

Quality of Life After Traumatic Brain Injury: A Review of Research Approaches and Findings

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Objectives: To assess existing knowledge of quality of life (QOL) of people with traumatic brain injury (TBI) and to make recommendations for methodologic and substantive research in this area.

Data Sources: Published research on QOL of persons with TBI, identified from databases, ancestry search, and the author's files.

Study Selection: Empirical, theoretical, and methodologic articles relevant to 5 areas: QOL as achievements, QOL as subjective well-being (SWB), QOL as utility, QOL experienced, and QOL measurement instruments applicable to TBI or specifically developed for people with this impairment.

Data Extraction: Selection of QOL indicators, with focus on TBI versus non-TBI differences.

Data Synthesis: Studies of QOL as achievements show that in almost all areas, people with TBI score lower than they did before injury and lower than comparisons groups. There are limited gaps in our knowledge in this area. Research into QOL as SWB shows that after TBI, people typically report, for example, somewhat lower life satisfaction and affect than do comparison groups, and that injury severity is not necessarily a predictor of SWB. There are almost no studies of QOL as utility of life after TBI.

Conclusions: Major research recommendations include: exploring the ability of TBI subjects to self-report; determining the salience of domains of life for this group; developing utility instruments that are sensitive to differences in deficits in cognition and other health and life domains; and doing qualitative studies that explore the experience of QOL.

Key Words: Brain injuries; Outcome assessment (health care); Quality of life; Rehabilitation.

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QUALITY OF LIFE (QOL) MEANS different things to different people. For some, life could not be better if it offered hunting in the morning, fishing in the afternoon. Others would be happiest shopping at the outlet malls all day. However, it is not just the content of the good life that is the topic

of debate. Scientists disagree among themselves, disputing how the concept of QOL should be defined and how that definition should be operationalized. Three different conceptions of the QOL are found in the literature.¹

The concept of QOL (but not the term) originally referred only to characteristics of social, political, or geographic entities—for example, the QOL of cities or countries. Economists began by comparing countries on gross domestic product and other indicators of the supply of goods; over time, less “material” goods were considered as indicators of QOL, for example, literacy level and number of hospital beds per 1000 population. Politicians in the post–World War II Western welfare states saw it as society’s responsibility to provide to its citizens these goods and services constituting or contributing to life’s quality. The term QOL was first used in a political context during Presidents Eisenhower’s administration.²

Political and other social scientists who were engaged in “social indicators research” on societal QOL indicators at some point switched from monitoring the supply of societal goods that are *presumed* to make people happy to the *actual* measured happiness and life satisfaction of people. Thus, an entire new field of study, that of the QOL of individuals, was created. In this arena, there are 3 entirely different conceptualizations of QOL, that figure 1 attempts to link. The starting point is that everyone has needs and desires that underlie their happiness,³ as well as aspirations and future plans. People emphasize life domains that they consider most important and that they expect to contribute most to maintaining or increasing their life satisfaction (fig 1, box D). Reality does not always match these needs and wishes: their statuses and achievements (eg, what they have, can do, accomplish; fig 1, box C) sometimes exceed their expectations, but often fall short: their health status does not allow participation in satisfying activities, or their income is insufficient, or old friends move away. The gap between what people want and what they have evokes certain reactions.⁴ If reality more or less matches dreams and hopes, they likely feel content, satisfied, and happy. If, however, health fails, if the economy sours and jobs disappear, or if a love affair ends, the reaction is likely one of dissatisfaction and discontent. The first conceptualization of QOL is that of the psychologists and social scientists who study life satisfaction and affect: QOL is equivalent to subjective well-being (SWB), the cognitive and emotional reactions (fig 1, box E) to the balance of achievements and expectations. SWB includes such phenomena as life satisfaction, morale, happiness, and (nonpathologic) negative affect. The term QOL, meaning feelings of “well-being as influenced by the good things in life,” is so commonplace that investigators can even ask subjects for a direct rating of their QOL.⁵

Individual expectations (fig 1, box D) are not necessarily idiosyncratic; most result directly from human nature, as modified by the culture of the society, social class, and age group to which a person belongs. People learn to enjoy specific foods, to aspire to certain positions, and to expect to have a loving family and friends.⁶ Individual physiology, personality, and history may add only minor variations to the standards and priorities that society teaches (fig 1, box B). In fact, some medical researchers seem to assume that there is so much

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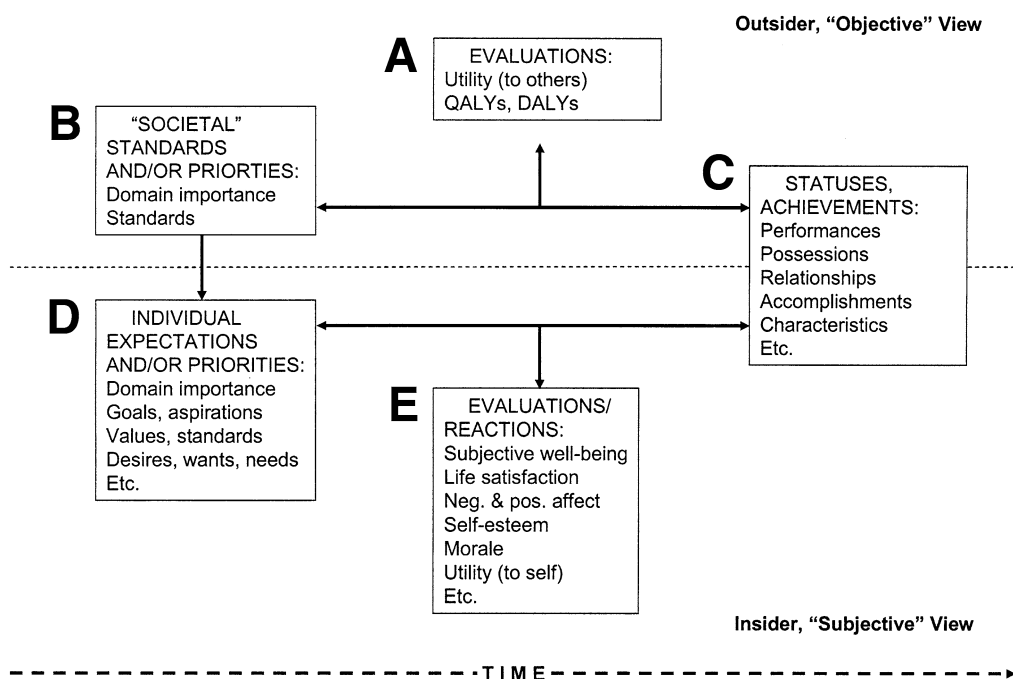


Fig 1. Linkages between 3 conceptualizations of QOL. Abbreviations: DALYs, disability-adjusted life years; Neg, negative; pos, positive; QALYs, quality-adjusted life years. ©2004 by the American Congress of Rehabilitation Medicine. Reprinted with permission.¹

communality in people's expectations and priorities that it is superfluous to investigate idiosyncratic needs and wishes or individual reactions. They reason that once achievements are known, reactions can be virtually predicted; therefore, a careful inventory of achievements in the major domains of life (fig 1, box C) is all that is needed to assess QOL. This is the assumption underlying most health-related QOL (HRQOL) instruments: the status of health in its physical, mental, and social domains is quantified, and the resulting number (or numbers) represents QOL. Thus, the second conceptualization of QOL is one's share of those characteristics that many people consider essential to "the good life" (eg, a job, friends, housing, health) and that can be determined with a large degree of objectivity.

