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ORIGINAL ARTICLE

# "Are You Better?" A Qualitative Study of the Meaning of Recovery

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***Purpose.*** **Research into the meaning of illness has often focused on an individual's transition *into* a state of being ill, for example the adoption of a sick role. The question "Are you better?" addresses the transition *out* of this state and is fundamental to the patient–clinician relationship, guiding decisions about treatment. However, the question assumes that all patients have the same meaning for "being better." The purpose of this study was to explore the meaning of the concept of recovery (getting better) in a group of people with upper limb musculoskeletal disorders.**

***Methods.*** **Qualitative (grounded theory) methods were used. Individual interviews were conducted with 24 workers with work-related musculoskeletal disorders of the upper limb. The audiotaped interviews were transcribed and coded for content. Categories were linked, comparisons made, and a theory built about how people respond to the question "Are you better?"**

***Results.*** **The perception of "being better" is highly contextualized in the experience of the individual. Being better is not only reflected in changes in the state of the disorder (resolution) but could be an adjustment of life to work around the disorder (readjustment) or an adaptation to living with the disorder (redefinition). The experience of the disorder can be influenced by factors such as the perceived legitimacy of the disorder, the comparators used to define health and illness, and coping styles, which in turn can influence being better.**

***Conclusion.*** **Two patients could mean very different things when saying that they are better. Some may not actually have a change in disease state as measured by symptoms, impairments, or function.**

**KEY WORDS.** Treatment effects; Patient perception; Repetition strain injuries; Outcome evaluation.

## INTRODUCTION

Patients go to their clinicians with individual worries, concerns, or symptoms. Treatment is aimed at relieving what ails the patient. Thus, the question "Are you better?" is a fundamental one for a practicing clinician, giving critical information on the effect of that treatment and guiding clinical decision-making regarding the next step (to alter care, terminate care, etc.) (1). Few would debate the significance of this information in the management of a disorder at an individual clinician–patient level. If we knew more about what this meant to patients, then we might better be able to help them.

Health care evaluation has recently turned to the use of

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standardized measures of health status and quality of life in order to provide some consistency to this meaning in an era of accountability (2). This has led to a search for the elusive "minimally clinically important difference" (3,4) in the scores of these measures, which ideally would identify when an individual or a group is "better." However, that fundamental question of "Are you better?" is at risk of getting lost in the numbers and statistical debates (5,6). Recalling Lord's warning in 1957, "the numbers do not remember where they come from" (7), it behooves us to struggle with the underlying meanings. What does it mean for a person to say that he or she is better? Only after answering that can we determine whether getting better is actually reflected in change in health status scores.

Perhaps the most pressing needs for understanding questions of "Are you better" are in areas where there are fewer observable characteristics of the disorder to use to determine progress. In contrast to a healing fracture or laceration, for instance (the healing of which can be evaluated more easily with x-ray or clinical exam), painful disorders of the soft tissue require the person to describe the impact, and the recovery, from his or her perspective (8). Work-related musculoskeletal disorders of the upper extremity (WMSD), also referred to as repetitive strain injuries (RSI) or cumulative trauma disorders, are a group of disorders of the muscle, tendon, or nerve that are caused or aggravated by work (9,10). These disorders can include very specific conditions, such as confirmed carpal tunnel syndrome, but the majority elude specific diagnostic criteria (11,12). Thus people with WMSD often present for care of truly "what ails them" without necessarily having clear, specific pathologies (13) and therefore are well suited for exploration of the meaning of being better.

The purpose of this study was to describe the process of responding to the question "Are you better?" and to explore the meaning of the answer in persons with upper limb musculoskeletal disorders.

## PATIENTS AND METHODS

**Methodological approach.** In order to explore issues of the underlying meaning of being better, a qualitative research methodology was employed (14). In particular, we chose to use grounded theory methodology (15,16) and followed the research approach developed by Charmaz in her work in chronic disease processes (17–20). Within the qualitative field, grounded theory is well suited to the description of processes and the development of new theory in a previously unexplored area (15,16,21).

**Recruitment of participants.** Twenty-four participants were recruited from among the workers participating in a study of the management of WMSD at a large urban newspaper (22). They were selected from a sample of 382 persons participating in the second stage of a research project. In the first stage, 1,003 workers (of 1,207 in the work force) were asked to complete a survey, and 588 of them also agreed to participate in the second phase. A total of 382 of them were recruited for the second phase.

Each participant had sufficient pain in the upper limb to meet 1 of 2 epidemiologic definitions for WMSD/RSI (22–25) at the time of the initial survey. The first 4 participants were randomly selected from the 382 eligible persons. They represented both sexes (3 women, 1 man) and both areas of work (we defined 2 unique areas: (a) editorial and (b) other departments such as circulation, advertising, etc.). Two other persons asked to be in the study and were also included. After these initial interviews were conducted, the remaining participants (n = 18) were selected using an open purposive approach (16). This meant that subjects who were identified by other participants, who might be an exception to a certain finding, or who might be able to clarify certain themes were sought out as study participants to deepen our understanding of a specific issue or theme (16,26,27).

Of the 24 participants, 45% were women; 70% had sought some sort of care for their symptoms. Half were from editorial, half from other departments. As mentioned above, all had upper limb musculoskeletal symptoms. This study was reviewed and approved by the research ethics board of McMaster University, Hamilton, Ontario.

**Data collection and analysis.** One-hour audiotaped interviews were conducted by one researcher (DEB) in a private setting on work time. Each interview covered 4 areas: a description of the participant's symptoms, the participant's appraisal of his or her current status (Are you better?), an exploration of what that meant or how the participant knew the answer, and the participant's account of the process of becoming better (e.g., what helped or did not help). As is typical of grounded theory (16), the interviewer would probe to explore certain themes as they arose, perhaps those that were similar to or dissimilar from previous participants. Immediately following the interview, the interviewer made extensive notes on key findings, links with other findings, new questions, and emerging themes (28). This systematic review of each interview prior to the next is typical of grounded theory methodology (16,27,29) and allows for followup in subsequent interviews.

