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Quality of life after spinal cord injury: a meta analysis of the effects of disablement components

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While objective measures of impairment, disability and handicap can serve as outcome measures for the providers of medical and vocational rehabilitation services, for persons with spinal cord injury (SCI) themselves the only relevant measure of quality of life (QOL) is their own judgment as to their well-being. Subjective QOL in persons with SCI has been measured as happiness, psychological well-being, morale and life satisfaction. Various studies have reported inconclusive or contradictory findings, likely **due to small sample** size, sample composition, measures used, and other methodological issues. A meta analysis was performed to try to resolve these apparent discrepancies.

A total of 22 studies, with an average sample size of 102, was retrieved. Information on the relationship between QOL and impairment, disability, and handicap, if provided, was abstracted. Findings include the following: persons with SCI tend to report lower subjective well-being than non-disabled people; the relationship between impairment and QOL is weak (mean correlation: -0.05 ; 95% confidence interval: -0.12 to 0.02), and generally not found to be statistically significant; the association between disability and QOL is somewhat stronger (mean r : -0.21 ; confidence interval: -0.27 to -0.14), but not found consistently; the relationship between QOL and (aspects of) handicap is strongest (range for mean r : -0.17 to -0.48), and fairly consistently found.

The number of studies available is too small to make analysis of factors that explain contradictory findings possible. Further use of subjective QOL measures in research on long-term outcomes of SCI is recommended, in order to properly reflect the perspective of the patients/clients themselves.

Keywords: quality of life; spinal cord injuries; meta-analysis

Introduction

Quality of life means many things to many people. Some emphasize material possessions; others focus on the integrity and functioning of the body; some refer to the quantity and quality of interpersonal relations and others again focus on life satisfaction or mental and spiritual well-being. Whatever one's conception, most people will agree that a spinal cord injury (SCI) constitutes a significant challenge to quality of life (QOL).

A spinal injury affects, directly or indirectly, those aspects of life that have been declared by researchers to constitute QOL or at least found to greatly influence people's judgments of QOL: health and personal safety, independence, the ability to earn an income, access to material comforts, the ability to have and raise children, the likelihood of developing a close relationship with a member of the opposite sex, or a

close and supportive network of friends. Body image, self-concept and one's understanding of self may be significantly affected, directly or indirectly.

However, as independent living proponents point out, a spinal cord injury does not necessarily diminish QOL. Provided resources are available (foremost, medical rehabilitation, assistance with coping and adjustment, and a supportive social network) and provided that social reactions, public policies and environmental barriers do not prevent the person from pursuing work, education, leisure, civic duties and other activities, the quality of the life of a person with SCI can be very similar to that of the average non-disabled person. It even may be better than before injury, or than experienced by non-disabled peers.¹

We have limited information on what are the determinants of QOL for persons with SCI, overall and in various subgroups. We know even less how subjective QOL changes over time after injury, as the person and his social circle adjust (or fail to adjust) to the new realities in their lives. More research in this area is needed.

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The measurement of quality of life

Two approaches have been used to investigate QOL of individuals.^{2,3} The *subjective* approach (also designated as the evaluative or internal determinants method), exemplified by the work of Andrews and Withey⁴ and Campbell *et al.*,⁵ defines QOL as the congruence between aspirations and accomplishments, *as perceived by the person involved*. Judgments on congruence can be either more cognitive – the approach taken by the life satisfaction proponents (eg Cantril⁶ and Zhan⁷), or predominantly emotional – the approach of those who focus on happiness or positive and negative affect (eg Bradburn⁸). The *objective* approach defines QOL as the sum total of a person's scores on characteristics that can be objectively determined. The components of QOL are such simple things as income level, the number of television sets in the home, and the desirability of the neighborhood in which it is located. All are characteristics that are (supposedly) valued with a high level of consensus by members of a society – eg to be well-educated is better than to be poorly educated; having few symptoms of a chronic disorder is better than having many symptoms.

Health-related QOL (HRQOL) refers to those components of overall (objective) QOL that center upon or are directly and indirectly affected by health, disease, disorder and injury: signs, symptoms, treatment side effects, physical, cognitive, emotional and social functioning, etc.³ It commonly is used as a measure of health care outcome, and as such overlaps with the concept of health status. There is quite some variety in the *nature* of the characteristics included in various HRQOL indexes and batteries used in the published literature – functional status, fatigue, pain, social and physical activities, bed or home restriction days, neuropsychological function, etc.

Quality of life after spinal cord injury

Over the years, a number of studies have investigated components of life quality (as defined in the *objective* QOL tradition) for persons with SCI. For instance, there are many publications on health status, impairment and disability levels after injury. Studies using the concept of handicap are increasingly being published (eg Whiteneck *et al.*⁹), and there is an extensive older research literature on each of the major constituent components of handicap, eg independent living, marital status, education and employment status, and to a lesser degree on avocational pursuits (see Dijkers *et al.*¹⁰). In the *objective* tradition of QOL research, these are all commonly considered major components of QOL. Some studies have actually used that term (eg DeVivo and Richards¹¹; Quiel¹²).

An even more extensive literature exists on the psychological and emotional sequelae of spinal cord injury, studied under such labels as coping and adjustment, depression, disability acceptance, and control.^{13–19} The self-reports most of these studies use reflect subjective QOL at least to some degree.

