

Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings

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Abstract—Quality of life (QoL) is increasingly becoming a key concept in research and clinical services. However, no agreement exists on what QoL is and how it is to be measured. This paper reviews three different yet linked approaches to QoL conceptualization: *QoL as subjective well-being*; *QoL as achievement*; and *QoL as utility*. People with spinal cord injury (SCI) tend to report fewer feelings of well-being, on average, than nondisabled persons; score lower on physical, mental, and social health and in other domains of life that people consider important to life quality; and have a health state that is preferred much less than that of the average person. Many QoL instruments used in SCI research have not been validated for this group, or have questionable assumptions, and clinical applications of QoL measures still have many problems. Much SCI QoL research tends to be atheoretical.

Key words: affect, health status, outcome assessment (health care), personal satisfaction, quality-adjusted life years, quality of life, reproducibility of results, review, spinal cord injuries, utility.

INTRODUCTION

Spinal cord injury (SCI) has been described as one of the greater calamities that can befall humans [1]. Learning of the paralysis, bladder and bowel dysfunction, dependence on others, mobility limitations, and high risks of complications (such as pressure ulcers) that a spinal injury entails, most people who contemplate being forced to live this way cannot see anything but a life of low quality and conclude that they would rather be dead [2]. Many individuals who actually incur an SCI indeed feel this way, at least initially. Some people with SCI very rationally decide to commit suicide [3], and others

may do so during a period of depression and despair that is not uncommon after SCI [4]. The suicide rate among

Abbreviations: ABS = affect balance scale; ASIA = American Spinal Injury Association; CHART = Craig Handicap Assessment and Reporting Technique; CI = confidence interval; DALY = disability-adjusted life year; EQ-5D = EuroQoL (5 dimensions); HRQoL = health-related quality of life; HUI3 = Health Utilities Index, version 3; ICF = International Classification of Functioning, Disability and Health; LSI-A = Life Satisfaction Index, version A; MCS = Mental Component Summary (of SF-36); NHP = Nottingham Health Profile; PCS = Physical Component Summary (of SF-36); PQVS = Profil de la Qualité de Vie subjective; QALY = quality-adjusted life year; QoL = quality of life; QoLI = (Frisch's) Quality of Life Inventory; QoLS = (Flanagan's) Quality-of-Life scale; QWB = Quality of Well-Being Scale; SCI = spinal cord injury; SD = standard deviation; SF-6D = SF-36-derived, six-dimension utility measure; SF-12 = Short-Form 12 questions; SF-36 = Short-Form 36 questions; SIP = Sickness Impact Profile; SWB = subjective well-being; SWLS = Satisfaction With Life Scale; WHO = World Health Organization.

This material was based on work supported in part by grants (H133N000027, H133G030026, H133A020501) from the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education Services, U.S. Department of Education to Mount Sinai School of Medicine.

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DOI: 10.1682/JRRD.2004.08.0100

individuals with SCI is about five times as high as the population at large [5] and may be underestimated because of the “indirect suicides” achieved by prolonged self-neglect. However, most people with SCI eventually “adjust” to their new body and the lifestyle it imposes and state that they would not have wanted to be allowed to die [6]. They seem to have, and report, a life of acceptable quality, especially individuals who live in developed countries; have access to medical care, adaptive equipment, and economic and social support; and live in cities and towns where housing, public buildings, public spaces, and transportation increasingly are accessible [7].

This review summarizes how quality of life (QoL) is defined and assessed, what is known about the QoL of individuals with SCI, what the gaps in our knowledge are, and where future research appears to offer the greatest payoff. This review joins earlier reviews that have focused primarily on measurement issues [8–9].

CONCEPTUALIZATIONS

Even though QoL is now established as a “marker construct of our times” [10], more disagreement exists on the definition and measurement of this concept than on that of any other construct that plays such a key role in medical, rehabilitative, social, and psychological research and is used increasingly in clinical service in these areas. While inconsistencies in the conceptualization and operationalization of latent constructs are common, the discrepancies around QoL are unusually large and persistent. Many have tried to bring some order to this “psychometric tower of Babel” [11], but to date none of the proposals have found acceptance. Even the basic schemes for classifying different definitions or conceptualizations of QoL have not been agreed upon [10,12–14].

In my opinion, conceptualizations of the QoL of individuals can be separated into three major groups: *QoL as subjective well-being (SWB)*, *QoL as achievements*, and *QoL as utility*. **Figure 1 (Boxes A–E)** attempts to show how these ideas are linked [15–16]. (The QoL of political and social entities—studied principally by economists, sociologists, and political scientists in the social indicators research tradition—is not considered here). Each human being has certain needs, desires, priorities, and standards, noted in **Box D (Figure 1)**. In part these are biological (as in the five basic needs of Maslow [17]) and in part social—modified or added to by the culture of the groups and soci-

ety in which one is a part. Against that background, people develop individual standards, priorities, wants, needs, etc., based on a unique physiological and psychological makeup and life history. When these needs, dreams, and wishes are compared to reality (**Box C**), reactions can range from positive to negative and be reflected in morale, life satisfaction, mood, etc. (**Box E**). These reactions comprise one definition of QoL: the sum total of the cognitive and emotional reactions that people experience when they compare what they have and do in life with their aspirations, needs, and other expectations [18]. This I call *QoL as SWB*, the area of interest of psychologists and many others who think of QoL as a subjective entity, something that is internal to the person.

In trying to predict QoL as SWB, researchers have looked mostly to the achievements and statuses in **Box C**. Health status, income level, marital status, number of friends, number of hospitalizations, etc., have been correlated with life satisfaction and positive affect in a number of studies, including much QoL research on individuals with SCI [19–20]. However, if SWB truly results from the balance between expectations and actuality [18], both sides of the equation deserve equal attention. One likely reason for the almost complete scholarly disregard for any of the elements in **Box D**, other than in some qualitative research on QoL, is that we lack adequate instruments to measure them. Another reason for focusing on achievements and statuses in predicting SWB may be the unspoken assumption that interindividual differences in priorities and expectations are trivial and offer little explanatory power once the achievements and statuses are introduced into the equation.

In fact, some researchers apparently believe so strongly in the primacy and determining power of the achievements and statuses that they disregard the subjective reactions altogether and operationalize QoL as people’s possessions, relationships, accomplishments, etc. I refer to this conceptualization as *QoL as achievements* (**Figure 1, Box C**). Health-related QoL (HRQoL) is a major subcategory of this type of QoL: in measures developed to operationalize HRQoL, the statuses are limited very much to those traditionally under the purview of the medical establishment, including physical and mental health and symptoms. Some researchers, basing themselves on the World Health Organization’s (WHO’s) encompassing definition of health [21], may add to this mix social health indicators such as interactions with others and social role functioning. The research on QoL as

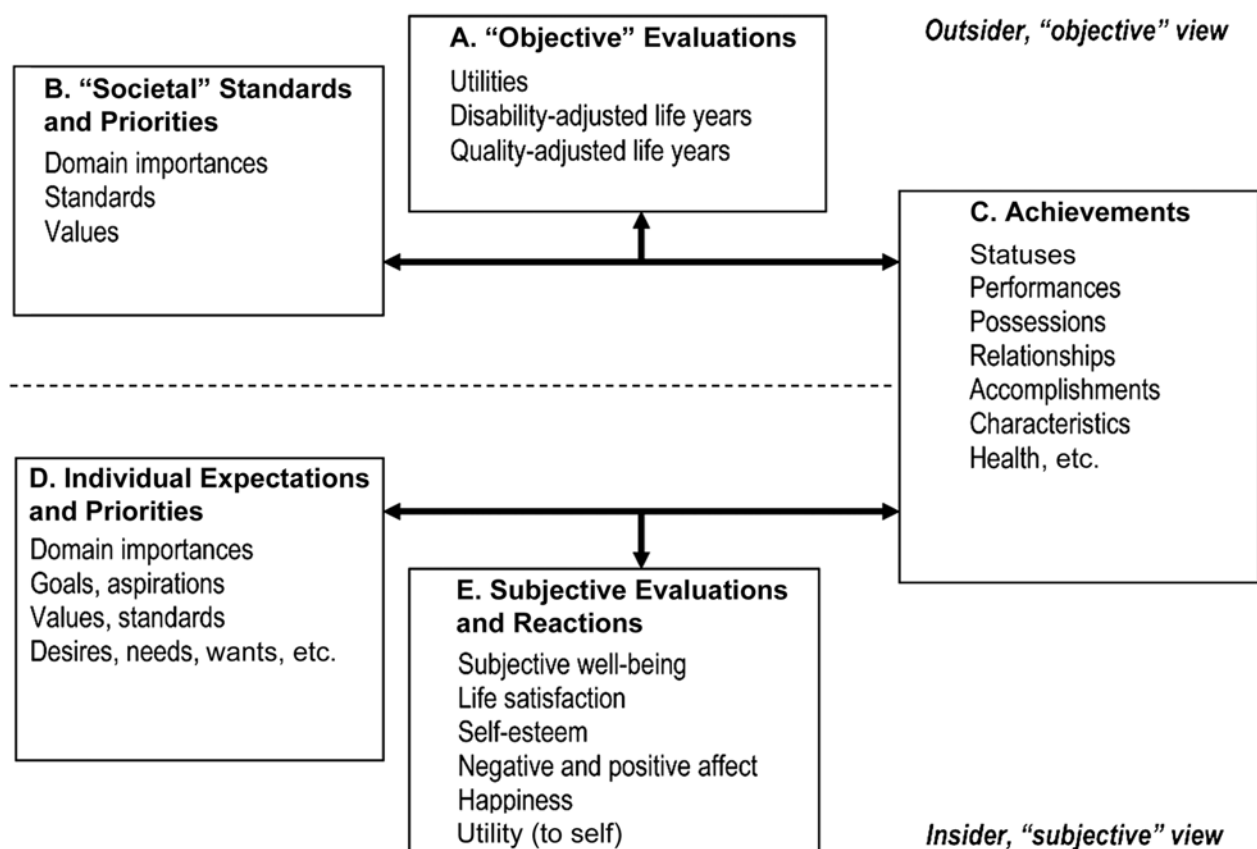


Figure 1.