The audiotapes were transcribed and imported into NUD*IST (30) software. Transcripts were compared with the tape by one researcher (DEB) for accuracy. As soon as they became available, entire transcripts were coded for content or themes. Key phrases or sentences were identified by a descriptive label. The labels, or codes, helped to organize the text within and between transcripts for comparison (16–19). A coding manual was maintained to list codes and their definitions and it was modified as necessary. At the end of this descriptive coding, all transcripts were reviewed with the final coding manual to ensure that all possible codes had been applied even to the early transcripts. Twelve transcripts were coded by one other coder to ensure consistency and transparency of this coding (28). Any discrepancies were resolved by discussion.

The second phase of coding (which often overlaps with the first) moves to the level of interpretation of the descriptive codes. As data collection proceeded, links between the descriptive labels were made. Links could clarify sequences of events, deeper meanings, or conditions surrounding the occurrence of a theme. These links would be explored further within the text of existing transcripts, or in subsequent interviews. Memos were written to explain the links, and patterns that began to emerge, and were recorded either in NUD*IST (30) or in a study logbook. In this interpretive phase higher-level concepts were built through these links. For instance, one concept was "experience of the disorder," which was built by linking symptoms, functional limitations, emotional and social impact, and role limitations.

The theory of what it meant to respond to the question "Are you better?" was built from this foundation. Logic maps (diagrams linking the concepts and descriptive codes) and memos were used to gather thoughts about how all these concepts and descriptive codes fit together into a story line (15,16,28,31). Attention was paid to identify what Strauss and Corbin call the core finding of the study, which is the essential or central phenomenon linking all of the emerging theory (16).

Presentations of the emerging theory were made to the workplace parties (union and management, but not the participants per se) as well as to the co-researchers to help improve the clarity of the overall theory and to identify gaps in it that required further investigation in the transcripts (e.g., who experiences a certain pattern of recovery and why only them?).

Finally, as the theory was consolidated and the core category identified, one investigator (DEB) recoded 12 randomly selected transcripts (16). The core finding was identified in each, and the fit of the 12 transcripts with the final theory was verified. This systematic review ensured that even the more abstract components of the theory were grounded in the words of the workers, an essential feature of grounded theory (16). At the same time the literature was reviewed to find support (or lack of it) for various aspects of the theory.

The following section will describe first the core finding of the study and then the different components of the theory of being better. As is typical of grounded theory, direct quotes from interviews will be used as illustrative examples and to provide evidence of the link to the words of the participants (16,32,33). Each is identified by a participant number and transcript lines in square brackets at the end of the quote. The literature supporting each component of the theory will be described in the Results section in order to clearly link the two (16,21).

## RESULTS

The core finding of this study is that the participants' affirmative responses to the question "Are you better?" reflected one of 3 different states (Figure 1). "Yes, I am better" could mean a resolution of the disorder, a state of readjustment to an ongoing disorder, or a redefinition of what being better would be like. Even when being better meant a resolution of the disorder, which is what we typically think of when we hear "better," the criterion for what was considered a "resolution" (to be discussed in detail below) also differed among participants. Very different experiences and processes were reflected in the same response to "Are you better?"

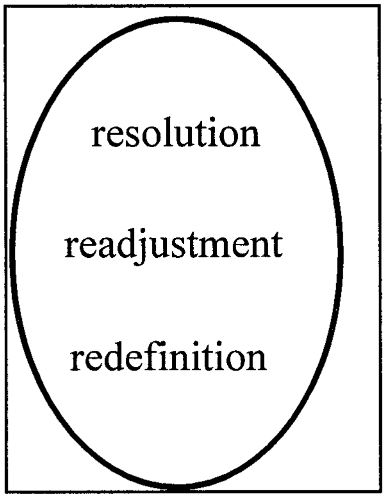

**Figure 1.** Participants' affirmative responses to the question "Are you better?" reflected one of 3 different states.

The theory around this core finding (Figure 2) suggests that the response is guided by individuals' personal experience of RSI (the disorder), their appraisal of that experience, and the mediating influence of 3 factors (perceived legitimacy, comparators, and coping style). The core finding and this supporting theory will now be described in more detail.

**Construction of "being better."** *1. Resolution of the disorder.* Many participants described changes in their health states as indications that they were better, suggesting a resolution of the disorder. However, the resolution took different forms. For some it was change of a certain magnitude (transition of state); for others it was change that made them cross a threshold that they defined as being better (e.g., "pain I can ignore"). One participant provided a common example of a threshold of symptom relief defined by the point where the limb can be forgotten: "I just think that I can type and I'm not aware of any parts of my body" [11:224–225]. Others described being better in terms of reaching that threshold when the pain had decreased enough that they could cope with it: "It doesn't get, as often, to the horrible way it used to get . . . where you would wake up and you would have pain. . . . I consider pain problematic when I can't ignore it. . . . It's amazing just how much [pain] you can live with constantly and just ignore . . . it isn't gone . . . I'm coping" [272:1108–1116,2242–2250].

A threshold for "being better" could be very high, and only reflected as a cure: "[Are you better?] . . . That's a good question . . . because it's a deceptive question isn't it? . . . I will say Yes, but then that's not it. . . . I still have it [RSI]" [355:956–965].

Transitions and achievement of thresholds could be experienced for different attributes. The most common attribute was pain intensity, but also common was the question of how symptoms translate into functioning in daily activities: "Everybody has a different threshold [for pain] . . . some people can put up with a fair amount of pain and