A third use of the term (individual) QOL stems from applications of economic and management decision-making theories. To evaluate the expenses and benefits of one health care program or medical intervention relative to another, common metrics for costs and outcomes are needed. Determining costs is fairly easy, but quantifying outcomes in such a way that they can be compared across many disorders such as psychiatric illness, traumatic brain injury (TBI), and cardiovascular disease is not. The methodology that economists and other social scientists developed uses panels of raters to review vignettes describing (in word, or video) cases that vary along relevant dimensions (eg, mobility, symptoms experienced, mental health problems). The panelists rate the desirability of those lives or conditions on a scale in which the extremes are marked 0 (death) and 1 (perfect health or optimal functioning).⁷ These preferences for one health status relative to another (referred to as utilities) concern a single point in time; however, by combining them with estimates of how long people will remain in each status, quality-adjusted life years (QALYs) can be calculated. For example, 2 years in a health status with a utility of 0.5 equals 1 year in perfect health. Disability-adjusted life years (DALYs) are a recent development along similar lines.⁸ Thus, the third conceptualization of QOL is the preference for, or utility of, a health status or even a life as a whole (fig 1, box A). Of course, the judgments by the panel members that result

in these utilities are based on the values and standards of the society and the groups to which the judges belong (box B), as modified by their own life experiences. In fact, an ongoing debate in QOL research concerns the issue of consensus on utilities.⁹⁻¹² Many studies have shown that people who have a specific disability or disorder that results in physical, social, or mental health deficits rate the utility of their health status much higher than does the general population that rates the same status. However, in other research, such discrepancies between the judgments of patients and nonpatients were negligible or nil.¹³

Figure 1 shows time explicitly because QOL is not a static phenomenon. In fact, change in people's QOL happens on at least 4 levels:

1. Societal expectations change in the light of new understandings of the person and his/her relationship to others and to society as a whole—for instance, the shift in emphasis from "man as producer" to "man as consumer" that occurred in Western societies over the 20th century.
2. Individuals' expectations and priorities change with lifetime development and experiences (fig 1, box D). Thus, SWB may change even if actual statuses and achievements (fig 1, box C) are stable.
3. Actual statuses (fig 1, box C) change as a result of aging and events in the outside world (eg, downsizing by an employer, winning the lottery, being in a car accident).
4. Even if "actuality" is constant, and expectations apparently do not change, people's subjective reactions may. Adaptation theory holds that over time humans experience less well-being (fig 1, box E) in the face of constant achievements. Similarly, there is much evidence that the positive effects of good events (eg, winning the lottery) or the negative effects of destructive events (eg, incurring a spinal cord injury) seem to be relatively short-lived: SWB levels rather quickly return to baseline.¹⁴

In addition, time is relevant to SWB in another way: "losses" are easier to accept if they are short term. Restricted mobility because of a leg broken while skiing is annoying, but most people can live with it and may (retrospectively) take pride in

Table 1: QOLS Scores for Persons With TBI and a Comparison Group

Domain	Brown and Vandergoot ⁸⁵						Dawson et al ⁸⁶			
	Importance			Needs Met			Needs Met			
	TBI	Comparison Group	t Test	TBI	Comparison Group	t Test	Mild TBI	Moderate TBI	Severe TBI	Comparison Group
1. Material comforts	2.50	2.50	NS	2.35	2.40	NS				
2. Health and personal safety	2.83	2.87	NS	2.47	2.64	<.001	3.2	3.5	3.8	3.9
3. Relationships with relatives	2.62	2.59	NS	2.44	2.51	NS	4.0	4.0	3.6	4.2
4. Having and rearing children	2.46	2.46	NS	1.97	2.34	<.001				
5. Close relationship with SO	2.62	2.73	<.05	1.90	2.36	<.001	3.9	3.8	3.2	4.1
6. Having close friends	2.58	2.69	<.01	2.18	2.54	<.001	3.6	3.3	3.6	4.0
7. Helping and encouraging others	2.55	2.53	NS	2.27	2.39	<.01				
8. Participation in public affairs	1.77	1.77	NS	2.15	2.29	<.05				
9. Learning (school and other)	2.63	2.63	NS	2.06	2.30	<.001	3.2	3.0	3.2	3.5
10. Understanding oneself	2.80	2.79	NS	2.37	2.55	<.001				
11. Interesting work (job, at home)	2.75	2.75	NS	1.84	2.20	<.001	3.4	3.8	3.5	3.9
12. Expressing oneself	2.50	2.38	<.05	2.14	2.33	<.001				
13. Socializing	2.31	2.22	NS	2.07	2.28	<.001				
14. Passive recreation	2.46	2.41	NS	2.45	2.57	<.01				
15. Active recreation	2.32	2.40	NS	2.11	2.36	<.001				
Unweighted										
Total score (mean \pm SD)	2.51 \pm 0.27	2.51 \pm 0.26	NS	2.18 \pm 0.20	2.40 \pm 0.13	<.001				
Weighted for Importance										
Total score (mean \pm SD)				5.51 \pm 1.22	6.10 \pm 1.09	<.001				
No. of cases (minimum)	411	280		411	280		25	8	16	15

Abbreviations: NS, not significant; SD, standard deviation; SO, significant other.

how they managed the problem. Having restricted mobility resulting from an above-knee amputation necessitated by injury or disease is a different matter. At a minimum, adjustment would be expected to be a much longer process. Thus, one's perspective—whether problems are seen as growing or diminishing, quickly or slowly—may influence how the current status is evaluated^{15,16} and how it affects SWB.

Clearly, these 3 conceptualizations of individual QOL are related. QOL as utility cannot be calculated without an evaluation of QOL as achievements in the light of (societal) standards. QOL as SWB results from a conscious or subconscious comparison between individual standards and the realities of one's life. In empirical studies, QOL as achievements is often used as a statistical predictor or cause of QOL as SWB.^{17,18} Instruments for quantifying HRQOL are now being related to utilities for the same or very similar health statuses, so that once someone has completed a self-report HRQOL measure, the utility of his/her health status can be immediately calculated.¹⁹⁻²¹ Individual (rather than societal) preference ratings for health statuses are sometimes used clinically to help patients make decisions about treatments with differing risks and outcomes.²²⁻²⁵ "Utility" here becomes more or less equivalent to expected well-being.

TBI is trauma with often lasting and serious effects on cognition; communication; physical health; behavior; personality and mood; and, indirectly, on most other aspects of life, through a cascade of indirect affects. One would expect that the QOL, however conceptualized, of people who incur a TBI is negatively affected. The purpose of this article is to review existing knowledge of the QOL of persons with TBI and to assess the methodologies and instruments available for measuring their QOL. Suggestions are made for future research into QOL after TBI.

This review complements several recent appraisals of research on QOL of people with TBI²⁶⁻²⁹; however, those assessments concentrated mostly on psychometric issues, and only

secondarily on the domains of life that have been included in measures of QOL. What is known about the QOL (however that term is defined) of persons with TBI has not been summarized, nor have other issues related to QOL and its assessment received adequate attention. The current article aims to rectify these shortcomings. The review is oriented by the 3 main conceptualizations of QOL outlined previously: QOL as achievements, QOL as utility, and QOL as SWB. (What appear to be 3 clear-cut QOL conceptualizations are, in practice, sometimes vague definitions or concepts seen to underlie a particular research approach. When it comes to measurement, the instruments used sometimes violate the demarcation lines drawn here.)

QOL AS ACHIEVEMENTS

What is important to you for QOL? People respond to the question in terms of broad, directly experienced, and "functional" material and immaterial goods, such as good health, a sharp mind, and financial security. HRQOL studies and social indicators research have identified those domains of life that most people consider important to their QOL. Based on thousands of interviews using the critical incident technique, Flanagan^{30,31} developed a list of 15 domains of life that can be used to inventory achievements and statuses considered important by most people (table 1). This list is used here in describing QOL as achievements of people with TBI.

