Review

Exploring quality of life following high spinal cord injury: a review and critique

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Study design: Review.

Objectives: To explore the concept of quality of life (QOL), critique the practice and problems of assessing QOL following spinal cord injury (SCI) and to review the findings of studies into QOL for people with SCI both below and above the level of C4.

Methods: Relevant articles were identified from the Medline and CINAHL databases for approximately the period 1990–2003, cross-indexing ‘spinal cord injury’ or ‘quadriplegia/tetraplegia’ with ‘quality of life’, ‘life satisfaction’, ‘social adjustment’ or ‘psychological adaptation’. This search was augmented through papers identified in reference lists. Articles were excluded if they were designed solely to examine the impact of a specific intervention upon QOL; or if they examined satisfaction with various life domains without explicitly linking these to perceptions of QOL. Papers were also accessed that addressed the philosophical and epistemological issues involved in QOL conceptions and assessment.

Results: Review of the literature highlights the philosophical and methodological difficulties associated with the quantitative measurement of a qualitative experience; and with the assessment of life domains chosen by researchers. Analysis of QOL research undertaken among people with all levels of SCI demonstrates that dissatisfaction with life following injury arises primarily from social disadvantage. However, little research has been conducted specifically to ascertain perceptions of QOL among people with high SCI.

Conclusions: Ensuring the relevance of future research into QOL following high SCI requires qualitative methodology and mixed methods. Further research is needed to determine how rehabilitation professionals can act on the findings of their QOL assessments and enhance the QOL experienced by people with spinal cord injury in the context of their environments.

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Introduction

Since the 1980s, people with profound physical impairments caused by spinal cord injury (SCI) at or above the level of C4 have been surviving in Western countries in increasing numbers.^{1,2} Although a significant body of research has explored perceptions of quality of life (QOL) among people with lower levels of SCI, little research has been undertaken to determine whether people with the highest cord lesions experience quality in living or whether they perceive survival to be worthwhile.² This gap in knowledge and understanding has serious implications. Since biomedical ethics and the law

demand a high standard of informed consent for medical interventions, health-care professionals require evidence-based support for the information they provide to patients and their families concerning the possibilities and opportunities for QOL after high SCI. Patterson *et al*³ asserted that because there are frequent misconceptions about life with a SCI, ‘those providing the information must be familiar with the literature’ (p 507). Currently, however, health-care professionals have few resources in the literature upon which to draw.^{3,4} Further, the belief that life with a high SCI would not be worth living pervades Western culture,^{3,5–7} the courts⁷ and the health-care professions,^{6–13} although DeLisa¹⁴ has noted that ‘the assumptions of those of us

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who are able-bodied bear little relationship to the realities of life for people with spinal cord injury, as shown by multiple investigators' (p 1).

Reflecting prevailing cultural beliefs, health-care professionals have been found to underestimate significantly the QOL experienced by people with high SCI.^{6–11,15–17} Gerhart and Corbet⁴ contend that if the information provided by health-care professionals is coloured by society's negative biases about QOL with an impairment, this may result in 'uninformed consent'. Gerhart⁶ further observed that: 'the implications of acting on, making recommendations because of, or even subtly communicating our quality of life biases are profound. Patients and survivors need accurate information. They need it from their providers, they need it from other survivors, and they need it first hand-gleaned from others' experiences living with a disability. We must educate ourselves, our clients, and the society in which we live' (p 83).

QOL has justifiably become both the ultimate goal of rehabilitation following SCI and a key outcome in determining the effectiveness of rehabilitation programmes for people with SCI.^{18–21} While the need to understand more about the QOL perceived by people with high SCI is undisputed, there are difficulties in studying a concept that lacks a clear definition and which is perceived differently by different people, in differing circumstances and at different times of their lives. This paper explores the concept of QOL, the contentious issues surrounding QOL research and assessment, and outlines the findings of quantitative and qualitative research into perceptions of QOL among people with SCI in general, and high SCI in particular. Finally, it suggests directions for researchers who strive to ensure the relevance and usefulness of their QOL studies; and for rehabilitation clinicians who seek to enhance the quality experienced in the lives of their spinal cord-injured clients.