Studies utilizing subjective QOL measures have become more common only during the last 10 years. Crewe²⁰ was the first one to systematically study QOL (defined as life satisfaction) in persons with SCI, using a method proposed by Flanagan.²¹ She found that her SCI subjects reported less satisfaction than the nondisabled persons in Flanagan's national study, especially in the domains of sexual relations with spouse, employment (work) and financial (material) well-being, but also in the domains of health and social relationships. This finding was replicated in a number of studies;^{22–27} only two studies involving (older) veterans report equal or better QOL than the comparison groups involved.^{28,29}

Most research has not compared the subjective QOL of persons with SCI with that of non-disabled peers, but has focused on sources of happiness and satisfaction in persons with a spinal injury. Family relationships, living arrangements, social life and passive recreation tend to be domains with which satisfaction is high, while low satisfaction ratings are common for finances, sexual life, and employment.^{20,27,30,31}

There is less consensus with respect to other findings. In a recent review, Fuhrer³² summarized findings of 19 studies (mostly published since 1990) of the relationship between subjective well-being (satisfaction, morale, happiness, etc) and the three components of disablement: impairment, disability and handicap. His results may be summarized as follows:

Relationship with subjective QOL

	None (zero)	Negative, not sign.	Negative, sign.
Impairment	13	1	1
Disability	4	1	2
Handicap			
occup. status	2		6
social activity	1		4
mobility			3

It is possible that the lack of a statistically significant relationship between disablement components and well-being reported by so many of these studies was due to a small sample size. Most investigations did not have sufficient power to demonstrate the existence of even a moderately strong relationship. The discrepant findings may also be due to other methodological weaknesses, the varying nature of the samples employed in the studies (in terms of age, time since injury, gender, etc), or the range of instruments used to measure subjective QOL. Fuhrer³² was limited to concluding that QOL appears to be little, if at all, related to impairment, inconsistently to disability, and commonly to various aspects of handicap. The relative strength of the relationships, or the circumstances under which disability affects QOL, could not be addressed in his qualitative review.

Meta analysis is a method of summarizing the results of existing studies in a particular area *quantitatively* rather than qualitatively. It statistically pools the results of multiple independent studies, using subgroups of studies (based on nature of sample, research design, etc) as necessary. Problems of small sample size, research design differences and varying nature of samples can be addressed by meta analysis. The purpose of this paper is to describe quantitatively the relationship of subjective QOL with three aspects of disablement; impairment, disability and handicap.

Methods

Medline, Excerpta Medica, and ClinPSYC searches were used to identify relevant papers. Key words used were spinal cord injury, and life satisfaction, well-being, and quality of life. This was supplemented by querying experts, searching the investigator's files, and review of references provided in the studies found. The following criteria were used in selection:

- a subjective QOL measure was used, either a global single item, or an index that combined scores on a broad battery of items. This excluded studies that considered solely eg sexual satisfaction (eg Siösteen *et al*³³).
- empirical data were reported in such a way that at least one effect size measure of the relationship between QOL and disablement could be calculated, for a sample containing *only* spinal cord injured individuals. This excluded studies that reported on mixed disability samples, eg Stensman³⁴ and

Chwalisz *et al*³⁵, or provided only qualitative findings (eg Dew *et al*²⁵).

A total of 29 publications describing 19 samples was identified (see Table 1). The average sample size was 102 persons, and for the average sample four useful effect sizes could be abstracted or calculated. No evaluation of the quality of research reports was performed. Abstracting of all information was done independently by two persons, using a custom-designed form. The following information was abstracted (if available): bibliographic information; size of sample; distribution by gender and neurological category; mean for current age, age at injury, time since injury, education at injury and current education; impairment, disability and handicap measures reported, and their relationship with QOL; identity of QOL measure(s) used. For those studies that offered a comparison of QOL between persons with SCI and non-disabled persons, QOL information for both groups was abstracted. Disagreements in abstracting were solved by discussion.

In order to maximize the number of effect sizes available for analysis, some estimates were used. For instance, if a report contained means for two groups, but no standard deviations, the standard deviation reported in a different study for the same QOL measure was substituted. All effect sizes and other relevant information was entered into computer files for further processing. The Pearson correlation coefficient was selected as the standard effect size indicator (except for comparisons of persons with SCI and non-disabled groups), and all other effect sizes

Table 1 Demographic and injury information on the samples included in the analysis

