and completely independent (FIM™ level 7).

Since there are 18 functional activities and four levels of performance through which to move each activity, 72 moves ($18 \times 4 = 72$) must be made to imagine recovery from complete dependence to complete independence. The procedure is divided into four stages, each consisting of 18 moves. Stage 1 describes recovery choices assuming severe, stage 2 moderate, stage 3 mild, and stage 4 very mild disability. The order of recovery choices is unconstrained. If a particular activity is deemed very unimportant, it may be left completely dependent until the last four game moves.

Clinicians built their recovery trajectory by numbering moves on the paper game board and provided recovery logic after each stage. During the pilot, patients demonstrated difficulties keeping track of moves on paper so a software tool was developed. This RPE prototype programmed in Visual Basic 6.0 runs on a tablet personal computer (PC) with a 160° viewing angle and active stylus touch screen capability. The format of the input screen was identical to the paper game board, but included a colored graphic interface and automatic move numbering. We also established a think-aloud protocol [26] where patients provided recovery logic with each move, allowing the administrator to track patients' understanding of the procedure and redirect them as needed applying a formalized script with probes.

Procedure

The RPE procedure was administered to patients by a research assistant and to clinicians by a resident physician, both supervised by an attending physician. To begin, the administrator reviewed definitions of the 18 FIMTM activities and the five performance levels. The player was asked to imagine that he or she was completely dependent in all 18 FIMTM activities and could control order of recovery at will. Patients were asked to disregard their own functional status and clinicians to disregard knowledge about typical recovery patterns. This partial decentering procedure required both patients and clinicians to imagine themselves in altered states of complete dependency (all starting from the same point) with their own attitudes, living circumstances, and life contexts. The example game board (Fig. 1) illustrates move 1 from complete dependence to some assistance in bowel management and move 2 from some assistance to supervision in bowel management. The gray shading delineates stages. All 72 moves were allowed.

Method of calculating utilities

To calculate utilities, decisions between different health states must be made under uncertainty. Since the player did not know how much imagined recovery he or she would be allowed to achieve, moves are being made under uncertainty. Therefore, the move numbers for each FIMTM activity can be used to calculate the utility of that activity relative to the other 17. The first step in calculating the utility of a particular FIMTM activity is to sum the inverse of the four move numbers associated with that FIMTM activity. The lowest possible value that can be obtained by summing the inverses of the move numbers is 0.05675 ($1/69 + 1/70 + 1/71 + 1/72$) and the highest possible value is 2.08333 ($1/1 + 1/2 + 1/3 + 1/4$). These values would occur if the player chose to imagine recovery for an activity during the last and first four moves of the RPE procedure, respectively. Because utilities are measured on a scale from 0 to 1, the sum of the inverses needed to be scaled to produce that range. In the example game board, the four move numbers for eating are 3, 12, 37, and 63. Summing the inverse of these moves ($1/3 + 1/12 + 1/37 + 1/63$) yields 0.45957. First, 0.05675 (the lowest possible sum) was subtracted from the sum of the inverses. The resulting value was then divided by 2.02658 (the highest possible sum, i.e., 2.08333, minus the lowest possible sum, i.e., 0.05675). Thus, the utility value for eating is $0.19877 = (0.45957 - 0.05675)/2.02658$. Utilities show the relative value of a FIMTM activity compared with all other FIMTM activities; for example, if the utility for eating is higher than the utility for stairs, the player values the ability to eat more than the ability to climb stairs.

Method of analyzing utilities

Patient to clinician comparisons were the primary analyses. The male to female analyses applied separately for patients and clinicians were intended to confirm that it is appropriate to compare all patients (i.e., male and female) to all clinicians (i.e., male and female). Utilities for each FIM™ activity were calculated individually for each player. Because RPE yields ordinal measures of utility, median values for each FIM™ activity along with the 25th and 75th percentiles within subgroups were defined on the basis of type of player (patient versus clinician). After noting substantial differences between patients and clinicians, males and females were compared and stratified by type of player. Consequently, three pairwise comparisons were made: patients versus clinicians, male versus female clinicians, and male versus female patients. Methods are described for the patient to clinician comparison, but approaches were similar for the two gender comparisons.