Assessing QOL following SCI

The concept of 'quality of life' lacks a clear definition. It has been used within medical research to refer both to the measurable, material conditions of life and to the experiences that make life meaningful and valuable.²² Reflecting this inconsistency, no unified approach has been taken towards QOL measurement and no consensus has been achieved on what QOL means,²³ who should measure it,²⁴ or, indeed, whether measurement of quality is a realistic or achievable goal.^{25,26}

'Measuring' quality

The majority of research into QOL following SCI has adopted a quantitative approach, with researchers using single-item rating scales, multiple-item rating scales (addressing general life satisfaction), and multiple-item questionnaires (including items rating satisfaction with specific aspects of life).²⁷ A thorough exploration of the methodological issues arising from these various

approaches has been provided by Dijkers.²⁵ Beyond the problems of comparison and cohesion that arise from such inconsistent approaches, quantitative research into QOL is inherently problematic for several reasons.

Primarily, the attempt to quantify a qualitative experience effectively erases the difference between the quantitative and the qualitative. Indeed, the premise that 'quality of life can be quantitatively measured'²⁸ (p 498) – that the quantity of quality can be computed – has been termed an oxymoron.²⁶

Further, the categories deemed worthy of consideration in a traditional survey are selected by 'experts',^{23,29} whose choices inevitably reflect their own values and culture^{25,30} and can be deemed neither 'neutral'³¹ nor 'objective'.²⁵ As Mor and Guadagnoli³² observed: 'Objectivity' is not bestowed upon a measure merely because another person makes it' (p 1056). Anthropologists and disability researchers note that Western conceptions of QOL reflect culturally specific and not universal values.³³ Miles³⁴ (p 59), for example, observed that while researchers from the dominant Western culture tend to associate QOL with having opportunities for an array of choices, material comforts and the freedom to engage in the 'pursuit of happiness' – and consequently design studies to assess these factors – such discussions appear naive and irrelevant to those whose values are informed, for instance, by Buddhist philosophy, where a life of quality comprises right conduct, right thinking and right living in response to the realities of every-day life.

Wolfensberger³⁵ and others²⁹ have noted that QOL assessments tend to reflect the norms and values of the dominant culture and privileged classes. Further, Dijkers³⁶ observed that many researchers appear to assume that their own judgements about what contributes to QOL are shared by others; that everyone wants the same out of life that they do. Dijkers²⁵ observed that QOL measurement is not a value-free endeavour, but one that is inherently political, being informed by assumptions, values and convictions with which the research subject may not agree at all.

In addition, much research has demonstrated the discrepancy between the 'objective' (ie the researcher's) assessment of QOL and the subjective satisfaction with that life.^{9,11–13,23,37–42} Slevin *et al*²⁴ reported that physicians could not adequately measure a patient's QOL and that there was a wide variability in QOL scores between different physicians and health professionals, even on ostensibly objective scores. This led them to conclude that 'if measurement of a patient's quality of life is required, it should be done by the patients themselves' (p 110). The researchers observed: 'What constitutes quality of life is a personal and individual question which lends itself to a philosophical rather than a scientific approach' (p 109). DeLisa¹⁴ cautioned against an over-reliance upon objective indicators – such as measures of functional independence – observing that the relative importance of these indicators to each individual is of far greater importance. However, in their review of quality of life

measures, Gill and Feinstein²³ observed that respondents are only rarely provided the opportunity to rate the importance of various factors to their own lives. Indeed, they contend that 'quality-of-life measurements would seem to be aimed at the wrong target unless individual patients are given the opportunity to express their individual opinions and reactions'²³ (p 624). Clayton and Chubon⁴³ found that people with SCI who were employed did not perceive their QOL to be significantly better than those who were unemployed, leading them to conclude that this 'underscores the limitations in inferring life quality from objective indicators' (p 638).

Some researchers claim to be assessing 'subjective' QOL by using standardized questionnaires that are completed by research 'subjects'. However, reliance upon QOL criteria that have been chosen by researchers constitutes forced 'choices' rather than a truly subjective appraisal of the factors deemed important to individuals' lives based on their own values and priorities. Measures based on those domains selected and ranked by study participants according to their relevance and importance⁴⁴ might more reasonably be termed 'subjective'. However, Dijkers³⁰ observed that in most instances the researchers who develop the QOL instrument (or those who select an existing instrument for use in their own research) define and determine what factors they believe affect QOL. Indeed, how someone attempts to 'measure' QOL perhaps says more about their own values, priorities and fundamental orientation to life than it does about the QOL of the people whose lives are ostensibly being studied.

