

Estimating social adjustment following spinal trauma – I: Who is more realistic – patient or spouse? a statistical justification

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Whilst assessment of functional independence has been accomplished, to a greater extent, following spinal trauma, assessing social adjustment remains an area requiring considerable further investigation. Providing premorbid estimation of adjustment is an area which presents a number of methodological difficulties both in the collection and interpretational of longitudinal data. Such analyses tend to allow overall estimates of adjustment to be made but which lack individual specificity. Analyses are presented of over 250 individuals, and their closest relative's assessment, of social adjustment to their spinal cord injury. Using a modification of an established scale for assessing social adjustment¹ it has been possible to establish the statistical level of agreement and address the hypothesis of differential perception of the extent of adjustment problems by the injured person and their closest relative. The study allows for the conclusion that an injured person's perception of adjustment is at least as reliable as their closest relative, and that there is further evidence to support the essential accuracy of their estimations of premorbid and current levels of adjustment. Both issues are of clinical importance, particularly in relation to any medico-legal compensation aspects.

Keywords: spinal cord injury; social adjustment

Introduction

Spinal trauma is one of the most devastating injuries which an individual may experience.² The sudden alteration from activity to often total immobility, associated with full cognitive awareness and control is unique to such trauma, and produces considerable demands on both the individual and their relatives.³ Adjustment to such an event is an immensely complex procedure, and considerable research effort has been made to assess those factors which may be associated with 'good' or 'bad' adjustment; can an individual who chooses not to work in the light of personally supportive social circumstances be viewed as any more well or less well adjusted than someone who chooses to return to work and support their family? Whilst cultural and moral mores may incline us to the view that the latter has done more to 'adjust' to their altered circumstances, both continue to function adequately in their receiving environment and community.

Assessment of an individuals level of functional independence has been accomplished in rehabilitation medicine, to a greater extent, using standardised scales, such as the Barthel Index (BI),⁴ and the PULSES profile.⁵ Such scales assess variables which may have an

agreed quantum applied to their occurrence and level of independent achievement. However, functional ability in an institutional setting may not equate with a willingness or an ability to manage in the community. Indeed the incidence of marital difficulty,⁶ suicide⁷ and admission for avoidable post-treatment complications such as pressure sores⁸ is testament to the fact that variables other than practical ability affect global adjustment to spinal cord injury. Valid and reliable assessment of social adjustment and quality of life are both less well defined and more difficult to quantify.

The ability to provide assessments of social adjustment and perceived quality of life have intrinsic value not only in respect to clinical care in the hospital and community but also in medicolegal work. Research has concentrated on those factors related to adjustment such as individual personality and social factors. The results of such studies have supported three often repeated and independently derived conclusions:

- 1 Specific disabilities, such as SCI, are not associated with identifiable personality types.
- 2 There is no simple relationship between severity of disability and degree of psychological impairment. ie, those whose injuries result in tetraplegia are not necessarily less well adjusted than those whose injuries result in paraplegia.

3 There exists a wide range of individual reactions to disability.

Despite the availability and continued development of standard scales to assess functional improvement there remains a paucity of valid and reliable information concerning the importance of psychosocial variables in measuring and promoting rehabilitation efficacy. Granger *et al*⁵ in a review of the reliability of functional assessment scales in assessing the impact of multiple sclerosis concluded that of the scales used, including the FIM, none were able to determine the individuals level of satisfaction with rehabilitation without the help of a further measure of affective state (the Brief Symptoms Inventory.⁹) Even the inclusion of such a measure of individual estimation of adjustment fails to provide conclusive evidence of rehabilitative efficacy and adjustment as it does not take account of either premorbid adjustment, or the demand effects of the experimental situation.

Other researchers have attempted to examine the longitudinal process of adjustment to spinal cord injury and other disabilities by including some measures of perceived quality of life.¹⁰⁻¹³ Crewe and Krause¹² surveyed individuals with SCI in 1974, 1985 and 1989 using the Life Situation Questionnaire (LSQ) which examined activity levels, frequency of medical treatment, ratings of satisfaction with various areas of life, and estimations of adjustment. The later surveys included most of the surviving participants of the 1974 study together with a group of more recent injuries. They grouped patients according to marital status and found considerable differences in satisfaction with life ratings for the married and single groups. There remain a number of methodological difficulties both in the collection and interpretation of longitudinal data and for this reason such studies are able only to provide overall estimates of adjustment which lack individual specificity.