Three conceptualizations of quality of life and their interrelations. (Adapted, with permission, from Dijkers MP. Individualization in quality of life measurement: Instruments and approaches. *Arch Phys Med Rehabil.* 2003;84(4 Suppl 2):S3–14.)

achievements continues traditions of the health status investigations that were prominent in the 1970s and the functional assessment work that has characterized rehabilitation research since its beginning.

While QoL as SWB reflects the insider's evaluation of achievements and statuses in light of desires and priorities, other QoL research exists that takes the outsider's point of view. In what can be termed the *QoL as utility* tradition, achievements and statuses are judged in terms of societal norms and standards (**Figure 1, Box B**); the resulting assessments (**Box A**) reflect the desirability of, relative preference for, or even value of the life summarized in the scores in **Box C**. Typically, the statuses evaluated reflect health aspects (mobility, sensory status, symptoms), and samples of lay people or professionals are asked to rate the preference for (desirability, "utility" of) combinations of the factors of interest on a scale ranging from a value of 0.00 for death to 1.00 for perfect physical, mental, and social health.

Note that QoL is not a static phenomenon. Because individuals change and society and the world at large change, statuses, achievements, and environments change, in turn affecting SWB reactions. Human beings try to optimize well-being and do so by maximizing statuses and achievements or by adjusting expectations and priorities [22]. Societal standards change and may affect what individuals want out of life. Negative situations presumably are easier to deal with emotionally if they appear to be improving rather than deteriorating. Although researchers have addressed change in QoL in a number of longitudinal and cross-sectional studies, in those prior studies they focused on scores on the instruments quantifying QoL as achievements and statuses (**Figure 1, Box C**), subjective well-being (**Box E**), and (very infrequently) QoL as utility (**Box A**). The dynamics of the situation—the fluid interplay of expectations, achievements, and evaluations—have been addressed mostly in qualitative research.

A note of caution: although linked as reflected in **Figure 1**, these three conceptualizations of QoL and the research traditions that are based on them are clearly distinct. Whenever the term *quality of life* is used in a research or clinical paper, one should ask oneself, “How is QoL defined by this author?” Unfortunately, most articles published in the professional and research literature do not define the concept at all, whether QoL is a secondary outcome measured in a clinical trial or the core variable of a study on the natural course of SCI. A worthwhile second question in these cases is, “How is QoL operationalized? What concept is reflected in the measure or measures used?” Most of the commonly used QoL instruments can be confidently assigned to a specific conceptualization. For instance, the three generic measures of QoL as utility are the Quality of Well Being Scale (QWB) [23], the European QoL measure (EuroQoL) or EQ-5D (five dimensions) [24], and the Health Utilities Index (HUI) [25]. Pure QoL-as-SWB measures include the Satisfaction With Life Scale (SWLS) [26]; the Life Satisfaction Index, version A (LSI-A) [27]; the Perceived Quality-of-Life-Scale (PQLS—in French, Profil de la Qualité de Vie Subjective or PQVS) [28]; and the Affect Balance Scale (ABS) [29]. The most popular measures in the QoL-as-achievements group are the Nottingham Health Profile (NHP) [30], the Short Form 36 (SF-36) [31–32], the General Health Questionnaire (GHQ) [33–34], and the Sickness Impact Profile (SIP) [35–36]. One phenomenon to note is that many authors who offer a *definition* of QoL that seems to be squarely in the QoL-as-SWB category present an *operationalization* that fits in the QoL-as-achievements tradition. That apparent confusion occurs with many who quote the popular WHO definition of QoL as “an individual’s perceptions of their position in life in the context of the culture and the value systems in which they live, and in relation to their goals, expectations, standards and concerns” [37]. Thus, the discrepancy between theoretical/conceptual and operational definitions is to be noted, as are other weaknesses in the definition and operationalization of QoL. This problem is as common in the SCI literature as in scholarly work dealing with other populations [12,38–40].

QUALITY OF LIFE AS UTILITY

Various methods have been developed to estimate QoL as utility, many of which reflect the economic and manage-

ment decision-making background of this definition of QoL [41–42]. Because the assumption is that utilities are measured on a ratio scale, they can be combined with time spent in a state to calculate quality-adjusted life years (QALYs), which can be used to evaluate the benefits of healthcare interventions or programs. A program producing, per average case, 4 QALYs (e.g., 8 years with a utility of 0.50) is assumed to be better than one that produces only 3 QALYs (e.g., 4 years with a utility of 0.75). Disability-adjusted life years (DALYs) [43], which are based on the same principle, are used for the same purposes.

All utility measures define three to eight different domains (dimensions) of health (defined broadly), with each domain having from three to six categories. Combined, these domains define from 243 (EQ-5D) to 972,000 (HUI3) individual health states, which all receive a rating of their relative preferability with, as extremes, death (a utility of 0.00) and perfect health (a utility of 1.00). The value of the states between 0.00 and 1.00 is determined by the average of the values assigned to them by community samples, with the use of one of several techniques available to develop ratings on a ratio scale: time trade-off, standard gamble, and direct rating. For measures with health states numbering in the thousands, obtaining a utility score for each one in this way would be too burdensome. In these instances, utilities are calculated only for key health states, and regression and other formulas are used to determine estimates for all other health states. Applying the utilities calculated in this way to actual individuals and their present or possible future health states requires establishing for every person his or her position on each of the constituent health domains; the corresponding utilities then can be averaged and, for instance, compared between trial treatment arms. Because of their straightforward meaning (“percentage of perfect health”), these scores in principle are more useful than the scores resulting from the instruments in the two other major QoL categories.

Two reports that used a QoL-as-utility measure with SCI samples were identified [44–45]. Both used the QWB, which uses four dimensions (domains) to develop an estimate that “people” would make of the relative desirability of a life. The QWB developers obtained community ratings of the utility-of-health statuses described in terms of mobility (“no limitations,” “restricted in use of public or private transportation,” or “in hospital”); physical activity (“no limitations,” “independent in wheelchair or limitation in walking,” or “in bed

or dependent in wheelchair”); and social activity (“no limitations,” “limited in major or minor role,” or “no major role and in need of help in self-care”) (Table). Symptoms and other medical problems are the fourth dimension, but only the one that is most significant contributes to the QWB total score. For the adult population, the average QWB score is 0.80 [46]; for the elderly, the average is 0.70 [47–48]. Andresen et al. reported that the average score for a sample of individuals receiving care from a U.S. veteran’s SCI program was 0.55, with a stand-

ard deviation (SD) of 0.09 [44]. Level of injury or the presence of upper-limb difficulties or work difficulties hardly made a difference in average score.

Phillips et al. reported on a trial that compared the effects on health-related outcomes of two versions of telehealth (a 9-week telephone or a televideo outreach program by a rehabilitation nurse) with standard care (calling in by the patient in case of problems) in SCI patients newly discharged from initial rehabilitation after SCI [45]. They reported a week-9 average QWB score of

Table.

Quality of Well-Being (QWB) dimension scores and total scores of eight hypothetical persons with spinal cord injury of differing level and completeness of injury, and health.* (The percentile of health status [within each neurological group] is given; in each pair of individuals, one is fairly unhealthy [25th percentile] and one is fairly healthy [75th percentile].)