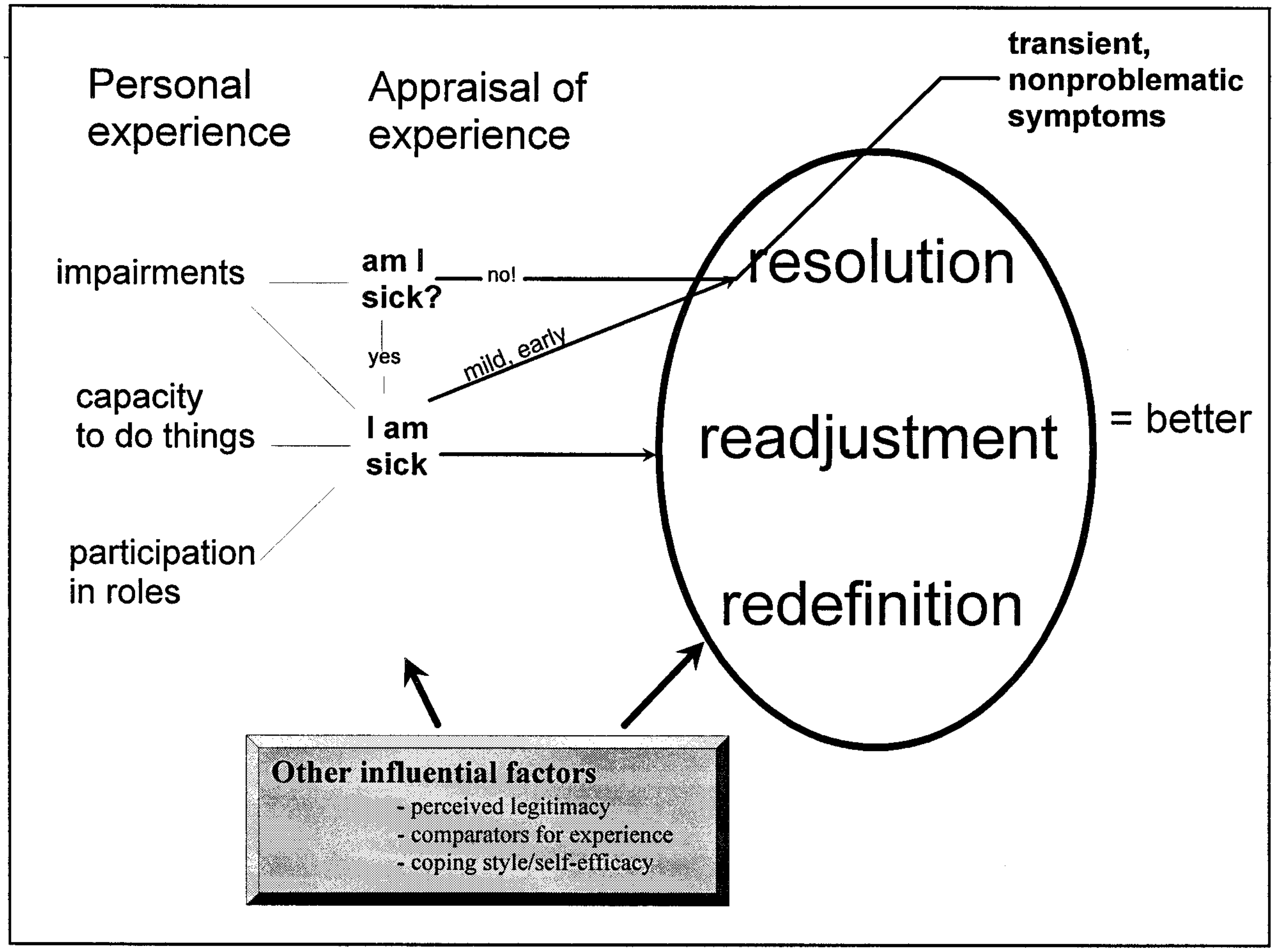

**Figure 2.** Participants' response to the question "Are you better?" is guided by their personal experience of their disorder, their appraisal of that experience, and the mediating influence of 3 factors: perceived legitimacy, comparators, and coping style.

still function. . . . So I mean, it [being better] is more the ability to do whatever you want to do" [691:1195–1205].

Some people depended on external cues, such as the dosage of pain medication prescribed, or the number of times the therapist wanted to see them in a week, as indicators that they must be better (or worse): "Therapy did go quite well because she had me down to twice a week and at one point once a week" [352:198–200]—regardless of other possible explanations for the scheduling.

Participants who used changes in pain to define being better varied according to what aspect of the experience of pain they thought about. For example, "better" could be defined according to the pain's intensity or frequency or the duration of time between episodes: (intensity) "Every diminishment in pain, every step of diminishment gave me more motivation" [355:745–748]. (frequency) "It's a lot better. Like I said, it doesn't happen as frequently" [418: 737–738]. (duration of time until recurrence of pain) "That would have said to me, it's getting better. If [my RSI] was improving the pain maybe didn't come back until Wednesday instead of having it on Monday. OK? I can't think of any other way. . . . I'm going for a longer period of time without feeling uncomfortable" [1031:1413–1441].

Finally, regardless of whether the experience of resolution was transitional or threshold, and regardless of the attribute (pain, function), participants were able to differentiate between changes that were significant or important to them and those that were not (such as small or short-lived changes in symptoms). Important change was defined by this participant: "You feel good about yourself when you can do that, things you used to do all the time. . . . [Interviewer: so that is important?] . . . Knowing that I could do it again . . . important, well you know, I can miss them [activities] if I had to, but important in the way that knowing that I could do it again" [252:965–996].

The resolution of the disorder, as defined by both the attribute considered and the question of whether it was transitional or threshold in nature, was the most common underlying construct for "being better" in this study. However, as described in the next 2 sections, there were definite exceptions to this, where being better was experienced in a state of ongoing disease process.

*2. Readjustment of life to accommodate the disorder.* A group of people described adjustments to their daily activities or lifestyles that helped them to work around or avoid aggravating the disorder that was still present. We have called this *readjustment.* One woman who still had ongoing symptoms but had made adjustments to her lifestyle to accommodate the disorder was able to describe herself as better because of what she was doing (or not doing) to manage the symptoms. This quote highlights the sometimes delicate balance and sacrifices that this readjustment of life requires: "It [the RSI] is problematic, but it's manageable. So maybe it is not problematic? . . . I can manage semi-effectively . . . it's well, I guess you could say it's a problem now if you look at the fact that I'm devoting all my energy into work and getting better. I can't imagine having to pick that child up at the end of the day. I want kids but I can't imagine having to do that. You know . . . having a life outside of journalism. That would be problematic. I'm manageable now . . . putting so much energy into [therapy] and then working. That just sucks up my whole life. If I had to do anything outside of that . . . serious problem" [119:967–984].

Many other examples were found, including adjusting work stations, using braces, altering techniques used at work, and abandoning or carefully selecting leisure activities. All of these are adjustments made to life activities in order to work around the disorder, similar to what Borkan described as "living around the pain" (8): "So I was doing very little typing and able to keep things under control. Keeping things under control is different from being cured" [106:395–398].