Sample # and references	Sample size	Gender		Current age		Age at Injury		Years since Injury		Current Education		Injury Level		Measure(s) of QOL
		%F	%M	Mean	SD	Mean	SD	Mean	SD	Mean	SD	%Par	%Tet	
1 ^a 36	42	33	64	33.1	—	21.4	—	13.4	—	12.8	—	0	100	9
1 ^a	45	22	75	36.6	—	27.8	—	8.9	—	13.9	—	0	100	9
2 37	174	13	87	—	—	33.0	—	—	—	—	—	—	—	9
3 38	100	20	80	33.7	—	27.3	—	6.9	—	12.6	—	34	66	1
4 39	91	19	81	—	—	21.6	—	9.5	—	—	—	—	—	4
5 26	60	17	83	36.2	7.9	—	—	11.9	7.2	—	—	50	50	2
6 40	43	28	72	47.2	—	34.2	—	12.1	—	—	—	—	—	9
7 18,22	100	10	90	56.0	—	35.0	—	—	—	—	—	—	—	2,7
8 30	31	39	61	35.0	—	—	—	—	—	—	—	—	—	10
9 19,27	140	29	71	37.0	11.5	26.4	11.0	10.6	7.8	—	—	—	—	2
10 ^b 23,41	98	17	83	33.5	—	—	—	2.3	—	—	—	—	—	9
11 42	70	0	100	55.2	7.5	25.3	7.6	29.5	8.1	—	—	47	53	5
12 43	40	0	100	51.4	10.2	—	—	22.3	12.3	12.1	2.4	50	50	6
13 44	17	12	88	—	—	—	—	—	—	—	—	41	59	9
14 45	128	14	86	—	—	—	—	—	—	—	—	0	100	9
15 9,46	282	13	87	53.2	—	—	—	—	—	—	—	65	35	2,3,7,9
16 ^c 14,31,47–52	449	18	82	35.2	13.0	25.7	12.0	9.5	6.0	13.1	3.0	45	55	8
17 53	29	21	79	23.0	—	—	—	—	—	—	—	38	62	11
18 54	15	33	67	38.1	—	—	—	—	—	—	—	27	73	9,12

^aInformation on two separate subsamples. ^bInformation from reference 27. See text. ^cInformation from reference 54. See text.

(most frequently, *t*-tests) were 'translated' into correlations using standard formulas.⁵⁵

Several publications provided information on the same sample (see reference listing in Table 1). These were compared, and duplicative effect sizes eliminated. Krause and colleagues wrote a series of papers^{14,31,47-52} on data resulting from a partly cross-sectional (cohorts established in 1973 and 1985), partly longitudinal (data collection in 1973, 1985 and 1989) design, with the number of cases dissimilar in most papers due to the subsample considered. After much study, it was decided to treat this as a single study. The two papers by Siösteen *et al*^{23,41} also appear to describe the same sample, with the later publication having a larger size. They were also considered one sample.

Most studies reported effect size information for multiple indicators for each of the categories of correlates of QOL (especially handicap), and some used multiple QOL measures. All effect size calculations based on the combined samples were done in two ways: with and without such duplications. This allows estimation of the contribution of studies that report multiple results.

In most social and behavioral research, not all subjects complete all questions or tests; consequently, the actual number of cases (N) for each reported statistical test is smaller than the nominal sample size reported in the 'Methods' section of publications. Most papers do not report the actual N for each test, and meta-analysis is forced to use the nominal N. This may artificially inflate the cumulative sample size, and make it more likely to find statistical significance. In the current analysis, for most effect sizes abstracted only the nominal N was available.

For comparisons between persons with SCI and non-disabled persons, a table presenting number of cases, mean, and standard deviation for the two groups is presented, as well as (if available), the results of a *t*-test (as reported by the authors or calculated from their data), and Cohen's *d*. The latter is defined as $(X_n - X_s)/SD_n$, where X_n is the mean for the non-disabled group, X_s the mean for the SCI group, and SD_n the standard deviation for the group that is the basis for comparison, the non-SCI sample.

For each of the other categories of correlates of QOL, a table is presented that contains all information that could be abstracted. The table gives the sample number (Sample #) (corresponding to the number in Table 1), the specific measure of QOL used (QOL #), the size of the correlation that was reported (or calculated based on other data provided by the authors) (Corr.) as well as the number of (actual or nominal) cases for that correlation (Cases). The significance level reported by the authors or determined using statistical tables is provided (*p*), as well as the lower and upper bound of the 95% confidence interval for the correlation. For those instances where authors did not report the correlation

(or equivalent information), the sign of the correlation is reported, if available. This allows one to assess whether non-reported correlations have a trend similar to reported ones. Lastly, an asterisk indicates those reported correlations that were included in the random sample drawn to prevent basing conclusions on multiple reports for the same sample. Figure 1 provides an index of the specific QOL measures used in each study included in the analysis. The separate tables indicate what specific measures of impairment, disability and handicap were used in each case.

At the bottom of the tables are provided the following meta analysis results, for all correlations and for the random sample: (1) the mean correlation (calculated by weighting each reported correlation by the applicable sample size); (2) its confidence interval; (3) the value of *p* for a statistical test of the hypothesis that the average correlation is not significantly different from 0.00. A test of homogeneity is also provided. If this test results in a *p*-value smaller than 0.05, it is likely that the correlations summarized are based on substantially different samples (eg US *versus* Sweden), and/or essentially different QOL measures or predictor measures; it suggests that computing a mean correlation in these instances is akin to calculating the mean of apples and oranges.

Results

The cases included in the samples selected for this analysis appear to be fairly typical of persons with SCI (Table 1): the majority are males (64 to 100%), injured at a young age (mean from 21 to 35 years), and about 10 years post injury. The major exception to the latter are the studies that on purpose selected 'older' cases (samples 9, 13, and 18). The percentage of cases with tetraplegia tends to be over 50%; again, some studies selected such cases exclusively (samples 1, 17).