There is extensive evidence that severe and moderate TBI, and often even mild TBI, affects several statuses that are central to the concept shared by most people of "the good life." An exhaustive review of the evidence is impossible and unnecessary; offered here is information from representative studies, with notes on the gaps in our knowledge. The emphasis is on losses as a result of TBI. However, it should not be overlooked that gains may result from the injury, such as new strengths in oneself, or opportunities to establish new relationships. Later, I address the limited literature that concerns gains.

Satisfying Work (Occupation)

Many studies have found that people with moderate or severe TBI lose their jobs^{32,33} and may not regain employment even with specialized vocational rehabilitation services. Those who return to work often do so part-time, in a lower-level job, and/or in a sheltered employment or similar setting.³⁴ Some studies, however, have found such negative vocational outcomes only among those with the most severe injuries.³⁵ Not uncommonly, the empty hours created by loss of employment, or termination of school attendance, are filled by expanding household activities. There is no evidence to document that this is only "make-work" or a real shift in taking responsibility for managing a household.

Employment is a major determinant of QOL because it affects many other important factors in QOL, such as standard of living, financial security, and opportunities to meet people. In addition, in Western societies employment is the major marker of responsible adulthood, in addition to marriage. O'Neill et al³⁶ found that employment had an impact on both perceived needs satisfaction and global QOL ratings, even after controlling for severity of and time since TBI, gender, education, marital status, and other predictors.

Learning

For those who are students at the time of TBI, the result commonly is an interrupted education.³² Students may return to school but often in a less intense program,³⁷ or require special assistance or curriculum modifications. For those past the age of compulsory education, TBI often results in an end to schooling. Little is known about differences between people with TBI and their peers in their attendance at adult education courses, self-study, and other similar opportunities for learning. It is reasonable to assume that such activity would be less frequent for people with TBI, given the cognitive difficulties many of them continue to have long after their injury.

Material Comforts

The loss of employment, employment in a lesser-paying job, or failure to be promoted in a current job, likely results in a significant decrease in income,³⁸ which is the major determinant of access to material goods. Social security schemes in Western countries often offer substitutes for salaries and wages^{32,39} but always at levels lower than one's preinjury income. Thus, TBI often is a factor in a significant decline in material comforts. This is especially true if a family member must quit his/her job to supervise or care for the person with TBI.

Close Relationship With a Significant Other, Having and Rearing Children

TBI may result in divorce or termination of similar (de facto) relationships that offer mutual support and intimacy. Although many studies have shown that high percentages of persons with TBI become separated or divorced after injury,^{40,41} no studies were found that compared the divorce rates with those for marriages of people without TBI, matched for age, age of partner, and duration of marriage. Similarly, no research has been done to show a lower rate of first marriage or remarriage among those with TBI than in comparison groups, although limited data suggest that the marriage rate is lower.³⁸ Because it is through marriage or a similar close relationship that most people have children, high rates of divorce or separations, or failure to establish ongoing relationships, can also reduce opportunities for having and rearing children. In addition, it is possible that people with TBI and their partners decide not to have (more) children because of the financial or other burdens

caused by the injury. No research on these topics was identified.

Relationships With Relatives

In numerous instances, relatives become the default interaction partners for persons with TBI. Brain injury can result in the loss of work relationships, friendships, romantic partners, and even spouses; blood relatives, especially parents, often take survivors into their home or supervise them when they maintain or regain an independent residence.^{32,42,43} Relationships with relatives may become more intense, and they often are reported to be stressful for the relatives³⁹ and full of conflict. It may be assumed that persons with TBI have similar judgments about the forced nature of their relationship with family,³⁷ but research is more limited. Certainly, as a group, people with TBI appear to have satisfactory relationships with relatives (table 1), but these data do not offer a statistical breakdown of those who lose their emancipated status because of brain injury.

Having Close Friends; Socializing

Moderate and severe TBI often results in a falling away of friendships.^{32,37,43-45} Forming new friendships is often difficult because interaction with others is restricted (no employment or school attendance) and constraints on mobility further reduces opportunities to meet potential new friends.⁴⁶ Poor self-control, reduced interpersonal skills resulting from the brain damage, and deficient communicative skills^{47,48} may add to this problem.^{37,39} Thus, people with TBI tend to have smaller social networks than their peers,³⁸ and in many instances their only friends are other people with TBI, whom they have met through treatment programs or support groups.⁴⁵

Helping and Encouraging Others

Because of factors described above (eg, limited or no roles in work and school, reduced circles of friends, mobility restrictions), TBI subjects may have fewer opportunities to assist, guide, or otherwise help other people. Formal volunteer work, especially mentoring other people with TBI,⁴⁹ may be the major approach through which they help others. No studies were identified to indicate whether people with TBI do more volunteer work than their peers. One article⁵⁰ found that in a small sample, "volunteer" is a role not often assumed after injury; volunteering was certainly not reported to compensate for the loss of the worker role.

Active and Passive Recreation

"Leisure disability"⁵¹ is a frequent finding in research on the sequelae of TBI. A number of studies reported that people with moderate or severe TBI have a lower level and lower "quality" of leisure activities after injury^{32,39,45,52,53} or compared with reference groups.^{54,55} Tate et al⁵³(p1132) state that in their study sample with severe disability, many engaged in activities that only could be described as "filling in time," or had no leisure interests at all. There is a strong link between lack of friends and relative social isolation and this leisure disability. For many people, leisure consists of activities engaged in jointly with others, and any shrinking of the social network thus often results in the decline in active recreational life. But it appears that solitary leisure activities may diminish as well: Hallett et al⁵⁰ reported that after TBI the loss of the "hobbyist" role is second in frequency only to the loss of the "worker" role.

Participation in Public Affairs

Flanagan included in this category activities related to local and national government, including keeping informed through

Table 2: SF-36 Scores for Persons With TBI and Comparison Groups, Various Studies

SF-36 Scales	Colantonio et al ⁶⁹			Paniak et al ¹³⁸		Findler et al ⁶⁶		
	Mild TBI	Moderate/Severe TBI	Normative	TBI	Comparison Group	Mild TBI	Moderate/Severe TBI	Comparison Group
Physical functioning	85±22	75±35	92±18	63±27	95±9	68±24	72±29	97±9
Social functioning	73±27	73±27	84±21	49±27	86±19	59±33	71±29	94±13
Role functioning—physical	79±37	75±37	89±27	20±32	88±25	43±43	59±40	94±21
Bodily pain	77±19	81±18	81±21	41±23	83±20	54±27	67±29	84±17
Mental health	47±16	47±17	75±18	62±22	76±16	59±22	68±20	77±15
Role functioning—emotional	82±33	76±38	83±31	51±43	80±31	55±43	74±37	94±19
Vitality	54±10	53±14	63±20	31±19	62±18	41±23	58±24	68±17
General health	64±27	68±23	76±18	73±18	76±19	59±27	68±24	82±17
Mental health composite				41±12	49±9			
Physical health composite				38±10	54±6			
No. of cases	24	27	—	120	120	98	228	271

NOTE. Values are mean ± SD.

the media, voting, communicating with politicians, and “having and appreciating one’s political, social and religious freedom.”^{30(p142)} No research was identified indicating that persons with TBI differ from others in their civic activities or that TBI results in decreased participation in these activities.