Attainment of an acceptable quality of life may thus be seen as the ultimate goal of rehabilitation. It clearly does not equate with functional loss as many people with tetraplegia report a good quality of life, while many lower level injuries report considerable dissatisfaction.² Quality of life is generally described as 'quantifiable estimation of happiness or satisfaction with those aspects of life which are important to the specific individual'.¹³⁻¹⁵ Quality is seen as being synonymous with satisfaction,^{16,17} and life satisfaction is considered to embody an assessment of life as a whole based on how well personal goals match with personal achievement.¹⁸ Other components of quality of life include self esteem,¹⁷ health and functioning, and social and economic stability.¹⁴

In assessing adjustment following trauma, there are a number of approaches available to the investigator, each of which brings its own problems. A major requirement of any estimate of adjustment, or change, is knowledge of the person prior to injury. Thus judgements by professionals are limited by the absence of knowledge of the SCI individual's pre-morbid

personality. Reports from significant others, such as school or work reports are the only options available to the investigator. However, by relying on such data, the principle advantage of the professional's assessment (namely expertise and objectivity) are lost. Furthermore, accurate clinical history taking is both time consuming and prone to inaccuracy by dependence on disparate and often contradictory opinions.

There is little available data which examines the reliability of self-report data in the SCI population, although evidence from other areas indicates such accounts to be questionable, reliant as they are on historical recollection and the increasing fallibility of such memories in the light of increasing time since trauma.¹⁹

Few studies have attempted to examine whether the reliability of such data may be verified by inclusion of a further referent. The use of relatives to provide an independent assessment of adjustment has been used in other areas. Despite evidence to suggest that families are also influenced by the processes involved in both denial and selective memories²⁰ it may be inferred that if both independently provide corroborative and comparable evidence, then the likelihood that such evidence has greater reliability is enhanced.

The Katz social adjustment scale has been used frequently to assess relatives estimates of function following trauma¹ and it has a number of advantages over similar scales which attempt to assess personality issues; it does not rely on a professional rater to complete the form, the items contained cover a wide range of social and emotional behaviour, the items are designed to assess behaviour in the community, and there are extensive comparative data available on psychiatric and normal populations.²¹ However, the Katz scale does not permit an evaluation of change, since pre-morbid adjustment is not measured. The scale was therefore modified in an earlier investigation by the present authors to allow such an examination, and was found to have good face and content validity, and reliability.²²

The purpose of the present investigation was to administer this scale to a group of people with spinal cord injury and a comparable scale to their closest relative or carer who had known them since before their accident, in order to assess the degree of concordance between the resultant responses.

Method

Information was obtained from 251 individuals, and their closest relative or carer, following spinal trauma; 156 in the UK, 95 from the USA. The two participating centres were the MRSIC, Southport, England and Craig Hospital Spinal Injury System, Englewood, Colorado, USA. Two hundred individuals were selected randomly from the databases held within each Centre ($n=400$), using criteria designed to obtain cases less than 10 years post injury, and with a known partner/established carer. The scales were sent out by

post with a reply paid envelope and resulted in a return rate of 302. Forty-five contained non-completed data either from the patient or partner, with a further six uncompleted by both parties. The Modified Katz Social Adjustment Scale (MKATS) consists of 126 questions, with each question scored on a 4 point rating scale; the injured person is asked, for example, 'Do you have bad dreams'. The person marks a 'X' on the scale for 'before the injury' and a 'O' on the scale for 'at the present time'. The responses are placed in squares marked 'Almost Never', 'Sometimes', 'Often' or 'Almost Always'. The relatives questionnaire differs only in terms of person (ie 'Does the injured person have bad dreams'). The statistics measured were: the percentage of concurrent ratings for each question, the value of kappa for each question, and the Wilcoxon signed rank test statistic for each question.