In seeking to measure QOL after SCI, many researchers have used without comment assessment tools borrowed from geriatric literature. Dunnum,⁴⁵ for example, used the Life Satisfaction for the Elderly Scale with a group of people who were as young as 18 years. The Life Satisfaction Index-A (LSI)⁴⁶ is considered to be most suitable for use with people over 65 years of age⁴⁷ yet has been used in several studies of people with SCI.⁴⁸⁻⁵⁰ This must be considered in light of evidence that the mean age of SCI in the USA is 32 years and that 55% of injuries occur among people aged 16-30 years.⁵¹ Further, while the majority of seniors are women, about 82% of those with spinal cord injuries are men.⁵¹ Presumably, these studies are grounded on an assumption that age has no impact upon determinants of QOL and indeed, that a positive score by a young man on a tool designed for elderly women produces a meaningful result. As Dijkers³⁶ has noted, the fact that some of the items in the LSI seem appropriate only for elderly people has not prevented researchers from using this tool with young people.

Similarly, Nieves *et al*⁵² sought to understand something of the QOL experienced by people with SCI by using the Quality of Life Index, a measure designed for use with patients with cancer. It is surely problematic to apply an assessment designed to reflect the lives of a nondisabled, terminally ill or elderly

population to a group that is predominantly young and permanently, profoundly physically impaired. It is possible that researchers have not asked the right questions.

Measuring what counts

Glass¹⁹ stated that 'the primary goal [in rehabilitation] must be achieving the highest level of quality of life. Implicit in such a statement is the involvement of the individual in deciding the parameters of quality' (p 123). Gill and Feinstein²³ concurred that 'quality of life can be suitably measured only by determining the opinions of patients and by supplementing (or replacing) the instruments developed by 'experts'' (p 619), otherwise 'quality of life may continue to be measured with a psychometric statistical elegance that is accompanied by unsatisfactory face validity' (p 624). More than a methodological issue, the approach taken to QOL 'measurement' is an issue of philosophy and epistemology.

Research has demonstrated the varying degrees of importance that people with SCI place upon specific QOL domains.⁵³ Thus, some researchers insist that QOL can only be measured by the individual whose life it is because perceptions necessarily reflect personal values.⁵⁴ Indeed, this epistemological belief led Dale⁵⁴ to suggest that any claims to have measured the QOL experienced by a patient, using existing standardized 'objective' tools are 'false' and the results of no value.

Many researchers share an underlying assumption: that the determinants of QOL will be the same for both disabled and able-bodied people.^{55,56} This would seem to validate assessment criteria established for disabled people by able-bodied researchers; but how can we know this? The vast majority of research that compares the views of people with and without impairments has relied upon criteria predetermined by the researcher's view of life; an instance of forced 'choices'.^{31,57} Dijkers⁵ noted that disabled people are frequently shown to have a lower QOL than non-disabled people if 'objective' measures are considered but that they do not have a lower subjective QOL.

Farquhar⁵⁸ reported that after enduring prolonged institutionalization, people might wish to include determinants of QOL that include concepts of privacy, freedom, choice and dignity: concepts rarely considered by those researchers who have always been able to take such rights for granted.

Fundamentally, the difficulty of assessing QOL centres on the problem of understanding a life different from one's own and of its value to the person whose life it is.⁵⁹ Walsh⁵⁹ suggested that people who have high lesion tetraplegia will do badly on any scale that employs objective factors to measure QOL, proposing that: 'the subjective experience of a life is more important than its outward expression'⁵⁹ (p 144). To understand this subjective experience demands research methods that can probe both the content and the context of that life.

Reconciling conflicting viewpoints

Researchers have demonstrated discrepancies between objective assessment of QOL and the subjective assessments of the quality of those same lives,^{9,11–13,23,37–41,60} as has been noted. These discrepancies have led some researchers to claim that patients' subjective assessments require objective (or outside) corroboration by adding a quantitative measure to qualitative research.^{31,61–64} Perhaps because the quantitative paradigm predominates among medical researchers,⁶⁵ it is less commonly argued that quantitative findings require qualitative corroboration.⁶⁶ The contention that subjective findings require objective corroboration does not enjoy universal support. Creswell⁶⁷ noted that 'Qualitative inquiry represents a legitimate mode of social and human science exploration without apology or comparisons to quantitative research' (p 9).

