

City University of New York (CUNY)

CUNY Academic Works

Publications and Research

Guttman Community College

2008

Exploring the Personal Reality of Disability and Recovery: A Tool for Empowering the Rehabilitation Process

Ashley E. Kurz

University of Pennsylvania

Nicole Saint-Louis

CUNY Guttman Community College

Janice P. Burke

Thomas Jefferson University

Margaret G. Stineman

University of Pennsylvania

[How does access to this work benefit you? Let us know!](#)

More information about this work at: https://academicworks.cuny.edu/nc_pubs/25

Discover additional works at: <https://academicworks.cuny.edu>

This work is made publicly available by the City University of New York (CUNY).

Contact: AcademicWorks@cuny.edu



Published in final edited form as:

Qual Health Res. 2008 January ; 18(1): 90–105. doi:10.1177/1049732307309006.

Exploring the Personal Reality of Disability and Recovery: A Tool for Empowering the Rehabilitation Process

Ashley E. Kurz and Nicole Saint-Louis

University of Pennsylvania, Philadelphia, Pennsylvania, USA

Janice P. Burke

Thomas Jefferson University, Philadelphia, Pennsylvania, USA

Margaret G. Stineman

University of Pennsylvania, Philadelphia, Pennsylvania, USA

Abstract

People experiencing disability and chronic disease often feel powerless, relinquishing medical control to “more knowledgeable” professionals. This article presents qualitative and quantitative results from three individual patients experiencing an emerging procedure called Recovery Preference Exploration (RPE). To inspire greater patient involvement, self-direction, and individual choice, we instructed participants to create an imagined recovery path, exposing recovery preferences while learning about clinical rehabilitation concepts. Results uncovered important values and feelings about disability, providing a richer context for patient evaluation and treatment goal modification. Applying mixed methods, RPE is presented as an explanatory process for quantifying recovery preferences in a way that stimulates rich narrative of how people see different types of disabilities. RPE shows promise for increasing depth of discussions among patients, family, and clinicians. RPE may promote greater quality of life through patient empowerment by directed learning, increased communication, and enhanced self-knowledge.

Keywords

phenomenology; communication; constructivism; coping and adaptation; decision making; clinical; disability; empowerment; positivism; mixed methods; narrative methods

Patient-centered care, as emphasized in family practice and rehabilitation, is valid for all forms of medicine (Gans, 2006; M. Stewart, Brown, Weston, McWilliam, & Freeman, 2003; Stineman, 2000). The model focuses on teaching and learning, with the assumption that clinicians already have a background in biomedical principles but also need to incorporate the human dimension into practice. Despite efforts in medicine to improve patient centeredness, the patient–clinician relationship appears to be deteriorating (Bergeson & Dean, 2006). As cost containment efforts intensify and encounter times shorten, there is less time available for clinicians to consider patients’ beliefs, understanding of illness, and therapeutic goals.

There is a movement in medicine to include the patient’s narrative. Arthur Kleinman, one of the leaders in the field of narratives and illness, states that the biomedical system, as opposed to the biopsychosocial system, replaces the salient meaning of illness for patients and families, or the “soft” and therefore devalued psychosocial concern, with the “hard” or scientifically overvalued technical quest for the control of symptoms (Kleinman, 1988). The patient’s illness narrative expresses his or her “lifeworld,” reflecting contextually grounded personal experiences and challenges resulting from his or her “natural attitude.” In contrast, the “voice of medicine” expresses abstract rules about illness through the “scientific attitude” and is

removed from personal and social contexts (Mishler, 1984). Recovery Preference Exploration (RPE) is an emerging technique (Stineman et al., in press) being designed for rehabilitation and medicine in general that contextualizes illness by asking patients to express their own stories (Docherty & McColl, 2003) about recovery from disabilities that are even more severe than those they are currently experiencing. As patients imagine recovery, they eventually reach and then surpass their current status. Protected by being in an imaginary space, illness narratives often emerge spontaneously, uncovering value-laden perceptions about disability and the contexts that shape deeper beliefs and desires for recovery. RPE invites the clinician to temporarily suspend the scientific attitude and enter the patient's sociocultural lifeworld (Ware & Kleinman, 1992). The process of uncovering the patient's beliefs about illness and disability encourages greater patient involvement and centeredness in health care decision making.

Maximizing Positive Outcomes Through Patient-Centered Approaches

It is widely understood that there is a link among patient involvement in health care choices, successful outcomes, and quality of life (Holman & Lorig, 2000; London Department of Health, 2001). In patients with diabetes and hypertension, Grosset and Grosset (2005) found patient-centered consultation styles to be associated with higher patient satisfaction and improved health outcomes. A randomized controlled trial by Tsay and Li-Oer (2004) demonstrated that patients with endstage renal disease who were given the opportunity to be involved in the goal-setting and decision-making processes showed lower levels of depression and higher levels of both empowerment and self-efficacy. Patients who leave the hospital satisfied with their medical treatment also tend to comply with treatments (Aharony & Strasser, 1993; Eisenberg, 1997; Williams, 1994), which can improve outcomes.

The World Health Organization (1977) recognized the importance of the communicative relationship between patient and health professional as far back as 1977. Patient outcomes appear to decline when doctors block patient communication (Elander & Barry, 2003). Connections between communicative treatment strategies and positive health status directly support RPE (M. A. Stewart, 1995). Here, we illustrate how RPE can function as an empowerment medicine tool. Empowerment medicine is a patient-centered approach that views self-acceptance, patient-caregiver communication, and compliance as interwoven factors in the patient-caregiver relationship (Stineman, 2000). With empowerment medicine, the clinician attempts to translate medical information into language that helps the patient take ownership of that information. RPE facilitates empowerment by providing the clinician with information about the patient's preferences for functional recovery (Stineman et al., in press), along with the narrative description of what drives those preferences. The process of forcing explicit choices of imagined recovery among such diverse functions as toileting and problem solving yields narrative information about the value of alternative functional states and thus provides clinicians insight into how disability is likely to be influencing the way patients see themselves. These insights enable the clinician to communicate information in ways that are more meaningful and understandable.

The role of personal suffering and self-identity loss through disability requires rehabilitation professionals to guide their patients toward successful acceptance of new identities that incorporate their disability. It has been suggested that loss of self is a phenomenon experienced by many people living with chronic disease and disability:

Chronically ill people frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones....Such losses are most marked at the onset of a serious, debilitating illness....Over time, accumulated loss of formerly sustaining self-images without new ones results in a diminished self-concept. (Charmaz, 1983, p. 148)

Rehabilitation may be critical not only for rebuilding physical strength and abilities but also for intercepting self-destructive thought processes and facilitating positive emotional progress when facing life-altering disabilities. In keeping with this idea, rehabilitation psychologists have gradually shifted from examining the negative aspects of disability adjustment to examining the qualities that promote positive adjustment (Dunn & Dougherty, 2005). We see RPE as a means toward encouraging renewed self-concept during a critical time of disability acceptance. In addition, it is a technique that allows individuals to share their illness experiences, the impact of stress, their views of disability, and personal motivations with health care professionals, thereby empowering patients and strengthening patient-caregiver communication. Terms related to RPE are defined in Table 1.

Data and Method

Patient Qualification, Sample

We present three RPE studies. In the first and second studies, a patient and his wife were selected to show how RPE can be applied to inspire shared learning between the patient and significant other. The third study discusses a patient with multiple sclerosis (MS) selected to show how RPE can be applied to gain an understanding of one individual's unique lifeworld. The two patients involved were purposely selected as having different diagnoses, genders, ages, familial situations, and life perspectives. They were drawn from different services, one from the orthopedic and complex medical rehabilitation service and the other from the neurological rehabilitation service.