*3. Redefining meaning of self, health, and quality.* A number of people described yet another construct underlying the meaning of being better. These people had adapted to the existence of the disorder in their lives not by changing their activities to accommodate and avoid pain but by accommodating the pain as part of their lives: "[The pain] is not getting better, it is a constant. It's there every day you know. . . . [*later in the interview*] I just won't give in to it, I try to keep on doing . . . I want my life to continue as it is. I live with it, that's what I do" [1015:360–362;686–694]. "What is the opening line of that book called *A Road Less Traveled*? The first line is 'Life is Hard.' Everybody has pain. Everybody has pain in their heads and their bodies. . . . I don't think just because somebody is hurting they can not work, don't work, shouldn't work . . . maybe at some level they should" [344:789–797].

Participants who had adapted to having a painful condition would forcefully state, "I'm not better, I'm coping . . . it won't go away" [272:2250–2252] as an initial reaction to the question "So, are you better?" Adaptation to the disorder, as reinforced through other studies (20,34–38), should not be equated to a cure, nor to an acceptable goal for reduction of a work-related disorder. It was clear that these people were moving on with life despite, not without, their pain. They shared that their pain had shifted from the dominant part of life to a less prominent part. Shaul captures this in describing mastery: "not control over the disease, but mastery in living with it, a redefinition of what constitutes quality of life" (ref. 35, p. 295). Indeed, others have suggested that quality of life is a shifting (38) or "dynamic construct" (39). Definitions, outlooks, goals, etc., may change in order to maintain "a sense of well-being" in life.

*Summary of core finding.* Three different health states were described by the participants when they spoke of being better. Being better could reflect a shift in some aspect of the disease state (resolution), or either a readjustment or a redefinition of one's life to accommodate an ongoing disease state. Though the response to the question "Are you better?" might be a simple "yes," our participants explained that the underlying latent construct may vary considerably between individuals.

The participants described an evaluative process that led up to reaching one of the 3 states. As shown in Figure 2 and described below, the process starts with their experience with the disorder, the appraisal of it, and then one of the 3 final states. Three additional influencing factors are also introduced.

**Experience of disorder.** Participants described WMSD/RSI most frequently as the experience of pain in their upper limbs. However, their experiences of the disorder extended beyond that as well (34,40,41). For some it was the emotional impact (feeling "so confused and so unhappy and so scared and so worried" [352:708–710]): "I get bitchy and I cry . . . like last night I was sitting on the couch . . . and lean on me the wrong way, and then I just break out crying. . . . I want to cut my arm off. I wish I could just do that, you know. I'm right handed so I can't do that" [1015:701–716].

Others described their experience in terms of the capacity to function in different activities: "I can't type as fast as I think" [11:290] or "I hated not being able to open a jar" [171:169]. In fact, when asked what it was like at its worst participants often shifted away from describing their symptoms to describing their burden in terms of functional limitations: They were unable to pick up groceries, hold their children, shower, and so on—"just the little things you take for granted" [1015:442]. In terms of being better, this emphasis on ability to function was also found. Being 100% better meant "being able to do things outside of work" [106:339].

Many described difficulty participating in their roles, be it leisure, work, or family life. Work roles were very important. For the journalists, writing was their passion as well as their job. Hand pain kept them away from both: "I think it's the nature of journalism. We're very competitive . . . it attracts competitive sorts of folk . . . one of the hardest things, I think, when you come down with RSI is to understand that your horizons are diminished" [119]. Writing (keyboarding) and deadlines ("short of a heart attack at 9:30 [PM] you get your work done" [80:1053]) were also factors associated with WMSD (22), and, although participants could articulate this, they expressed reluctance to give up what they love: "Not typing [is the solution to the pain]. Yes, absolutely. And yet I love to type. I like all the mechanics of my work, I love pens, paper. I have a pen fetish . . . I like many different kinds of pens, but I won't write with a ball point . . . fountain pens are my favourite . . . so I like all the equipment, I love it! I'm infatuated with it! I love my computer! I love the internet! I like all that stuff, so, you know, if it gets to the point where it hurts me to type, that will be horrible" [171:515–527].

Participation in work reflected both the fulfillment of their career goals and the source of their pain. Their hands, previously an instrument of their creativity and sense of self, now also became a barrier and constraint to it, a breakdown in the self–body unity (42). The nature of the work at the newspaper seemed to place our participants' desires up against the limitations of their bodies.

Family life roles were also affected by symptoms. Being better was often defined in terms of roles outside of work: "It [RSI] is a problem. As long as it's interfering with . . . not just my work, but outside work, it's a problem. . . . I think the hardest part was not being able to lift up my kids . . . that kind of stuff" [106:470–475;494–499]. Illness also caused shifts in responsibilities at home, often forcing attention to be focused on caring for oneself: "Listen, I can't help. You'll have to do it yourself" [419]. In her study of women with RSI, Reid refers to these as challenging and often permanent shifts for the family (34). Saying that one is better might lead to the assumption that all previous roles could be resumed.

As with other disorders, chronic pain for example, the full impact of RSI must be considered, and rarely will this be limited to only the symptoms and biologic findings. As Eisenberg suggests, all aspects of what is affecting the ill person will likely need to be addressed in an effective treatment (43). Our participants recounted both the psychological and the social impact of this painful disorder as well as symptoms and functional limitations (40).

**Evaluation of experience.** Participants described the transition from symptoms to illness—when the individual decided that these symptoms and signs were abnormal. Other literature has also described this identifiable transition point (34,43–48) and emphasizes the difficulty in defining the pain as problematic in disorders that are symptom-based (like RSI) in contrast to those having a clear underlying accepted pathology (e.g., cancer, fractures, arthritis) (34,44,46,47). In our study people with symptoms were found who did and did not define those symptoms as "problematic." The latter therefore could not define themselves as "better."

*No, I'm not better because I am not sick.* A few participants in the study had symptoms but did not feel that they had "RSI." In fact they did not describe their pain as a problem at all, despite meeting a perhaps overly sensitive epidemiologic case definition for having RSI (23,23,25). Rarely had their symptoms interfered with their capacity to do things or their ability to work. In general, they experienced some symptoms, and the symptoms resolved (Figure 2, upper arrow). It was not considered "better" because they had not appraised themselves as sick. They merely had the resolution of inconsequential, nonproblematic pain: "How do I know if it's better? See, it's not a question of better or worse. I don't think it flares up enough time for me to take concern. . . . I don't necessarily say that my pain is getting better. I don't think it's there to begin with" [866:555–562].