QWB Domain, Category, and Utility Value of Category	Level and Completeness of Injury							
	C2 ASIA A		C5 ASIA A		T12 ASIA A		T12 ASIA D	
	25th	75th	25th	75th	25th	75th	25th	75th
Mobility								
No limitations for health reasons: -0.000	—	—	—	—	—	—	—	✓
Limited public/private transportation: -0.062	—	✓	✓	✓	✓	✓	✓	—
In hospital: -0.090	✓	—	—	—	—	—	—	—
Physical Activity								
No limitations for health reasons: -0.000	—	—	—	—	—	—	—	✓
Independent in wheelchair (WC)/limitation in walking: -0.060	—	✓	—	✓	✓	✓	✓	—
Dependent in WC/in bed or chair most of day: -0.077	✓	—	✓	—	—	—	—	—
Social Activity								
No limitations for health reasons: -0.000	—	—	—	—	—	—	—	✓
Limited in major role or other role -0.061	—	—	—	✓	✓	✓	—	—
No major role and needing help in self-care: -0.106	✓	✓	✓	—	—	—	✓	—
Symptoms and Problems								
None: -0.000	—	—	—	—	—	—	—	—
Death: -0.727	—	—	—	—	—	—	—	—
Major burn: -0.370	—	—	—	—	—	—	—	—
Trouble thinking: -0.340	—	—	—	—	—	—	—	—
Hands/feet paralyzed: -0.333	✓	✓	✓	✓	✓	✓	✓	✓
Pain/weakness torso/arms/legs -0.299	✓	✓	✓	✓	✓	✓	✓	✓
Pain/other difficulty evacuation/urination: -0.292	✓	✓	✓	✓	✓	✓	✓	✓
General tiredness: -0.259	—	—	—	—	—	—	—	—
Upset, depressed: -0.257	✓	—	✓	—	✓	—	✓	—
Overweight: -0.188	—	—	—	—	—	—	—	—
On medication or diet: -0.144	✓	✓	✓	✓	✓	✓	✓	✓
Requiring glasses or contact lenses: -0.101	—	—	—	—	—	—	—	—
Sexual performance problems: -0.257	✓	✓	✓	✓	—	—	✓	—
Total Score	0.394	0.439	0.422	0.484	0.484	0.484	0.439	0.667

*QWB total score is calculated as 1.00 less point value of category selected within Mobility, Physical activity, and Social activity, less point value of selected symptom and problem that has highest point value. Total reflects preference for each state (column). See “Quality of Life as Utility,” main body text. ASIA A and D = American Spinal Injury Association, Impairment Scale Class A and D, respectively.

0.49 ± 0.08 SD, which had improved to an average of 0.52 ± 0.10 at the week-52 follow-up; the telehealth groups saw a slight increase in scores, and the comparison group, a slight decrease in scores. The increase may have resulted from minor improvements in mobility or physical activity or from the disappearance of more serious symptoms such as depression or pain. The authors do not report sufficient detail for the possible reasons for score changes to be determined.

The major issues explaining the difference in QWB scores between people with SCI (0.55) and the population at large (0.80) are unlikely to disappear even with optimal care and support: mobility limitations (-0.06 points on the QWB), being limited in a major role (-0.06 points), or problems with sexual performance (-0.26 points) (**Table**). For that reason, the QWB and other QoL-as-utility measures may lack sensitivity to differences between individuals with SCI and to intra-individual changes over time. The **Table** offers hypothetical cases scored on the QWB. Within each impairment group, defined by the level of injury and American Spinal Injury Association (ASIA) completeness score, the “low” category represents a person who is near the 25th percentile in terms of health status and functioning. Similarly, the “high-category” person is someone estimated to be at the 75th percentile. These vignettes were prepared by a physician with experience in SCI rehabilitation. The **Table** shows that except for the well-functioning person with a T12 ASIA Impairment Scale Class D injury, none of the individuals attain maximum scores on mobility, physical activity, or social activity. Almost all have multiple symptoms related to the SCI. The presence or absence of depression is a major point of difference between high-functioning and low-functioning individuals within each ASIA group. However, this diagnosis is not reflected in the total scores because only the symptom with the highest point value (paralysis of hands/feet) is scored.

QUALITY OF LIFE AS UTILITY: SHORTCOMINGS AND SOLUTIONS

Those who use a broad definition of QoL are likely to criticize QoL-as-utility measures as being limited to the measurement of health, and a fairly restricted concept of health at that. Utility QoL measures recognize a limited number of health domains and distinguish a small number of categories within each. The original reason for

doing so was the burden of developing utility estimates separately for every health state, although the problem is smaller now that formulas for interpolating between key states can be used, as in the HUI3. However, because of the small number of domains and of categories per domain, these measures may lack sensitivity [49], as indicated previously. Although the QWB, and presumably the other generic utility measures, may be adequate to differentiate the QoL of the average person with SCI from that of other individuals with chronic disorders (e.g., people with migraine headaches) or from the population at large, these measures lack the sensitivity to differentiate between people with SCI or to reflect changes in their health status over time. The all-or-nothing scoring of symptoms, without the opportunity to differentiate, for instance, between spells of being upset and major depressive disorder, especially contributes to this lack of sensitivity. The HUI3 and the EQ-5D have more than only two categories in their domains of “emotion” and “anxiety/depression,” respectively, but even five categories may be insufficient to reflect the QoL implications of the full range of emotional states, that is, ranging from slight emotional discomfort to depression that necessitates hospitalization.

Utility QoL measures have been developed within the “clinimetric” tradition of measurement [50–52], in which a single item or indicator is considered adequate to determine a person’s status on a dimension or domain. This tradition differs from the psychometric tradition underlying the QoL-as-SWB and QoL-as-achievement measures. Psychometrics stresses the need to use multiple indicators for each dimension, which may be needed both to cover all aspects of the domain and to allow variables reflecting the same domain to cancel out each others’ measurement errors. Although psychometricians consider the use of a single indicator for abstract constructs a shortcoming of the utility measures, to economists and clinicians, using a single indicator does not constitute a problem; they focus on the “valuation” of each category within each domain and the utility of the health statuses that can be distinguished by the permutations of domains [53]. The SF-6D (Short-Form-36-derived six-dimension) is a new utility measure developed to parallel the SF-36, and its categories within the six domains that are distinguished are based on multiple SF-36 questions [54]. In the future, other “marriages” between the psychometric and the clinimetric approaches may be concluded to create utility QoL instruments of greater sophistication.

Most utility measures use additive models to calculate total QoL scores and disregard the effect of combinations of particular categories on valuations. For instance, the QWB assumes that if individuals who are confined to a hospital (-0.090) are also limited in their major role, the utility of their health status is decreased by another -0.061 points. However, common sense suggests that once one is confined to a hospital, the limitation in major role hardly counts anymore. (And one wonders how the sample used by the QWB developers even managed to provide a rating for the combination “in hospital” and “no limitations [in social role] for health reasons.”)

Even more serious questions can be asked about the premise underlying utility measures. Although the definition of “dead” is fairly simple, what is that of “perfect health”? Would perfect health be attributed to an Olympic athlete with supreme self-confidence and an extensive social support system with which he or she interacts constantly? If the “perfect health” state is not defined or definable, we cannot assume that QoL is measured on a ratio scale. At the other end of the spectrum, very poor health states (e.g., “in coma”) are sometimes rated by sample respondents as being “worse than death” (a score of <0.00) and must be “swept under the carpet” to make the system work [55]. All generic utility measures use the same extremes (death valued at 0.00 , and perfect health at 1.00) and, consequently, should provide the same utility score for a health state, except for “rounding errors.” However, that is not the case. Kopec and Willison determined the utility of the status “unable to walk but no other problems” (essentially, a healthy paraplegic) in four systems and derived a value of 0.42 for the HUI3, 0.55 for the QWB, 0.85 for the EQ-5D, and 0.88 for the SF-6D [49]. These values mean that 1 year of life with paraplegia is worth 153 days in perfect health according to the HUI3, but more than twice as much, 321 days, according to the SF-6D. With discrepancies this large, believing that QoL-as-utility measures manage to quantify preferences for health states is difficult. The divergences between measures may be due to the selection of health domains, the categories distinguished within them, the methods used derive valuations (time trade-off, standard gamble, etc.), or a combination of these factors. The makeup of the sample making the judgments (country of residence, own health status, risk aversiveness, etc.) may also play a role.

The lack of sensitivity and responsiveness of utility measures compared with QoL-as-achievement measures

has been noted in various studies [49]. Ceiling effects may occur because the highest category within each domain, “no limitations for health reasons,” indeed describes many people, especially if the alternative, the next-lower category (e.g., “independent in wheelchair/limitation in walking”), seems inappropriate. Of the total range between “death” and “perfect health,” a major area may not be available because of the perceived difference between the lowest-rated health status and death. For instance, on the QWB, the lowest state possible is valued at 0.357 (for a major burn resulting in the lowest status on all three other dimensions), squeezing all other states into two-thirds of the range theoretically available. Although this representation may be correct regarding how people value health states relative to death and perfect health, because of its limited responsiveness and sensitivity, researchers may prefer to use a QoL-as-SWB or QoL-as-achievement instrument.

Individuals with SCI may object to the fact that the “societal,” outsider view reflected in the scoring of utility measures does not correspond at all with their own insider views. To these individuals, paralysis and the mobility and physical activity limitations that result are at best major irritations that, with adequate societal and personal arrangements in place, need not detract from well-being and a satisfactory life—on a par with that of the average nondisabled person. Although various users of utility measures have noted the discrepancy between ratings of desirability of a health status made by insiders and those made by outsiders [56–58], this methodology has not been abandoned. Exploration has only recently begun of the psychological and other factors underlying the discrepancy [59–60].

QoL utilities, QALYs, and DALYs are very much contested concepts because of the underlying assumptions and the numbers that result, which are seen as discriminating against people with a disability or chronic disease. The claimed “universality” of utility values across societies and cultural groups is also debated [61–66]. Allotey et al. argue that the context of life significantly affects how much a particular injury or disease diminishes the value and enjoyment of life [7]. Having an SCI in one of the western welfare states—with extensive health, social, and vocational services and accessible environments—is quite different from incurring it in a small village in a third-world country. If the domains of a QoL-as-utility measure are defined in terms of impairment, context presumably is unimportant. But the value of life and the quality people

see life as having presumably are determined more by what they do day-to-day and the social and life roles they fulfill [67]. Context—accessibility, aides and aids available, rehabilitation, and other services—very much affects activities and activity limitations and even more affects participation and participation restrictions. Thus, defining QoL domains and their categories in terms of these issues would seem to be crucial for utility measures to truly reflect what is important in life.