The cases presented were from a larger, ongoing, National Institutes of Health-funded technology-development study occurring at an in-patient rehabilitation facility. The RPE data pool was purposefully established to include adults of all ages with a wide array of disabilities, medical conditions, and socio-economic circumstances. Patients recruited to participate were required to have cognitive Functional Independence Measure (FIM) scores of 6 or 7 in comprehension, expression, social interaction, problem solving, and memory, representing modified independence or complete independence. This meant that to be included in the study patients needed to be able to perform these functions with only mild or no difficulty (UB Foundation Activities, 2001).

Informed consent was obtained in accordance with institutional review board requirements. After discussing the procedure, all participants signed consent and Health Insurance Portability and Accountability Act forms, explicitly delineating the specific type of information to be collected and how it was to be used. Patients in this report signed an additional consent for full interview publication privileges, including the use of verbatim deidentified quotes from their interviews. Patients' interviews were recorded using a small, unobtrusive digital recorder. Voice files were deidentified and stored in password-protected files. Patient recordings were transcribed verbatim with personally identifying information removed. All participants' names were changed and nonessential personal and diagnostic details eliminated to protect identity.

Procedure Used in This Study

RPE, which was derived from the Features Resource Trade-off Game, was administered by a research associate who was supervised by a physician (Stineman et al., in press; Stineman, Maislin, Nosek, Fiedler, & Granger, 1998). The RPE procedure was completed in approximately 45 minutes to 1 hour using a computerized game board. Figure 1 shows how the computer screen appeared to patients at the beginning of the procedure. Participants were first asked to imagine a state of complete disability and dependence on a caregiver in the same set of activities as measured by the FIM. These activities included eating; grooming; bathing; dressing the upper body; dressing the lower body; toileting; bladder management; bowel

management; bed, chair, and wheelchair transfer; toilet transfer; tub or shower transfer; walking or wheelchair use; stairs; comprehension; expression; social interaction; problem solving; and memory (UB Foundation Activities, 2001). These 18 activities are listed along the left edge of the screen. Starting from complete dependence, patients were asked to indicate their order of preferred recovery on the game board through four levels of independence: some assistance, supervision, takes longer or needs device, and complete independence. The four levels through which patients indicated recovery preferences are listed along the top of the game board. Patients allocate their recovery “resources” (i.e., possible recovery moves) to those FIM activities of greatest value to them.

To start RPE, the patient indicated the activity in which he or she would most like to begin recovery by pressing the empty box on the screen directly to the right of the selected activity. The computer colored in the *some assistance* box to indicate an imagined change from complete to some assistance. The patient was then asked to select a second move toward recovery. He or she could choose either the same activity, increasing it from some assistance to supervision, or a different activity, beginning at complete dependence and going to some assistance. Once the patient pressed the empty box for the second move, the computer colored that box. The process continued for 72 moves, defining the patient’s ideal patterns of imagined recovery, beginning with total dependency and ending with complete independence in all activities. Numbers appeared in the boxes, tracking the patient’s order of moves. After each move, the pattern across the game board represented the optimal outcome assuming total initial dependency and a specified degree of recovery. The computer changed the fill in colors every 18 moves, depicting patterns of early, early-middle, late-middle, and late recovery preferences.

The patterns of recovery preferences recorded through the order of moves yield utilities that measure the strength of preference for particular outcomes on a numeric scale (Sox, Blatt, Higgins, & Marton, 1988). Several methods of determining utilities from RPE data are being explored. With the method used here, the inverse sum of the move numbers was taken across the four levels of imagined performance for a given activity. This yielded a numerical value, which represented the relative importance of that activity to the patient compared to the other 17 activities. These utilities were then plotted as value rulers. The value ruler is a bar chart in which the height of the bar associated with each of the 18 activities indicates the relative importance the individual assigns to them. Patients were encouraged to reflect on their recovery preferences as indicated by the value ruler and to share their RPE results with significant others, physicians, therapists, psychologists, nurses, and other health care professionals. When family members were present, they were encouraged to perform RPE and to compare their results with the patient’s, providing an opportunity for patient–caregiver exchange and facilitation of joint decision making.

RPE participants were asked to explain their choices by thinking aloud (Fonteyn, Kuipers, & Grobe, 1993) as they made recovery preference selection. They were asked to describe how RPE influenced their thinking about their current disabilities. Example questions included “What driving forces in your life influenced you to make the choices you did today?” and “What are some of your long-term goals for yourself?” The procedure ended with the patient’s illness narrative.

RPE results were presented at patients’ clinician team meetings. Each week during rehabilitation group meetings, nurses, occupational therapists, physical therapists, recreational therapists, neuropsychologists, social workers, and physicians met to discuss patient status, goals, and discharge plans. Staff members discussed application of RPE results and applied findings to treatment planning.

Data Analysis

The approach applied mixed methods (Creswell, Fetters, & Ivankova, 2004; National Institutes of Health, Office of Behavioral and Social Science Research, 1999). The underlying rationale was that both deductive and inductive reasoning are required to determine the meaning of disability. The data that emerge from RPE simultaneously attach a (quantitative) utility to each functional skill and identify (qualitative) life contexts that provide rationale for those utilities. The quantitative and qualitative information was collected concurrently and given equal priority in analysis and interpretation. The interview was initially structured beginning with the choice-making task and ending with the unstructured illness narrative. Quantitative and qualitative information was integrated at the conclusion of RPE in discussions with the patient and/or family and later at the interdisciplinary team meeting. Clinicians at the team meeting applied both numeric utilities from the patients' value rulers and thematic content from their narratives to better understand the implications of the patients' actual disabilities as measured by the FIM instrument during initial assessment.

We felt that the richness of each patient's story and resulting RPE explanations called for a comprehensive presentation of individual cases. Concepts were guided by Kleinman's (1988) concepts of illness narrative. The qualitative aspects of RPE complemented the quantitative choices throughout the procedure, providing unique richness to each individual's story. The purpose of the narrative was to explore contextual aspects of the game moves. The narrative analysis was designed to capture the phenomenological nature of disability applying cognitive and social constructionism paradigms. Anything spoken by the patient was viewed as a legitimate "manifestation of the essence of meaning" (D. Stewart & Mickunas, 1990) and was applied to help make sense of and conceptualize the inner logic driving each patient's unique imagined recovery choices. We assumed that people create their lifeworld meanings through personal experience, which is continuously shaped and refined by membership in a community (Whitman, 1993). The role of RPE was to facilitate the creation of a lived experience for the patient or family member in which meanings could emerge independent of the clinician's scientific attitude. Through the analysis of narrative content in combination with the patients' quantitative utilities, similarities, differences, and distinctions among individuals became apparent.

The therapeutic value to both clinician and patient, expressed through Kleinman's (1988) idea of the "illness narrative," emphasized to us the importance of incorporating personal qualitative accounts of illness with our quantitative RPE procedure. To Kleinman, empathetic listening, translation, and interpretation are meant to complement the standard biomedical treatment of disease to treat the whole person rather than merely the medical symptoms. Similarly, RPE seeks to integrate the scientific biomedical model with what is deeply and personally meaningful to the patient. By linking these two rich data sources, we were able to "envision in chronic illness and its therapy a symbolic bridge that connects, body, self, and society," thereby revealing "that our social world is linked recursively to our inner experience [of illness]" (Kleinman, 1988, p. X111). We further expand on Kleinman's concept, recognizing that this "symbolic bridge" between body, self, and society must include the physical environment to adequately inform our understanding of disability and ultimate empowerment (Stineman, 2001).