Understanding Oneself

Impaired self-awareness is a problem that confronts rehabilitation providers and family members in their interaction with many people with moderate and severe TBI because many of these patients evince limited awareness of cognitive, emotional, and behavioral deficits.^{34,56} From the patients’ perspective, unawareness may have a protective effect, allowing them to disregard painful changes in their lives. Godfrey et al⁵⁷ reported greater emotional distress in patients with more accurate self-awareness. Beyond self-awareness deficits, the self-understanding of persons with TBI has been little studied. Some research examines attitudes toward acceptance of disability.⁵⁸ Research that has addressed understanding of self at a deeper level has been exclusively qualitative in nature (see below) and has not involved comparison groups. Consequently, there is little information on how self-understanding by people with TBI is quantitatively or qualitatively different from that of others; there is only limited understanding of the changes from pre- to postinjury.^{59,60}

Expressing Oneself

Expressing oneself, as used by Flanagan,³⁰ involves creative expression in arts and crafts, in practical activities, and in leisure—not the traditional verbal and nonverbal expression with which rehabilitation professionals are familiar. Flanagan did not specify expression through vocational activities but did not exclude it, either. Given the findings on impoverished leisure, unemployment, or employment in jobs offering less opportunity to use one’s imagination, one can assume that people with TBI have less occasion to express themselves. However, information in this area is scarce; a study of the satisfaction and expression people with TBI find in their work, free time, and other activities could not be found.

Health and Personal Safety

Even mild brain injury may bring about several health concerns and complaints, many of which do not diminish with time.^{61–65} Moderate or severe TBI commonly results in physical and mental health problems that can be assessed objectively. Functional status (eg, ability to perform self-care, problem-

solve, communicate) may be affected immediately after injury, although physical abilities return to normal or close to normal in most cases. Numerous studies have indicated that TBI survivors report many more symptoms and health problems, spontaneously or based on standard checklists, than matched comparison groups.^{34,49,66–70}

HRQOL measures typically combine into 1 total score or a number of subscores (a profile) information on physical, mental, and social health, and sometimes symptoms. As such, these measures tend to overlap with, or to a degree incorporate, socializing, occupational role performance, recreation, and further indicators of functioning in other Flanagan domains. Several studies have collected information on self-reported HRQOL for people with TBI, and compared it with reports by non-TBI groups, directly or based on norms. Because the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) is the most commonly used HRQOL measure, some relevant studies are presented here (table 2); similar information could be cited for such measures as the Sickness Impact Profile-5^{67,71–74} (SIP-5), Nottingham Health Profile,⁷⁵ General Health Questionnaire,^{38,76} and other HRQOL or health status measures. All studies that used the SF-36 have shown lower mean scores on all of its 8 scales, and on its 2 summary scales (mental health component, physical health component), for those with TBI compared with comparison group members or normative groups, indicating poorer health. Surprisingly, the mild TBI groups had lower means than the moderate to severe groups in 2 studies.^{66,69} In the study by Findler et al,⁶⁶ this difference persisted (except for the physical functioning scale) after controlling for age, income, and gender. It largely disappeared after depressed mood was used as an additional control factor.

Fatigue is not part of the SF-36 and similar HRQOL instruments, but it is possibly measured indirectly through relevant symptoms and complaints. Van der Naalt et al⁷⁷ found that complaints of fatigue after TBI were common with 45% of subjects reporting it 1 year after mild to moderate TBI. LaChapelle and Finlayson⁷⁸ reported that subjects with TBI had high scores on both objective and subjective measures of fatigue and that more than half rated fatigue as their worst symptom. Fatigue may be related to, or even caused by, other problems common in the TBI population, including sleep disturbances and daytime somnolence,⁷⁹ pain, and depression.^{80,81}

Several domains of life not on Flanagan’s inventory could be listed in which TBI survivors, on average, are less “successful” than their peers. Flanagan may have omitted them because they

Table 3: SWLS Scores for Persons With TBI and Comparison Groups, Various Studies

Author	Subjects	SWLS Scores
Studies cited in Pavot and Diener ¹³⁹	College students (5 samples)	
	Lowest (N=358)	23.0±6.4
	Highest (N=271)	25.2±5.8
	Disabled students: sample 1 (N=32)	20.8±8.4
	Disabled students: sample 2 (N=29)	24.3±7.4
	Older adults (N=39)	24.2±6.1
	Health care workers (N=255)	23.6±6.1
	Printing trade workers (N=304)	24.2±6.0
	Male prisoners	12.3±7.0
	51 persons with moderate to severe TBI (avg 10y postonset)	17.9±8.3
Brzuzy and Speziale ³⁹	95 persons with moderate to severe TBI (avg 2.5y postonset)	18.9±8 (est)
Corrigan et al ⁶⁷	Persons with moderate to severe TBI	
Corrigan et al ¹²⁴	At 1y postonset (N=170)	20.3±8.1
	At 2y postonset (N=160)	20.8±8.4
Bryant et al ¹⁴⁰	Persons with severe TBI	
	With PTSD (N=26)	12.9±5.5
	Without PTSD (N=70)	19.1±8.9

NOTE. Values are mean ± SD.

Abbreviations: avg, average; est, estimated; PTSD, posttraumatic stress disorder.

include the basics that people do not question unless satisfaction of needs is significantly reduced—for example, breathable air or being treated as an adult.⁸² For instance, independent living is impossible for many people with severe TBI because of medical, financial, or behavioral problems.⁴⁵ Some live in nursing homes or other long-term care facilities; others move back in with parents or never move out. Use of private and public transportation and the freedom to interact with people and pursue one's interests similarly are often restricted because of loss of driving privileges, problems with orientation, and so forth. Cognitive functioning (to the degree that it is not captured under "health" or "understanding oneself") is another domain missing from most generic HRQOL measures⁸³ and from much of the research on HRQOL after TBI.²⁷ Communication problems are characteristic of many persons with TBI. Although these problems may be rather subtle and limited to "discourse,"^{47,84} adequate communication is central to many of the domains on Flanagan's list. It might be isolated as a QOL dimension by itself if his methodology was replicated with a TBI sample.

QOL AS SWB

In the formulation used here, SWB is the end result of weighing what one has and is (defined as broadly as possible) against one's standards and expectations. These standards may be absolute, comparative with oneself (eg, "prior to my injury"), or relative to others. There is no claim that making these comparisons is a conscious process; in fact, only life satisfaction is considered to be the result of such a formal accounting, and many people may never evaluate their QOL unless asked to do so by a researcher. Mood states (in which positive and negative affects must be considered independent dimensions rather than one another's complement), as well as morale and self-esteem, are the products of a much less (self-)conscious process.

Life satisfaction has been assessed in people with TBI using different instruments, including the Flanagan Quality of Life Scale³⁰ (QOLS). This instrument uses separate ratings of the importance of domains and of one's satisfaction of needs with respect to each domain. A total life satisfaction score is calculated as the mean of weighted domain need satisfaction scores.

The data in table 1 are from a study by Brown and Vander-goot.⁸⁵ Surprisingly, the differences in importance ratings between subjects with TBI and the comparison group are relatively minor; despite large sample sizes, statistically significant differences were found only for the importance attached to the domains of "close relationship with significant other," "having close friends" (which subjects with TBI considered less important), and "expressing oneself" (which was more important). Controlling for gender, age, marital relationship, and ethnic and racial group made no difference in these findings. TBI survivors did, however, believe that their needs were less well satisfied in all but 2 domains. Their total needs satisfaction score was lower, whether it was based on weighted or unweighted domain scores. Comparable results for needs satisfaction on the QOLS were reported by Dawson et al.⁸⁶

Research using global, rather than domain-specific, satisfaction ratings has resulted in similar findings: compared with their peers, TBI survivors tend to report lower life satisfaction.^{73,74,85-87} The Satisfaction With Life Scale (SWLS) is increasingly used in TBI research, and table 3 summarizes findings from 5 studies. None used comparison groups, so reported scores for other population groups are provided as a basis for comparison. It is clear that the typical subject with TBI reports a lower level of overall life satisfaction than do comparison groups, except for male prisoners. However, there was sizable variability in all samples, and many subjects with TBI had life satisfaction similar to or even higher than the average non-TBI person.