Wilcoxon rank-sum tests with significance level $P < 0.0027$ were used to determine if there were statistically significant differences in utilities for each of the individual 18 FIM™ activities between patients and clinicians, male and female clinicians, and male and female patients. Due to the large number of tests performed, “a Bonferroni correction” was used to calculate the significance level for the Wilcoxon rank-sum tests. The significance level was calculated by dividing 0.05 by the total number of tests performed for each comparison.

The median utility values for the patients and clinicians were plotted along the y-axis and x-axis, respectively. A line equidistant from the x- and y-axes was drawn on the plot. If the utility profiles for the clinicians and patients were identical, all utilities would have fallen on this line. If a utility fell above the line, the associated activity was valued more by the patient group, and if a utility fell below the line, the activity was valued more by the clinician group.

To compare the overall magnitude of utility preference differences between patients and clinicians, between male and female clinicians, and between male and female patients, the mean absolute difference (MAD) in median utilities between each of the two groups was calculated. The MAD was calculated by first finding the absolute value of the difference in median utilities for each FIM™ activity according to each group. The resulting values were then summed and divided by 18 to yield the MAD between each pairwise comparison. The larger the MAD value, the smaller the agreement in utilities between the groups.

The relative magnitude of disparity was assessed for the three pairwise comparisons. Relative magnitudes were expressed as ratios of MAD values thereby expressing the relative magnitude of differences in each pairwise comparison by way of unitless measures.

Results

The clinical and diagnostic characteristics of the 79 patients (45.6% female) are shown in Table 1. The demographic characteristics of the 93 clinicians (63.4% female) are displayed in Table 2.

For patients, the most valued FIM™ activity was eating (median utility = 0.126, Q1 or 25th percentile = 0.045, Q3 or 75th percentile = 0.496), which was also extremely variable. The next most valued activities was bathing, followed closely by toileting, bowel management, and bladder management. The lowest valued activity was stairs (median = 0.029, Q1 = 0.008, Q3 = 0.048).

For clinicians, the most valued FIM™ activities were expression (median = 0.355, Q1 = 0.239, Q3 = 0.579) and comprehension (median = 0.255, Q1 = 0.108, Q3 = 0.509). Both utilities were extremely variable. There was a large decrease in utility between comprehension and the next

most valued activity, memory (median = 0.115, Q1 = 0.052, Q3 = 0.200). The lowest valued FIM™ activity was stairs (median = 0.007, Q1 = 0.002, Q3 = 0.014).

There were statistically significant differences in utilities between patients and clinicians ($P < 0.0027$) for the majority of the FIM™ activities except for eating, toileting, bowel management, bladder management, bed, chair, wheelchair transfer, walking, and social interaction, even after using the Bonferroni correction. Utilities for those activities that were statistically significantly different in pairwise comparisons showed two- to threefold differences between the groups. Although women patients placed more relative value than men in being able to dress, the utility differences were no longer statistically significant after applying the Bonferroni correction. There were no significant differences in the utilities for any of the FIM™ activities between male and female clinicians before or after the Bonferroni correction. The profile of utilities reflected in the clinician gender comparison appeared nearly identical (data available from the authors).

Table 3 shows the median utility values and the 25th and 75th percentiles along with P -values from the Wilcoxon rank-sum tests for differences in the utility values between clinicians and patients. For both groups, variation in utility was most pronounced in the activities with the highest median utilities. The highest compared with the lowest median utility was many fold times greater for clinicians than for patients. The range in median utilities was from 0.007 to 0.355 for clinicians and from 0.029 to 0.126 for patients. Data on gender differences are available from the authors.

Figure 2 compares patient and clinician median utility patterns. The medians for 11 out of the 13 physical activities cluster above the equidistant line, indicating that achieved physical independence was relatively valued more by patients than by clinicians. Conversely, all five cognitive activities are below the equidistant line, indicating that communication and cognition were valued relatively more by clinicians than by patients. The greatest utility value difference was for expression, followed by comprehension.