QUALITY OF LIFE AS SUBJECTIVE WELL-BEING

The concept of QoL as SWB can be differentiated into two separate yet related constructs: cognitive QoL and affect. Cognitive aspects of well-being concern judgments that life and life circumstances are satisfactory, that quality of life is present, and even that life as it is scores high on a preferences scale. A large number of life-satisfaction instruments are in use, which can be split into two groups: global and domain-based measures [68]. *Global* measures require subjects to answer one question (e.g., Life-3 [69]) or (more typically) multiple questions, judging life *as a whole* in terms of their satisfaction with it (e.g., the SWLS [26], Michalos' life satisfaction scale [70], the LSI-A [27], and Fugl-Meyer's life satisfaction measure [71]). *Domain-based* measures ask for separate judgments of satisfaction, with a number of enumerated life domains (physical health, family relations, job, mental health, etc.), which are then summed into a total score and/or subscale scores as appropriate. For calculation of the total score, some domain-based measures use domain-importance weights supplied by the person; this is the case with the Quality of Life Index [72–73]; the Flanagan Quality of Life Scale [74–75] from which it was derived; and the PQVS [28], which is very popular in French-speaking countries. The use of importance ratings allows maximum individualization of the measure, which is in line with the notion that QoL-as-SWB instruments should reflect the person's viewpoint, not that of the investigator or of society [15].

Over the last few decades, the concept of QoL has migrated from scientific to lay vernacular, starting with the idea of QoL of cities (“best cities to live in”), of countries (the welfare state), and of employers (“best companies to work for”). As a consequence, individuals now can be directly asked about their “quality of life,” and if the investigator does not supply a quantitative rating

scale, subjects themselves may do so spontaneously [76]. Presumably, the answers reflect the satisfactoriness of individuals' overall circumstances, including physical and cognitive faculties and health, and the degree of happiness this satisfactoriness affords them. When used by individuals to assess their *own* current and potential future QoL, utility measures also fall into the cognitive QoL-as-SWB measures group. In the clinical situation, a patient's rating of QoL afforded by various possible life scenarios on a 0.00 to 1.00 scale may be elicited to assist individuals to choose between health treatments with dramatically different outcomes, side effects, and risks [77].

While affect, the second main component of QoL as SWB, is typically closely aligned with life satisfaction [78], the two are theoretically and empirically sufficiently different that separate measures are indicated. Within affect, various aspects can be distinguished. Positive affect (the frequency and intensity of happiness and similar moods) and negative affect (sadness) should be considered not the two extremes of a single continuum, but independent experiences [79]. The ABS [29] is often used to quantify both aspects. Other components of affect may be distinguished, such as morale (often quantified with the Philadelphia Morale Scale [80]) and self-esteem, which can be measured with such instruments as the Rosenberg Self-Esteem Scale (RSES) [81]. In addition, many of the measures of “adjustment” to disability that rehabilitation researchers have developed contain aspects of positive and negative affect, self-esteem and morale, sometimes mixed with items that tap into life satisfaction [82].

Research that has assessed the SWB of individuals with SCI and compared it with that of their nondisabled peers typically has found that the well-being of the latter *on average* is somewhat higher; however, within both groups, the variance is great, and stating that most people with SCI have lower SWB than those with whom they are compared would be wrong. **Figure 2**, which summarizes the results of a number of investigations [74, 83–94], shows the difference of the SWB mean for the SCI sample and the mean for the comparison group, divided by the SD for the latter group: $(\text{mean}_{\text{SCI}} - \text{mean}_{\text{control}}) / \text{SD}_{\text{control}}$. All differences were divided by the SD of the control group so that all outcome measures would be put on the same metric. A negative “effect size” here indicates that the persons with SCI report less well-being. A positive effect size was found in only one study; this study concerned a small sample [93]. Other studies possibly exist in the literature in which the average well-being

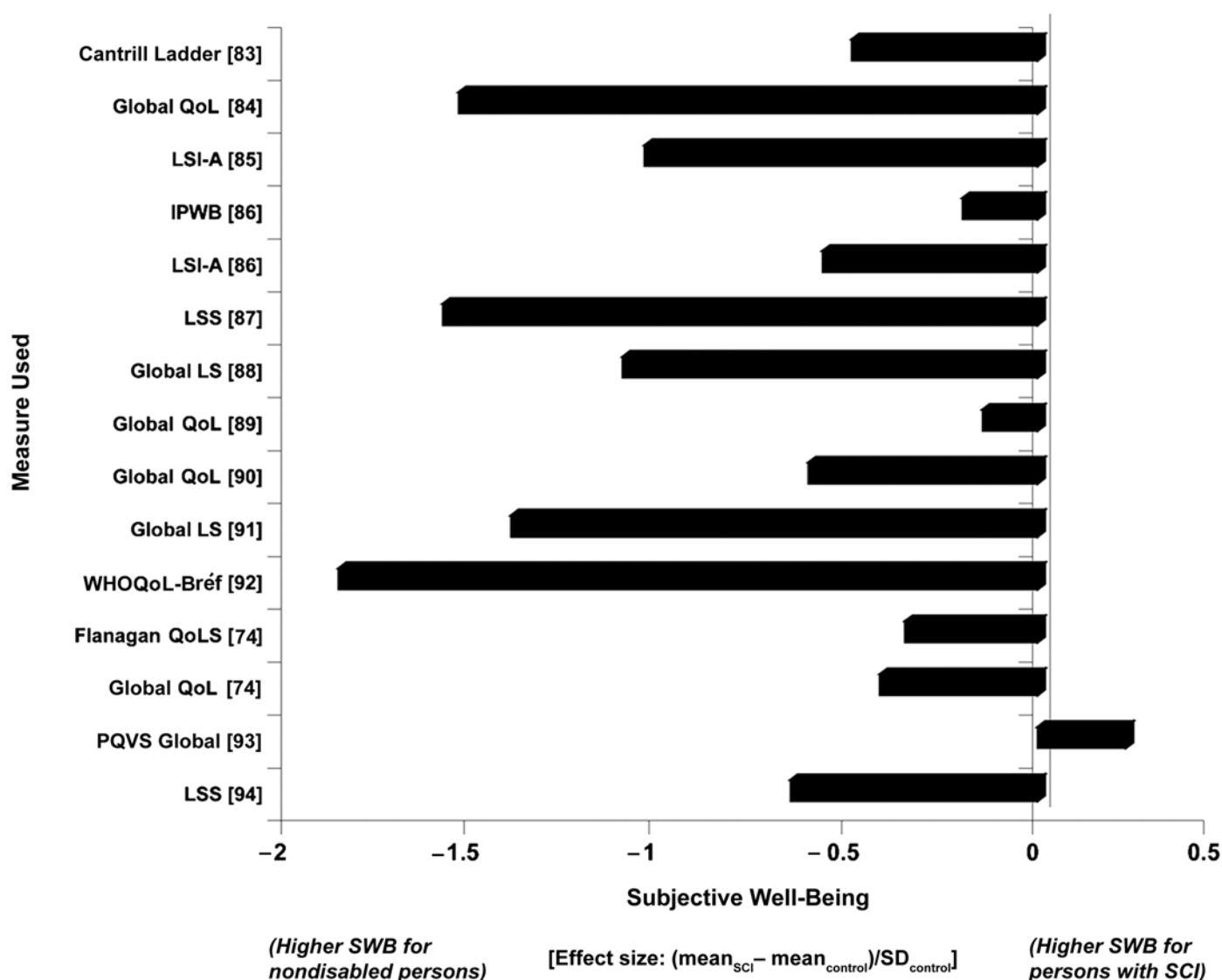


Figure 2.

Standardized subjective well-being (SWB) scores of spinal cord injury (SCI) samples and comparison groups, various studies. Study from which data are taken is listed behind name/nature of SWB measure used and found in “References” section in main body text. IPWB = Index of Psychological Well-Being, LS = life satisfaction, LSI-A = Life Satisfaction Index, version A, LSS = Life Situation Survey, PQVS = Profil de la Qualité de Vie Subjective, QoL = quality of life, SD = standard deviation, WHOQoL = World Health Organization Quality of Life.

score for the SCI group was higher than for the controls; a nonexhaustive search did not find them.