Negative affect shows parallel results in most studies: people with TBI report more depressed mood, anxiety, and other undesirable mood states than do comparison groups. The SF-36 data for the mental health scale shown in table 2 are a good indication of the impact of TBI and its sequelae on affect. This scale includes questions on nervousness, peacefulness, happiness, and feeling down in the dumps and blue. The vitality scale also has mood elements (feeling worn out or full of pep), and the role functioning–emotional scale quantifies the behavioral consequences of mood as it translates into limitations of functioning. Similar results can be shown for measures of specific emotions and feelings such as anxiety,^{73,74,76,88} depression,^{66,88-91} and self-esteem.^{92,93}

QOL AS UTILITY

An extensive literature discusses methods of deriving utilities and other methodologic issues in health status preference studies and the application of those methods.^{7,94-97} However, only 1 study was found that used a utility QOL measure with a sample with TBI. Taylor et al⁹⁸ evaluated the benefit of very early decompressive craniectomy in children with severe brain injury, and used the Mark 1 Health Status Utility to assess outcomes at about 6 months postinjury. Of the 13 children who received the operation, 7 had a favorable outcome (defined as a Mark 1 score range between .70 and 1.00); the other 6 had an unfavorable outcome (a score between .69 to -.21; this measure allows states to be rated as "worse than death"). Of the 14 children who received medical management, 13 had unfavorable outcomes, including 9 who died. Unfortunately, only broad outcome categories were reported; no median or mean Mark 1 scores or individual scores were provided.

Published values for the dimensions of the Quality of Well-Being (QWB) Scale,⁹⁶ another utility measure, makes possible the calculation of the utility of the health status of persons with TBI. These weights (table 4) are based on evaluations (by a

Table 4: QWB Scale Weights for Selected Categories in 4 Dimensions

Description	Weight
Mobility categories	
No limitations	-.000
Did not drive a car, or did not use public transportation, or needed help to use public transportation	-.062
In hospital	-.090
Physical activity categories	
No limitations	-.000
Independent in wheelchair; or trouble with lifting, stooping, bending, or stair climbing, or limitation in walking	-.060
Dependent on others for wheelchair mobility, or in bed or chair for most of the day	-.077
Social activity categories	
No limitations	-.000
Limited in major (primary) role; or limited in other role activity (eg, recreation)	-.061
Performed no major role activity and needed help in performance of 1 or more self-care activities	-.106
Symptoms and problems categories (only the most severe one is scored)	
Loss of consciousness such as seizures	-.407
Trouble learning, remembering, or thinking clearly	-.340
General tiredness, weakness, or weight loss	-.259
Spells of feeling upset, being depressed, or crying	-.257
Headache, or dizziness, or ringing in ears, or spells of feeling hot, nervous, or shaky	-.244
Eyeglasses or contact lenses	-.101
Trouble sleeping	-.257
Problem with sexual interest or performance	-.257
Excessive worry or anxiety	-.257

Limitations are counted only if they are because of health reasons (not age, preference, etc). Weights indicate the value to be subtracted from 1.000 (optimal well-being) to calculate utilities. Modified from Patterson et al.⁹⁹ Reprinted with permission.

Table 5: QWB Scale Utilities of Hypothetical Persons With TBI

Description	Utility
Average person in population	.80
Mild TBI	.599
Mobility: no limitations (-.000)	
Physical activity: no limitations (-.000)	
Social activity: limited in primary role: work (-.061)	
Symptoms and problems: general tiredness; trouble learning and remembering; trouble sleeping (-.340)	
Moderate TBI	.470
Mobility: did not drive car (-.062)	
Physical activity: no limitations (-.000)	
Social activity: limited in primary role: work (-.061)	
Symptoms and problems: seizures, trouble learning and remembering, dizziness (-.407)	
Severe TBI	.432
Mobility: did not drive car (-.062)	
Physical activity: trouble lifting and bending (-.060)	
Social activity: limited in primary role: work and needs help in self-care (-.106)	
Symptoms and problems: trouble learning, remembering, and thinking; tiredness; depressed; headaches; problems with sexual performance; anxious (-.340)	

Modified from Patterson et al.⁹⁹ Reprinted with permission.

random population sample) of more than 400 case vignettes.⁹⁹ In table 5, the information has been applied to 3 hypothetical (but not atypical) cases differing in TBI severity. As a reference point, the average utility for a probability sample of the San Diego population is provided. The health of the average citizen does not receive a preference score of 1.000 (optimum health), because points are lost for common health problems such as poor eyesight necessitating glasses (-.101) or being depressed (-.257). However, the 3 hypothetical TBI cases score lower than the population average.

Similarly, published values for the 8 dimensions (vision, hearing, ambulation, dexterity, cognition, speech, emotion, pain) of the Health Utilities Index Mark 3 (HUI3), a later version of the measure used by Taylor,⁹⁸ allows for similar calculations.⁹⁷ Applying these values to the impairments that might be reported by hypothetical persons with mild, moderate, or severe TBI (or their proxies) results in HRQOL estimates of .632, .329, and .125, respectively. This compares with an average of .925 for the population at large. The average utility for individual attributes for the reference sample indicates that most persons reported no impairment on the 8 HRQOL dimensions of the HUI3.

Averages on the QWB or the HUI3 for TBI survivors can be calculated overall and in various subgroups once information is available to categorize them along the 4 or 8 dimensions involved. It is reasonable to expect that such data would show that the health status of the average person with TBI is valued as less than that of the average person without TBI. The ratio-scale measurement afforded by the utility measures permits a precise quantitation of how much less.

QOL EXPERIENCED

The literature on HRQOL, QOL, and other outcomes after TBI addresses losses, burdens, and deficits exclusively, tempered by success stories of treatment, training, and development of compensatory skills that enable those with TBI to regain, at least partially, what was lost because of the injury and its cascade of effects. The data on SWB suggest that most subjects with TBI perceive the injury and its direct and indirect consequences negatively, even after treatment and rehabilitation. In terms of QOL as achievements, the losses or missed opportunities result in HRQOL levels lower than those of the average person without TBI. The hypothetical data on utility scores for subjects with TBI (table 5) suggest that society agrees with them and that life with TBI (or at least with the deficits typical of TBI) is seen as less desirable than life with a typical or normal health status. The only literature that has indicated some positive effects of TBI, some gains from this event, has been that reporting on qualitative research.

Although this literature does have a strong emphasis on negatives, its focus is not so much on the quantification of functional limitations or neuropsychologic deficits, as much as it is on the meaning of TBI and its physical, cognitive, and behavioral consequences. The primary theme of the narratives of persons with TBI reflected in this literature is loss of a future,³⁷ of chances to participate in the typical things teenagers do,^{37,92} of control over one's emotions and behaviors,³⁷ and of autonomy and privileges.³⁷ However, the most salient result of TBI seems to be, for the moderately or severely injured, a change in the sense of self³⁷ or even a loss of self.¹⁰⁰⁻¹⁰⁴ The studies vary in their emphasis on different aspects of this. Duggan¹⁰¹ suggests that there is a profound sense of disorder resulting from the many losses experienced and the "biographical disruption" caused by the TBI. "Emptiness" and lack of personal fulfillment contribute to the "feeling of being lost" in many of her subjects, she notes.¹⁰¹ Nochi,¹⁰³ however, suggests that the loss of self is not a direct consequence of the brain damage, but the result of, or is experienced only in, the interactions with others. His subjects reported a loss of self because they felt they were not understood by others, both when they were equated with a "damaged brain" and when they managed to pass for "normal."

It may be that these are only apparent contradictions; the rich material collected by qualitative researchers permits selection and analysis of many aspects of life. The types of questions that are asked and the answers given in samples of differing social backgrounds, ages, and injury severities are the likely causes of the discrepancies. Qualitative research into TBI is fairly new, and one can expect that in the future investigators will compare their data collection and analytical methods and will be better positioned to determine what experiences, meanings, and narrative elements are universal, or nearly so, and which are restricted to more limited subgroups.