Figure 3 compares female and male clinician median utility patterns. Most of the utilities lie close to the equidistant line, indicating that female and male clinicians have relatively similar recovery preferences. Figure 4 compares female and male patient utility patterns. Again, most of the utilities lie close to the equidistant line.

Despite large differences in comprehension and expression, some similarities were observed between patients and clinicians. Among the motor FIM™ activities, independence in eating, toileting, bladder management, and bowel management were among the highest, and stair climbing the least valued achievement for patients and clinicians.

The MAD value between patients and clinicians was 0.058. The MAD value between male and female clinicians was 0.012, which is 4.8 times smaller than the MAD value between patients and clinicians. The MAD value between male and female patients was 0.016, which is 3.6 times smaller than the MAD value between patients and clinicians.

Discussion

Results support our hypotheses that recovery preferences differ sharply between patients with acute-onset disabilities undergoing inpatient rehabilitation and the rehabilitation clinicians caring for them. While clinicians consistently sought early imagined recovery of comprehension and expression, “a cerebral recovery choice pathway,” patients tended to prefer early imagined recovery in eating, bathing, and toileting functions, “a physical recovery choice pathway.” These preference differences are supported by earlier studies [27,28], further

supporting the expectation that the two groups have different outlooks about priorities in functional recovery.

When patients are hospitalized, the importance of being able to eat, bathe, and toilet is thrust upon them in daily interactions with nurses and therapists. Dependency erodes the little autonomy they can have in that restricted setting. In sharp contrast, clinicians, unchallenged by these routines, are more focused on the need to achieve the high levels of comprehension and expression central to their daily practices. Moreover, social class differences could be another one of the many contexts that might be contributing to recovery preference disparities. Clinicians are more likely than patients to be able to afford helpers for assistance with physical functions. Communication skills would logically be prerequisite to directing such care. Thematic analyses of clinician recovery choice logic support this outlook [23] where expression and comprehension were seen as important to building a foundation for recovering other skills, directing care, and expressing needs. Unacknowledged discrepancies in beliefs about what abilities are most important to QoL could generate tensions between patients and clinicians. Patients' beliefs about the value of early recovery of the abilities to eat, bathe, and toilet independently stress the importance of enabling and respecting individual autonomy in these basic activities during hospitalization.

The striking magnitude of difference between patients' and clinicians' recovery choice pathways is highlighted both by much smaller gender-related differences and by much smaller differences between clinician specialty types reported previously [19]. Gender-related differences were sufficiently small to allow comparisons of all patients to all clinicians. Still, very small differences, even though limited to the patient group, suggest that women compared with men tend to place greater value in activities which influence how they appear to others, such as dressing. Consequently, there is some need for caution when exploring the meaning of this type of activity in gender-pooled patient populations.

In sharp contrast to current findings, in an earlier study community-dwelling people with severe long-standing physical disabilities selected recovery of cognitive and communication activities over physical activities [12]. This suggests that people with disabilities might experience a time-related response shift in recovery preferences as their circumstances evolve [29,30]. Constantly experiencing the day-to-day challenges of living in the community logically changes the basis through which they make QoL judgments. Their internal standards and values will evolve [6] as they strive to functionally integrate themselves within their physical and sociocultural environments and reorganize their life goals [31].

There were also some similarities in patients' and clinicians' recovery preferences. Looking just at the physical activities, both groups tended to view independence in bowel and bladder functions as among the most essential. The importance of bladder management for both groups related to the avoidance of shame and caregiver burden. Similarly, both groups saw stair climbing as least important, noting that one can configure the environment to eliminate this need.