Domain-based life satisfaction measures allow us to investigate the areas of life that are sources of lack of global SWB of persons with SCI. **Figure 3** graphically presents data reported by Brown and Vandergoot [74], who used an alternative scoring algorithm to present results of the Flanagan QoLS, which is a measure that uses weighting of need fulfillment by rated domain importance. In

this graph, high scores reflect important unmet needs. As can be seen, in all areas except material comforts, relatives, and passive recreation, those with SCI rate their needs higher than the nondisabled group; the discrepancy is significant only for health and personal safety, work, and active recreation. The differences are partly due to higher perceived needs and partly to higher ratings of the importance of various domains. Several of the domains that show large differences between SCI and control

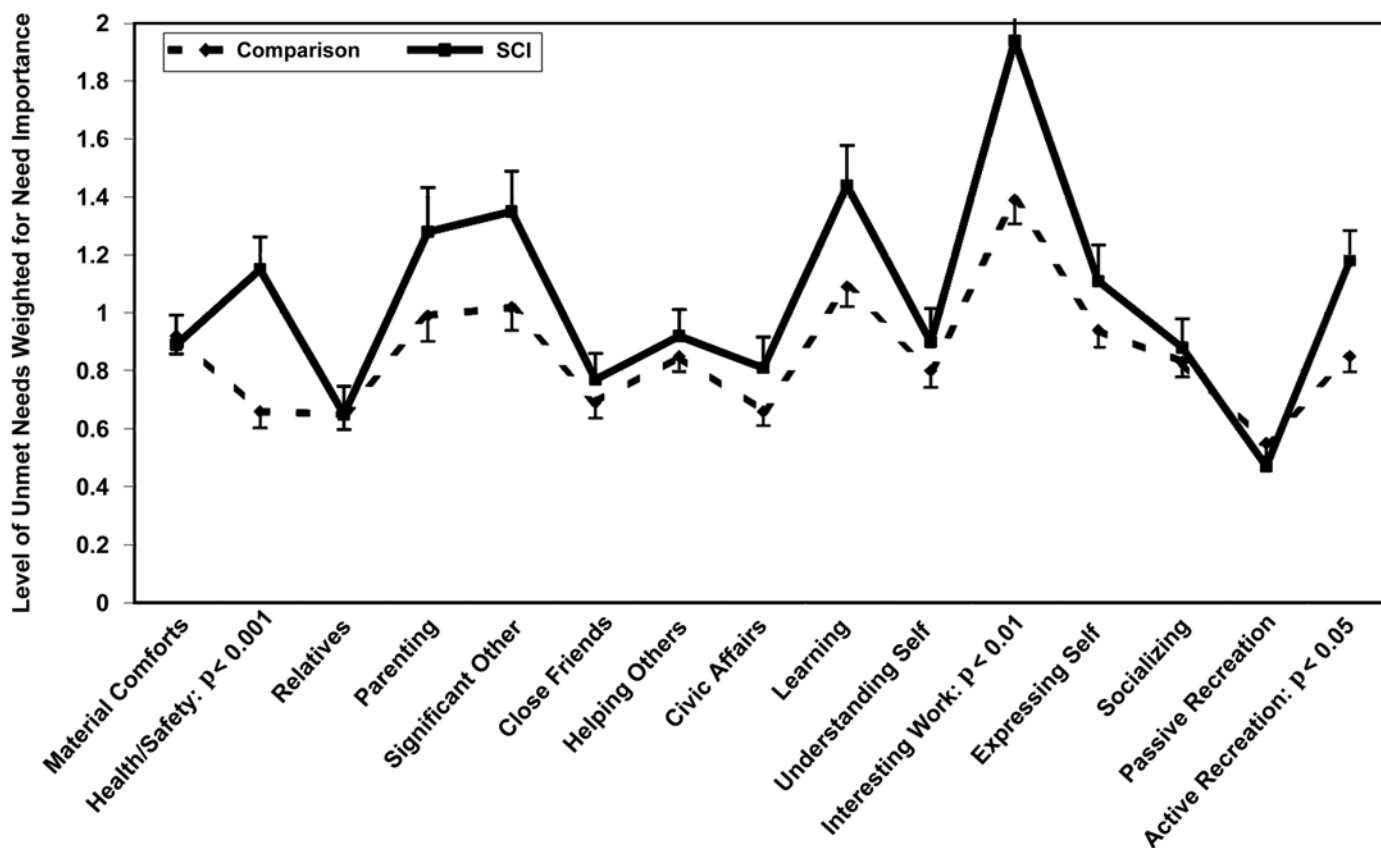


Figure 3.

Mean and standard error for unmet important needs; sample with spinal cord injury (SCI) and comparison group (Source: Brown M, Vandergoot D. Quality of life for individuals with traumatic brain injury: Comparison with others living in the community. *J Head Trauma Rehabil.* 1998; 13(4):1–23).

groups in this and other studies (e.g., Benony et al. [93]) have been investigated with more specialized measures, e.g., sexual satisfaction [95], work satisfaction [96]; and marital satisfaction [90]. Even more “microscopy” is feasible; for instance, Costa et al. describe the Qualiveen, a measure of urinary-difficulties-related QoL [97], which because of the nature of the questions, should be assigned to the QoL-as-SWB group.

Because the domains of life that affect the SWB of people with an SCI the most may not be represented in “generic” measures, or at least not represented well, a few investigators have developed SCI-specific SWB instruments. One of the earliest was the Life Situation Questionnaire by Crewe and Krause [98], which offered a mix of objective items (e.g., sitting tolerance) and subjective ones (e.g., satisfaction with employment). The revised version has a more specific focus on well-being aspects, omitting factors that quite likely *affect* SWB, but do not

constitute it [99]. May and Warren developed the SCI version of the Ferrans and Powers Quality of Life Index, adding to the standard items SCI-specific ones, e.g., “ability to have children” [100–101].

The search for predictors of SWB among individuals with SCI has occupied many researchers. Time has been a prominent area of focus and has been quantified as “time since injury,” “age at injury,” and “current age.” These three designations are not independent from one another, but reflect different aspects of the passage of time [102]. A meta-analysis indicated that the correlation of SWB with current age was a very weak -0.04 (with a confidence interval [CI] of -0.11 to 0.03); that with age at injury was 0.00 (CI -0.09 to 0.09), and that with time since injury, 0.09 (CI 0.00 to 0.18) [103]. All these correlations may have been underestimated because the authors of the studies included in the meta-analysis assumed, with one exception, that the relationships were

linear, which may be incorrect [104]. For instance, if SWB is at a low point immediately after injury and improves over time, one can reasonably assume that the slope of the recovery curve is steep initially but flattens after the period of “adjustment,” which has been estimated to last from 2 to 5 years. Most of this research has been cross-sectional rather than longitudinal, although noteworthy exceptions exist [105–106].

Even more attention has been given to the impact of SCI disablement components on SWB, such as impairment, disability, and handicap, or—in terms of the International Classification of Functioning, Disability and Health (ICF) [107]—impairment, activity/activity limitations, and participation/participation restrictions. A meta-analysis of the published literature indicates that impairment has minimal or no effect on SWB (a correlation of -0.05 ; CI -0.12 to 0.02); activity limitations, a small effect (-0.21 ; CI -0.14 to -0.27); and participation restrictions, a fairly strong effect (correlations of -0.17 to -0.48 , depending on the specific social or role domain selected) [67]. Studies published later similarly suggest that impairments resulting from SCI have minor effects themselves; what affects well-being is the impact of these impairments on the capacity for self-care and mobility and especially on the ability to fulfill “normal” social roles and to participate in family and social life.

The search for predictors of SWB has not been limited to time and disablement; health has been assessed in terms of the number and nature of secondary conditions of SCI, the presence and severity of mental health problems, the pain experienced, and the number and duration of hospitalizations [108]. The extensive series of other predictors that have been investigated [82] includes gender, race and ethnicity, etiology of injury, education level, current and future financial security, various psychological processes and, most recently, perceived environmental accessibility [109].

QUALITY OF LIFE AS SUBJECTIVE WELL-BEING: SHORTCOMINGS AND SOLUTIONS

Created by psychologists and other social scientists, SWB measures mostly have been developed with attention to psychometric qualities as stressed by classical test theory: reliability, validity, and responsiveness. Hallin et al. [8] offer an overview of QoL measures used in English-language SCI research; they do not differentiate between

instruments that measure QoL as SWB and those that quantify QoL as achievements (solely or predominantly). However, they offer a useful overview of the evidence for psychometric qualities, including interpretability, practicality, and cross-cultural applicability. Unfortunately, most of these instruments have been used in only a few studies and often by only one team of investigators. Hallin et al. conclude that the evidence for psychometric quality was generally limited or absent and, when present, the evidence often was unsatisfactory [8]. On the other hand, the generic measures such as the SWLS, ABS, and LSI-A have been used in a large number of studies outside the SCI arena and extensively reviewed (e.g., Pavot and Diener) [110]. Unfortunately, since the often excellent qualities of these generic measures have not been demonstrated for SCI samples, their use in SCI research, strictly speaking, is not justified.

The search for predictors of SWB in SCI populations generally has not been guided by theory; for that reason, the search may have resulted in unsatisfactory findings. Specifically, the assumption underlying Calman’s formulation of QoL [18] that QoL results from the balance between expectations and actuality has not guided the research. Investigators (implicitly) assume that expectations are unchanged, or change very little, after SCI and therefore SWB declines with the onset of impairments, activity limitations, and participation restrictions and recovers only to the degree that functioning is regained. However, the evidence from one of the earliest investigations into SWB after SCI would have suggested a different approach. Brickman et al. [111] found that both for “winners” (people who won the lottery) and “losers” (people who incurred a spinal injury), SWB initially changed strongly after the event (and in opposite directions for the two groups), but fairly soon returned to “usual.” Stensman, who followed a small sample of individuals with SCI intensively for 5 years, starting at inpatient rehabilitation, found quite some variability around the average described by Brickman et al.: in some individuals, QoL as SWB never changed from a high level; for others, it “nosedived” never to recover; for a third group, it had the “predictable” downturn followed by return to near-preinjury levels; and for yet others, it displayed “unpredictable” ups and downs [106]. Expectations and shifts in expectations may be one of the major explanatory factors, as Duggan and Dijkers suggest [76].