Findings

Case I: Bob and His Wife Pam

Bob was in his 50s. Previously admitted to the hospital after pelvic resection for carcinoma, Bob was readmitted for debridement of infection. His hospital course was complicated by numerous comorbidities and complications.

Bob's close relationship with Pam was evident through her daily participation in therapy, observation, and general support of him. The pair was almost always seen together on the rehabilitation floor, and Pam was often found asleep on a chair next to Bob's bedside late into the night.

Bob's first four moves in the RPE procedure brought him from complete dependence to some assistance in comprehension, expression, social interaction, and problem solving (see Figure 2). He described his desire to achieve a certain level of cognitive functioning early:

There are some things I'd rather do before the others, but comprehension, that's number one—some assistance. Expression is number two and the reason because comprehension—you need to be able to do the other things and expression—I want other people to know what I'm thinking, what I'm doing.... Problem solving is, again, important to me because it helps me to do the other things that I have to do to be able to figure out some of these things.

For Moves 7, 8, 9, and 10, he brought walking or wheelchair use through four levels to complete independence, stating, "Definitely, that's the most important." His wife agreed, and noted that "it's a point he's dealing with, so it's right at the front of his mind."

Bob explained his view of recovery trade-off across different activities through his explanation of eating because "eating is important, because you are going to die if you don't eat. ... I would want some assistance, but since I'm eating, I could go to something else." Help with eating was tolerable so long as proper nutrition was being obtained. This was his reasoning for moving eating to some assistance as Move 5 and then leaving it at the level of some assistance until Move 24. Bob explained, "When I get to a certain point, then other things may be a little bit more important at that point, and I try to get them ahead at that point." Toileting was an activity that he would begin to work on at a higher level as soon as he had reached a certain level of assistance or independence cognitively and physically. This was represented by choices for toileting through all four levels as Moves 6, 37, 38, and 39. Because of his other physical limitations, however, Bob did not want to accept help walking or using a wheelchair, preferring complete independence in these activities as soon as possible, demonstrated by his early and complete progression with these activities.

Once some assistance was achieved with most of the 18 FIM items, Bob focused on the activities of daily living (ADLs) through Moves 11 to 36, including bathing, dressing both the upper and lower body, grooming, and eating independently. Higher levels of cognitive functioning were selected amid some of the ADLs, as shown by Moves 25 to 28, 33, and 34. Bob explained the importance of "social interaction, because it's important to me because of my family." Other activities such as stairs were less meaningful (Moves 55, 56, 65, and 66): "Stairs doesn't mean anything to me because I don't have any.... Stairs I would say would be the least important." The activity of least value to Bob was bladder management (Moves 69, 70, 71, and 72): "I have no bladder left. ... I don't have one, they took it away." A sensitive subject, Bob explained how losing his bladder to cancer has been sad yet enlightening: "I do get sad I don't have a bladder, you know, other things bother you. You can't go through this without being bothered, you get crazy."

Personal dignity is a theme that "rolls into everything" else (all of the other activities), according to Bob. "They do a pretty good job of that here," he mentioned, referring to the maintenance of a patient's sense of dignity in rehabilitation.

Bob's Illness Narrative

After completing RPE, Bob gave a detailed account of his experiences with illness and health care, which provided further insight into his value ruler and recovery choices:

I had a large, large, large, large basketball-size tumor ... in my bladder, in my prostate, and other things. Then I didn't heal, and I got infected, and I had to come back in here. I was in this place for a couple months, or a month, and I left. I was able to walk with my walker, get up, go down, only to find out it was getting worse and worse. To find out that the radiation had gone down into my nerves that affect my legs. So I come back in, and they tell me they have to clean this out and sew it up. Well they cleaned it out, but they opened it up as big as you can imagine. ... Come out of that and have a [serious complication]. ... Been through a lot, but I'm conscious enough to know that I've been blessed. I mean, there are so many people worse off than me.

The RPE procedure allowed Bob to realize how well he actually was doing, his strong family support, and his positive attitude:

I have great family support, even if I don't get to walk, it will bother me terribly ... but know that I could be worse. I could be dead, and sometimes dead is not worse off, I'll tell you that. Sometimes dead is okay. But if you are not conscious and you are not able to express what I just did to you, it could be terrible. I have it good. I've got some troubles. See if I can overcome them, that's all, but all in all I'm okay.

He had the opportunity to share his ambitions and goals for the future in light of the advice and assistance he had received on the unit: "I'd like to get out and hunt and fish again. I'd like to do that." At this, his wife also added that "he runs and plays with the kids, and that's all the things that are the most fun and maybe the most satisfying in life for him." Through RPE, Bob verbalized that he would "like to be able to walk unassisted at some point" and "[the rehabilitation team] seem to think that I'm going to walk again. They seem to think that, with a little walker. ... I'm going to try, that's for sure, and hopefully, hopefully, with God's help, I will."

The desire to walk and participate in a wide variety of physical activities was a common theme throughout Bob's narrative. The dominance of walking as a theme was consistent with the extreme value Bob placed in being able to walk relative to the other 17 activities (see value ruler, Figure 3). The narrative Bob shared, along with his quantitative preferences for recovery, demonstrated his positive attitude and objectivity with respect to his recovery potential. After completing RPE, it was felt that Bob's motivation for rehabilitation was exceptionally strong and vitally important to his recovery. His value ruler and preferences were presented to the clinical team in an effort to improve planning for his discharge.

The RPE results were presented at the weekly team meeting. After reviewing Bob's value ruler, the clinical team revised his ongoing recovery plan. In Bob's case, the team had goals to rehabilitate him to a "solid supervision or minimal assistance" level. His wife was trained, knowledgeable, and capable of caring for him. This was reinforced by her constant presence in daily therapies and nursing care. The entire rehabilitation team reevaluated Bob's goals in comparison to his RPE results, thereby extending his stay by approximately 1 week to accommodate his desire for greater progress. In this case, the clarification of patient goals, coupled with professional recommendations and knowledge of the patient's potential progress, enabled the social work case manager to advocate for approval of a longer length of stay. In a market driven by managed care, the patient's voice indirectly speaking to the insurer is invaluable.

Although Bob's RPE results indicated his strong desire to walk unassisted, his wife Pam imagined a more balanced recovery and "becoming independent at all of these things, small things." Walking or using a wheelchair was in fact one of the least important activities in her mind. Comprehension, expression, and social interaction were of greatest value, ADLs fell in between, and transfer and mobility activities were left to be accomplished last (see Figures 4 and 5).

Explanations for her choices centered on female concerns with bathroom privacy and highlighted her role as a home health aid, which she had been in years past:

I have probably a different perspective. ... I did home health care for people when I was young, for people who were in certain circumstances to people who had a stroke ... heart conditions, all kinds of things like that.

Now put in this role again, but this time for her husband, the RPE allowed her to juxtapose her values to those of her husband. Pam was better able to see the differences in recovery preferences between them and recognize his individual goals as unique expressions of his self-concept.

After both Bob and his wife completed RPE, they were able to understand each other's values about recovery. Increased understanding of Bob's individual goals enabled Pam to help him achieve these goals. This sensitivity and awareness were seen by the clinical team as critical to Bob's successful medical management, psychological coping, and quality of life once discharged.