Differences in subjective appraisals [13,19,28,32,33] highlight the ideographic and nonontological nature of meaning, where the QoL implications of activity limitation are driven in part through each person's internal explanations of external life contexts as they understand them [31]. Various individuals and groups of people logically judge the relative importance of recovering through different objective frames of reference, subjective standards of comparison, and personal reference points [21]. It is essential to acknowledge the value-laden and nonstandard nature of disability meanings [34]. Some patients developed highly cerebral recovery choice pathways more typical of clinicians whereas some clinicians developed highly physical ones more typical of patients. Others imagined pathways that differed strikingly from

either group; for example, although stair climbing was believed least essential by most players, a patient who needed to be able to climb several flights of stairs to return home gave stair climbing the highest priority. The typically low value assigned to stair-climbing ability is clearly bound to the USA experience. When the first author administered RPE informally to therapists in German, the therapists consistently placed great value in stair climbing, explaining that life in most German homes requires it. There are subtle geographic differences even in the USA. People in Philadelphia found stair climbing more important than people living in Texas, where fewer buildings have multiple stories [12].

RPE has some similarities to the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) [35] and the Canadian Occupational Performance Measure (COPM) [36], which determine the areas of functioning a person sees as most important. Rather than the person nominating domains as in the SEIQoL and COPM, in RPE the person evaluates the relative importance of being able to perform each of a selected set of functional activities. Thus, RPE provides a tool for determining the relative value a patient places in being able to perform each activity within particular sets of specified functional activities. Such sets might be selected to match the battery of activities being assessed for which treatment is being planned. RPE is appropriate when the intent is to understand individual beliefs regarding the relative QoL implications of recovering across a specific set of activity limitations or symptoms at one point in time. Utilities can be applied to quantify meanings, while emerging themes about choice making explain the life contexts driving those meanings. Valuable applications may emerge to research or to rehabilitation medicine and to other medical specialties such as gerontology or neurology whose patients have disabilities.

Early applications to clinical practice suggest that RPE empowers patients, enhances the depth of patient–practitioner dialogue, and inspires clinicians to change therapeutic goals to be more patient focused [13]. Future research might further develop therapeutic applications, explore the influence of culture, education, or other life contexts on recovery preferences, and apply alternative symptom or functional status inventories. RPE might also prove useful in studying response shifts in recovery preferences over time or as life circumstances change [30].

Our study has several limitations. Results from this small sample may not be generalizable and are considered exploratory. Larger samples are needed to confirm findings. Also, about 20% of patients were unable to complete RPE. RPE requires fairly intact cognitive skills. Recognizing this, we are developing a less cognitively demanding companion procedure [28]. Also, our study was performed among clinicians and patients living in a particular region of the USA. Clearly, these results are culturally bound to the USA experience. Difference in the nature of thought [37] can be expected among people in different cultures or nations. Finally, difference in preferences between persons with short- and longer-term disabilities warns against the application of acutely obtained RPE utilities in establishing long-term goals. Future cross-sectional and longitudinal studies will be essential to understanding associations among life contexts, time, and recovery choice pathways.

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Abbreviations

RPE	Recovery preference exploration
MAD	Mean absolute difference

ICF	International classification of functioning, disability, and health
WHO	World Health Organization
QoL	Quality of life
FIM TM	Functional Independence Measure
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
COPM	Canadian Occupational Performance Measure
PC	Personal Computer