Kappa measures the level of agreement between two raters; in this case, 'self' and 'relative'. Kappa is a normalised measure of the proportion of agreements in excess of that expected purely by chance, ie by assuming ratings to be independent. If a_e is the expected proportion of cases for which both methods agree (assuming independence), and a_o is the observed proportion of cases for which ratings agree, then kappa is given by

$$\frac{a_o - a_e}{1 - a_e} \quad \text{Eqn1.1}$$

Kappa is generated by SPSS/PC⁺, with an associated t statistic. Brown and Benedetti²³ suggest that $0.4N$ is a suitable approximation to the degrees of freedom, where N is the total number of observations. Most complete two-way tables contained responses from between 220 and 240 patients and relatives; therefore 90 degrees of freedom was taken as an appropriate approximation.

No individual comparisons of statistical tests were carried out due to the problems of assessing significance associated with multiple testing. The probability of a type 1 error (the null hypothesis is rejected) increases as the number of tests increases. The true experiment-wide significance level of a number of tests, each with individual significance of 0.05, is as follows;

Number of Tests	Overall P
1	0.05
2	0.975
5	0.23
10	0.60

Therefore, it was considered more appropriate to compare the distribution of the observed t -values to a t -distribution on 90 degrees of freedom.

The Wilcoxon signed rank test was used to examine the hypothesis that patients exhibit more denial (identify fewer problems) than relatives.

Results

The mean agreement rate was 69.2% (sd=15.04, range=36.1%–100%) for all questions. For the majority of questions, relatives and patients concur in their assessments at least 60% of the time.

Comparison of the curves in Figure 1 shows that the t -statistics associated with the kappa scores from the present investigation differ considerably from the Student's t -distribution with 90 degrees of freedom. This indicates that the level of agreement between patient and relative is higher than would be expected by chance alone.

Figure 2 compares the observed z -values from the Wilcoxon signed rank tests to a standard normal distribution. This indicates that although the mean is closer to zero there is much greater variation in the z -scores than would be expected if the null hypothesis (that patients and relatives agree) were true.

Further examination (Figure 3) indicates that the majority of mean differences are small (range -0.3 to +0.15), so high z -scores are a function of the high number of cases. More importantly, the mean

Distribution of Kappa t-statistics compared to t distribution on 90 degrees of freedom

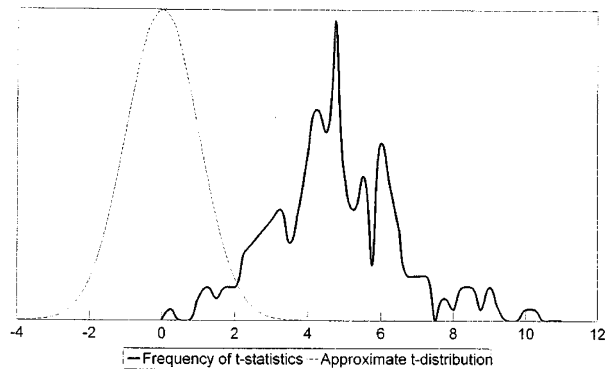


Figure 1

Comparison of observed z-scores from Wilcoxon signed-rank tests to Normal (0,1)