Case II: Maggie

Maggie came to the in-patient rehabilitation unit after an acute MS exacerbation. For 8 years Maggie had been living independently with MS, which was increasingly affecting her daily routines and lifestyle. She managed to keep knowledge of her disease from many of her past employers, her close friends, and her family members. She noted that her ability to conceal her MS was becoming more difficult, however, as her compensatory mechanisms and worsening physical limitations became increasingly visible to those around her.

Maggie felt that having MS compromised many of her social relationships, and she had "already become like a hermit or recluse." She explained,

I didn't know if I was ashamed, but I was just, I didn't want [her friends] to see me this way ... cause I work too. I want people to see me as a normal person. ... A lot of people don't know that I have MS because I'm just so secretive and I don't want anybody to know.

Maggie contextualized RPE into a framework based on what the most vital activities would be if she experienced another acute exacerbation in her home. In this way, the RPE served a highly specialized and evaluative purpose, expressing her unique human information through a standardized tool. At the forefront of her limitations, being able to walk or use a wheelchair and maneuver the stairs were overall high-leverage goals according to her value ruler. Clinically, her actual competence in these two activities was low (FIM scores of 2), with the personal importance of the activity high. As shown in Maggie's game board graphic, she advanced bed, chair, and wheelchair transfer to some assistance and continued by addressing bathroom-related activities such as bladder management (Move 2) and toileting (Move 3) at the level of some assistance. She moved bathing, grooming, and transferring in and out of the tub and shower all at the level of some assistance (Moves 4, 5, and 6; see Figure 6). Maggie offered comprehensive reasoning reflective of her high degree of planning and execution of compensatory tasks:

See, if I was at home, let's say, and I was sleeping and I woke up and I'm having an attack and I can't move, I can't do nothing, my first thing would be "I've got to get to the bathroom." Then it would be trying to get washed and dressed. ... Now, once I'm dressed, I'll try to think. "If I'm having a hard time, how the heck am I going to get down the steps?" I'd start thinking, which would be comprehension.

Once out of bed, washed, and dressed, the next task would be to get down the two flights of stairs in her home (Moves 13 and 14). With minimal use of her legs, Maggie saw this as an enormous challenge threatening her mobility around her home. Problem solving and memory tied in closely with figuring out how to get down the stairs (Moves 11 and 12). She remarked that she would “have to think, using what I’d done in rehab, how did I get down there [downstairs] before?” These tasks reflected the methodical logic and organization used by Maggie to proceed in the RPE:

Once I get down the stairs, then I’m trying to get something to eat, which is in the kitchen. While I’m eating, I’d start to think more of how I’m going to— who can I call? How am I going to deal with this?

Once Maggie achieved some assistance with all activities (Moves 1 to 18), she viewed recovery some-what differently. Her familiarity with medication and compensatory strategies shows how she had concealed her disease from those around her:

Well, first ... when I wake up and I can’t move, I’ve got to figure out how to get out of bed. When I figure out how to get dressed and get moving, and then by the second time, second stage, I’m already moving, so it’s a little different ... hopefully I have something—an anti-inflammatory or something in me because I’m already aware of what’s going on with my body. ... I no longer have to go into my drawers to grab clothes because I have clothes in piles, so all I have to do is ... pick out my shirt. ... I have everything at arm’s reach.

Maggie’s Illness Narrative

When Maggie was first diagnosed, doctors told her

“you’ve got one of two things. ... You have something with your spinal cord, fluid in your spinal cord. ... Two, you have MS, or three, you have a brain tumor.” And I said, “Okay, and number four?”

[The doctor] looked at me and she said, “This is not funny.” “Well, I would like to have a choice number four.” ... You know, I started to laugh, right? ... She said, “This is very serious.” And I’m thinking ... I am [an age in the 20s stated] years old and I was thinking, “Give me a break. What do you expect from me? Do you want me to start crying?” ... My aunt just got done having a cystic neuroma brain tumor taken out of her, and I’m thinking ... I’m going to go through exactly what she went through. ... It was a little heavy, and I’m trying to find something to joke with, to laugh a little.

Laughing and joking is a coping strategy for Maggie, although the fine line between mental coping and physically destructive behavior is often blurred. Because she was previously very physically active, it is not surprising that Maggie’s physical limitations disturbed her. Pushing herself beyond her capabilities caused her to injure herself multiple times:

I tried riding a bike and I got going, I got my balance straight, and I was going and I was like “Yeah!” And then when it came time for me to stop, I had to put down this leg. I couldn’t stop. I ended up falling over because my leg couldn’t hold me. ... Another time ... I was working the midnight shift, and I started running. I said “Let me see if I can run,” and I started to run. I was like “Yeah!” ... Next thing you know, when it was time for me to stop, I couldn’t stop. I ended up falling straight on my knees, and I ended up ripping my pants. ... “Oh my God! I’ve got to get another pair of pants because they’ll question me [at work] why I have holes in my pants.”

As it became more and more difficult to hide her illness from employers, family, and friends, Maggie was even more resolute in her decision not to share this information with the people in her life: “I’m leaving it fine as is. I have no plan to tell them [other people generally]. I think

what they don't know won't hurt them, won't hurt me, and I won't be asked any questions." At the clinical team meeting, staff expressed that they believed Maggie was in denial about her condition. Denial in MS patients is seen as a common, often self-destructive coping strategy (Baker, 1998). An alternative interpretation is that Maggie's narrative reflects the intensity of her desire to live a full, active, and unconstrained life.

During her RPE, Maggie talked about her hope that a cure for MS was right around the corner. She believed that if she could manage her condition until then, she would be able to resume her "normal" life. Failure to disclose her condition to her previous employer resulted in a layoff from a sedentary job. When "they wanted me to get from behind the desk, go out, and work in the shops and stuff, and I couldn't do that, because I couldn't walk. ...Once... that happened, they laid me off."

For Maggie, completing the RPE and presenting her results made the clinical rehabilitation team aware of potentially hazardous decisions that she was planning to make postdischarge. She planned to live independently on her multiple-floor setup and to return to work the first day after being discharged. The RPE provided important information that allowed the rehabilitation team to develop an intervention to encourage Maggie to rethink these decisions.

Social workers were able to advise Maggie. Therapists worked with Maggie to give her the knowledge and courage to assert herself in the workplace and to accept her own condition both personally and around family and friends. Presenting Maggie's RPE results one day prior to her discharge also prompted a team intervention, in which Maggie was strongly encouraged to have a first-floor setup prepared, daily familial monitoring, and some time off from work.

The staff saw this intervention as vital because of the hazardous situations that Maggie was planning to place herself in on discharge. Her desires to return directly to work, live independently on multiple floors, and other unrealistic expectations she had for herself placed her at great risk for further injury and hospital readmittance. Her extreme motivation was seen as a double-edged sword. Despite being motivated to progress, her unrealistic expectations of herself often put her at risk:

I've had the chance [because of rehabilitation] to get in a good position. I want to keep that condition and I want to stay, so called, healthy, and I don't want to regress, I want to progress ... and that's why I am so crazy right now, trying to get somebody to come out to my house and look and tell me what I need to do, or what can I do. ... I want my life back to how it was!

Maggie was desperate to get a therapist to evaluate her home environment to "physically see [it, to advise her], because it's easier said [in an in-patient facility] than seeing it." She felt that nobody could possibly understand the extreme difficulty she has in her home without observing the challenges she faces on a daily basis. She hoped to inspire a home therapist to give her the tools to improve on her own because insurance coverage had limited her stay at acute in-patient rehabilitation facilities. Her environment was a significant barrier she had to conquer to "save face," as she said, with people at her work and those around her.