Within the health-care professions, knowledge claimed to be objective or scientific ('ours') has traditionally been accorded privilege over expertise derived from lived experience ('theirs'),⁶⁸ because while health-care professionals consider themselves to have 'knowledge', patients are deemed to have 'beliefs': 'Knowledge requires both certitude and correctness; belief implies uncertainty, error, or both.'⁶⁹ (p 17). Accordingly, Bach⁶¹ has argued that subjective assessments ought not to be relied upon, because they sometimes deny what are 'known to be basic conditions of quality of life' (p 130), although he did not state what these conditions are, or to whose certain knowledge he refers. Bach claimed that at an intuitive level, researchers 'know' that some conceptions of QOL are better than others and to deny this is to fall into an unacceptable ethical relativism. Holmes⁶² concurred: 'it makes little sense to assert that people who, in appalling circumstances, nevertheless regard themselves as enjoying a high quality of life, do indeed have a high quality of life' (p 836). It has been suggested that those people who report high life satisfaction in poor circumstances do so as a result of 'false consciousness' and limited expectations.³¹ There are three fundamental problems with this position.

First, people with high lesion tetraplegia, who are completely paralysed below the neck and who require assistance for every daily life task could, without question, be viewed as living in 'appalling circumstances'. Indeed, these circumstances lead many people to conclude that death would be preferable to life in this condition^{5,6} and prompted Menter⁷⁰ to observe that 'high-level spinal cord injury with complete paralysis below the fourth cervical neurologic level is one of the most devastating catastrophes that can befall an individual' (p v). People with high SCI would be seen, by some, as enjoying few of what are 'known' to be basic conditions of QOL,⁶¹ but they are also unusual among severely disabled people, in that they have experienced another form of living and thus have some expectations for comparison. Yet, researchers have found that, 'while surely living at the edge of what is tolerable

for human beings they express a strong desire to continue living'⁵⁹ (p 144).

Further, if researchers reject the positive perceptions of QOL reported by people who it is believed lack the basic conditions for a life of quality, they must also reject the negative assessments of QOL among people whose privileged circumstances demonstrate that they do, by objective appraisal, enjoy a high degree of QOL. This position is difficult to maintain, given the dissatisfaction with life reported by many people who possess both health and wealth.⁷¹ Indeed, the reality that depression is considered to be an epidemic in the minority ('developed') world despite comparative affluence, material comforts and what is termed a high 'standard of living',⁷¹ suggests that the experience of quality in living is not dependent upon the quantifiable, material conditions of life but upon subjective qualitative factors: the content and context of life.

Finally, social scientists recommend caution in applying a term such as 'false consciousness' to other people. This concept, originated by Marxists,⁷² is deemed to constitute any idea or ideology that is held to be inappropriate in light of the 'real' or 'objective' situation as this is more 'correctly' perceived by those wielding greater power. Social scientists contend that use of the term 'false consciousness' implies that the truth of a given situation is understood correctly and with certitude by someone possessing a superior consciousness and suggest that use of the term demonstrates contempt for those whose perceptions are being disparaged.^{72–74}

QOL following SCI: quantitative findings

A small number of researchers have reported that perceptions of satisfactory QOL are negatively correlated with the level of spinal cord lesion,^{10,43,75,76} although this association is not generally found to be statistically significant.³⁶ In contrast, a substantial body of research has found no correlation between QOL/life satisfaction and level of SCI: the degree of impairment or extent of physical independence.^{9,15,20,48,49,52,60,77–106}

Meta-analyses of research into QOL following SCI reported by Evans *et al*⁷⁵ and Dijkers³⁶ have demonstrated the wide variety of research designs and instruments, modes of analysis and sample characteristics that make comparisons and overall conclusions problematic. These difficulties were further explored in a review published by Hallin *et al*,¹⁰⁷ who identified the need for 'carefully constructed condition-specific instruments that can capture dimensions of specific interest for the SCI population' (p 520). Researchers have noted that the number of different instruments used to evaluate QOL following SCI nearly equals the number of studies conducted.^{55,107} Attempts to compare findings from multiple studies are impaired due to conceptual ambiguity surrounding the use of different terms, such as 'life satisfaction', 'well-being' and 'quality of life'. Indeed, Ville *et al*¹⁰⁸ note that these terms are sometimes used interchangeably without being clearly defined.