Although this may seem disconcerting—that people met an epidemiologic case definition but did not consider themselves to have a problem—it is far from the first time that this has been described. In fact, Chrisman (44) details several factors that could influence an individual making the decision that his or her symptoms might reflect a disorder of concern or a problem. Reid describes a period of "symptom evaluation" (34), when aches and pains are attributed to natural aging or activity outside of work. For these people, symptoms had not exceeded what they considered to be the range of normal for them, what is to be expected—a decision made by comparing oneself to one's current understanding of being well (39,43,45–47). Few participants in our study described themselves in that state, but almost all of the others who believed that they did have a problem remembered being in that state of appraisal before defining or realizing that their symptoms were "a problem" and wished, in hindsight, that they had paid more attention to those early signs and symptoms.

*Yes, I am sick.* Persons who had decided that they were ill experienced one or more of the 3 states of being better. Within this group were those whose experience was either mild or brief ("Yes I am sick, but not that bad"), and they seemed to pass directly through the resolution-of-disorder state, with no hint of either adjustment or redefinition as it was not necessary: "Like a mild ache . . . it's not so bad that I can't use it, but I know it would feel better if it didn't [ache]" [693:507–509]. Others, specifically those with more long-standing or severe pain, could move to any one of the 3 end-states: resolution, readjustment, or redefinition.

**Other influential factors.** As described above, 3 other factors (perceived legitimacy, comparators used, and coping style) emerged as influential on the appraisal of the experience and of being better.

*Perceived legitimacy of their disorder.* Study participants often struggled with issues of the perceived legitimacy of the disorder, even in a workplace clearly interested in dealing openly with upper limb pain and its management. Participants felt that they were "derided as slackers" [171:1162]: "But every time I'd go like this [*rubbing his arm*] and they [coworkers] could see—Oh there goes xxx again, he's building up to it [taking time off work]. . . . They laughed at me" [252:386;598–602].

Part of the issue of legitimacy is the lack of any socially and medically accepted diagnostic label for these disorders. Diagnosis, usual clinical course, and effective management tend to elude people with WMSD/RSI. Diagnosis often relies on self-definition (48), and such illnesses are often open to disbelief and stigma (34,40,41,43,47). One participant summarized the struggle to get a legitimate diagnosis: "You'll hear this story a million times over. When you initially get RSI as a reporter . . . RSI is very tough, because there are no physical scars. So you're there . . . there's an initial "Is she really sick?" kind of thing. . . . Secondly you can't get a proper diagnosis. Your doctor . . . your family doctor isn't going to believe you, because he doesn't even know what RSI is. So you're stuck between the medical establishment not understanding and the workplace not understanding. Then you go to workers' comp which is a whole other nightmare, because they don't understand RSI, especially back then" [119:1154–1201].

As Eccleston suggests, "pain is most often constructed as a symptom in need of corroborating evidence" (ref. 41, p. 700).

There were exceptions to the struggle for legitimacy that, because they stand out as exceptions, serve to reinforce the issue. There were people who, for various reasons, were recognized for excellence in their work. To these people the issue of the legitimacy of their complaints was diminished: "My stock had gone up [after getting recognized for work]. I think that was really important to me because now I don't feel like a liability, I feel like an asset" [106:592–606]. They no longer felt that they would be perceived as someone who was trying to get out of work. As a result, their experience and their definition of being better were no longer mixed in with issues of legitimacy.

*Comparators.* In order to define the meaning of symptoms or experiences, or to evaluate whether they are better, people make comparisons (43,44,49). Some are social: comparisons to others who are perceived as being in a better, worse, or comparable state (49,50). Others are temporal: comparisons to oneself at a different point in time (50,51). The influence of these comparisons on well-being can be positive or negative (49,52,53), depending on whether the person identifies himself or herself as similar to or distinct from the other (49,50,52), but it is generally agreed that they influence self-evaluations (49,51,54). In our participants the internal (temporal) comparisons tended to be associated with a better sense of well-being: "I mean the old thing "why me?" Well, why not you. It's going to affect 1/1000 people why shouldn't it be you? . . . I think in some cases you just press on and get used to it or things like that. . . . I've had some setbacks and heartbreaks, but what the hell! As I say, it's part of life's rich teeming pageant, what do you expect?" [351:1024–1046].

And there is this from a participant with permanent physical impairment: "People's coping skills . . . depending on what else is going on in their lives. . . . That was my first reaction—nothing can happen to my arm, I can't let it. . . . I know what it's like to lose something you know" [268:140;573;704].

Without that internal comparator, other participants described their experience in relation to other people with RSI, who often were worse off (downward social comparison). These stories often took the form of "horror" stories, and they elicited negative emotions and fear: "I knew a girl and she said that her mother is practically crippled in her one arm from RSI. And I'm like, no does it get that bad?" [668:693–698]. These comparisons had influence in ways very similar to those summarized by Gibbons (49). In the temporal comparison the person felt a distinction between his or her RSI and this other condition and described a "not as bad" or coping attitude. In the external comparison group, the comparison was often to someone worse, to whom they could relate (the "horror stories"), and it created a negative sense of the future course for the participant.

*Coping style/self-efficacy.* Another influential factor is coping style, or the closely related concept of self-efficacy (55). By coping we mean a set of beliefs about being able to manage the RSI problem: through a belief that one can effect control over one's symptoms (Bandura's self efficacy) (55) or that one can adjust to the challenge of having RSI (34,42). In our study those participants who had had symptoms for a long time or who believed that RSI "doesn't go away" [1031] often articulated their coping pattern. Some had difficulty seeing any way of coping ("I can't bear to think about going on like this" [352:1000]), with little sense that they could effectively manage their pain or situation. Others had developed a sense of control over their situation: "I think it has something to do with attitude. I won't let it defeat me" [419:350]. The literature suggests that coping or self-efficacy could have a moderating effect on patients' engagement in the management of painful conditions (55–57), the most widely studied being chronic pain and arthritis (58,59). Furthermore, some suggest that it can be a learned skill (55,60,61). However, given the cross-sectional nature of this study, it is impossible to determine the temporal nature of this relationship. Those who described a more positive coping strategy could also be those who have already redefined their sense of well-being.