Nochi has observed that "people with TBI may gradually shift the focus of their self-narratives from 'In spite of TBI' to 'Because of TBI.'"¹⁰² Most qualitative research studies report some elements of positive results of the injury, although it is often limited to "a feeling of being glad to be alive"^{92,101} hardly a ringing endorsement of beneficial impacts. Other positive outcomes noted by some of Duggan's¹⁰¹ subjects was: being more appreciative of the little things in life and having a greater understanding of other people's frailties. Growth (in a moral sense) and insight into self and others was also mentioned by Nochi's¹⁰² subjects, some of whom also revealed that TBI put a stop to a self-destructive course of substance abuse.

RESEARCH NEEDS

The National Institutes of Health (NIH) consensus conference on rehabilitation of persons with TBI¹⁰⁵ made 2 broad recommendations concerning QOL: (1) QOL predictors for persons with TBI, their families, and significant others should be studied, and (2) generic HRQOL assessment instruments must be validated for use with persons with TBI and TBI-specific instruments must be developed and validated.

Substantive issues (recommendation 1) cannot be studied without development of better QOL measures (recommendation 2), but development of these tools must be guided by knowledge of TBI and its sequelae, and understanding of how survivors, their families, and friends understand the injury, and recreate their lives, or create a new life, after TBI. The need for research tools is broader than just developing TBI HRQOL instruments or validating generic ones.

The second recommendation was also made in several reviews of the literature on QOL measurement as it relates to TBI. Riemsma et al²⁶ evaluated the degree to which general health status measures (ie, HRQOL measures) have been evaluated for use with people with cognitive impairments, including TBI. They reported that of 34 measures used in samples with cognitive impairments, only 6 have been extensively validated in these groups. A second finding was that samples of cognitively impaired subjects generally showed poorer validity results than samples with nonimpaired subjects. Riemsma concluded that "there are no validated instruments available for use in cognitively impaired respondents,^{26(p iv)} and that instruments developed for the general population should be used cautiously in studies of persons with cognitive "impairment." Almost all of the studies that provided useful information on psychometrics relevant to persons with TBI (for 5 measures: SIP, Brain Injury Community Rehabilitation Outcome-39¹⁰⁶ [BICRO-39], VAS-QOL,⁷³ Vitanen Life Satisfaction Interview,⁴⁵ Patient Competency Rating Scale¹⁰⁷) were criticized for including fewer than 50% of persons with cognitive impairment in their samples.

Berger et al²⁷ focused on the areas of life included in studies of the QOL of people with TBI. They noted that 4 functioning domains were frequently used: physical (including pain), psychologic (eg, affective disorders, personality changes), social (especially vocational status and relationships with family and friends), and cognitive. Only a minority of studies considered all 4 domains, however. Berger noted that studies lacked definitions of the concept of QOL (a complaint not unique to the TBI literature), frequently failed to address the multidimensionality of the construct, and often relied on reports by professionals or other proxies rather than on patient self-report.

The latter complaint was shared by the TBI Consensus Group that considered available generic and TBI-specific measures of QOL relevant to 3 phases: acute care, rehabilitation care (approximately up to the first anniversary of injury), and the long term.²⁸ The TBI Consensus Group noted that available measures applicable to the latter phases have several shortcomings, including lack of ratings by subjects of the importance domains and issues have for them, absence of qualitative data, lack of information on preinjury life, focus on negative aspects of QOL, lack of norms, and omission of 2 important dimensions of QOL after TBI—cognition and the "existential domain." The CHI Consensus Group noted that self-report was even rarer in the child and adolescent population, even though this group, too, defined the perspective of the person as the quintessential characteristic of QOL.²⁹ They found 6 existing generic child QOL measures that satisfied a minimum number

of the criteria they had set forth, but noted that none had been used with children with TBI.

There are several other issues about which our knowledge of the QOL of persons with TBI is insufficient. The following are suggested high priority areas for research.

Issues Cross-Cutting QOL Conceptualizations: Ability to Self-Report

Most QOL research depends on self-report by subjects, and research on QOL after TBI is no exception. QOL-as-achievements information commonly relies on statements by the person involved, although proxy reporting has been used. These same reports are the basis for determining QOL as utility. And for assessment of SWB, self-report is indispensable, although a few studies have relied on proxy reports to measure well-being.¹⁰⁸ The QOL literature indicates that a sizable percentage of the general population cannot complete more complex QOL instruments, especially those that attempt to establish the salience various life domains have for an individual.¹ However, whether people with TBI can be reliable self-reporters has not yet been resolved. Some investigators have concluded that people with moderate or severe TBI lack the insight, memory, or communication skills to provide useful and complete answers to researchers' questions. Others claim that without input from the insider, descriptions lack crucial information; consequently, unless there is solid evidence that a person cannot contribute to an understanding of his/her situation, proxy reports should not be used. Most researchers have taken a more pragmatic stance and have used survivors' answers to their questions because they are easily available.

There is lack of solid information concerning at what point cognitive and communicative deficits prohibit a TBI survivor from reporting what type of information. Self-report by people without apparent cognitive deficits has been studied in the "cognitive laboratory," with a focus on how people reply to various types of survey questions. Studies have shown that survey respondents use several cognitive processes when answering a question; the basic ones are comprehension and encoding, retrieval and recall, evaluation, and response.¹⁰⁹⁻¹¹¹ Details of these processes differ by type of interview and question (self-administered vs other-administered, open-ended vs closed), the nature of the relation between respondent and researcher/interviewer, and question content type (eg, sensitivity of the information, beliefs, knowledge, behaviors, judgments). It would be useful to investigate what specific cognitive skills are needed to perform adequately in these 4 areas and how the skill level of people who are likely to have cognitive or communicative problems can be assessed as part of survey research without administering a complete neuropsychologic battery. Simply administering the Mini-Mental State Examination (MMSE) or a similar screening instrument is not sufficient because some studies have found that people who fail the traditional MMSE cutoff point (24) may still report reliable QOL information.¹¹²

Unawareness of deficits is an example of cognitive problems that may interfere with reporting. Researchers disagree as to how common the problem is and what deficits are primarily underreported. It seems clear that, as in many other disorders affecting cognition,¹¹² awareness of emotional problems is involved more so than discernment of physical or even cognitive difficulties, or of one's own feelings.^{34,56} This finding suggests that, in describing QOL as achievements, impairments (fig 1, box C) may be underreported, especially those involving remembering, problem solving, and communicating. As a consequence, QOL utilities based on the self-report (box A) would also be affected, resulting in a higher preference value than

would have been calculated if the report of status on the relevant dimensions was made by a proxy. However, unawareness might be irrelevant to reports of happiness and life satisfaction (box E): what is not noted does not affect well-being.

Formal evaluation of the ability of people with mild, moderate, or severe TBI to reliably report on their life and life circumstances has barely begun. A pilot study¹¹³ indicated that there may be differences between those classified as having a severe TBI and those with mild or moderate injury, in their consistency in reporting SWB, statuses, and achievements (test-retest reliability, internal consistency). However, it was not clear whether this difference was only qualitative or if the former group should be barred from serving as self-reporters.¹¹³ If people with more severe TBI are shown to be unable to reliably answer the standard questions used in QOL research, that does not necessarily mean that they should be disqualified as self-reporters altogether. It may be that they can report on their own priorities, feelings, and judgments if researchers adapt their instruments. Researchers dealing with other populations have shown that when they simplify the questions, limit the number of answer categories to 2 or 3, and take similar steps, people with mental retardation¹¹⁴ or Alzheimer's disease¹¹² can reliably complete interviews about their QOL.