However, the phenomenon described by Brickman et al. [106] also may be seen as an example of what is

known as the *hedonistic treadmill*: striving for satisfaction and happiness is a race that never can be won because people very quickly become accustomed to new achievements, and the boost in affect that these achievements provide disappears. Then, people need to obtain new possessions and other acquisitions (money, relationships, promotions at work) to increase their happiness; however, these acquisitions quickly lose their impact. This focus on striving for SWB by maximizing the occasions and intensities of pleasures and avoiding negative situations, pain, and unpleasant feelings is characteristic of the hedonistic (or hedonic) tradition in psychological research. This perspective has been contrasted by other QoL researchers with the eudaemonic perspective.

Eudaemonia refers to living a life of reason, aspiring to being who one truly is, and finding and following one's true purpose in life [112]. In this perspective, investigators emphasize activities and traits such as engaging in life's challenges, having autonomy, experiencing personal growth, gaining self-acceptance, achieving competence and mastery, having positive relationships with others, and experiencing a purpose in life. Although this "personal well-being" [113] may generate SWB, SWB is not guaranteed. Optimally realizing one's true human nature is not always accompanied by pleasant feelings, e.g., when making sacrifices [114]. To date, studies explicitly using the eudaemonic perspective have mostly focused on the elderly and well-being during the years of physical decline and shrinking social circles in the later decades of life. That focus does not mean that some studies on individuals with SCI have not addressed aspects of the traits and activities that are central to the eudaemonic perspective: acceptance of disability [115], coping [116], self-esteem [117], and spirituality [118], to name a few. However, no SCI study has comprehensively assessed the various aspects of life and functioning that "eudaemonists" see as central to well-being.

Another theoretical perspective on well-being that to date has not been used with SCI samples is that of QoL as a top-down versus bottom-up phenomenon. *Bottom-up* refers to the assumption that an overall judgment of life satisfaction (e.g., as measured with global life-satisfaction measures such as the SWLS [26] or Life-3 [69]) is created by the "summation," after weighting as necessary, of the satisfaction individuals have with all relevant domains of their life: health, income, love life, etc. *Top-down* reflects the conjecture that a "central generator" of satisfaction exists, which extends the basic satisfaction or dissatisfac-

tion judgment to all areas of life—just like wearing a set of rose-colored glasses makes the whole world look better. Various studies that have found an association between SWB and personality characteristics such as neuroticism and extraversion support this viewpoint [119–120]. Of course, as a dynamic phenomenon, SWB quite possibly is generated both top-down and bottom-up; some research with nondisabled subjects has indeed found support for this perspective [121]. Application of this perspective in SCI may be enlightening since in the typical person with SCI, sizeable discrepancies exist in the satisfactions with various domains in life: very negative for physical functioning, independence, and spontaneity of living; generally positive for cognitive functioning, support from family, and opinion of self; and in-between for healthcare, vocational situation, and accessibility of the home and wider world [76].

In predicting SWB, most studies with SCI subjects to date have focused exclusively on nomothetic factors—those that affect, or are assumed to affect, everyone and more or less to the same degree: functional status (a lower level of injury is better), employment (working, and working at a high salary, is better), etc. These studies have been able to predict only a relatively small percentage of variance in life satisfaction or happiness, which may be due to poor measures (both of outcome factors and of predictors), faulty assumptions (especially those of linear relationships of the factors involved), and multiple causation of the phenomena at hand. However, another possibility is that no simple determinants of well-being exist that have an effect across all persons, whatever their culture, gender, age, level of injury, and preinjury achievements. Perhaps this nomothetic perspective needs to be abandoned, and effective prediction of happiness and satisfaction can be better achieved if an ideographic perspective is adopted: well-being is determined by achieving (or maybe by just striving for) whatever each person sets out for him or herself to be the minimal requirements and optimal goals of life.

Theoretical underpinnings for this view exist [22], and support has been found in several studies with nondisabled persons [122–125]. SCI would seem to be an ideal "laboratory" for studying the hypotheses that can be derived from, for example, Ormel et al.'s "social production functions" theory [22] because of the sudden and complete change of lifestyle that SCI imposes. Much of whatever "worked" for the person in creating happiness, satisfaction, and a positive view of self almost certainly is no longer of benefit after SCI. Prospective investigations studying a small group of subjects starting soon after injury, beginning with

a retrospective exploration of preinjury life, is an optimal design for this type of research. Unfortunately, the major existing prospective SCI studies (such as the SCI Model Systems National Data Base [126] and Krause's long-running project [127]) involve too few assessment points, spaced many years apart, and too wide a variety of subjects to produce much useful information. A longitudinal qualitative study such as that of Stensman [106] with only 17 subjects may generate some useful information but is unlikely to have sufficient consistency in systematically assessing a range of factors from one time point to the next to do much more than generate hypotheses.

QUALITY OF LIFE AS ACHIEVEMENTS

In principle, any aspects of their life and environment that people consider relevant to QoL could be investigated by SCI researchers to characterize the direct and indirect consequences of the injury and the effectiveness of the medical, social, and rehabilitative services available to lessen or reverse the cascade of consequences of the injury. However, most studies have focused on secondary conditions and symptoms and on the disablements, or subsets of disablements, listed in the WHO taxonomies of impairments, activities/activity limitations, and participation/participation restrictions [107]. Even before the construct of QoL was used as an organizing concept for this type of research, a focus on activities of daily living and major social roles (e.g., occupation and marital status) came naturally. For impairments and activities, an obvious metric was available—"normal functioning." Measures such as the ASIA Motor Scale [128] and the Functional Independence Measure [129] have as their reference point the abilities of nondisabled persons. By definition, individuals with SCI score less than this ideal, and research has focused on how much less, given varying levels of injury and the nature and extent of medical and rehabilitative efforts. For participation aspects such as fulfilling major life roles, although no such simple metrics are available [130], researchers have not stopped attempting to quantify "handicap" (e.g., the Craig Handicap Assessment and Reporting Technique [CHART] [131]), community integration (e.g., the Community Integration Questionnaire [132]), participation (e.g., Life-H [133]), and related constructs.

Researchers interested in the consequences of illness and injury on "health-related" aspects of QoL have

attempted to combine a number of aspects of physical and mental functioning in instruments to describe HRQoL. HRQoL measures have been used with samples with SCI in a number of studies, all showing that generally this group scored low on physical functioning aspects and subscales but about average on mental functioning scales. For instance, Andresen et al. administered the SF-36 to a sample of individuals with SCI who received care at a regional veterans' SCI program and identified age- and gender-matched data from the National Survey of Functional Health Status [44]. They found sizeable differences in mean scores for the subscales that reflect physical health—such as "physical functioning," "role physical" (which refers to the impact of physical problems on the fulfillment of major roles), and "bodily pain"—but minimal or small differences on the mental-health subscales, including "role emotional" and "mental health" (**Figure 4**). Similar findings have been reported in other studies in which SF-36 data were obtained from individuals with SCI and controls—e.g., Westgren and Levi [134], Forchheimer et al. [135], and Lucke et al. [136].

Many SCI studies have explored aspects of functioning, statuses, relationships, and possessions that can be considered as important to QoL, but they fall outside the narrow area of "health-related." The major domains are employment and education, marriage and spousal relations, sexuality, other major social relations such as friendships, leisure activities, spirituality and religion, healthcare, equipment and accessibility, and personal caregivers. Work, spousal relations, other social relations, and leisure often are captured in one or more of the domains of the standard HRQoL measures, such as the SIP [35]; however, much more detailed information is available in these separate studies, which may describe changes over time (especially from before injury to after injury), correlates, and consequences. Although much of this research has not been put explicitly in the perspective of QoL, we can presume that the authors explored issues such as family relationships or community integration exactly because they consider these issues to be important to life quality for persons with SCI, and everyone else.

The last two domains listed previously, equipment and accessibility and personal caregivers, are applicable only to persons with SCI (or other major disabilities), but for the first seven categories, literature can be found comparing the situation of individuals with SCI with their nondisabled peers. In one of a few exceptions, Kreuter summarizes what is known about partner relationships