Quantitative research among people with all levels of SCI has demonstrated positive correlations between QOL/ life satisfaction and: self-assessed health,^{48,49,87,102,106,109–111} perceived social support,^{48–50,86,100,102,109,110} social functioning/integration,^{10,21,43,48,49,81,83,84,87,100,108–116} mobility,^{10,49,83,87,88,106,111} accessibility (home/health care¹¹⁷), preferred living situation,⁷⁷ adequate income,^{43,85,108,117} perceptions of having control over one's life,^{48,49,88,109,110,118–120} marital status,^{10,76,106,108,121} satisfaction with relationships,^{88,122} community access/participation^{36,43,49,95,110,112,123} and satisfaction with occupational engagement and/or employment status.^{10,48,49,76,82,83,87,88,100,102,108,113,115,121,124–126} There have been conflicting reports of the relationships between age, length of time since injury, gender and 'race' with perceptions of QOL. However, because none of these factors is susceptible to intervention, these findings have been deliberately omitted. Other studies were omitted if they assessed satisfaction with specific researcher-identified domains (eg employment status, living arrangements or CHART domains) without explicitly ascertaining whether these domains contributed to the study participants' perceptions of QOL.

Life satisfaction/QOL has been reported to be negatively correlated with: rehospitalizations/perceptions of poor health (including respiratory problems and pressure sores),^{76,81,87,106} pain,^{81,82,84,85,108,115,122,127–129} spasticity,⁸¹ inadequate income,^{79,118} reduced life opportunities,^{118,127} reduced social interaction,^{87,127} loneliness and boredom,¹²⁴ unemployment/dissatisfaction with occupations,^{87,126} reduced mobility,⁸⁷ residence in a nursing home,^{10,60} and perceptions of having reduced control over one's life.^{87,124,127}

Researchers who use standardized questionnaires to assess various dimensions of QOL will find only what they are looking for because specific questions inevitably restrict the range of possible responses. Pain, for example, might more generally be experienced as detracting from the experience of quality in living, but if it is not included in researchers' measures, it will not be included in their findings. Further, existing measures may not include those factors that people with SCI feel are important contributors to the quality of their lives.²⁹

QOL following SCI: qualitative findings

Few qualitative studies have been undertaken to explore QOL following SCI from survivors' perspectives, despite increasing recognition of the value of this approach for exploring both the meaning of QOL for people with SCI and the factors they identify as contributing to the quality of their lives.^{10,15,18,25,29,41,78,83,130–136}

Bach and McDaniel¹³⁷ held focus groups with 14 people whose level of SCI ranged from C4 to C8. Length of time since injury was up to 15 years. Thematic analysis of their data identified six determinants of QOL that would be similar to those of the general population¹³⁸ (and thus likely to be included in traditional

QOL research): relationships, work and productivity, finances, health, having inner resources and control of one's life, and level of activity. However, two additional components were identified: assertiveness, and balancing dependence and independence.

Another study in the USA sought to explore the life domains that 12 people with SCI felt contributed to QOL.^{53,139} Study participants defined QOL as a subjective experience that changed throughout life in response to changing priorities. They identified the following domains as strong influences on perceptions of QOL: attitude towards life, and opportunities to contribute and create through occupation. The availability of resources was described as being a necessary foundation for QOL (including attendant care, transportation and adequate income). These domains were described as being 'interdependent' and 'interactive', in that each domain that was considered to be an important contributor to QOL was dependent upon other important domains. Participation in meaningful occupations, for example, was dependent upon having reliable, quality attendant care. The researchers, therefore, proposed that the interaction of life domains should be considered important in assessing QOL.⁵³

Duggan and Dijkers^{140,141} undertook a qualitative study to describe subjective QOL among 40 people with SCI. While few participants could define QOL, the majority could identify indicators of QOL and they were able to provide clear ratings of their own QOL. QOL ratings were highest among those who had satisfying relationships, meaningful social roles, financial security and material assets, and the opportunity to pursue valued occupations (such as hobbies, travel or community service). Issues related to personal development and changes in values were also of significance. The data suggested that a complex relationship between personality attributes (outlook and values), material conditions and the passage of time since injury lead to higher perceived QOL.¹⁴¹ Echoing the findings of Boswell *et al*,^{53,139} the researchers identified a complex relationship between various QOL domains, suggesting that each domain, on its own, is insufficient to imbue life with quality. Rather, it is the interaction of relationships and meaningful roles, or material assets and occupations (for example) that contributes to the experience of quality in living for people with SCI. QOL might best be understood, therefore, to be a multidimensional matrix, rather than a set of unidimensional cause-and-effect relationships.