For Maggie, RPE made explicit the particular everyday activities she saw as most essential to enhancing freedom, reducing suffering, and maintaining self-image. Not only did she identify these activities, but she was also able to actively evaluate them and place them in the context of her own value schema, a self-designed program to suit her.

Like Bob, themes in Maggie's narrative were dominated by desires to perform physical activities, and walking showed the highest utility (see value ruler, Figure 7). Maggie's and Bob's value rulers and narratives, however, demonstrated very different choice-making strategies. Maggie's explanations of her RPE choices expressed the sequential building of

imagined recovery across the activities she saw as essential to the temporal progression of her day. She dealt with losses from an imaginary MS exacerbation relative to the qualities and demands of her architectural home environment. She recognized barriers interacting to block her ability to realize the unfolding sequence of her daily needs. She recognized a need to be able to function alone. Consequently, she sought to balance her imagined recovery pattern, expressing similar recovery preferences across each of the 18 FIM activities. In sharp contrast, for Bob, being able to walk was many orders of magnitude more important than being able to perform any of the other 17 FIM activities. Rather than focusing on the need to manage his own daily needs, he stressed an over-whelming desire to be able to actively interact with his family.

Discussion and Conclusion

Implications to Care: RPE as a Vehicle to Facilitating Better Clinical Care and Patient Outcomes

RPE is a technique being developed for administration by any clinician. It can be administered jointly to patients and family members to enhance discourse and empathy or separately to single patients to increase self-knowledge and expression. Our case examples illustrate both approaches as applied in the inpatient rehabilitation setting. Patient centeredness, early discharge planning, and therapeutic interventions were enhanced by the RPE procedure in the two patient cases presented. Bob was empowered by recognizing the challenges he had already surmounted. In formulating Bob's discharge plan through RPE results, staff became increasingly aware of Bob's supportive family network. His wife Pam also gained valuable perspective about his desires to be able to walk and maintain personal dignity throughout recovery. This recognition occurred once Pam saw the subtle differences between their RPE value rulers. Through these insights, she would then be more able to help him to continue reaching these goals once home. Experiencing RPE, Maggie became better able to face her denial of disability and her unrealistic wishes to completely eradicate her limitations. Through guided dialogue, she began to make more realistic life decisions. The emergence of Maggie's denial of her disease through narrative allowed social services to more fully address her struggles and issues. Therapists working with both Bob and Maggie were able to focus on specific goal-oriented achievements, as revealed by individual recovery values in RPE.

The importance of these two patient narratives to interdisciplinary decision making suggests the value of using RPE clinically. Giving patients the power to understand and express their own rehabilitation desires and preferred outcomes and to convey their personal illness narratives fostered deeper communication and trust. It inspired and informed clinical staff and family members in caring for these patients. In addition, patients gained insight into rehabilitation, forging deeper connections and greater levels of understanding among the patients, clinicians, and family members. By providing a more comprehensive and humanistic view of the patient, staff were better able to make complex medical decisions and appropriately advise patients. Although this illustration is for rehabilitation, we believe RPE could be of benefit in any setting where the goals are to manage chronic illness and disability.

Qualitative and quantitative data are traditionally separate entities, but here we demonstrate a procedure in which both types of information are obtained simultaneously in a comprehensive manner that is complementary and beneficial to both the patient and clinical staff. As an analytic tool, narrative provides the means to examine stories of life disruptions caused by illness or injury (Becker, 1997). The quantitative choice-making task in RPE supplied the underlying stimulus to each individual's story as the imagined recovery configuration emerged. The two patients' concepts of actual disability experiences were reshaped through the imaginary choice-making and story-telling processes. The illness narratives that emerged after the RPE choice-making tasks had common plots. Life was disrupted by illness severe enough to require medical

intervention and to limit participation in life situations that were previously meaningful. Discussions of this disruption uncovered the idiosyncratic life contexts that determined each patient's attitudes and feelings and shaped hopes for future recovery. The recovery preferences indicated by the patients presented in this article and their associated explanatory narratives are rich with clinically useful information expressed through qualitative narrative and quantitative recovery preference choices. Patient value rulers were created with simplicity and clinical relevance in mind so that the information collected made sense even to clinicians who had never met these patients.

RPE results have the potential to capture and quantify the life implications of objective rehabilitation goals. We believe that meaningfulness of a function to a patient is not the same concept as that patient's measured functional performance. Transferring on and off a toilet and in and out of a bed may require similar motor skills, but the implications of needing someone to help with these skills certainly differ. Because RPE integrates the standard FIM activities into its method, when utilities are combined with patients' actual status on these activities, it can translate measured performance into implications to quality of life (Stineman, Wechsler, Ross, & Maislin, 2003). In presenting the two preliminary RPE case results to the rehabilitation staff, we explored potential clinical applications of the RPE procedure. The procedure shows promise for enhancing individually tailored care plans, integrating team interventions, and achieving more evaluative discharge planning as data are shared.

The qualitative narrative associated with RPE encouraged discussion about design and functioning in the home environment. This topic is often missed during therapeutic encounters. Open discussion between patients and clinicians about disability, assistive technology, and creative compensatory mechanisms is seen as vital for successful community reintegration and quality of life maximization (Stineman, 2000). The choices patients made and explanations they gave helped fill clinical gaps where perhaps embarrassment or discomfort might have prevented truthful reporting.

Although both patients chosen for these case studies presented different issues and challenges, RPE functioned therapeutically for each. By imagining complete disability at the beginning of the procedure, patients are temporarily disengaged from current concepts of self, allowing them to speak freely about types of disabilities that are troubling, deeply embarrassing, or out of their realm of awareness. Both patients focused on the positive aspects of recovery and were amazed by how far they had actually progressed during their rehabilitation stays. After introducing them to the idea of complete disability, RPE revealed patients' remaining abilities, helping them recognize that their situation could have been much worse. Through its enhancement of patient engagement and the expression of meaning, the process is hoped to inspire self-wisdom, knowledge of self, and courage (Seligman, Steen, Park, & Peterson, 2005). By helping patients to recognize their residual abilities, RPE helps solidify a foundation on which recovery can further progress.

Charmaz (1983) states that "as long as an individual feels that he or she exercises *choice* in valued activities and some freedom of action to pursue these choices, everyday life does not seem so restrictive" (p. 172). She also explains that when patients experience "positive reflections of self in interaction ... they are more apt to regard themselves positively" (p. 172). In addition to imagining complete disability, here positive psychology embodied within the RPE method can be empowering and become valuable to individuals suffering from chronic disease or disability. The procedure gives patients the authority to describe their personal values. This autonomy is seen as fundamental in patients living with chronic disease or disability.

Directions for Future Study

RPE has many applications in research aimed at evaluating the meaning of alternative states of disability. Some of these research studies might focus on applications to clinical practice. RPE may provide a highly effective, multidimensional tool for accessing individual recovery preferences while simultaneously accomplishing a number of other clinical benefits. Promotion of positive psychological health for those facing terminal illness or disability and more carefully executed clinical management, therapeutic sessions, and community reintegration may be facilitated by a patient's completion of the RPE procedure. Furthermore, these results may improve quality of care and recovery rates and make rehabilitation more cost-effective.