Impairment

Comparisons of the QOL of persons with SCI to that of non-disabled persons are summarized in Table 2. In

- 1 LSS: Life Situation Survey
- 2 LSIA-A: Life Satisfaction Index-A
- 3 Quality of Life and Individual Needs Questionnaire
- 4 Life 3 Measure
- 5 Quality of Life Index (Michalos)
- 6 Quality of Life Index (Padilla and Grant)
- 7 IPWB: Index of Psychological Well Being
- 8 LSQ: Life Situation Questionnaire, Factor 1
- 9 any single-item life satisfaction measure
- 10 LSES: Life Satisfaction of the Elderly Scale
- 11 any single-item happiness item
- 12 Cantril ladder

Figure 1 Index of QOL measures used in various studies of the relationship of QOL with disablement

all instances but two, the QOL of the SCI sample is lower than that of the comparison group selected. The two exceptions are comparisons of the *same* SCI sample with back pain patients ($N=22$) and prisoners ($N=44$), respectively.³⁸ Because of the extensive overlap within the SCI samples and the non-SCI samples, no cross-samples effect size was calculated.

Studies that considered the relationship of QOL to impairment level (Table 3) are based most frequently on a comparison between persons with paraplegia and those with tetraplegia, but ASIA motor scores,⁵⁶ differences between persons with complete and incomplete injuries, and differences between ventilator-dependent and non-dependent tetraplegic individuals are also included. This combination may

explain the heterogeneity of results, although it is not exorbitant. The average correlation of -0.05 indicates that degree of impairment by itself has a very minor effect on QOL. In fact, the correlation is not significantly different from 0.00, absence of a relationship. Figure 2 provides a graphic presentation of all mean effect sizes calculated, and their confidence intervals.

Disability

Seven studies reported on the association between disability and QOL, which generally was found to be negative (the higher the disability level, the lower the QOL reported), and was weak to moderately strong

Table 2 Results for the comparison of persons with SCI with non-disabled persons

Sample #	QOL # ¹	SCI group			Non-SCI group			t-test		Cohen's d
		Cases	Mean	SD ²	Cases	Mean	SD ²	t	p	
1	9	45	4.09	1.73	259	5.36	1.18	-6.14	<0.001	-0.99
1	9	42	4.39	1.75	259	5.36	1.18	-4.56	<0.001	-0.76
3	1	100	89.5	15.0	50	107.0	11.2	-7.25	<0.001	-1.26
3	1	100	89.5	15.0	22	81.1	20.9	—	—	0.55
3	1	100	89.5	15.0	44	74.0	14.9	5.68	<0.001	1.03
7	2	100	10.8	4.3E	4254	13.2	4.3E	-5.52	<0.001	-0.56
7	7	100	2.96	1.28	6928	3.23	1.51	-1.78	>0.05	-0.18
9	2	140	8.8	4.3	4254	13.2	4.3E	-11.91	<0.001	-1.02
10	9	96	58.6	40E	83	16	—	—	—	-0.61
17	11	29	2.96	—	22	3.82	—	-2.68	<0.01	—
18	12	15	5.86	1.7	12	6.50	1.31	-1.03	>0.05	-0.40
18	9	15	—	—	12	—	—	—	>0.05	—

¹See Index of QOL measures in Figure 1. ²Standard deviations denoted by 'E' are estimates

Table 3 Results for association of QOL with impairment

Sample #	QOL # ¹	Imp # ²	Cases	Corr.	Confidence Interval Low	Confidence Interval High	p	Undupl. sample	Homo-geneity
4	4	2	91	?	—	—	>0.05		
7	2	3	100	neg	—	—	>0.05		
11	5	3	70	?	—	—	>0.10		
15	7	2	282	?	—	—	>0.05		
16	8	3	390	?	—	—	<0.01		
12	6	2	40	-0.28	-0.54	0.03	<0.05	*	
3	1	2	100	-0.32	-0.49	-0.13	<0.01	*	
13	9	2	17	0.02	-0.47	0.50	>0.05	*	
5	2	3	60	-0.19	-0.42	0.07	>0.05	*	
6	9	2	43	-0.10	-0.39	0.21	>0.05	*	
10	9	2	96	-0.07	-0.27	0.13	>0.05		
10	9	4	96	-0.06	-0.26	0.14	>0.05	*	
6	9	4	43	0.14	-0.17	0.42	>0.05		
9	2	5	140	0.04	-0.13	0.20	>0.05	*	
1	9	1	89	0.09	-0.12	0.29	>0.05	*	
14	9	1	123	0.11	-0.07	0.28	>0.05	*	
All			847	-0.05	-0.12	0.02	>0.05		<0.05
Undupl.			708	-0.05	-0.12	0.02	>0.05		<0.05

¹See Index of QOL measures in Figure 1. ²Index of impairment measures used in various studies: 1 Ventilator dependence; 2 Paraplegia vs tetraplegia; 3 Unspecified 'severity of injury' or 'level of lesion'; 4 Complete vs incomplete injury; 5 ASIA total motor index score

(Table 4). The apparent lack of homogeneity may be related to the variety of measures of disability that was used in these studies. The average correlation was -0.27 , which is significantly different from 0.00 .