References

1. Baron J, Asch DA, Fagerlin A, Jepson C, Loewenstein G, Riis J, et al. Effect of assessment method on the discrepancy between judgments of health disorders people have and do not have: A web study. *Medical Decision Making* 2003;23:422–434. doi:10.1177/0272989X03257277. [PubMed: 14570300]
2. Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: A review. *Journal of Clinical Epidemiology* 1992;45:743–760. doi:10.1016/0895-4356(92)90052-O. [PubMed: 1619454]
3. Ubel PA, Loewenstein G, Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Quality of Life Research* 2003;12:599–607. doi:10.1023/A:1025119931010. [PubMed: 14516169]
4. Bach JR, Barnett V. Ethical considerations in the management of individuals with severe neuromuscular disorders. *American Journal of Physical Medicine and Rehabilitation* 1994;73:134–140. doi:10.1097/00002060-199404000-00012. [PubMed: 8148105]
5. Bach JR, Tilton MC. Life satisfaction and well-being measures in ventilator assisted individuals with traumatic tetraplegia. *Archives of Physical Medicine and Rehabilitation* 1994;75:626–632. doi:10.1016/0003-9993(94)90183-X. [PubMed: 8002759]
6. World Health Organization. International classification of functioning, disability and health: ICF. Geneva, Switzerland: World Health Organization; 2001.
7. Nagel, E. *Structure of science: Problems in the logic of scientific explanation*. Hackett; Indianapolis: 1979.
8. Brown M, Gordon WA. Empowerment in measurement: “Muscle,” “voice,” and subjective quality of life as a gold standard. *Archives of Physical Medicine and Rehabilitation* 2004;85:S13–S20. doi:10.1016/j.apmr.2003.08.110. [PubMed: 15083418]
9. Mattingly, C.; Fleming, M. *Clinical reasoning. Forms of inquiry in a therapeutic process*. FA Davis; Philadelphia: 1994.
10. Groce NE. Disability in cross-cultural perspective: Rethinking disability. *Lancet* 1999;354:756–757. doi:10.1016/S0140-6736(99)06140-1. [PubMed: 10475203]
11. Thorne S, McCormick J. Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International* 1997;18:1–16. [PubMed: 9119779]
12. 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. *Archives of Physical Medicine and Rehabilitation* 1998;79:1522–1529. doi:10.1016/S0003-9993(98) 90413-0. [PubMed: 9862293]
13. Kurz AE, Saint-Louis N, Burke J, Stineman MG. Exploring the personal reality of disability and recovery: A tool for empowering the rehabilitation process. *Qualitative Health Research* 2008;18:90–105. doi:10.1177/1049732307309006. [PubMed: 18174538]
14. Stineman MG, Ross RN, Maislin G, Marchuk N, Hijirida S, Weiner M. Recovery preference exploration: Analysis of patient feedback after imagined scenarios. *American Journal of Physical Medicine and Rehabilitation* 2007;86:272–281. doi:10.1097/PHM.0b013e3180383acb. [PubMed: 17413540]