Recent work documents recovery preference differences between clinician and patients, highlighting the need to convey and evaluate patient goals individually (Freas & Stineman, 2005; Stineman et al., 1998). Variation in understanding recovery priorities among patients and clinicians may also exist cross-culturally (Ditunno et al., 2006) and across people living in different natural environments (Stineman et al., 1998). The existence of value differences across people may lead us to believe that patient recovery preferences are more individually unique than the medical community previously assumed. Future studies may apply RPE to studying ethnic, cultural, and gender-related differences in recovery preference. These studies are essential because cross-cultural differences in the social interpretation of disability can be as limiting as the functional sequel of disability itself (Groce, 1999).

The clinical potential of this tool for obtaining both quantitative and qualitative information about patient recovery preferences supports further inquiry into recovery preference and patient-oriented goal setting. Currently, the RPE procedure can be fairly time-consuming, depending on the patient's understanding of concepts. The procedure requires a relatively high level of cognitive functioning and may therefore exclude some patients from participation. It is essential to continue to simplify the RPE procedure and to devise ways to extend participation to cognitively impaired patients. The effects of RPE need to be studied at a greater number of rehabilitation facilities and in different settings to determine if it can improve the quality of care provided and positively influence outcomes.

Acknowledgments

This work was supported in part by National Institutes of Health Grant R21-HD045881, Protocol 800766. The opinions of the authors are not necessarily those of the sponsoring agency.

Biographies

Ashley E. Kurz, BA, is a clinical research assistant, physical medicine and rehabilitation, at the University of Pennsylvania, Philadelphia.

Nicole Saint-Louis, MSW, LSW, is a social worker and case manager, Piersol Rehabilitation Unit, University of Pennsylvania, Philadelphia.

Janice P. Burke, PhD, OTR, is chair and professor, Department of Occupational Therapy, Thomas Jefferson University, Philadelphia.

Margaret G. Stineman, MD, is a professor in the Department of Physical Medicine and Rehabilitation, a senior fellow at the Leonard Davis Institute of Health Economics, an associate scholar in the Clinical Epidemiology Unit, Center for Epidemiology and Biostatistics, and a senior fellow at the Institute on Aging, University of Pennsylvania, Philadelphia.

References

- Aharony I, Strasser S. Patient satisfaction: What we know about and what we still need to explore. *Medical Care Review* 1993;50(1):49–79. [PubMed: 10125117]
- Baker LM. Sense making in multiple sclerosis: The information needs of people during an acute exacerbation. *Qualitative Health Research* 1998;8(1):106–120. [PubMed: 10558325]
- Becker, G. *Disrupted lives: How people create meaning in a chaotic world*. University of California Press; Berkeley: 1997.
- Bergeson SC, Dean JD. A systems approach to patient-centered care. *Journal of the American Medical Association* 2006;296(23):2848–2851. [PubMed: 17179462]
- Charmaz K. Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness* 1983;5(2):168–195. [PubMed: 10261981]
- Creswell JW, Fetters MD, Ivankova NV. Designing a mixed methods study in primary care. *Annals of Family Medicine* 2004;2(1):7–12. [PubMed: 15053277]
- 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(9):567–575. [PubMed: 16317422]
- Docherty D, McColl MA. Illness stories: Themes emerging through narrative. *Social Work in Health Care* 2003;37(1):19–39. [PubMed: 12921404]
- Dunn DS, Dougherty SB. Prospects for a positive psychology of rehabilitation. *Rehabilitation Psychology* 2005;50(3):305–311.
- Eisenberg B. Customer service in healthcare: A new era. *Hospital & Health Services Administration* 1997;42(1):17–31.
- Elander J, Barry T. Analgesic use and pain coping among patients with haemophilia. *Haemophilia* 2003;9(2):202–213. [PubMed: 12614373]
- Fonteyn M, Kuipers B, Grobe S. A description of think aloud method and protocol analysis. *Qualitative Health Research* 1993;3(4):430–441.
- Freas, D.; Stineman, M. An analysis of recovery preference: A tool to transcend professional bias. 2005. Unpublished manuscript
- Gans BM. Is PM&R teetering on the precipice of a dark age? *Archives of Physical Medicine and Rehabilitation* 2006;87(3):315–316. [PubMed: 16500162]
- Groce NE. Disability in cross-cultural perspective: Rethinking disability. *Lancet* 1999;354(9180):756–757. [PubMed: 10475203]
- Grosset KA, Grosset DG. Patient-perceived involvement and satisfaction in Parkinson's disease: Effect on therapy decisions and quality of life. *Movement Disorders* 2005;20(5):616–619. [PubMed: 15719417]
- Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *BMJ*. 2000 320(7234):526–527. from <http://www.bmj.com>. [PubMed: 10688539]
- Kleinman, A. *The illness narratives. Suffering, healing and the human condition*. Basic Books; New York: 1988.
- London Department of Health. *The expert patient: A new approach to chronic disease management for the 21st century*. 2001. Unpublished manuscript
- Mishler, EG. *The discourse of medicine. The dialectics of medical interviews*. Ablex; Norwood, NJ: 1984.
- National Institutes of Health, Office of Behavioral. Social Science Research. *Qualitative methods in health research: Opportunities and considerations in application and review, organized by the NIH Culture and Qualitative Research Interest Group*. [Retrieved October 18, 2004]. 1999 from <http://www.csr.nih.gov/archives/reviewcriteria.htm>
- Seligman ME, Steen TA, Park N, Peterson C. Positive psychology progress: Empirical validation of interventions. *American Psychologist* 2005;60(5):410–421. [PubMed: 16045394]
- Sox, HC.; Blatt, MA.; Higgins, MC.; Marton, KI. *Medical decision making*. Butterworth; Boston: 1988.

- Stewart, D.; Mickunas, A. Exploring phenomenology: A guide to the field and its literature. 2nd ed. Ohio University Press; Athens: 1990.
- Stewart, M.; Brown, JB.; Weston, WWMI.; McWilliam, CL.; Freeman, TR. Patient-covered medicine transforming the clinical method. 2nd ed. Radcliffe; Oxon, UK: 2003.
- Stewart MA. Effective physician-patient communication and health outcomes: A review. Canadian Medical Association Journal 1995;152(9):1423–1433. [PubMed: 7728691]
- Stineman MG. Medical humanism and empowerment in medicine. Disability Studies Quarterly 2000;20(1):11–16.
- Stineman MG. A model of health environmental integration. Top Stroke Rehabilitation 2001;8(2):34–45.
- 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(12):1522–1529. [PubMed: 9862293]
- Stineman MG, Ross RN, Maislin G, Marchuk N, Hijirida S, Weiner M. Recovery Preference Exploration. American Journal of Physical Medicine & Rehabilitation 2007;86(4):272–281. [PubMed: 17413540]
- Stineman MG, Wechsler B, Ross R, Maislin G. A method for measuring quality of life through subjective weighting of functional status. Archives of Physical Medicine and Rehabilitation 2003;84(4, Suppl. 2):S15–S22. [PubMed: 12692767]
- Tsay S-L, Li-Oer H. Empowerment of patients with end-stage renal disease—A randomized controlled trial. International Journal of Nursing Studies 2004;41(1):59–65. [PubMed: 14670395]
- UB Foundation Activities. IRF-PAI training manual. Vol. Vol. 3. Author; Buffalo, NY: 2001.
- Ware NC, Kleinman A. Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. Psychosomatic Medicine 1992;54(5):546–560. [PubMed: 1438658]
- Whitman N. A review of constructivism: Understanding and using a relatively new theory. Family Medicine 1993;25(8):517–521. [PubMed: 8405799]
- Williams B. Patient satisfaction: A valid concept? Social Science & Medicine 1994;383(4):509–516. [PubMed: 8184314]
- World Health Organization. Primary health care. 1977. Unpublished manuscript