Issues Cross-Cutting QOL Conceptualizations: Salience of Domains of Life

Distinguishing domains of life such as the social and economic, is common in lay and scientific discourse. In QOL research, it is important to differentiate domains to the degree that QOL total scores are calculated by summing over domains; this is a common approach in utility, HRQOL, and SWB measures. Some measures in the latter category use rating of the relative importance of domains in scoring.¹ However, reports are limited as to which domains people distinguish spontaneously, and how they are weighted relative to one another in assessing one's overall QOL. Flanagan^{30,31} did the most systematic research, interviewing nearly 3000 subjects and using the critical incident technique to elicit situations and happenings that had affected QOL positively or negatively. Based on the responses, he distinguished 15 domains of life. Later researchers have generally used a smaller number of domains (typically, 3 to 5), without approximating Flanagan's extensive research; most seem to have made the decision based on their expert knowledge, or for convenience's sake (keeping the number of questions to be answered down to a reasonable number), or in imitation of others.

Approaches other than that of Flanagan are certainly possible. For instance, O'Boyle et al¹¹⁵⁻¹¹⁸ used direct nomination of domains that subjects consider important for their QOL. For simplicity, they capped the number at 5, and some people had difficulty nominating even that number. There was no exploration of the definition or boundaries of the domains nominated, nor of possible overlap. Qualitative research is needed to explore if and how people spontaneously segment their life in domains, how they define them, and how the various domains are related. It is possible that there is a significant overlap from 1 person to the next in this subdividing of the whole of life, thus justifying the use of fixed lists of domains with standard definitions by researchers. It is also possible, however, that enormous variety exists (as suggested by O'Boyle)¹¹⁵ and that personal construct psychology methods are needed to determine for each person how life as a whole is compartmentalized in segments that play different roles in the experience of QOL.

Even if it is assumed that 4 or 7 or 15 specified (standard) domains of life are sufficient to capture all information relevant

to QOL, it should not be presumed that their importance relative to one another is constant across individuals or groups.²⁶ Much interindividual variation has been reported.^{85,119,120} But there are also intergroup differences and secular trends that make assigning standard weights for domains a hazardous procedure. For instance, Flanagan reported systematic differences in the 1970s between people in their 30s, 50s, and 70s. His respondents assigned much greater importance to "civic activities" (participation in activities relating to local and national government and public affairs) than have samples studied in the 1990s.¹²¹ Thus, even in research focusing on group, rather than individual differences, individualized measures that allow for weighting of domain importance may be needed.¹

QOL as Achievements: Substantive Issues

As indicated earlier, there is a lack of information on the status of persons with TBI in many areas: for example, marriage and divorce rates and participation in public life. To the degree that these are considered important domains of "objective" QOL, research to fill the gaps would be useful. In the areas in which there is substantial knowledge, a systematic review followed by meta-analysis, if indicated, might be useful. Various authors have noted that TBI research typically uses small samples; consequently, estimates of, for example, school dropout rates or community integration levels vary considerably. The study-to-study variability in design and in subject TBI severity and other characteristics (eg, age, gender) at the time of injury adds to this problem. A systematic review of research that takes these factors into account can resolve some of these issues. Alternatively, larger databases (eg, that of the Traumatic Brain Injury Model Systems)^{122,123} can be used to answer some of the questions. The same reviews or original studies can provide information relevant to predictors of QOL, which is the first recommendation of the NIH panel. In fact, no area of QOL after TBI has been researched more extensively than that of the predictors of QOL as achievements, generally quantified as impairment (deficits), activity limitations (disabilities), and participation restrictions (handicaps). The lack of agreement on instruments for measuring predictors (eg, severity, preinjury achievements) and QOL outcomes (eg, community integration, need for supervision) has hindered integration of this body of knowledge. Inconsistencies in the timing of assessments is another issue that prohibits a systematic overview of what is and is not known about the cascade of sequelae of TBI.^{27,29}

QOL as Achievements: Measurement Issues

There is quite an array of measures of outcome after TBI, all of which quantify at least some aspect of QOL as an objective status. Most were developed before health researchers began focusing on QOL issues (eg, the Glasgow Outcome Scale [GOS], Glasgow Outcome Scale-Expanded, Community Integration Questionnaire, Disability Rating Scale [DRS]), or without specific attention to QOL concerns (the SIP, Aachen Quality of Life Questionnaire, BICRO, European Brain Injury Questionnaire). HRQOL measures tend to focus on the status of health broadly defined, with emphasis on everyday functioning. QOL researchers distinguish between generic QOL measures and disease-specific ones. The former are sensitive to physical, mental, and social health problems that are typically affected by a broad range of diseases and injuries. Disease-specific measures are instruments designed to be sensitive to those deficits and problems that are unique to specific disorders. There has been extensive discussion of the advantages and disadvantages of these 2 types of measures in various research situations. Berger et al²⁷ claim that generic QOL

measures are not appropriate for research into TBI and its treatment because the measures do not cover some domains that typically are significantly affected—especially cognitive functioning. A similar criticism is leveled by Bullinger et al.²⁸ who also specified that existing instruments do not cover the "existential domain." Including that domain would expand the coverage of HRQOL measures into the area typically encompassed by SWB measures. Pain is another area that is dealt with insufficiently by several existing instruments.

Riemsma et al²⁶ questioned the validity and applicability to TBI of most generic QOL measures, because of the self-report problems described previously, and the inadequate coverage of salient domains. In their review of relevant studies of the psychometric qualities of these instruments in populations with cognitive-communicative problems, they concluded that most studies were of poor methodologic quality and thus provided limited evidence of the validity of the data they generated by using these instruments. Consequently, the measures should be used with care. Validation of generic HRQOL instruments for use in TBI has begun. For instance, Findler et al⁶⁶ designed their study to assess to what degree the SF-36 provides reliable and valid data when used with this population. Similar studies underway with other instruments, and the pessimism of Riemsma²⁶ may soon be outdated.

Given that several well-validated measures of "outcomes" after TBI (eg, the GOS, DRS) provide the information typically included in HRQOL measures, or that one would assume would be included in a TBI-specific measure, the need to develop disease-specific TBI QOL measures is debatable. It may be more efficient to explore whether it is possible to develop modules that quantify status in areas typically omitted in generic QOL measures—for example, cognitive functioning. In addition, if validation studies suggest that existing generic measures are not reliable when used with the TBI population or significant subgroups, researchers might focus on modifications in wording, presentation, and other aspects that may resolve the problems.

QOL as SWB: Measurement Issues

For many purposes, "global" measures of life satisfaction adequately assess the evaluative aspect of QOL as SWB. However, in some studies, the interest is in life satisfaction or need satisfaction in specific domains, and in these circumstances instruments such as the QOLS^{30,31} or Ferrans and Powers's Quality of Life Index^{119,120} (QLI) might be insufficient, because they inadequately cover domains such as cognition and communication. It appears that an instrument similar to the QLI that is specific to the life situation of persons with TBI is warranted.

QOL as SWB: Substantive Issues

Several studies have attempted to explain variations in SWB between persons with TBI, using as predictor variables demographic, injury severity, and other characteristics. These efforts have been marginally profitable.^{17,67,124} Only when other SWB elements are included among the predictors of, for example, life satisfaction, are such efforts more successful.^{124,125} This points to 2 issues.