## DISCUSSION

The main finding in this study is that individuals construct their response to questions like "Are you better?" in unique ways, some of which do not reflect the resolution of the disease state. Even when it was described in terms of resolution, people varied in their definitions, both in terms of the type of change that they considered to be indicative of improvement and in the importance of that change to them.

In our participants, the experience with the disorder influenced the experience of getting better. Borkan's work with low back pain had similar findings: The "illness behaviors" can only be understood within the framework of past experience, personality, family and cultural standards, and current interpersonal interactions (8). These factors act as "filters for the physiologic changes involved in pain" (ref. 8, p. 985). Our work would therefore suggest a link between Feinstein's fundamental questions (1,13): "What's wrong?" and "Are you better?"

**Strengths and limitations.** This study followed the methodology outlined for a rigorous grounded theory study (16). Attention to the approach and documentation of coding, the link with the words of the participants, and the intersection with the existing literature all helped to support the trustworthiness of these findings as expressions of our participants' experiences of being better (15,16,21,28,32,33,62).

There were limitations to this study. The sample size was small, only 24 persons, though not atypically so for studies of this nature (15,29,35,63) and not necessarily a limitation if a full, "saturated" understanding of the concept is reached (14,16,32). It would have been ideal to reconfirm the findings with the actual participants. However, in our study only one interview was conducted with each participant as we were only permitted to access workers for one interview (15,16). The study may also have been influenced by the fact that we interviewed people within the context of a workplace study of WMSD/RSI and on work time. These factors could have led participants to describe their experiences differently than they might have in another setting such as a clinical setting. Later appraisal of these findings in a clinical setting with patients awaiting upper extremity surgery did confirm their relevance and importance there (64).

Participants experiencing WMSD/RSI were ideal for our research question, and we have some indication of the clinical relevance of the findings (64). However, the generalizability to other populations should not be assumed; for example, issues of maintaining work roles, or of perceived legitimacy, may not fit in other groups. This is not really a limitation of the current study's rigor but is rather a caution in terms of transferability of the findings (28,33,65,66). Details of the setting, sample, and links to existing literature may help with an individual's judgment of the applicability of these findings in another setting (28,32,66), as will Cronbach's reminder that "any generalization is a working hypothesis, not a conclusion" (ref. 65, p. 124–125).

Finally, in this study the descriptions of legitimacy, comparators, and coping style are presented as potential influencing factors, not alternatives to the process of being better. Support for the influence of these findings on recovery and hence on questions of being better is available in the literature, though each warrants more attention than is given in this paper (43,44,47,55).

**Potential implications of findings.** The study findings regarding the complex processes and various states that underlie a response to the question "Are you better?" may have applicability to 3 audiences: first for clinicians, second for researchers doing similar worksite-based studies of WMSD/RSI, and third for researchers in the outcome measurement movement.

For the clinician, the results of our study reinforce the need to understand the full impact of a disorder on a patient's life in order to completely understand what getting better means. Outcome measures, and in particular those reflecting the patient's perspective, are becoming a recognized component of clinical practice (2). Our findings suggest that there would be an advantage in selecting outcome measures that could allow for patients to express how the disorder has affected them, as well as allowing for all 3 types of states of being better to be expressed: resolution, readjustment, and redefinition. Measures where patients generate their own item content are steps in that direction (67–71). Other measures of coping, and of the sense of well-being within the current health state, should also be considered. Our study findings also remind clinicians about the cues that they give in defining their clients' health. As described above, participants could define their sense of being better based on what the clinicians said and did, whether or not that was a clear intention (47). Good suggests that clinicians recognize their role as mirrors of a reality for patients: "Clinical models . . . are 'models for' reality, influencing perception and behavior, shaping the course of illness and the evaluation of medical outcomes, and producing the realities they posit" (ref. 46, p. 178). Thus, the way we work with clients, and the messages that gives, should be considered seriously.

Our findings have implications for workplace-based studies of WMSD/RSI, offering greater insight into the burden—complementing the work of Reid (34) and others (72) in this area—and showing how some other aspects of the workers' lives were sacrificed in order to maintain the work role. Measures of the impact of a disorder and its recovery would need to be broader in order to capture this.

The theory developed in this study might have the strongest link to efforts to gain the patient's perspective in the outcomes movement (2). The primacy of the patient's perspective on health and the benefit of care is reflected in the plethora of self-completed questionnaires on health status, physical function, and symptoms developed over the past 2 decades. However, in doing stochastic tests of statistical significance to show the benefit of treatments, researchers are assuming that fluctuations in the scores from these measures will have equal meaning across individual clients in a study (38). The findings of our study would suggest otherwise. Two people could have the same amount of change in a certain area, but the meaning of that change could be quite different.

In a related issue, methodological work in the area of responsiveness (ability of an outcome measure to accurately detect change when it has occurred) (73–76), and in particular the determination of minimally clinically important differences (77–79), often depends on an external marker to act as a construct for improvement (80–83). Such a marker may ask for a response to "Are you better?" on a 10-point scale. High variability in change in health status scores around this external marker is a common challenge in health measurement and might now be explained by the differences that could lead to the response to "Are you better?" for a given individual. Further work is needed in this area in terms of defining the best way to establish an external marker for the kind of recovery we hope to measure with our outcome measures (84,85). Our work has added to this literature.

We have developed a theory that suggests increased complexity in understanding what it means to be "better" for people with upper limb pain. We have suggested potential implications of these findings for clinicians, for workplace-based research, and for researchers especially in the area of responsiveness. Our work is not making the quest for understanding this concept of being better more complex without reason. Rather we are asserting that we can no longer afford to look at "being better" as a simple construct. The complexity of this concept must be recognized given that a clinician's or researcher's interpretation of responses to "Are you better?" may have the very real potential of influencing the care of our clients and ultimately their expected quality of life.