As part of their larger project,^{140,141} Duggan and Dijkers¹⁴² reported a smaller, comparative study that explored the differences in outcomes between 10 people who sustained SCI as a result of interpersonal violence and 10 people whose SCIs were the result of other aetiologies. Both groups cited the importance of social relationships and social support to the experience of QOL. The factors that were identified as contributing to QOL for those with non-violence-related injuries were at the opposite end of a continuum of factors identified as detracting from QOL by those whose injuries resulted

from violence: financial independence/financial pressures; having an accessible home/not having an accessible home; having meaningful work roles/not having meaningful work roles. In addition, those with SCIs related to violence cited other community barriers as negative factors. This report demonstrates how small-scale, qualitative studies can be used to identify and probe contextual issues that might be missed by using a standardized questionnaire and a large study population.

Noting that there has recently been a significant increase in the percentages of people with SCI who are being discharged to nursing homes in the USA, Duggan *et al*¹⁴³ undertook a longitudinal, qualitative study into the impact of nursing home residence on the QOL experienced by six people with SCI. Two findings are particularly notable. People were sent to nursing homes on the basis, not of the severity of their impairments, but of their lack of social and economic power. Powerlessness and denial of the opportunity to exert any control over their own bodies or lives also characterized their nursing home experiences. In addition, the factors that were identified as inserting some quality into their lives – for example, having their teeth brushed at least twice a week, or their hair washed at least twice a month – demonstrated the irrelevance of most standard QOL measures. The researchers note: ‘Researchers of QOL would hardly think of investigating whether privacy, control over one’s body, and the ability to leave one’s home affect life satisfaction ratings because they are so basic and not lacking in the lives of most people’ (p 127). Their findings provide evidence-based support for the premise that QOL can only be measured by the individual whose life it is, according to their own values and experiences; and that existing measures may not be asking the relevant questions.

Duggan and Lysack¹⁴⁴ provide a brief report of a qualitative investigation into changes in self-rated QOL from the onset of SCI to 30 months postinjury. Although they found that QOL declined sharply 6 months after injury, for many, although not all the respondents self-related QOL improved at 1 year after injury. The researchers attributed this upward trajectory to the passage of time, a change in values and a revised self-concept. The researchers suggest that QOL would appear to be a complex equation of impairment factors, personal factors and environmental factors.

Although some previous investigators have highlighted the importance of value change^{10,25,53,142,145,146} and of revised self-concept^{142,147} to perceptions of QOL, these factors have not been pursued by QOL researchers, perhaps because they are not readily amenable to quantitative analysis. However, suggestion that the parameters of QOL are unstable – that the goal-posts keep moving – requires consideration in any attempt to assess or measure QOL.

QOL following high SCI: quantitative findings

In the absence of studies to the contrary, it cannot be assumed that the determinants of life satisfaction will be

the same for people who are paralysed from the neck down as they are for people who have lower levels of SCI, some residual use of their arms and hands and higher degrees of physical independence. However, it does not appear that qualitative studies have been undertaken to explore QOL from the perspectives of people with high SCI, and the following brief review is undertaken solely with quantitative studies.

One of the earliest papers to examine adjustment to life with a high SCI (above C4) identified the need for rehabilitation professionals to assist the individual in achieving control of his or her life and environment and to provide consistent support and a source of reference during the search for a meaningful life.¹⁴⁸

The first comprehensive study of people with high-level tetraplegia studied 216 people with lesions at C4 or above. In all, 92% of the study participants reported to be glad to be alive at the time of the study. Each person was asked to rate his or her overall QOL on a 5-point scale, from excellent to very poor. Fully 86% of the group reported that they enjoyed an average or better than average QOL. Level of activity was significantly correlated ($P < 0.001$) with both QOL and self-esteem.¹⁴⁹

In the UK, eight community-dwelling people with ventilator-dependent high SCI were asked about their satisfaction with their current lives. Every person stated they were glad to be alive and they were unanimous that the most important factor contributing to QOL was the quality of their relationships with families and friends. All the respondents identified the importance to their lives of maintaining high levels of activity.⁸⁰

Fuhrer *et al*¹⁵⁰ examined the educational and employment situation of people with high lesion tetraplegia approximately 1 year following discharge. They did not explore any other indicators of QOL but noted that because readaptation to home and community life following such profound injury takes a considerable period of time, appreciation of the life situation of people who are tetraplegic and ventilator dependent requires studies that track such individuals for a lengthy period of time.