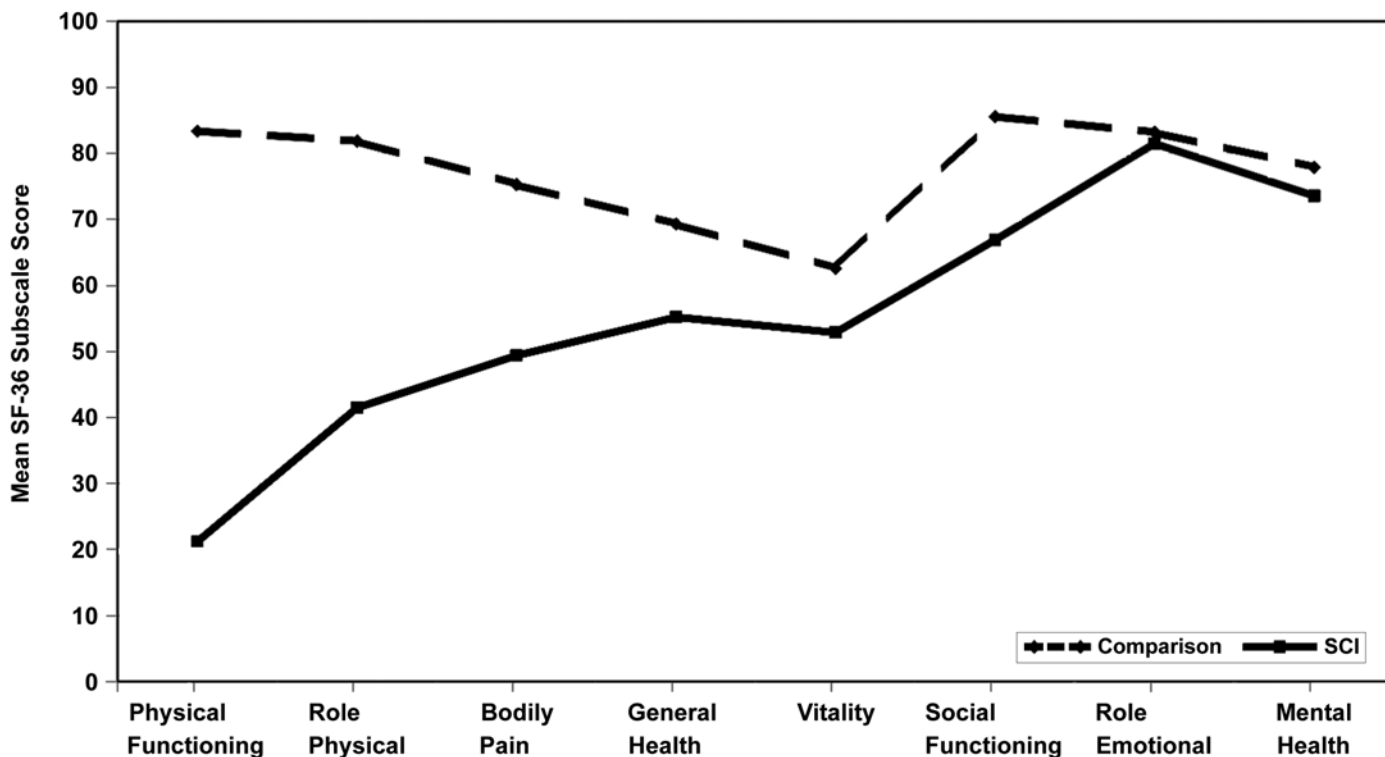


Figure 4. Mean score on SF-36 subscales: individuals with spinal cord injury (SCI) and matched controls.

and concludes that “partner relationships seem to be impacted by a spinal cord injury, although not as much as is widely believed” [137, p. 5]. In other areas of life that most people would consider important to their experience of quality, similar comparative summaries are lacking. For some areas, systematic reviews of the literature are entirely absent (e.g., leisure activities) or out-of-date (e.g., sexuality). Newly emerging domains of study, e.g., technology and accessibility, also have not benefited from reviews that enable SCI investigators to pinpoint crucial areas for clinical attention or further study.

QUALITY OF LIFE AS ACHIEVEMENTS: ISSUES

Within the HRQoL tradition, distinctions are made between generic QoL instruments, such as the SF-36 and the SIP, and disease-specific ones. Although both categories tend to collect information relevant to multiple domains (physical and mental health, major life roles, social relations, etc.), the latter group has in addition, or mostly, indicators that are specific to the disorder in question—e.g., cognitive functioning or symptoms for multiple sclerosis.

To date, an HRQoL measure specific to SCI has not been developed. Existing SCI-specific measures such as the CHART [131] and the Spinal Cord Independence Measure [138] are too limited in their scope to be called an HRQoL measure, something the authors never aspired to in any case. Another useful distinction in HRQoL measures is between measures that provide a profile, with each dimension or domain offering a score, and instruments that add all items together, directly or by way of subscale scores, to derive a total score [68]. Some developers of measures consider the various domains of QoL they distinguish too dissimilar to combine into a total score; that is the case with the SF-36, for instance, which does offer algorithms to combine the eight subscales into a Physical Component Summary (PCS) and a Mental Component Summary (MCS) but does not add these two. Other researchers offer a simple total score to summarize a person’s QoL, just as in the QoL-as-utility tradition; that is, a single score expresses the valuation of or preference for a health state.

SCI-specific HRQoL measures, if created, would be likely to avoid some of the problems that have been found with the generic ones. Again, the SF-36 is taken as an example, although similar problems have arisen with

other generic HRQoL instruments [139]. To identify the impact of illness or injury on functioning, the SF-36 and other instruments contain questions such as, “Does your health now limit you in [the following] activities?” No consensus exists as to what health means and, specifically, whether health includes major disability [140]. Many persons with an SCI make a distinction between their disability (a permanent paralysis) and their health (presence or absence of diseases such as the flu and diabetes). Those who make the distinction in this way presumably would answer, “No” to the SF-36 questions. What they would mean is, “I am not limited by my health because at the moment I am completely healthy. It is my disability that limits my functioning.” For instance, Tate and colleagues administered the SF-12 to an SCI sample and afterward asked the sampled individuals how they had interpreted health—including or excluding their disability. The mean SF-12 scores (MCS and PCS) were different for the two groups.*

Hays et al. link this perspective to the difference between the medical and social definitions of disability [140]. HRQoL measures arise from the health status measurement tradition, which is linked to the medical definition of disability. Many people with SCI, and specifically more politically aware people, adhere to the social definition, which also was incorporated, to quite a degree, in the ICF. The SF-36 has such questions as, “Does your health now limit you in . . . walking more than a mile?” which some people with SCI find insulting from an investigator who is interested in their functioning because they are spinally injured [141]. If the goal of the investigator is to measure impairment or activity limitation (ambulation), this question is reasonable and could be asked with the explanation that some people with SCI manage to walk. However, if the goal is to assess participation restrictions (getting around in the house and neighborhood), then replacing “walk” with some other word that is less offensive would be better and allow consideration of mechanisms such as wheelchairs. “Going” has been substituted by some investigators, but we cannot always be sure that these investigators realized that they were changing the conceptual basis of the SF-36 and

destroying comparability with data for the population at large [135].

The major problem with health-related QoL measures is that they focus on health. Even though these measures define this concept quite broadly, and operationalize it as such, quite a few domains of life that are of concern to people and affect their judgments of the good life are still left out: income and financial security now and in the future, quality and location of the home, political and social arrangements in their city or country, etc. These investigators “treat the person with a disability too little as a person and too much as a disability” [142, p 7]. The “health-related” qualification relieves developers of measurement instruments of the need to quantify the additional statuses and achievements. However, in many studies these health-related QoL measures then are used with the (unspoken) assumption that they capture all of life or at least all of life that is of any significance [12,143]. Of course, these measures do not capture all of life but, unfortunately, no simple measures have been created that capture the “rest of life” and quantify it in a few additional dimensions. Sociologists, political scientists, and economists have developed a number of measures that capture relevant indicators in simple or very complex ways—from “Are you working: yes/no” to “Culture of the organization in which employed.” Ideally these measures would result in a metric that can be used along with the standard QoL-as-achievement measures.

For people with SCI, who experience a “cascade” of effects from their injury (dependence on others, the need to switch jobs, a lack of access to the wider world, high out-of-pocket expenditures for equipment and supplies, etc.), the standard HRQoL measures may have even less “content validity.” Administering the SF-36 or the NHP to this group may allow a comparison with the population at large, or with other groups characterized by injury or chronic disease, but claims of good or poor QoL based on these findings are at least incomplete and possibly misleading. Qualitative research has been used to find domains of life that affect well-being or subjective QoL for people with SCI [144–147]. Salient QoL issues that are absent from most or even all HRQoL measures include freedom from pain, societal attitudes toward people with a disability, financial security [147], stigma, accessibility [146], opportunities to contribute to society, equality of rights, individual safety, and stability and prosperity of the nation [148].

*Personal communication with Denise Tate, PhD; Department of Physical Medicine and Rehabilitation, University of Michigan; Nov. 16, 2001.

Surprisingly, many of these issues are not so much characteristics of individuals, but of the world in which they live. A whole field of study deals with the QoL of cities, states, and other political entities, which started with the first nation-to-nation comparisons of gross national product per caput by economists and, in fact, gave rise, through the social indicators methodology, to the individual QoL approaches covered in this paper. Moving away from HRQoL with its narrow focus on health, one finds a need to consider a broad range of factors that the ICF categorizes in the environment taxonomy as determinants (of QoL-as-SWB) or components (of QoL-as-achievements) of QoL of people with SCI. The systematic study of the impact of various aspects of the environment on the functioning of people with a disability has hardly begun, and very few studies have focused on QoL. Part of the reason may be that instruments have not been developed for describing environments in the many aspects that potentially affect functioning and QoL [149]. Two instruments that have been created with the ICF concept and taxonomy of environment in mind—the Craig Hospital Inventory of Environmental Factors (CHIEF) [150] and the Measure of the Quality of the Environment [151]—were the brainchild of groups of investigators who have been active in SCI research for many years, and we may expect that studies relating environment to QoL (however defined) will be published in the near future.