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## REFERENCES

1. Feinstein AR. Twentieth century paradigms that threaten both scientific and humane medicine in the twenty-first century. J Clin Epidemiol 1996;49:615–7.
2. Relman AS. Assessment and accountability: the third revolution in medical care. N Engl J Med 1988;319:1220–2.
3. Feinstein AR. Zeta and delta: Critical descriptive boundaries in statistical analysis. J Clin Epidemiol 1998;51:527–30.
4. Redelmeier DA, Guyatt GH, Goldstein RS. Assessing the minimal important difference in symptoms: a comparison of two techniques. J Clin Epidemiol 1996;49:1215–9.
5. Michell J. Measurement scales and statistics: a clash of paradigms. Psychol Bull 1986;100:398–407.
6. Nesselroade JR. Interindividual differences in intraindividual change. In: Collins LM, Horn JL, editors. Best methods for the analysis of change. Washington (DC): American Psychological Association; 1991. p. 92–105.
7. Lord FM. On the statistical treatment of football numbers. Am Psychol 1953;8:750–1.
8. Borkan J, Reis S, Hermoni D, Biderman A. Talking about the pain: a patient-centered study of low back pain in primary care. Soc Sci Med 1995;40:977–88.
9. Armstrong TJ, Buckle P, Fine LJ, Hagberg M, Jonsson B, Kilbom A, et al. A conceptual model for work-related neck and upper-limb musculoskeletal disorders. Scand J Work Environ Health 1993;19:73–84.
10. Hagberg M, Silverstein B, Wells R, Smith MJ, Hendrick HW, Carayon P, et al. Work related musculoskeletal disorders (WMSDs): a reference book for prevention. London: Taylor & Francis; 1995.
11. Buchbinder R, Goel V, Bombardier C. Lack of concordance between the ICD-9 classification of soft tissue disorders of the neck and upper limb and chart review diagnosis: one steel mill's experience. Am J Ind Med 1996;29:171–82.
12. Beaton DE. Examining the clinical course of work-related musculoskeletal disorders of the upper extremity using the Ontario Workers' Compensation Board administrative database. Toronto: University of Toronto; 1995.
13. Feinstein AR. The diagnostic taxonomy of disease: problems in criteria. In: Feinstein AR, editor. Clinical judgement. Baltimore: Williams & Wilkins; 1967. p. 89–102.
14. Goering PN, Streiner DL. Reconcilable differences: the marriage of qualitative and quantitative methods. Can J Psychiatry 1996;41:491–7.
15. Creswell J. Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks (CA): Sage; 1998.
16. Strauss A, Corbin J. Basics of qualitative research: grounded theory procedures and techniques. Newbury Park (CA): Sage; 1990.
17. Charmaz K. Studying lived experience through grounded theory realist and constructivist methods. Unpublished work; 1993.
18. Charmaz K. The grounded theory method: an explication and interpretation. In: Emerson R, editor. Contemporary field research: a collection of readings. Prospect Heights (IL): Waveland Press; 1988. p. 109–26.
19. Charmaz K. 'Discovering' chronic illness: using grounded theory. Soc Sci Med 1990;30:1161–72.
20. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. Sociol Health Illn 1983;5:168–95.
21. Denzin NK. The art and politics of interpretation. In: Denzin NK, Lincoln YS, editors. Handbook of qualitative research. Thousand Oaks (CA): Sage; 1994. p. 500–15.
22. Polanyi M, Cole DC, Beaton DE, Chung J, Wells R, Abdolell M, et al. Upper limb work-related musculoskeletal disorders among newspaper employees: cross-sectional survey results. Am J Ind Med 1997;32:620–8.
23. Hunting KL, Welch LS, Cuccherini BA, Seiger LA. Musculoskeletal symptoms among electricians. Am J Ind Med 1994; 25:149–63.
24. Bernard B, Sauter S, Fine L, Petersen M, Hales T. Job task and psychological risk factors for work-related musculoskeletal disorders among newspaper employees. Scand J Work Environ Health 1994;20:417–26.
25. Beaton DE, Cole DC, Bombardier C. Estimating the burden of WMSD: does case definition make a difference? J Occup Rehabil 2000;10:39–54.
26. Robbins L. Qualitative research: contributions to scientific inquiry and patient care [editorial]. Arthritis Care Res 1998; 11:225–7.
27. Arcury TA, Quandt SA. Qualitative methods in arthritis research: sampling and data analysis. Arthritis Care Res 1998; 11:66–74.
28. Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. Thousand Oaks (CA): Sage; 1994.
29. Quandt SA, Arcury TA. Qualitative methods in arthritis research: overview and data collection. Arthritis Care Res 1997;10:273–81.
30. Qualitative Solutions and Research. QSR NUD*IST Revision 3 user guide. Thousand Oaks (CA): Sage; 1996.
31. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Lincoln YS, editors. Handbook of qualitative research. Thousand Oaks (CA): Sage; 1995. p. 273–85.
32. Rowan M, Houston P. Qualitative research articles: information for authors and peer reviewers. CMAJ 1997;157:1442–6.
33. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. Qual Health Res 1998;8:341–51.
34. Reid J, Ewan C, Lowy E. Pilgrimage of pain: the illness experiences of women with repetition strain injury and the search for credibility. Soc Sci Med 1991;32:601–12.
35. Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. Arthritis Care Res 1995;8:290–7.
36. Sprangers MAG. Response shift bias: a challenge to the assessment of patients' quality of life in cancer clinical trials. Cancer Treat Rev 1996;22:55–62.
37. Tack BB. Fatigue in rheumatoid arthritis: conditions, strategies, and consequences. Arthritis Care Res 1990;3:65–70.
38. Koch T. Life quality vs. the 'quality of life': assumptions underlying prospective quality of life instruments in health care planning. Soc Sci Med 2000;51:419–27.
39. Allison PJ, Locker D, Feine JS. Quality of life: a dynamic construct. Soc Sci Med 1997;45:221–30.
40. Kleinman A, Brodwin PE, Good BJ, Delvecchio Good M-J. Pain as human experience: an introduction. In: Delvecchio Good M-J, Brodwin PE, Good BJ, Kleinman A, editors. Pain as human experience: an anthropological perspective. Berkeley: University of California Press; 1992. p. 1–28.
41. Eccleston C, Williams C, Stainton-Rogers W. Patients' and professionals' understanding of the causes of chronic pain: blame, responsibility and identity protection. Soc Sci Med 1997;45:699–709.
42. Gadow S. Body and self: a dialectic. J Med Philos 1980;5:172–85.
43. Eisenberg L. What makes persons "patients" and patients "well?" Am J Med 1980;69:277–86.
44. Chrisman NJ. The health seeking process: an approach to the natural history of illness. Cult Med Psychiatry 1977;1:351–77.
45. Mechanic D. Social psychologic factors affecting the presentation of bodily complaints. N Engl J Med 1972;286:1132–9.
46. Good B, Delvecchio-Good M. The meaning of symptoms: a cultural hermeneutic for clinical practice. In: Eisenberg L, Kleinman A, editors. The relevance of social science for medicine. Boston: D. Reidel; 1980. p. 165–96.
47. Brown P. Naming and framing: the social construction of diagnosis and illness. J Health Soc Behav 1995;Spec No:34–42.
48. Sakalys JA. Illness behavior in rheumatoid arthritis. Arthritis Care Res 1997;10:229–37.
49. Gibbons FX. Social comparison as a mediator of response shift. Soc Sci Med 1999;48:1517–30.