Handicap

The relationship of a large number of aspects of handicap with QOL is reported in this literature, making it possible to analyze the association between

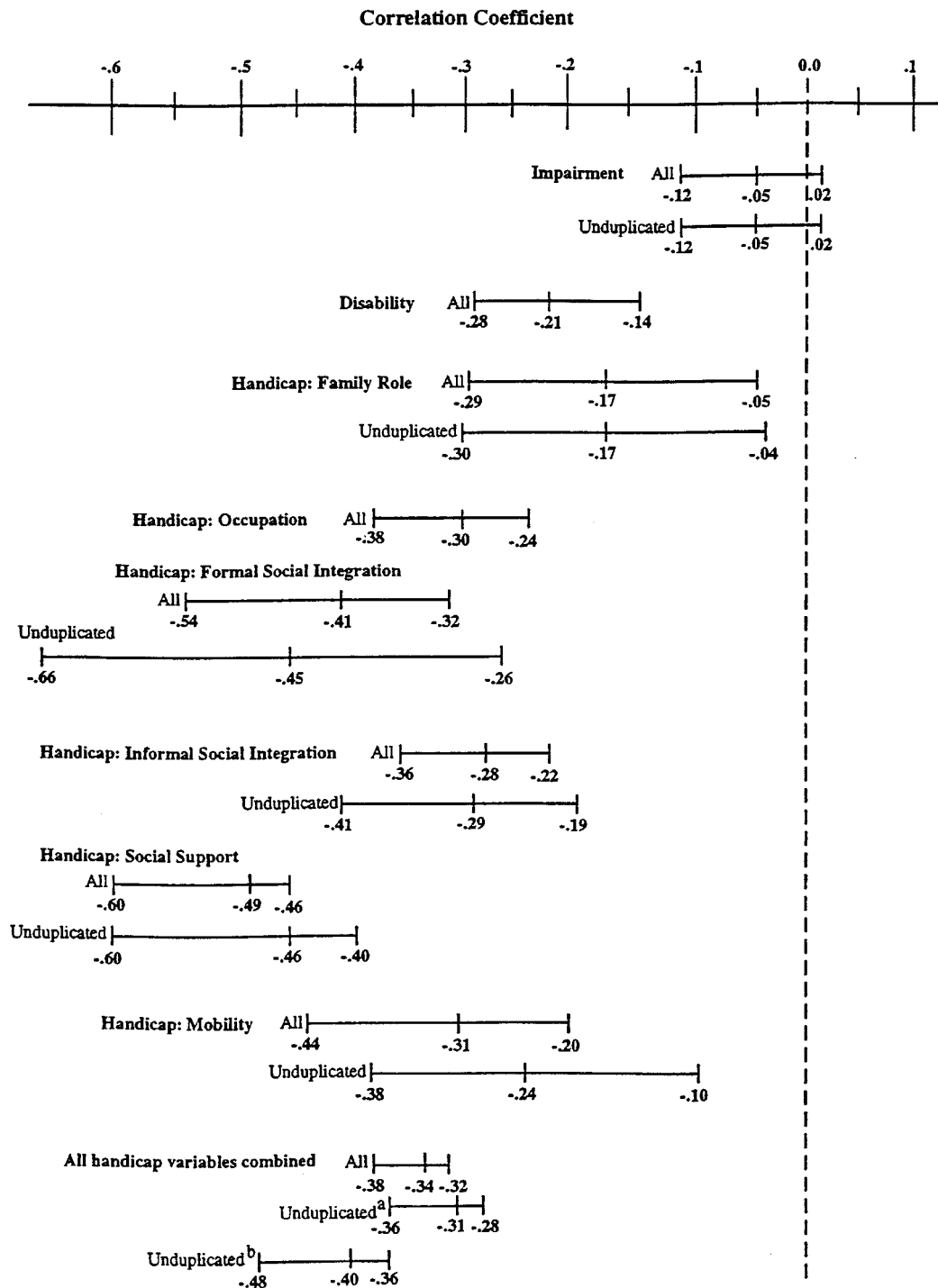


Figure 2 Relationship between QOL and disablement components: correlations and their 95% confidence interval, based on reports in all studies combined. ^aIncludes duplications within a single sample of measures of distinct categories of handicap. ^bIncludes only one measure of handicap per sample

Table 4 Results for association of QOL with disability

Sample #	QOL # ¹	Disability # ²	Cases	Corr.	Confidence Interval Low	Confidence Interval High	p	Undupl. sample	Homogeneity
11	5	5	70	?	–	–	>0.05		
8	10	2	31	–0.66	–0.82	–0.39	<0.001	*	
7	2	4	100	–0.35	–0.51	–0.16	<0.001	*	
13	9	4	17	–0.02	–0.50	0.47	>0.05	*	
4	4	1	91	–0.24	–0.42	–0.04	<0.05	*	
15	9	6	276	–0.29	–0.39	–0.18	<0.05	*	
2	9	3	174	–0.13	–0.27	0.02	>0.05	*	
9	2	5	140	0.07	–0.10	0.23	>0.05	*	
All			829	–0.21	–0.27	–0.14	<0.05		<0.01

¹See index of QOL measures in Figure 1. ²Index of disability measures used in various studies: 1 Katz ADL scale; 2 Barthel index; 3 FIM motor component; 4 ad-hoc ADL assistance measures; 5 FIM (full); 6 increased need for help

QOL and specific handicap dimensions. Lack of a family role (spousal or parental) seems to result in a lower QOL (Table 5 section A); the average correlation is -0.17 . Occupation (work, attending school, or other productive activity) is an even stronger determinant, according to the consensus of ten reports (Table 5 section B). The mean correlation is -0.30 ; there is heterogeneity among the reported associations, however, which may be due to both the nature of the samples and the specific occupational activities reported.