15. Kogan SM, Gale JE. Decentering therapy: Textual analysis of a narrative therapy session. *Family Process* 1997;36:101–126. doi:10.1111/j.1545-5300.1997.00101.x. [PubMed: 9248822]
16. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association* 1963;185:914–919. [PubMed: 14044222]
17. Granger CV, Hamilton BB, Keith RA, Zielezny M, Sherwin FS. Advances in functional assessment for medical rehabilitation. *Topics in Geriatric Rehabilitation* 1986;1:59–74.
18. Hamilton, BB.; Granger, CV.; Sherwin, FS.; Zielezny, M.; Tashman, JS. *A Uniform National Data System for Medical Rehabilitation*. Paul H. Brookes; Baltimore, MD: 1987.
19. Rist PM, Freas DW, Maislin G, Stineman MG. Recovery from disablement: What functional abilities do rehabilitation professionals value the most? *Archives of Physical Medicine and Rehabilitation* 2008;89:1600–1606. doi:10.1016/j.apmr.2007.11.060. [PubMed: 18597736]
20. Torrance GW. Utility approach to measuring health-related quality of life. *Journal of Chronic Diseases* 1987;40:593–600. doi:10.1016/0021-9681(87)90019-1. [PubMed: 3298297]
21. Rapkin BD, Schwartz CE. Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. *Health and Quality of Life Outcomes* 2004;2:14. doi: 10.1186/1477-7525-2-14. [PubMed: 15023229]
22. Sox, HC.; Blatt, MA.; Higgins, MC.; Marton, KI. *Medical decision making*. Butterworth; Boston: 1988.
23. Stineman MG, Rist P, Burke J. Through the clinician's lens: Objective and subjective views of disability. *Qualitative Health Research* 2009;19:17–29. [PubMed: 19029242]
24. Linacre JM, Heinemann AW, Wright BD, Granger CV, Hamilton BB. The structure and stability of the functional independence measure. *Archives of Physical Medicine and Rehabilitation* 1994;75:127–132. [PubMed: 8311667]
25. Stineman MG, Shea JA, Jette A, Tassoni CJ, Ottenbacher KJ, Fiedler R, et al. The functional independence measure: Tests of scaling assumptions, structure, and reliability across 20 diverse impairment categories. *Archives of Physical Medicine and Rehabilitation* 1996;77:1101–1108. doi: 10.1016/S0003-9993(96)90130-6. [PubMed: 8931518]
26. Fonteyn M, Kuipers B, Grobe S. A description of think aloud method and protocol analysis. *Qualitative Health Research* 1993;3:430–441. doi:10.1177/104973239300300403.
27. Bunch WH, Dvorch VM. The “value” of functional independence measure scores. *American Journal of Physical Medicine and Rehabilitation* 1994;73:40–43. [PubMed: 8305180]
28. Stineman MG, Kurz AE, Kelleher D, Kennedy BL. The patient's view of recovery: An emerging tool for empowerment through self-knowledge. *Disability and Rehabilitation* 2007;30:1–10.
29. Norman G. Hi! How are you? Response shift, implicit theories and differing epistemologies. *Quality of Life Research* 2003;12:239–249. doi:10.1023/A:1023211129926. [PubMed: 12769136]
30. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: A theoretical model. *Social Science and Medicine* 1999;48:1507–1515. doi:10.1016/S0277-9536(99)00045-3. [PubMed: 10400253]
31. Stineman MG. A model of health environmental integration. *Topics in Stroke Rehabilitation* 2001;8:34–45. doi:10.1310/OL5G-NQHY-GH4K-HV58. [PubMed: 14523744]
32. Ditunno PL, Patrick M, Stineman M, Ditunno JF. Who wants to walk? Preferences for recovery after SCI: A longitudinal and cross-sectional study. *Spinal Cord* 2008;46:500–506. doi:10.1038/sj.sc.3102172. [PubMed: 18209742]
33. Ditunno PL, Patrick M, Stineman M, Morganti B, Townson AF, Ditunno JF. Cross-cultural differences in preference for recovery of mobility among spinal cord injury rehabilitation professionals. *Spinal Cord* 2006;44:567–575. doi:10.1038/sj.sc.3101876. [PubMed: 16317422]
34. Browne JP, O'Boyle CA, McGee HM, Joyce CB, McDonald NJ, O'Malley K, et al. Individual quality of life in the healthy elderly. *Quality of Life Research* 1994;3:235–244. doi:10.1007/BF00434897. [PubMed: 7812276]
35. Joyce CR, Hickey A, McGee HM, O'Boyle CA. A theory-based method for the evaluation of individual quality of life: The SEIQoL. *Quality of Life Research* 2003;12:275–280. doi:10.1023/A:1023273117040. [PubMed: 12769139]

36. Donnelly C, Eng JJ, Hall J, Alford L, Giachino R, Norton K, et al. Client-centred assessment and the identification of meaningful treatment goals for individuals with a spinal cord injury. *Spinal Cord* 2004;42:302–307. doi:10.1038/sj.sc.3101589. [PubMed: 14993893]
37. Nisbett RE, Peng K, Choi I, Norenzayan A. Culture and systems of thought: Holistic versus analytic cognition. *Psychological Review* 2001;108:291–310. doi:10.1037/0033-295X.108.2.291. [PubMed: 11381831]

	WITH HELP			NO HELP	
	Complete Dependence	Some Assistance	Supervision	Take longer/ Need device	Completely Independent
Eating	Complete Dependence	3	12	37	63
Grooming	Complete Dependence	9	21	42	62
Bathing	Complete Dependence	10	22	43	54
Dressing-Upper Body	Complete Dependence	20	38	59	70
Dressing-Lower Body	Complete Dependence	19	39	60	71
Toileting	Complete Dependence	14	23	36	53
Bladder Management	Complete Dependence	4	11	33	52
Bowel Management	Complete Dependence	1	2	32	51
Bed, Chair, Wheelchair Transfer	Complete Dependence	17	28	34	56
Toilet Transfer	Complete Dependence	5	13	35	55
Tub/Shower Transfer	Complete Dependence	18	24	45	58
Walk/Wheelchair	Complete Dependence	29	30	44	57
Stairs	Complete Dependence	40	46	69	72
Comprehension	Complete Dependence	8	27	50	66
Expression	Complete Dependence	6	7	49	67
Social Interaction	Complete Dependence	31	41	61	68
Problem Solving	Complete Dependence	16	26	48	65
Memory	Complete Dependence	15	25	47	64

Key to Colors Used in Figure 1.