Completely Dependent	Some Assistance	Supervision	Take Longer / Need Device	Completely Independent
Eating				
Grooming				
Bathing				
Dressing Upper Body				
Dressing Lower Body				
Toileting				
Bladder Management				
Bowel Management				
Bed, Chair, WC Transfer				
Toilet Transfer				
Tub/Shower Transfer				
Walk/Wheelchair				
Stairs				
Comprehension				
Expression				
Social Interaction				
Problem Solving				
Memory				

Figure 1.
Example of an Empty Game Board

Completely Dependent	Some Assistance	Supervision	Take Longer/ Need Device	Completely Independent	Sum	Activity	Sum_Reverse
Eating	5	24	30	35	94	Eating	0.0106383
Grooming	23	32	49	67	171	Grooming	0.00584795
Bathing	19	29	36	48	132	Bathing	0.00757576
Dressing Upper Body	11	21	50	57	139	Dressing Upper Body	0.00719424
Dressing Lower Body	12	20	51	58	141	Dressing Lower Body	0.0070922
Toileting	5	37	38	39	120	Toileting	0.00833353
Bladder Management	69	69	69	69	276	Bladder Management	0.00362319
Bowel Management	15	16	31	59	121	Bowel Management	0.00826446
Bed, Chair, WC Transfer	13	52	53	60	178	Bed, Chair, WC Transfer	0.00561798
Toilet Transfer	17	22	54	63	156	Toilet Transfer	0.00641026
Tub/Shower Transfer	14	61	62	64	201	Tub/Shower Transfer	0.00497512
Walk/Wheelchair	7	8	9	10	34	Walk/Wheelchair	0.02941176
Stairs	55	56	65	66	242	Stairs	0.00413113
Comprehension	1	18	27	34	80	Comprehension	0.0125
Expression	2	46	47	68	163	Expression	0.00613497
Social Interaction	3	26	28	43	100	Social Interaction	0.01
Problem Solving	4	33	40	44	121	Problem Solving	0.00826446
Memory	25	41	42	45	153	Memory	0.00653595

Figure 2.
Bob's Game Board

Note: The game board is a graphic representation of the choices and individual moves Bob made while completing the Recovery Preference Exploration (RPE) procedure. It is possible to trace each move that Bob made in the RPE through this chart. Moves 1 to 68 are clearly labeled, and bladder management is represented by four moves all indicated by 69. This is because Bob left bladder management blank until the end of the procedure because he felt it did not pertain to him. Bladder management was calculated as his least valuable activity to be able to do independently. The sum across each activity is indicated, as is the inverse sum. These values were then used to create Bob's value ruler.

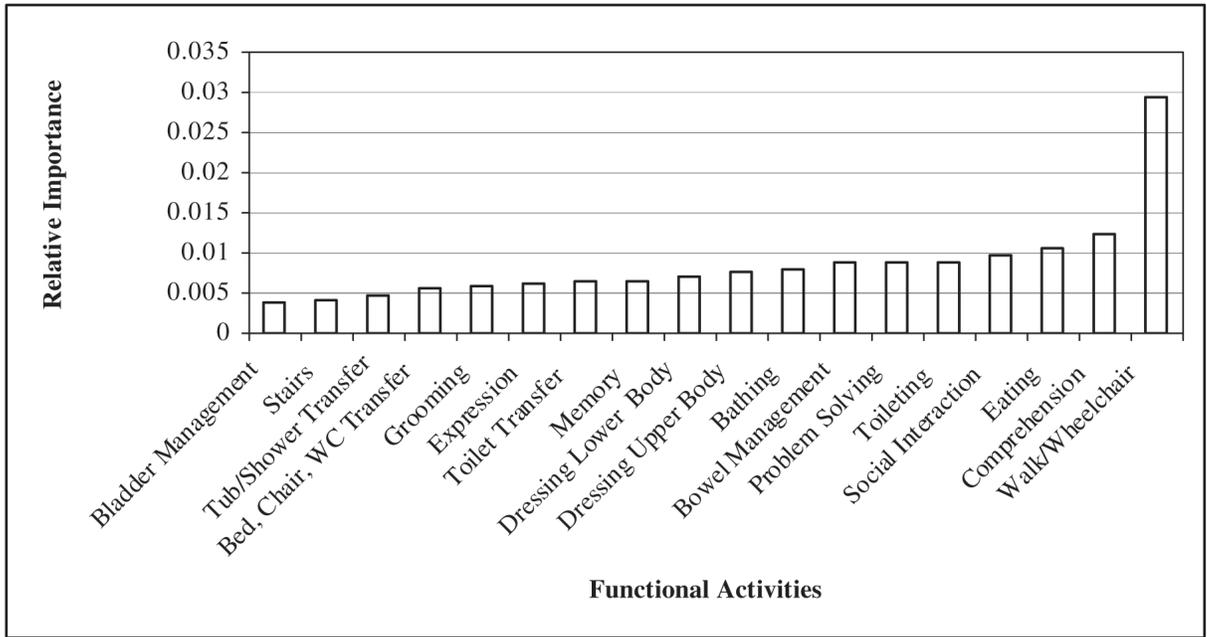


Figure 3.

Bob's Value Ruler

Note: As shown by his value ruler graph, Bob valued the ability to walk or use a wheelchair most, followed by comprehension, eating, and social interaction. Relative to the other activities, however, the most emphasis was placed on walking, as the highest relative importance for this activity demonstrates. Through his game board choices, Bob indicated that climbing stairs was a low priority, and bladder management was insignificant to him, because he was not able to perform this activity anyway. Relative importance was calculated by summing the move numbers across an activity and taking the inverse of this sum.

Completely Dependent	Some Assistance	Supervision	Take Longer/ Need Device	Completely Independent	Sum	Activity	Sum_Reverse
Eating	13	14	37	45	109	Eating	0.00917431
Grooming	21	22	38	46	127	Grooming	0.00787402
Bathing	29	30	39	47	145	Bathing	0.00689655
Dressing Upper Body	25	27	40	48	140	Dressing Upper Body	0.00714286
Dressing Lower Body	26	28	41	49	144	Dressing Lower Body	0.00694444
Toileting	19	20	42	50	131	Toileting	0.00763359
Bladder Management	15	17	33	35	100	Bladder Management	0.01
Bowel Management	16	18	34	36	104	Bowel Management	0.00961538
Bed, Chair, WC Transfer	61	62	63	64	250	Bed, Chair, WC Transfer	0.004
Toilet Transfer	53	54	55	56	218	Toilet Transfer	0.00458716
Tub/Shower Transfer	57	58	59	60	234	Tub/Shower Transfer	0.0042735
Walk/Wheelchair	65	66	67	68	266	Walk/Wheelchair	0.0037594
Stairs	69	70	71	72	282	Stairs	0.0035461
Comprehension	1	3	4	5	13	Comprehension	0.07692308
Expression	2	7	9	11	29	Expression	0.03448276
Social Interaction	6	8	10	12	36	Social Interaction	0.02777778
Problem Solving	31	32	43	51	157	Problem Solving	0.00636943
Memory	23	24	44	52	143	Memory	0.00699301

Figure 4.