50. King KB, Clark PC, Friedman MM. Social comparisons and temporal comparisons after coronary artery surgery. Heart Lung 1999;28:316–25.
51. Wilson AE, Ross M. The frequency of temporal-self and social comparisons in people's personal appraisals. J Pers Soc Psychol 2000;78:928–42.
52. Buunk BP, Collins RL, Taylor SE, Vanyperen NW, Dakof GA. The affective consequences of social comparison: either direction has its ups and downs. J Pers Soc Psychol 1990;59:1238–49.
53. Aspinwall LG, Taylor SE. Effects of social comparison direction, threat, and self-esteem on affect, self-evaluation, and expected success. J Pers Soc Psychol 1993;64:708–22.
54. Butler R. Making judgements about ability: the role of implicit theories of ability in moderating inferences from temporal and social comparison information. J Pers Soc Psychol 2000;78:965–78.
55. Bandura A. Self efficacy: the exercise of control. New York: W. H. Freeman & Co.; 1997.
56. DeGood DE, Shutty MS Jr. Assessment of pain beliefs, coping, and self-efficacy. In: Turk DC, Melzack R, editors. Handbook of pain assessment. New York: The Guilford Press; 1992. p. 214–34.
57. Turner JA, Clancy S, Vitaliano PP. Relationships of stress, appraisal and coping, to chronic low back pain. Behav Res Ther 1987;25:4:281–8.
58. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum 1989;32:37–44.
59. Taal E, Rasker JJ, Wiegman O. Patient education and self-management in the rheumatic diseases: a self-efficacy approach. Arthritis Care Res 1996;9:229–38.
60. Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum 1993;36:439–46.
61. Lorig K, González VM, Laurent DD, Morgan L, Laris BA. Arthritis self-management program variations: three studies. Arthritis Care Res 1998;11:448–54.
62. Lincoln YS, Guba EG. Postpositivism and the naturalist paradigm. In: Naturalistic inquiry. Beverly Hills: Sage; 1985. p. 14–46.
63. Goering PN, Streiner DL. Reconcilable differences: the marriage of qualitative and quantitative methods. Can J Psychiatry 1996;41:491–7.
64. Jacobson NS, Traux P. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. J Consult Clin Psychol 1991;59:12–9.
65. Cronbach LJ. Beyond the two disciplines of scientific psychology. Am Psychol 1975;30:116–27.
66. Lincoln YS, Guba EG. The only generalization is: there is no generalization. In: Naturalistic inquiry. Beverly Hills: Sage; 1985. p. 110–28.
67. Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: an outcome measure for occupational therapy. Can J Occup Ther 1990;57:82–7.
68. Pollock N, Baptiste S, Law M, McColl M, Opzoomer A, Polatajko H. Occupational performance measures: a review based on the guidelines for the client-centred practice of occupational therapy. Can J Occup Ther 1990;57:77–81.
69. Wright JG, Young NL. The patient-specific index: asking patients what they want. J Bone Joint Surg Am 1997;79:974–83.
70. Buchbinder R, Bombardier C, Yeung M, Tugwell P. Which outcome measures should be used in rheumatoid arthritis clinical trials? Clinical and quality-of-life measures' responsiveness to treatment in a randomized controlled trial. Arthritis Rheum 1995;38:1568–80.
71. Rockwood K, Stolee P, Fox R. Use of goal attainment scaling in measuring clinically important change in the frail elderly. J Clin Epidemiol 1993;46:1113–8.
72. Tarasuk V, Eakin JM. "Back problems are for life": perceived vulnerability and its implications for chronic disability. J Occup Rehabil 1994;4:55–64.
73. Beaton DE, Bombardier C, Katz JN, Wright JG. A taxonomy of responsiveness. J Clin Epidemiol; in press.
74. De Bruin AF, Diederiks JPM, de Witte LP, Stevens FCJ, Philipsen H. Assessing the responsiveness of a functional status measure: the Sickness Impact Profile versus the SIP68. J Clin Epidemiol 1997;50:529–40.
75. Wright JG. The minimal important difference: who's to say what is important? J Clin Epidemiol 1996;49:1221–2.
76. Wright JG, Young NL. A comparison of different indices of responsiveness. J Clin Epidemiol 1998;50:239–46.
77. Goldsmith CH, Boers M, Bombardier C, Tugwell P. Criteria for clinically important changes in outcomes: development, scoring and evaluation of rheumatoid arthritis patient and trial profiles. J Rheumatol 1993;20:561–5.
78. Redelmeier DA, Goldstein R, Min ST, Hyland RH. Spirometry and dyspnea in patients with COPD: when small differences mean little. Chest 1996;109:1163–8.
79. Redelmeier DA, Guyatt GH, Goldstein RS. On the debate over methods for estimating the clinically important difference. J Clin Epidemiol 1996;49:1223–4.
80. Fortin PR, Stucki G, Katz JN. Measuring relevant change: an emerging challenge in rheumatologic clinical trials [editorial]. Arthritis Rheum 1995;38:1027–30.
81. Jaeschke R, Singer J, Guyatt GH. Measurement of health status: ascertaining the minimal clinically important difference. Control Clin Trials 1989;10:407–15.
82. Jaeschke R, Guyatt GH, Keller J, Singer J. Interpreting changes in quality of life score in N of 1 randomized trials. Control Clin Trials 1991;12 Suppl 4:226S–233S.
83. Lydick E, Epstein RS. Interpretation of quality of life changes. Qual Life Res 1993;2:221–6.
84. Testa MA, Simonson DC. Assessment of quality-of-life outcomes. N Engl J Med 1996;334:335–40.
85. Guyatt GH, Cook D. Health status, quality of life, and the individual. JAMA 1994;272:630–1.