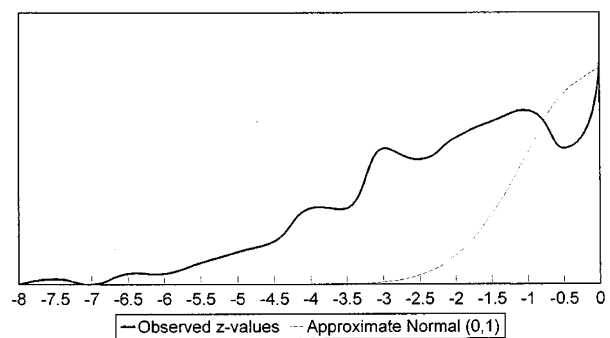


Figure 2

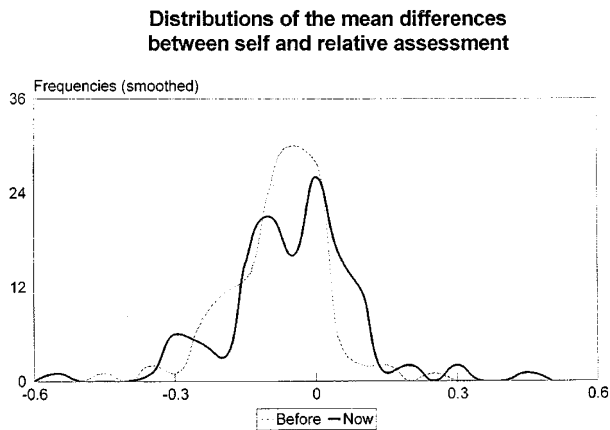


Figure 3

differences tend to be in the same direction, the 'Before Injury' and 'Now' curves being similar, indicating that the influence on the quantity of interest (the difference score before injury-now) is minimal. Clinically this can be interpreted as indicating that the differences between how relatives and patients assess adjustment is consistent over time.

Interpretation of test results

The majority of questions in the MKSAS ask how often 'negative' personality traits are observed. As a result, it is common for most responses to be 'almost never' or 'sometimes'; hence, a high level of agreement might be expected by chance. This was the motivation behind the use of kappa; if a high level of agreement is to be expected by chance, then an even higher level must be attained for significance to result, which was the case in this investigation.

Intuitively, given the large number of variables assessed, it may be expected that some variability would exist between the perceptions of patients and relatives; in particular, whether patients indicate, for example, some element of denial. Current analyses offer no support to a hypothesis that patients experience more denial than relatives. There is some weak evidence to the contrary, ie that patients appear to identify more problems than relatives, and this is shown by the more frequent occurrence of negative values in Figure 3.

Figure 3 also shows that the tendency for patients to identify more problems is more pronounced for the 'before' scores than for the 'now' scores. Since the difference score is calculated by subtracting the score for 'before' from the score for 'now', the net effect may be for a relative's difference score to be higher than the patient's. There are two possible explanations for such a discrepancy: relatives identify more problems post-injury, or patients identify more problems pre-injury. The above analyses indicate the latter to be correct in this instance.

Examination of the questions for which the mean differences are greatest (eg can't get certain thoughts out of my mind; do you curse other people?; do you talk too much?) shows no identifiable trend. It is common for questions showing a large mean difference, to do so both pre- and post-injury; the effect on the difference scores for these is therefore minimal. There are only two instances of large differences in opposite directions: the questions 'are you able to remember the names of people you know well?' and 'do you speak clearly?' For both of these, relatives identified fewer problems pre-injury and more problems post injury. This would clearly lead to a large disagreement on the difference scores; relatives would appear to be indicating a greater change for the worse since the injury, which is not reflected in patients' own assessments.

Ratings show a reasonable level of agreement between patient and relative, although it is difficult to assign an arbitrary cut-off point between 'acceptable' and 'unacceptable' levels of agreement. The mean differences between ratings were small (Figure 3); some bias exists, but this is generally in an 'acceptable' direction, in that patients showed less of a tendency towards denial than relatives.

On the basis of these results, it may therefore be concluded that patient self-report is at least as reliable as relative assessment of adjustment using the MKSAS. Such a statement is of considerable clinical significance, particularly in relation to medicolegal cases where compensation is being sought. Intuitively it may be anticipated, given the adversarial nature of the British and American legal systems, that those involved in such a process might be more likely to overestimate the difficulties they experience in adaptation. Given that patients and relatives completed scales independently greater inconsistency might be expected amongst those seeking compensation in two directions:

- 1 Both partners would considerably overestimate all difficulties which would show up as extremely high factor scores for all factors, which was not highlighted in the present data set.
or
- 2 There would be lack of consistency between patient and relative data due to estimates being made on non-observable behaviours. The justification for rejection of this hypothesis is given below;

Twenty-nine patients in the present sample were currently in the process of claiming compensation for their injuries. Completed returns were available from all 29 together with estimates from 24 partners. The levels of agreement between the patient and relative/significant other for this subgroup of patients were measured using kappa, and compared to a selected 'control' group of patients matched by age, time since injury, marital status, and employment status (These variables had been found to have greatest influence on adjustment in other investigations).²

Comparison of agreement between patient and relative for cases pending compensation claims and matched "controls"