Bach and Tilton⁹ sought to evaluate the effect of complete traumatic tetraplegia on the life satisfaction and well-being of 87 people. The authors did not provide the lesion levels of their respondents, although all had complete cervical injuries and were at least 2 years since discharge. No significant differences were found in any of the life satisfaction domains between the 45 respiratory independent and 42 ventilator-supported individuals. On a scale of 1–7 (with 1 being completely dissatisfied), the mean life satisfaction of the respiratory independent group was 4.11 and was 4.39 among the ventilator assisted group.¹⁶

Bach and Barnett¹⁷ used a questionnaire to assess life satisfaction among 27 people with ventilator-dependent tetraplegia. At a mean of 13 years since injury, 69% of the SCI ventilator users claimed to be satisfied with their lives, demonstrating a strong belief that life was ‘worthwhile’.

Hall *et al*² undertook a follow-up study to that reported by Whiteneck *et al*¹⁴⁹ a decade earlier. Their study population comprised 91 people with complete cord lesions at C4 and above. In response to the question: 'are you glad to be alive?', 88 out of 91 people responded 'yes'. All individuals were asked to rate their overall QOL on a five-point scale. Among the ventilator-assisted group, 83% rated their QOL as either excellent or good, as did 72% of the respirator independent group. Compared to the 1985 study findings,¹⁴⁹ the follow-up study in 1994 found that the participants were much more active and demonstrated higher self-esteem ratings. The researchers concluded that the high levels of activity and community integration exhibited by their participants, the satisfaction they reported with the quality of their lives and their longevity clearly demonstrated that people with high lesion tetraplegia have the potential for excellent QOL.

Although media and case reports indicate that suicide may sometimes be preferred to life with a high SCI,^{151,152} the research literature suggests that people with high SCI can attain meaningful lives and the experience of quality in living. However, because there are no reports of qualitative studies that have sought to explore QOL following high SCI from the perspectives of survivors, little is yet known about the dimensions that contribute to – and detract from – the experience of QOL after high SCI.

Future directions: research

DeLisa¹⁴ suggested that reducing the gap between traditional outcome measures and the needs of people with SCI requires researchers to ensure that their research is guided by those outcomes that are valued most highly by SCI survivors. Many variables contribute to the formation of values, including education, professional and employment status, material wealth, gender, 'race', ethnicity, age, social class/caste, sexual orientation, marital status, [dis]ability and religion and there may be a poor match between the values and priorities of researchers and their 'subjects'. In addition, several researchers have suggested that a serious injury can prompt a revision of values and a re-evaluation of the dimensions that are considered to be personally important and to be contributors to QOL.^{10,25,53,142,145,146} These discrepant values pose a challenge to researchers.

Boswell¹³⁹ found that a group of people with SCI identified different 'QOL domains' through a process of ranking predetermined categories than were identified in focus group discussions. The domains included in the questionnaire were ones commonly used in QOL studies (eg by Kinney and Coyle¹⁵³) and indicated the following items as most salient: family relationships, physical and psychological well-being. Coding of the focus groups' transcripts indicated that the three most important domains were attitude toward life, work opportunities and resources. Boswell attributed this discrepancy in findings to the lack of participant input permitted in

ranking the questionnaire, highlighting the inherent problems in seeking to assess the QOL using predetermined categories. Mixing qualitative and quantitative research methods may be a promising direction for future research into QOL after SCI.

Mixing quantitative and qualitative methods

Researchers recognize that in many instances the nature of a research issue and its contextual nature require the use of both qualitative and quantitative methods to tease out and illuminate different dimensions of this complexity.^{65,154–156} Since perceptions of QOL are necessarily context-specific and imbued with subjective meanings, mixing methods would seem to be especially appropriate in QOL research.

Quantitative and qualitative methods may be mixed using sequential or concurrent designs. In the sequential design, one method informs the other. Typically, qualitative research precedes quantitative research by exploring both the context and the meanings of an issue – such as QOL – to the study participants. This enables the identification of variables that might be measured and statistically analysed, ensuring that the language used will be clear to study respondents.^{154,156–159} Conversely, Mallinson¹⁶⁰ employed qualitative methods to evaluate patients' experiences with an existing quantitative research tool: the Short-Form 36 Health Status Questionnaire. Mallinson's findings prompted her to observe: 'without more assessment of people's understandings of survey questions it is difficult to see how one can establish their validity as subjective health measures' (p 20).