Stage 1	
Stage 2	
Stage 3	
Stage 4	

Fig. 1.

Example game board showing how one individual imagined recovery. The numbers included in each box represent the order of moves made by the individual from which utilities were calculated. The pattern illustrates a primarily physical pattern in which the person chose to recover the physical activities before the cognitive activities (i.e., the physical activities had lower move numbers). Reprinted from Archives of Physical Medicine and Rehabilitation, 89, Rist, P. M., Freas, D. W., Maislin, G., & Stineman, M. G., Recovery from disablement: What functional abilities do rehabilitation professionals value the most?, 1600–1606, (2008), with permission from Elsevier

Fig. 2.

Comparison of patient and clinician median utility profiles. Activities falling above the line equidistant from the *x*- and *y*-axes are relatively more valued by patients than clinicians whereas activities falling below the line are relatively more valued by clinicians than patients. Key to letters used in Figs 2–4: Ea, Eating; G, Grooming; Ba, Bathing; Du, Dressing upper body; DL, Dressing lower body; To, Toileting; Bl, Bladder management; Bo, Bowel management; Be, Bed chair wheelchair transfer; Tt, Toilet transfer; Ts, Tub/Shower transfer; W, Walk/Wheelchair; S, Stairs; C, Comprehension; Ex, Expression; Si, Social interaction; P, Problem solving; M, Memory

Fig. 3.

Comparison of female and male clinician median utility profiles. Activities falling above the line equidistant from the x - and y -axes are relatively more valued by female than male clinicians whereas activities falling below the line are relatively more valued by male than female clinicians

Fig. 4.

Comparison of female and male patient median utility profiles. Activities falling above the line equidistant from the x - and y -axes are relatively more valued by female than male patients whereas activities falling below the line are relatively more valued by male than female patients

Table 1

Patient demographics, showing clinical characteristics for all patients, and for male and female patients

Characteristic	Total population (N = 79)	Male (N = 43)	Female (N = 36)
<i>Age: average in years (SD)</i>			
Race, N (%)	54.4 (15.7)	52.2 (15.5)	57.3 (15.6)
American Indian or Native Alaskan	1 (1.3)	0 (0.0)	1 (2.8)
Asian	1 (1.3)	1 (2.3)	0 (0.0)
Black or African American	28 (35.4)	16 (37.2)	12 (33.3)
Hispanic or Latino	2 (2.5)	1 (2.3)	1 (2.8)
White or Caucasian	47 (59.5)	25 (58.1)	22 (61.1)
<i>Primary diagnosis, N (%)</i>			
Stroke	5 (6.3)	2 (4.7)	3 (8.3)
Brain dysfunction	6 (7.6)	2 (4.7)	4 (11.1)
Neurological conditions	9 (11.4)	4 (9.3)	5 (13.9)
Spinal cord dysfunction	5 (6.3)	3 (7.0)	2 (5.6)
Amputation	11 (13.9)	9 (20.9)	2 (5.6)
Pain syndromes	1 (1.3)	0 (0.0)	1 (2.8)
Orthopaedic disorders	25 (31.7)	10 (23.3)	15 (41.7)
Cardiac disorders	1 (1.3)	1 (2.3)	0 (0.0)
Pulmonary disorders	2 (2.5)	1 (2.3)	1 (2.8)
Major multiple traumas	5 (6.3)	4 (9.3)	1 (2.8)
Medically complex conditions	9 (11.4)	7 (16.3)	2 (5.6)
<i>Marital status, N (%)</i>			
Never married	20 (25.3)	10 (23.3)	10 (27.8)
Married	43 (54.4)	26 (60.5)	17 (47.2)
Widowed	7 (8.9)	1 (2.3)	6 (16.7)
Separated	1 (1.3)	1 (2.3)	0 (0.0)
Divorced	8 (10.1)	5 (11.6)	3 (8.3)
<i>Admit from, N (%)</i>			
Initial rehabilitation	5 (6.3)	5 (11.6)	0 (0.0)
Transitional living	1 (1.3)	1 (2.3)	0 (0.0)
Acute unit of own facility	60 (75.9)	35 (81.4)	25 (69.4)