Pam’s Game Board

Note: Pam’s Recovery Preference Exploration (RPE) choices can be visualized by the move numbers represented on the chart. Pam’s initial focus was on cognitive activities such as comprehension, expression, and social interaction. Eating, bladder management, and bowel management were all activities moved to the level of supervision early in the RPE procedure. The last activities Pam chose to advance were walking or wheelchair use and the stairs. Activity moved number sums and inverses are indicated to the right of the chart.

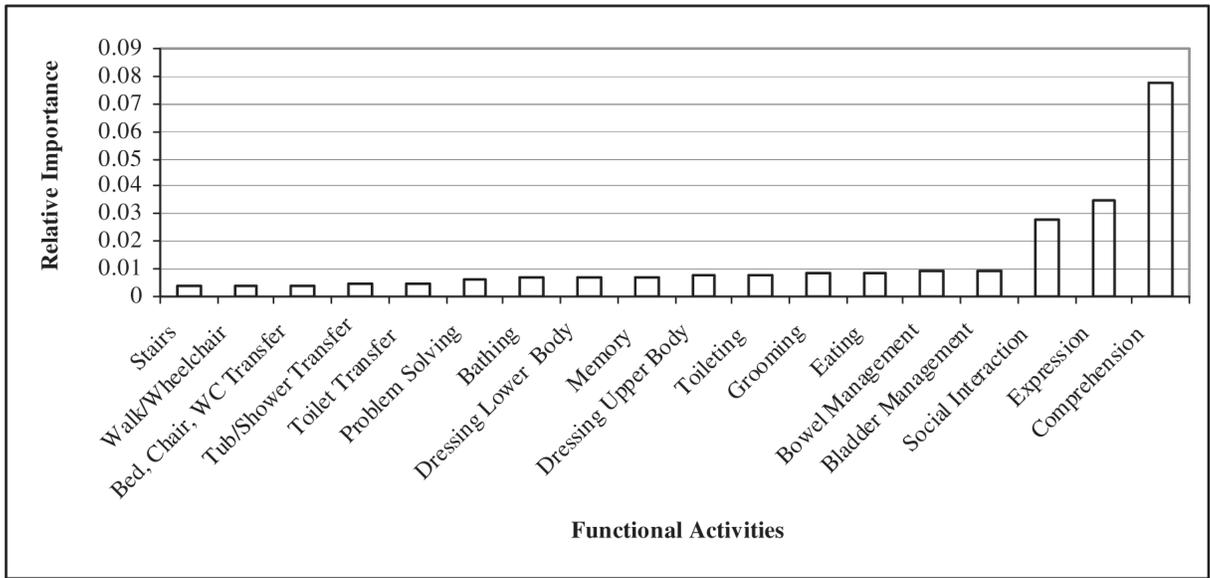


Figure 5.

Pam's Value Ruler

Note: Bob's wife Pam expressed similar views as Bob with respect to the cognitive functions of comprehension and social interaction. She did not value the ability to walk or use a wheelchair nearly as much as Bob did because this activity appeared next to last on her value ruler. Pam also showed variation from her husband in bladder management. It was considered a fairly important activity for her (fourth highest ranked item) compared to Bob's least valuable activity. These differences were made clear through presentation of the value rulers to both Bob and Pam, demonstrating how personal illness experience and recovery preference are inextricably linked and vary individually.

Completely Dependent	Some Assistance	Supervision	Take Longer/ Need Device	Completely Independent	Sum	Activity	Sum_Reverse
Eating	15	31	39	47	132	Eating	0.007575758
Grooming	5	21	40	56	122	Grooming	0.008196721
Bathing	4	22	41	55	122	Bathing	0.008196721
Dressing Upper Body	9	29	49	67	154	Dressing Upper Body	0.006493506
Dressing Lower Body	10	30	48	66	154	Dressing Lower Body	0.006493506
Toileting	3	26	52	53	134	Toileting	0.007462687
Bladder Management	2	27	68	69	166	Bladder Management	0.006024096
Bowel Management	8	28	71	72	179	Bowel Management	0.005586592
Bed, Chair, WC Transfer	1	24	46	50	121	Bed, Chair, WC Transfer	0.008264463
Toilet Transfer	7	25	57	65	154	Toilet Transfer	0.006493506
Tub/Shower Transfer	6	23	42	60	131	Tub/Shower Transfer	0.007633588
Walk/Wheelchair	13	20	37	43	113	Walk/Wheelchair	0.008849558
Stairs	14	19	38	44	115	Stairs	0.008695652
Comprehension	17	34	58	61	170	Comprehension	0.005882353
Expression	18	36	59	70	183	Expression	0.005464481
Social Interaction	16	35	45	62	158	Social Interaction	0.006329114
Problem Solving	11	33	51	64	159	Problem Solving	0.006289308
Memory	12	32	54	63	161	Memory	0.00621118

Figure 6.
Maggie’s Game Board

Note: Imagining a multiple sclerosis exacerbation, Maggie indicated on her Recovery Preference Exploration game board that the first and therefore most important activities to deal with would be transferring from the bed and then using the bathroom (bladder management, toileting, bathing, and grooming). Her individual moves are outlined in the chart. Overall, she showed preference for a balanced and comprehensive recovery in all activities, proceeding further with the most highly valued activities once the level of supervision was achieved (walking or wheelchair use and stairs).

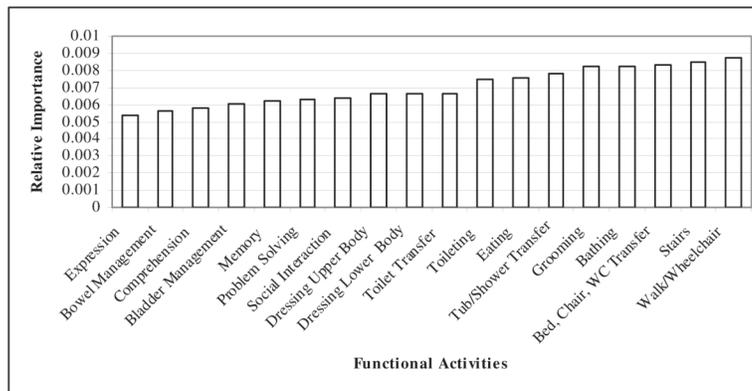


Figure 7.
Maggie’s Value Ruler

Note: Maggie’s value ruler indicates her preference for a fairly balanced recovery in all activities, with walking or using the wheelchair and stairs as her most valued recovery items. She designed her own recovery path, imagining what it would be like for her to experience an acute multiple sclerosis exacerbation. With this in mind, she built her priorities during Recovery Preference Exploration around her home environmental setup.

Table 1

Explanation of Terms

Terminology	Description
Recovery Preference Exploration (RPE)	A computerized procedure in which patients, through a choice-making task, show how they would want to recover across specified sets of activities, imagining complete initial dependency in all activities. The procedure produces utilities for each activity and narratives uncovering the contexts that shape patients' natural attitudes and beliefs about disability.
Utility	Strength of preference for achieving a particular outcome. In the RPE procedure illustrated, a utility is generated for each of the 18 Functional Independence Measure (FIM) activities compared to the other 17 through a structured choice-making activity.
Value ruler	A graphic display of utilities established through RPE. The relative height of the bar associated with each activity expresses the relative importance of each compared to the other activities included in the RPE procedure.
The FIM	A standardized measure of functional status mandated for the assessment of all patients who receive hospital-level rehabilitation in the United States. The FIM is applied to assess patient status at admission, to set therapeutic goals, and to assess outcomes at discharge from rehabilitation. RPE applied to the same 18 skills specified by the FIM makes it possible to gain insights into the relative implications of each deficit to the patient.