First, SWB elements are strongly related to one another.¹²⁶ Happy people tend to have high life satisfaction; people with high self-esteem seldom suffer extensive negative affect. The correlations are not strong enough to disregard distinctions between SWB components, but it is evident that 1 SWB component is a better predictor of another than is an objective characteristic describing the person, such as employment, income, or physical health. Brown et al⁸⁵ proved this by system-

atically comparing models predicting global QOL judgments. As in previous research, the percentage of variance that was explained when using purely objective factors was low (13%–15%); it nearly doubled when cognitive complaints (a somewhat subjective issue) were added to the model, or objective indicators of satisfaction of common human needs (eg, income, hours spent in hobbies and reading) were used as predictors. However, when subjective indicators of needs satisfaction were used, the percentage of variance explained increased to 45% or higher.¹⁸

Second, without taking into account differences between people in what they want out of life, explaining SWB based on achievements alone is likely to be unsuccessful. Minor cognitive and communicative impairments from TBI may be less problematic for a factory worker than for a schoolteacher because of the differing requirements of their occupations. Some people attach lower importance to financial security than do others. After TBI, certain people manage to redefine who they are and bring expectations and standards for their life in line with the new reality, while others cling to the hope that they can again be the person they were preinjury. QOL researchers in all arenas have just begun to address the expectations and desires people have that affect SWB, and changes in these aspirations and dreams that do or do not occur because of life's vicissitudes. In particular, there are no instruments that reliably measure "realistic" expectations that people have for their lives.¹ A start was made with the development of the Living Life After TBI Scale,¹²⁷ which asks how frequently a subject engages in certain activities (eg, work, socializing, eating out), and whether he/she would like that level to be higher, lower, or unchanged. The degree of change desired, if any, is not assessed; however, one can imagine that having slightly less than one's ideal affects SWB less than having almost nothing. Although the technique works for concrete activities and possessions, it is difficult to see how it would be applied to more abstract goods, such as those relevant to Flanagan's self-expression domain, without trivializing the concept.

The phenomenon of response shift¹²⁸ is increasingly invoked in the QOL literature to explain SWB changes or differences that run counter to changes or differences in objective circumstances (HRQOL, in the terminology adopted here). Response shift theory postulates that people adapt to the negative impacts of chronic illness or injury by changing their internal standards, values, and even their conception of QOL. Through recalibration (changing the "minima" and "maxima" on one's internal scale for measuring, eg, pain and forgetfulness), reprioritization (modifying the relative importance of domains of life considered relevant to SWB), and reconceptualization (a complete overhaul of the domains that are considered relevant), people may manage to live in circumstances that they would have considered unacceptable before injury or disease, or that would be reasons for low QOL estimates by people without a disorder. Response shift theory has much in common with older theoretical perspectives familiar to rehabilitation specialists, such as Wright's "acceptance of loss theory."^{129,130} No studies were identified that applied this perspective in the study of QOL after TBI. The qualitative research by Nochi¹⁰² indicates that response shift is indeed a reality, at least among those who succeed in living with TBI.

Hill,¹⁰⁰ in her autobiographical statement, emphasizes that severe TBI is an event from which no recovery is possible, and that it makes no sense to compare the TBI survivor with the person he/she was before injury. To do so is self-defeating, she argues, because the past always prevails, if for no other reason than that autobiographical memory is selective. One issue that

is not clear from the qualitative studies on the aftermath of TBI is when and how (if ever) a shift is made from "losses due to TBI" to "achievements in spite of TBI." Possibly an even more significant shift is from the "in spite of TBI" to "because of TBI" that Nochi mentioned.¹⁰² One group of rehabilitation providers has made such a shift in perspective, the lynchpin of their TBI services. "We have rejected the view of rehabilitation as restoration of function. In our opinion, it makes little sense to ask clients who have an acquired brain injury to work as hard as they do in therapy in what is typically a vain attempt to recapture their previous level of functioning and experiences" noted Maitz et al^{131(p7)}: "... we encourage patients to explore 'who they want to become' rather than 'who they have been in the past' ... unconstrained by their previous lifestyle, personality, and expectations of self and others." This, of course, requires that the client can make a major shift in perspective: a break with the past which seemingly adds to the loss of self. Response shift and the development of changed selves and identities is an area ripe for qualitative and quantitative research.

QOL as Utility: Measurement Issues

The major claim for utility QOL measures is that they quantify preferences for various health states on a ratio scale, which has several advantages, including the option to calculate QALYs. The comparison of benefits and cost benefits of alternative medical and rehabilitative interventions and public health policies is made easier, if not possible at all, by the availability of the universal QALY currency. However, it would seem that the existing utility measures lack sensitivity to the differences between categories of people with TBI. For instance, the QWB scale subtracts .340 (from perfect health set at 1.00) for "trouble learning, remembering, or thinking clearly." All 3 problems are fairly common in people with mild, moderate, or severe TBI. However, the severity of the problems typically varies between these groups, for example, from a minor difficulty remembering where one put the car keys to total inability to learn any new material. Between these 2 extremes, there is room for improvement from medication, restorative rehabilitation, training in compensatory skills, or environmental changes (eg, use of calendars, diaries). However, if the QWB were to be used as an outcome measure in studies of such therapies, it would lack sensitivity unless the therapies completely eliminated the problem, which is unlikely.

Disease-specific utility measures have been developed for several diagnostic groups,^{132,133} and it appears that development of such an instrument that is specific to TBI would be useful. It should include functions most frequently affected by TBI and the symptoms most commonly reported and most bothersome to the patient and family. As such, a TBI-specific utility measure would facilitate studies that compare TBI populations—for instance, studies comparing outcomes between traditional and contextual approaches with cognitive rehabilitation.¹³⁴ The results of research on HRQOL and SWB in TBI, as well as qualitative research on existential issues as experienced by people with TBI, might be a good basis for identifying crucial dimensions to be included, and the number and type of distinctions (categories) to be made within each domain. For studies contrasting the cost-effectiveness of rehabilitation for people with TBI and, for example, rehabilitation for people with spinal cord injury, generic utility measures would be needed. Obviously, these still might need to be modified to make them more sensitive to the changes typically achieved in TBI rehabilitation.

QOL as Utility: Substantive Issues

Even though TBI is a leading cause of morbidity and disability in the United States,¹³⁵ with an estimated annual cost in 1985 of more than \$37 billion,¹³⁶ there has been very limited research on the costs of various treatment programs and the cost benefits of alternative rehabilitation programs. As indicated previously, only 1 study was identified that used utility estimates to evaluate neurosurgical interventions. QALYs and DALYs have not been applied in the study of the outcomes, burdens, and economic costs of TBI. Although methodologic, health policy, and ethical and philosophic problems related to utilities exist, they are an accepted method of assessing QOL. There are data to suggest that, especially after mild and moderate TBI, there is significant lack of services, given the continuing need for them.¹³⁷ It is unclear whether services are underutilized because patients, their families, and professionals are unaware of them, or because of access problems, including insurance coverage of relevant medical and rehabilitative services. It may be worthwhile to research to what degree the problems and symptoms reported by these community-living persons with TBI can be mitigated, at what costs, and what improvement in QOL as utility are feasible, also at what costs. A second area for research is to compare the QOL of persons with TBI with that of people with disorders of different etiology; as of now, there are no estimates of the impact of TBI on QOL, compared with other ill or injured population groups.

CONCLUSIONS

TBI, especially if moderate or severe in nature, has many effects that threaten QOL. The 3 conceptualizations of QOL offer different perspectives on the nature of the QOL decrement that may result. Knowledge of the impacts of injury on QOL as achievements is extensive, although some areas have not been researched adequately. QOL as subjective well-being has often been studied, although more is known about life satisfaction than about happiness and other mood states. Although the life satisfaction of persons with TBI is generally lower than that of comparison groups, the differences are smaller than one would expect. Response-shift phenomena may play a role here. Finally, QOL as utility is an area that has been studied minimally; there is no information on the preferences society has on the death-to-perfect health scale for life with TBI resulting in a variety of disablement types and levels.

Research on QOL after TBI is hampered to some degree by shortcomings in the existing QOL measures; however, the shortcomings may be less significant than other issues. Areas in need of more research include changes in QOL over time and an explanation of QOL as SWB. In the latter area, a focus on the standards and priorities that people with TBI use, explicitly or implicitly, may have benefits. In this and other topic areas, judicious use of qualitative research before, or in conjunction with, quantitative approaches is suggested.

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