Results for the effects of mobility are also provided in Table 5 (section C); these suggest that mobility is a fairly strong correlate, with a mean value of -0.31 , indicating that those with a mobility handicap have a lower QOL.

Social integration, into formal social organizations or into networks of friends and acquaintances, is also a fairly strong determinant; however, most correlations reported are from a single study. When duplications are eliminated, a rather strong relationship (-0.45 for formal; -0.29 for informal) remains (sections D and E).

Social support is yet another aspect of social integration, which reflects the operation of social networks (to the benefit of the respondent), rather than their existence per se. The four samples for which findings are available show a very strong link between QOL and social support, with a mean value of -0.49 ; the test of homogeneity indicates, however, that the sample and/or measure differences produced significantly different results (Table 5 section F).

Two studies reported on aspects of handicap that were not classifiable in the categories listed above; the one paper that reported the size of the correlation found a negative one (section G).

A comparison of the overall effects of handicap on QOL with those of other characteristics can be based upon the mean correlations reported in Table 6. That there is lack of homogeneity among the correlations considered should not be surprising; if one is willing to disregard such, the correlation between the typical handicap component and QOL can be calculated as

-0.34 . Eliminating duplicative items within the categories gives about the same result (-0.31). If duplication from one category to the next is also eliminated, the sample of items drawn happens to show an even higher correlation (-0.40).

Comparison of disablement components

With the caveats suggested earlier, the mean correlations listed in the above may be compared with one another. In the present case, z-transformed correlations for unduplicated cases were used. The correlation of QOL with handicap (-0.32) is significantly higher (at the $p < 0.001$ level) than the correlation of QOL with impairment (-0.05). It similarly is stronger (at $p < 0.01$) than the relationship of disability with QOL (-0.21). The latter in turn is higher (at $p < 0.01$) than the correlation between impairment and QOL.

Within the area of handicap, the correlation of social support with QOL is significantly higher (at $p < 0.05$ or higher) than the correlation of any other handicap component with QOL. The correlation of formal social integration with QOL (-0.46) is statistically stronger (at $p < 0.05$) than the correlation of the component with the weakest link (family role, with -0.17). All other correlations are not significantly different from one another.

Discussion

These data indicate that persons with SCI on average report a lower level of subjective well-being than the population at large, or the specific non-disabled comparison groups reported on by the papers identified. The only exceptions are comparisons to populations that may be *expected* to have a poor subjective well-being – those in jail, or a different disability group, persons with chronic back pain. The comparisons made by the various authors have a number of shortcomings – especially the fact that major determinants of QOL other than health status/disablement, especially socioeconomic status, gender and age, were not controlled for, statistically or

Table 5 Results for association of QOL with various components of handicap

<i>Sample #</i>	<i>QOL #¹</i>	<i>Handicap #²</i>	<i>Cases</i>	<i>Corr.</i>	<i>Confidence Interval Low</i>	<i>Interval High</i>	<i>p</i>	<i>Undupl. sample</i>	<i>Homo-geneity</i>
A: family role									
6	9	11	43	?	—	—	>0.05		
9	2	11	140	?	—	—	>0.05		
11	5	11	70	?	—	—	>0.05		
16	8	11	85	neg	—	—	<0.05		
16	8	11	286	neg	—	—	>0.05		
10	9	12	56	−0.41	−0.61	−0.16	<0.01	*	
13	9	11	17	−0.17	−0.60	0.34	>0.05		
13	9	11	17	−0.14	−0.58	0.37	>0.05	*	
2	9	11	174	−0.09	−0.24	0.06	>0.05	*	
All			264	−0.17	−0.28	−0.05	<0.05		>0.05
Undupl.			247	−0.17	−0.29	−0.04	<0.05		>0.05
B: occupation									
4	4	32	91	?	—	—	>0.05		
6	9	32	43	neg	—	—	>0.05		
10	9	32	98	neg	—	—	<0.001		
13	9	35	17	−0.21	−0.63	0.30	>0.05	*	
5	2	32	60	−0.39	−0.59	−0.15	<0.01	*	
16	8	32	232	−0.46	−0.56	−0.35	<0.01	*	
10	9	35	50	−0.31	−0.54	−0.03	<0.05	*	
7	2	32	100	−0.33	−0.49	−0.14	<0.001	*	
11	5	32	70	−0.29	−0.49	−0.06	<0.05	*	
19	2	24	140	−0.24	−0.39	−0.07	<0.01	*	
2	9	31	174	−0.09	−0.24	0.06	>0.05	*	
All			843	−0.30	−0.36	−0.24	<0.05		<0.05
C: mobility									
6	9	71	43	?	—	—	>0.05		
10	9	73	56	−0.53	−0.70	−0.31	<0.01		
10	9	74	56	−0.32	−0.54	−0.06	<0.05	*	
9	2	72	140	−0.21	−0.36	−0.04	<0.05	*	
All			252	−0.31	−0.42	−0.19	<0.05		>0.05
Undupl.			196	−0.24	−0.36	−0.10	<0.05		>0.05
D: formal social integration									
3	1	43	100	−0.49	−0.63	−0.32	<0.05		
3	1	41	100	−0.45	−0.59	−0.28	<0.05	*	
3	1	42	100	−0.25	−0.43	−0.06	>0.05		
All			300	−0.41	−0.50	−0.31	<0.05		>0.05
Undupl.			100	−0.45	−0.59	−0.28	<0.05		—
E: informal social integration									
10	9	57	56	−0.39	−0.59	−0.14	<0.01	*	
3	1	53	100	−0.40	−0.55	−0.22	<0.05		
3	1	54	100	−0.34	−0.50	−0.15	<0.05		
3	1	51	100	−0.27	−0.44	−0.08	>0.05	*	
3	1	55	100	−0.27	−0.44	−0.08	>0.05		
9	2	56	140	−0.26	−0.41	−0.10	<0.01	*	
3	1	52	100	−0.09	−0.28	0.11	>0.05		
All			696	−0.28	−0.35	−0.21	<0.01		>0.05
Undupl.			296	−0.29	−0.39	−0.18	<0.05		>0.05