Characteristic	Total population (N = 79)	Male (N = 43)	Female (N = 36)
Acute unit of another facility	13 (16.5)	2 (4.7)	11 (30.6)
Location before hospitalization, N (%)			
Home	74 (93.7)	41 (95.3)	33 (91.7)
Transitional living	2 (2.5)	1 (2.3)	1 (2.8)
Other	2 (2.5)	1 (2.3)	1 (2.8)
Alternate level of care unit	1 (1.3)	0 (0.0)	1 (2.8)
Motor FIM™; mean (SD)	46.2 (9.3)	48.7 (8.8)	43.3 (9.2)
Cognitive FIM™; mean (SD)	32.3 (1.3)	32.6 (1.3)	31.9 (1.2)

* Percentages do not always add to 100% because of rounding error

Clinician demographics, showing average age and racial breakdown of all clinicians, and male and female clinicians

Table 2

Characteristic	Total population (N = 93)	Male (N = 34)	Female (N = 59)
Age: average in years (SD)	33.4 (8.8)	34.6 (8.2)	32.7 (9.1)
Race, N (%)			
American Indian or Native Alaskan	1 (1.1)	2 (5.9)	1 (1.7)
Asian	15 (16.1)	5 (14.7)	10 (16.9)
Black or African American	12 (12.9)	0 (0.0)	10 (16.9)
Hispanic or Latino	0 (0.0)	0 (0.0)	0 (0.0)
Native Hawaiian or other Pacific Islander	1 (1.1)	1 (2.9)	0 (0.0)
White or Caucasian	63 (67.7)	25 (73.5)	38 (64.4)
Caucasian-Asian	1 (1.1)	1 (2.9)	0 (0.0)

Table 3
Patient and clinician median utilities with 25th and 75th percentiles and *P*-values from Wilcoxon rank-sum tests

FTM™ item	Median patient utility (interquartile range)	Median clinician utility (interquartile range)	<i>P</i> -value
Eating	0.126 (0.045, 0.496)	0.065 (0.035, 0.100)	0.0030
Grooming	0.060 (0.021, 0.102)	0.026 (0.012, 0.042)	<0.001
Bathing	0.095 (0.054, 0.139)	0.036 (0.021, 0.052)	<0.001
Dressing upper body	0.054 (0.019, 0.086)	0.019 (0.010, 0.034)	<0.001
Dressing lower body	0.060 (0.026, 0.093)	0.019 (0.010, 0.034)	<0.001
Toileting	0.085 (0.043, 0.159)	0.059 (0.037, 0.131)	0.0753
Bladder management	0.081 (0.046, 0.217)	0.073 (0.051, 0.159)	0.7837
Bowel management	0.081 (0.041, 0.200)	0.082 (0.057, 0.193)	0.2812
Bed-chair transfers	0.042 (0.027, 0.066)	0.030 (0.016, 0.050)	0.0069
Toilet transfers	0.056 (0.026, 0.080)	0.031 (0.021, 0.045)	0.0003
Tub transfers	0.041 (0.015, 0.068)	0.018 (0.010, 0.027)	<0.001
Walk/wheelchair	0.046 (0.026, 0.109)	0.034 (0.018, 0.062)	0.0267
Stairs	0.029 (0.008, 0.048)	0.007 (0.002, 0.014)	<0.001
Comprehension	0.045 (0.015, 0.107)	0.255 (0.108, 0.509)	<0.001
Expression	0.033 (0.013, 0.063)	0.355 (0.239, 0.578)	<0.001
Social interaction	0.034 (0.010, 0.078)	0.054 (0.023, 0.118)	0.0043
Problem solving	0.031 (0.011, 0.047)	0.079 (0.041, 0.142)	<0.001
Memory	0.033 (0.013, 0.061)	0.115 (0.052, 0.200)	<0.001