Concurrent designs may be used to explore both what happens (using quantitative methods) and why, and in which specific contexts (using qualitative methods).¹⁵⁶ Using concurrent qualitative and quantitative methods in QOL research may potentially produce findings which appear contradictory,¹³⁹ thus requiring sensitive analysis and careful examination of discrepancies and inconsistencies.¹⁶¹ As Hansen *et al*¹²³ have proposed, 'We must challenge ourselves to consider other variables... that have received little attention, to listen to our subjects, and to consider a variety of methodologies' (p 71).

Qualitative evidence is increasingly being used as a basis for evidence-based practice¹⁶² and the British National Health Service Centre for Reviews and Dissemination has recognised the importance of qualitative evidence in systematic reviews.¹⁶³ The systematic review is a rigorous and explicit research method that aims to locate, appraise and synthesize the findings of multiple studies pertaining to a specific research question.^{164,165} Some researchers perform systematic reviews that employ a quantitative meta-analysis in concert with a qualitative meta-synthesis.¹⁶⁶ It is possible that meta-syntheses of qualitative research exploring the perceptions of people with SCI concerning their own QOL – how they assess this, what factors are perceived to contribute to, or detract from the experience of a life

worth living – might provide a client-centred and evidence-based foundation for future assessments of QOL following SCI.

Future directions: rehabilitation

The Consortium for Spinal Cord Medicine¹⁵ stated that 'analysis of the factors that are likely to influence quality of life may help to focus interventions that could maximize quality of life outcomes' (p 24). Because analysis of the factors that have been found to influence QOL outcomes demonstrates that dissatisfaction with life after SCI predominantly arises, not from the injury, *per se*, but from social disadvantage, the process of focusing interventions towards maximizing QOL outcomes will require a bold stand.

Safilios-Rothschild¹⁶⁷ found that 'rehabilitation entails a highly stressful resocialization process into an 'inferior' status' and that the process of 'accepting' disability necessitates 'the relinquishing of majority status rights' (p 7). 'Adjustment' to disability, it is argued, is not so much a psychological process but a process of adjusting to changes in others' perceptions, in social positioning, and in access to educational, economic and social opportunities.¹⁶⁸ Indeed, the onset of impairment has been described as the experience of a 'fall from privilege'¹⁶⁹ (p 184).

The rehabilitation professions claim to be involved in striving to enhance the quality of their clients' lives.^{18,19} It is, perhaps, ironic, that the professionals who enjoy the greatest prestige, remuneration and research funding are those engaged in seeking to reduce the impact of impairments. The therapy professions, which enjoy more limited privileges, focus, primarily, upon enhancing physical independence, yet neither degree of impairment nor level of independence correlate with perceptions of QOL. Advocacy for changes in those social policies and conditions that appear to have the strongest impact upon perceptions of QOL among people with SCI are left, almost exclusively, to unpaid disability activists and their supporters. Indeed, it has been claimed that rehabilitation professionals have an un auspicious record in the struggle to change social policies that might benefit disabled people, tending to reserve advocacy in the political and institutional arenas for issues pertaining to their own professional interests.¹⁷⁰

Chase *et al*¹⁷¹ observed that understanding the components that are important to QOL for people with SCI is 'the first step in making it a reality' (p 18). However, this is only the first step. There would be little point in measuring range of motion (ROM) unless the rehabilitation professions were committed to enhancing reduced ROM. Similarly, there would seem little merit in documenting either the considerable social disadvantage that accompanies SCI (eg using CHART) or measuring the diminished QOL experienced by those who are sent to nursing homes, or who experience occupational deprivation and other forms of social

disadvantage, unless the rehabilitation professions are committed to working to alleviate these conditions also.

If the medical and rehabilitation professions are to take seriously the results of our research, a way must be found to address the problems associated with SCI at *both* the cellular and the societal levels. If it is acknowledged that social, physical, economic, legal and political environments increase the problems confronted by people with SCI and reduce the quality of their lives then interventions must be targeted not solely at individuals – teaching them to live in a world designed to meet the needs of the dominant population – but at influencing public policies and community planning.^{172,173} Commitment to reducing, for example, pain, spasticity, pressure sores and respiratory problems (factors equated with poor QOL) should be matched by a commitment to reducing, for example, nursing home admissions, occupational deprivation, inadequate access to health-care and poverty (also factors associated with poor QOL). How this might be accomplished would be a worthy avenue for future research.

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