(continued)

Table 5 (continued)

Sample #	QOL # ¹	Handicap # ²	Cases	Corr.	Confidence Interval Low	Confidence Interval High	p	Undupl. sample	Homo-geneity
F: social support									
11	5	64	70	-0.75	-0.84	-0.63	<0.01		
11	5	62	70	-0.72	-0.82	-0.58	<0.01	*	
11	5	63	70	-0.66	-0.77	-0.50	<0.01		
7	2	61	100	-0.45	-0.59	-0.28	<0.001	*	
5	2	61	60	-0.39	-0.59	-0.15	<0.01	*	
7	7	61	100	-0.42	-0.57	-0.24	<0.001		
9	2	65	140	-0.33	-0.47	-0.17	<0.01	*	
9	2	61	140	-0.32	-0.46	-0.16	<0.01		
All			750	-0.49	-0.54	-0.43	<0.01		<0.001
Undupl.			370	-0.46	-0.54	-0.38	<0.05		<0.001
G: other aspects of handicap									
6	9	91	43	?	-	-	>0.05		
2	9	92	174	-0.18	-0.32	-0.03	<0.05		
All			174	-0.18	-0.32	-0.03	<0.05		-

¹See index of QOL measures in Figure 1. ²Index of handicap measures used in various studies: 11 marital status; 12 home making; 13 parenting; 31 student status; 32 employment status; 33 yes/no employment income; 34 CHART occupation; 35 work/study status; 41 activity in social organizations; 42 frequency of attendance church services; 43 voluntary organization memberships; 51 frequency visiting neighbors; 52 number of close friends; 53 frequency of interacting with friends/relatives; 54 in-home visits by friends; 55 out-of-home visits friends; 56 CHART social integration; 57 social activity level; 61 Decker/Schulz measure; 62 ISEL-instrumental; 63 ISEL-information; 64 ISEL-emotional; 71 driving; 72 CHART mobility; 73 owning a car; 74 neighborhood mobility; 91 regular exercise; 92 frequency out exercising

Table 6 Results for association of QOL with all handicap variables combined

Sample #	Cases	Corr.	Confidence Interval Low	Confidence Interval High	p	Homo-geneity
All	3279	-0.34	-0.37	-0.31	<0.001	<0.001
Undupl. ¹	2226	-0.31	-0.35	-0.27	<0.001	<0.001
Undupl. ²	949	-0.40	-0.45	-0.34	<0.001	<0.001

¹Includes duplications from studies listing handicap measures for two or more categories of handicap. ²Includes only one measure of handicap per sample

otherwise. However, the consistency of the result is quite convincing: the average person with a spinal injury experiences a lower quality of life than the average person without such injury.

Components of disablement are likely explanations for this discrepancy. The World Health Organization's distinction of three separate, but causally and temporally related constructs is a useful conceptualization to 'tease apart' the train of consequences of disease and injury.⁵⁷ Spinal cord injury is an 'ideal type' (in the Weberian meaning of the term) for the study of disablement, for several reasons. The most important is that the three components can be measured separately, with a high level of sensitivity. In addition, cognitive deficits, which generally cannot so neatly be split into impairments and disabilities,⁵⁸ in most patients with SCI are absent or of minor import. Lastly, SCI typically is incurred by young people who are basically healthy; deficits due to other disorders or to aging are not there to cloud the

picture. While the specific findings from the current meta-analysis may not be generalizable to other disability groups, the overall outline of the linkages between disablement components and subjective well-being should apply broadly.

It would appear that Fuhrer³² was right in concluding, based upon his *qualitative* summary of the literature, that QOL appears to be little, if at all, related to impairment, and commonly to various aspects of handicap. His characterization of the relationship between QOL and disability as inconsistent would seem less appropriate: six out of seven correlations identified were negative with a range from -0.02 (for a small study with *N* of 17), to -0.66 (from a report that *may* be marred by typographical or statistical problems).

While it is tempting to think of the relationship between QOL and the various disablement components as one of simple one-way causation (that is: disablement is the cause of quality of life), that is not

necessarily correct, and reciprocal causation should be seen as a possibility. It is conceivable for quality of life to affect impairment, especially if secondary disablement resulting from lifestyle issues etc. are considered. Even more likely, subjective well-being may affect disability and handicap. Someone who for whatever reason does feel that his or her life is not the best it could be is not likely to engage in self care activities that constitute an effort, let alone spend energy in taking up or discharging the various social roles that are wrapped up in handicaps. Without longitudinal designs that make it possible to statistically separate out the effects of QOL on eg handicap and *vice versa*, it is difficult to estimate to what degree subjective well-being affects handicap and disability.