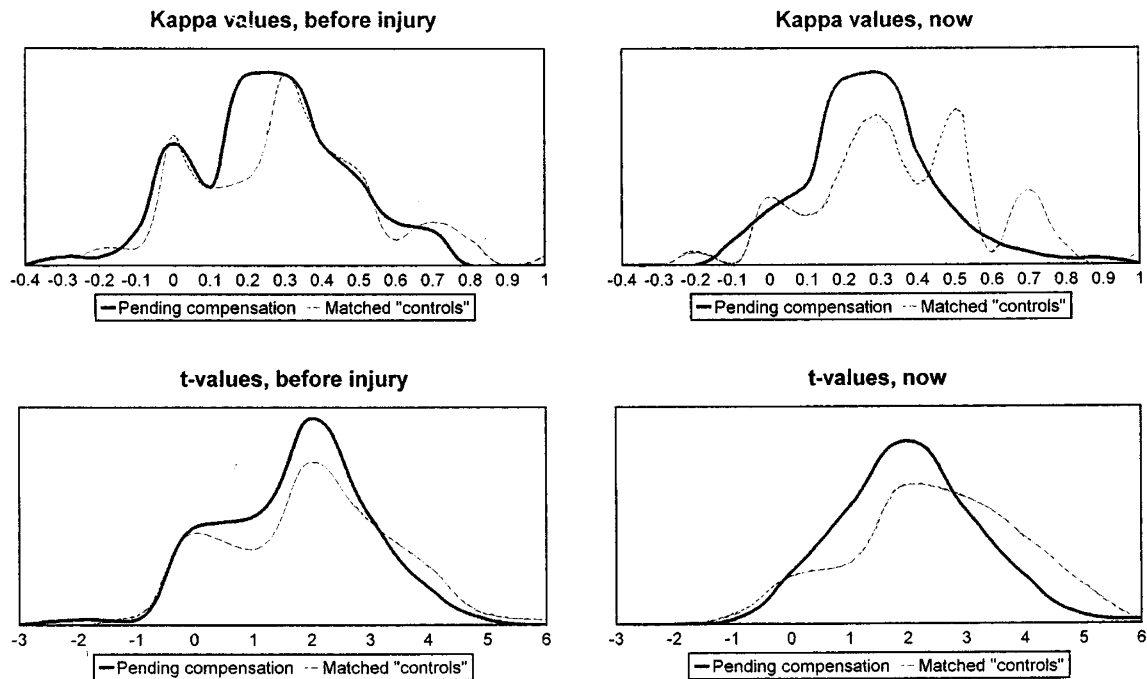


Figure 4

The comparison between those patients pending compensation and their 'controls' are shown in Figure 4. There is no significant difference between the concordance of response for patients and relatives for these two groups.

Discussion

Estimations of change following any trauma must rely on essentially subjective assessment of pre-morbid functioning, and earlier investigators have often commented upon the potential inaccuracy of clinical history taking due to the increasing fallibility of recollection over time.¹⁹

The present investigation has provided some evidence to support a contention that patients estimates of pre-morbid adjustment are comparable to those of their closest relative or carer.

However consistency does not equate with reliability. Both partners may recall the same information but the absolute accuracy (reliability) of such recollection is, by the absence of objective evidence pre-trauma, impossible to establish. This may be considered to present insurmountable difficulties in medicolegal claims for damages and losses. However, the consistency of independently derived estimates of adjustment using the MKSAS provides some support to the contention that both partners recall accurately the changes in situation attributable to their trauma.

That the responses of those seeking compensation do not appear intrinsically different from the main data set implicitly supports the contention of accuracy.

Hunter²⁴ in discussing the effects of time on recollection of events, noted that;

'Facilitatory effects of repeatedly attempted recall are also experienced by people who, for one reason or another, dwell on past events.'

Hunter (1978) p.226

With the daily implications of a spinal trauma providing constant, continual feedback to the patient and their family it may be concluded that such individuals are most likely to have clear memories of the effects of their trauma on their adjustment. Furthermore, whilst it might be suspected that those involved in compensation cases might over-emphasise their difficulties in order to maximise their claim, the present evidence does not support such a contention. Those who experience severe spinal trauma have indeed suffered enough; they do not either need nor desire to exploit their situation further.

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Editor's Note: Part II of this communication by Glass *et al.*: 'Population trends and effects of compensation on adjustment', will be published in the next issue of 'Spinal Cord'.