Many HRQoL measures incorporate aspects of SWB such as depressed mood and vitality; for instance, the SF-36 [31–32], without doubt the most frequently used HRQoL measure, incorporates these aspects. This mixing of elements from two conceptualizations (QoL as SWB and QoL as achievements) reflects the fact that operationalizations of QoL are not always as pure as one would expect. Alternatively, developers may adhere explicitly to the idea that QoL is simultaneously both objective and subjective [152–153]. However, from the perspective of life satisfaction, a distinction can be made between affect, or feeling states, and judgments about these feeling states. Although all people like to avoid pain, the same type and level of pain can have a different meaning to two individuals based on their background and expectations. Some might be dissatisfied with pain because their reference point is an earlier state in which they experienced no pain; others may be indifferent or even satisfied because they can compare the present state with one in the recent past in which they had unbearable pain. While this approach can be extrapolated too far

(“How happy are you with your level of happiness?”), it is a basis to distinguish mental health, pain, and similar subjective elements that are considered in QoL-as-achievements measures and parallel subjective components in QoL-as-SWB instruments.

While, in theory, information on QoL as achievements can be derived from many sources (the person involved, his/her family and friends, and healthcare providers), in practice the major source is self-report, except for people with seriously impaired communication and cognition. In addition, many of the questions used in HRQoL measures leave room for much subjectivity, even if the researcher may have intended to obtain purely objective information. For instance, “Do you use a wheelchair?” asks for a simple fact. “Do you experience difficulties getting into public buildings?” appears to ask a simple fact about accessibility and functional ability, but the answer is very much tied up with aspirations, standards, and other subjective issues that determine when an *obstacle* is experienced as a *difficulty*. Are the individuals trying to lead an active life and participate in society on a par with others without impairment [154]? Do they consider themselves superachievers for whom no barriers are too high? Are these newly injured persons, whose basis of comparison is a nondisabled lifestyle, or veterans living with SCI, who remember the days before the Americans with Disabilities Act when lack of accessibility was the rule rather than the exception? When individuals are being interviewed, many items that are intended to operationalize an objective state may elicit subjective evaluations of that state. Investigators may need to consider carefully whether such items are to be placed in objective (QoL as achievement) or subjective (QoL as SWB) measures.

CLINICAL APPLICATIONS OF QOL MEASURES

Of the diverse categories of QoL measures distinguished here, HRQoL instruments have received the most attention for clinical applications. Various authors have suggested that HRQoL measures can serve a number of useful purposes, including [155–158]:

- Standardizing the clinical interview;
- Assessing the patient, especially identifying commonly overlooked functional and psychosocial problems;
- Prioritizing problems;

- Screening patients for behavioral or pharmacological interventions;
- Monitoring treatment effects, including evaluating the efficacy of competing medical and psychosocial interventions;
- Tracking functional changes over time;
- Facilitating shared clinical decision making;
- Improving the quality of communication between patient and healthcare provider; and
- Monitoring the quality of care.

In practice, very few healthcare providers use HRQoL measures systematically or even incidentally. The barriers to use have also been discussed in a number of papers [155,159]:

- HRQoL instruments take time of clinicians or their support staff to administer and score and time of the patient to complete. Most providers seem to consider the information gained not worth the investment of time and other resources. A possible solution for this is computer self-administration, which patients could do in the waiting room, with scored and interpreted results available to the provider by the time patients are called into the examination or treatment room. Computer administration also would make possible the use of computer-adaptive testing, which uses algorithms to administer to each individual a subset of QoL instrument questions that are optimally matched to the patient's abilities or need level [160].
- Patients lack the cognitive ability to complete an HRQoL measure, even if supported by staff [161]. Various authors have noted that HRQoL measures [162], and especially individualized measures [163], may require skills that some patients (e.g., the elderly or those with acquired brain injury) do not have, even if they are aided in completing the measure.
- QoL instruments lack questions or items needed to assess the domains or symptoms most salient to the provider's patients. However, given the hundreds of disease-specific HRQoL instruments that have been published, this lack of significant measures is unlikely to still be a real barrier, especially with the availability of individualized measures such as the Patient-Generated Index (PGI) [164] and the Schedule for the Evaluation of Individual Quality of Life–Direct Weighting (SEIQoL-DW) [165].
- QoL instruments are not needed in clinical practice; the provider can assess the patient's status regarding salient QoL issues through informal questioning [166].
- Even some of the best-developed HRQoL instruments (NHP, SF-36) lack precision required for use at the individual-patient level [167]. However, the alternative—questions by the provider such as “How are you doing?” and “Any improvement since the last visit?”—has even less reliability.
- Clinicians do not know what specific HRQoL scores mean in the same way that they know the meaning of, for example, a specific blood-pressure reading (in terms of risks, potential for intervention, etc.) [157]. Various ways of establishing the interpretability of QoL measures (anchor based, distribution-based) are being explored [168].
- For monitoring patients specifically, what a “clinically significant” change in HRQoL score is is unknown—when does a difference make a difference? The “clinically important difference” or “minimal clinically important difference” have received extraordinary attention, with some researchers discussing various methods of determining these values [169–171] and others doubting that a single value can validly be determined [172].
- QoL data are “soft” and should not be substituted for hard data such as laboratory test results. However, QoL data should be a supplement to biological data, not a replacement, allowing the provider to manage illness and injury in a way that optimizes outcomes that are important to the patient.

The few studies that have assessed how much difference a one-time or sequential HRQoL assessment makes in patient outcomes have produced meager results, with little impact on recognizing mental disorders or on longer-term psychosocial functioning [173–174]. Although clinicians stated that they welcomed the information provided by the HRQoL instruments, the information was rarely incorporated into routine clinical decision making. This may be why patients did not have the impression that they had been included in the setting of treatment goals or the planning of care [161].

In theory, utility assessment of the outcomes of alternative interventions open to patients is an ideal method of decision-making assistance: if the likely outcomes and side effects of treatment x have a utility of 0.70 over an anticipated survival of 6 years versus a utility of 0.75 over 5 years for treatment y , x clearly is preferable. In practice, several drawbacks of utility assessment have been noted for individual patient decision making. The methods involved are complex and cognitively taxing (for both patient and provider), patients do not necessarily behave according to the

predictions of utility theory, and the methods are not sufficiently reliable that clinical decisions can be based on the results. Although various providers have used utility measures to assist patients in deciding on treatments [175], a more common use may be as a means of helping patients to clarify their preferences and the values that are at stake [176]. Alternative techniques, called probability-trade-off methods or treatment-preference methods, are now commonly used to determine patients' treatment preferences [177]. Neither the utility methods nor these alternatives should be implemented without consulting specialists in medical decision-making techniques.

QoL-as-SWB measures have found some use in psychotherapy. For clinicians who stress "positive psychology" and the need to address mental health and positive outcomes as well as mental illness and other undesirable states, QoL-as-SWB measures are a natural supplement to measures of psychiatric symptoms and negative affect. The main proponent of this approach has been Frisch et al. who proposed an integrative psychotherapy approach, called *quality-of-life therapy* [178–179]. The key to this therapy is the Quality of Life Inventory (QoLI), which is used to identify problem areas in patients' lives by having them rate life satisfaction in 17 domains. A narrative section of the QoLI asks patients to list problems that interfere with their life satisfaction in these domains, giving the therapist an easy start on identifying problems; strategies for increasing client satisfaction are listed in the QoL therapy manual [180]. The QoLI is also used to evaluate the outcome of therapy, and Frisch also sees a role for this tool in quality assurance of therapy programs.

CONCLUSIONS

This review indicates that, whatever operationalization of QoL is used, individuals with SCI report, or are considered to have, lower QoL than their peers. Although the difference may be relatively minor (suggested by SWB measures) or major (based on utility measures), it exists and appears to be pervasive. Opportunity for change for the better exists, not only for people living in developing and second-world countries [7,181], but also for those in the most developed societies. As long as the QoL of individuals with SCI on average is below, or well below, that of their nondisabled peers, there is room for improvement through the development and use of

improved technology, better rehabilitative methods, medical and psychological care, and other measures.

Research to evaluate such technology, techniques, and services would do well to incorporate QoL measures to assess whether changes result in the aspects of life that are of most concern to the individuals involved. Although some QoL instruments are better for that purpose than others, all categories of QoL measures can be improved. The research on QoL after SCI to date has often used poor and nonvalidated measures or instruments with a conceptual basis that may have been inappropriate or discrepant from the author's notion of QoL. In addition, most of this research has been rather atheoretical; concepts such as the top-down versus bottom-up nature of QoL judgments or response shift [182] have not been applied, at least not systematically and explicitly. A higher level of sophistication in conceptualization and operationalization of QoL and a better understanding of theoretical issues explaining changes over time or differences (or lack of differences) between categories of people with SCI should help us better understand the impact of this injury.

The clinical application of QoL measures (especially those in the QoL-as-SWB and QoL-as-achievements approach) is far from straightforward, with many of the same conceptual and methodological issues playing a role. In addition, the precision of measures for clinical application is being debated, as well as the cost involved in collecting the information.

SCI specialists should collaborate with QoL experts to advance the state of the art in both areas: improved knowledge of QoL and its conceptualization and measurement and a better understanding of the factors underlying QoL improvement after SCI. A similar cooperation with QoL and decision-making experts is suggested for clinical applications.

ACKNOWLEDGMENTS

Thanks to Thomas Bryce, MD, for preparing the vignettes on which the **Table** is based. This work was presented in part at the 3rd International Congress Restoration of (Wheeled) Mobility in SCI Rehabilitation: State of the Art III, Amsterdam (the Netherlands), April 19–21, 2004.

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Submitted for publication August 11, 2004. Accepted in revised form December 1, 2004.