This meta analysis did not correct effect sizes for various methodological shortcomings of the studies summarized, as is practiced by the adherents of the approach of Hunter and Schmidt.⁵⁹ Specifically, many of the studies used single-item measures of QOL, which have low reliability. This attenuates the correlation between QOL and its predictor variables. Similarly, no correction was made for dichotomization of continuous variables, eg impairment, which generally was reported as a paraplegia *versus* tetraplegia or other two-group distinction. Handicaps also were often measured as simple dichotomies (yes/no married, for instance), although more sensitive measures were not uncommon.

On the other hand, the association between QOL and its best predictors among the handicap factors may have been artificially inflated. As is the case in almost all studies of social support, social support was never measured *independently* from the recipient, the person with SCI. Because generally the subjects in these studies completed social support measures at the same time that they completed subjective well-being measures, contamination may have occurred. Some subjective well-being indices even include support items, indicating how closely related the two are. For that reason, one may want to exclude the concept of social support from the factors constituting handicap. Even if there is no need for such, and there is no overlap between QOL measure and social support measure, tainting of the association is a possibility. Quality of life indices, both life satisfaction and happiness ones, would seem to be subject to social desirability problems, although Diener *et al*⁶⁰ reported there was no such problem with the Satisfaction with Life Scale.

An earlier meta-analysis of the relationship between disablement and QOL in spinal cord injury by Evans *et al*⁶¹ also came to the conclusion that among persons with SCI, QOL is negatively correlated (-0.22) with disability. However, as was pointed out by Fuhrer,³² that analysis used both 'objective' and 'subjective' QOL measures interchangeably, and did not distinguish between impairment, disability and handicap.

Evans and associates⁶¹ did, however, address the 'file drawer problem' – the concern that because of

the bias of researchers, peer reviewers and editors, positive (that is, statistically significant) results get into the published literature, while negative ones (no rejection of the null hypothesis) never get written up, or at least never get further than the file drawer or an editor's desk. Evans *et al* performed a test to determine to what degree the result of their analysis was 'at risk' for the same reason, and found that 22 studies confirming the null hypothesis (of no relationship) would need to exist to offset their result – an unlikely state of affairs. Most of the studies included in the present analysis did not have a specific hypothesis to begin with, but aimed to describe an SCI sample, using a variety of socio-psychological and other outcome measures, including an index or item of QOL. The authors avoided a file drawer destination by reporting selected findings of interest. 'Negative' results were frequently reported (see the Tables), although generally not with as much specificity as is needed for meta analysis: in case of the 'not significant' test result, the specific parameters were not supplied. However, given this pattern, and Evans *et al*'s earlier finding,⁶¹ it is not expected that unpublished research exists to contradict the current findings.

At several points it was noted that the effect sizes reported were heterogeneous. Analysis of those characteristics of the samples (average age, percent female, etc.) or the variables (specific QOL measure used, disablement measure used, etc) distinguishing low from high effect sizes is a possible solution to such a problem; the samples (effect sizes) are split into smaller, more homogeneous groups which are used to test *ad-hoc* hypotheses (eg 'single item QOL measures will result in weaker correlations due to more extensive attenuation'). However, the number of studies currently available is too small, and the *N* of cases for each too limited, to make possible analysis of factors that explain contradictory findings, beyond weak *ad-hoc* guesses based on the data. Presumably, with the focus on QOL currently found in the medical and rehabilitation literature, in 5 or 10 years there may be more studies, reported in adequate detail, and such an analysis will be possible.

Because subjective quality of life is such a new area of study, the literature is lacking in hypotheses as to what specific elements of the 'cascade of consequences of injury'³ have the most effect on well-being. The findings reported here may come as a surprise to some – for instance, that body integrity issues play no large role. To others, they may constitute a confirmation – eg that integration into family, the world of work and the larger community is the most crucial element. In a sense, the ranking of the three disablement constructs in terms of their correlation with QOL is good news: while there currently is little that can be done to decrease impairment (especially in chronic SCI patients), rehabilitation specialists have the skills to diminish disability (using training, providing aids and appliances, etc). They also can do

much to minimize handicap, although changes in the larger society often are also needed, eg breaking down of attitudinal barriers.

Further research in this area is needed, in order to investigate the relationship of subjective well-being to disablement in more detail. Specifically needed is longitudinal research utilizing clinicometrically strong measures of impairment (eg ASIA motor scale⁵⁶), disability (eg FIM⁶²), and (elements of) handicap (eg CHART⁶³) in one and the same study, along with valid and reliable measures of (various aspect of) subjective well-being.

Knowledge as to what factors contribute most to subjective QOL after SCI may assist policy makers in deciding which interventions to support in order to maximize QOL generated per dollar invested. The measurement of QOL may contribute to a very realistic and pragmatic evaluation of the outcomes of policies, programs and interventions. Similarly, knowledge of QOL and its determinants may assist service providers to be more aware of interindividual variations, and of the effect of social variables (race, ethnic group, generation) on this patterning. Only the perspective of patients/clients themselves is a useful guide to where resources can be utilized most effectively.

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