

A Study of Quality of Life Issues for Individuals with Spinal Cord Injury Following Treatment and Financial Settlement

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Abstract. *Over one-quarter of a million Americans are effected by spinal cord injuries based on data from the Christopher Reeve Foundation (Reeve, 2001). As medical technology has advanced and more individuals with spinal cord injury (SCI) are surviving their injuries and living with SCI, improvement of quality of life has evolved as a primary focus. For this current study, three hundred participants were selected from a clinical database of individuals with spinal cord injury. Twenty-one respondents (7%) completed a demographic questionnaire and a multi-dimensional adjustment profile (MAP) that measures the participants' subjective estimates of quality of life in work, health, finance, relationships, and other areas. Results of the study are presented as well as a discussion and concluding comments.*

Introduction

Nationally known organizations and funding sources have generated significant funding to study issues involving individuals with spinal cord injury (e.g., National Institute on Disability and Rehabilitation Research/NIDRR, Veterans' Administration/VA, Christopher Reeve Foundation, etc.). Most individuals with spinal cord injuries resulting in lower extremity paralysis retain some hope of ambulation, but the possibility of ambulation depends upon whether the individual is paraplegic or quadriplegic (Reeve, 2001). Technology has advanced in the last fifty years to assist in ambulation, but successful application of this technology to severe spinal cord injuries has not matched this advancement. Saulino and Vaccaria (2003) concluded in a study that both physical progress and quality of life improvement issues are closely related. Quality of life issues have been studied for over 40 years, and the general conclusion is that specific quality of life improvements are subjective and based upon individual perceptions (Bishop & Fiest-Price, 2001). This literature has identified quality of life as a primary goal of rehabilitation outcomes for individuals with spinal cord injuries (Bishop & Fiest-Price, 2001).

The spinal cord plays an essential role in communications between the brain and the central nervous system, and contains cells and neurons that carry signals both to and from all parts of the body creating an "information highway" of significant proportion. Unfortunately, spinal cord neurons do not generate after a severe injury, resulting in the achievement of complete function more challenging, since medical science has not yet developed techniques to restore neuron function. Literature review emphasizes the quality of life as a primary goal of rehabilitation and counseling because the medical issues are so complex and resistant to treatment. Psychological disorders are common among individuals with spinal cord injuries, as they are vulnerable to bouts of depression, anxiety, and hopelessness. The psychological and emotional reactions to such traumatic disabilities as spinal cord injuries can be as strong as the actual physical trauma and its residual effects. Further, the emotional and psychological aftermath often create a vicious cycle of depression, despair, and dysfunction (Bishop & Fiest-Price, 2002).

Researchers have noted that frustration and boredom often accompanying spinal cord injury can lead to stress, hostility, delinquency, and substance abuse (Cairns & Baker, 1993). Excessive amounts of free time and its accompanying boredom can sometimes be a problem for anyone, but can be especially frustrating for an individual with spinal cord injury. In fact, research shows that individuals with spinal cord injury have three to four more hours of free time than their non-disabled counterparts. Helping individuals with spinal cord injuries learn to fill this time constructively is a challenging goal for rehabilitation counseling and, when successful, can help to contribute to their overall quality of life. Murphy and William (1999) found that work is still the overarching value for quality of life improvements, as there is a dynamic interaction between quality of work life and quality of life in general. Further, Cairns and Baker (1993), studied the literature regarding individuals with spinal cord injuries and their coping processes, and came to the conclusion that the literature had not yet explained why and how some people adjust effectively and others do not. Perception of one's quality of life may be one explanation for the individual differences. Employment is a significant contributor to one's perception of quality of life, although family, recreation, self-esteem, integrity, physical and material well-being, freedom of independent action, sense of purpose and occupational achievement are all elements that have been shown to effect quality of life (Bishop & Feist-Price, 2002). There is little, if any, indication that spinal cord injuries will decrease in the future, and continued research to examine the dynamics of spinal cord injury and its resulting effects on quality of life will remain important. Many American corporations employ a large number of individuals in jobs that are dangerous and require great physical dexterity; therefore, the number of spinal cord injuries in the United States is unlikely to be reduced significantly in the foreseeable future.

Quality of Life Issues

Although there have been various studies on spinal cord injury, the author has been able to identify only a few studies that attempted to identify therapeutic approaches that are most effective in maximizing the quality of life for individuals with spinal cord injuries. One area that appears to have been neglected is an analysis of the possible relationship between the financial settlement following litigation for an individual with spinal cord injury and the resulting quality of life measures. Although lump sums and structured settlements are often negotiated for individuals involved in litigation following spinal cord injuries, there appears to have been no attempt to correlate these settlements and quality of life benefits.

In this author's experience, motivation to recover from spinal cord injury could be related to monies received through litigation/settlements, as this often provides resources and access to treatment that might otherwise be unobtainable. Faced with long and demanding rehabilitation therapy, individuals with few financial resources could easily give up and view their situation as hopeless. This study was designed to examine the relationship between certain demographic variables of individuals with spinal cord injury as well as financial settlements, and their relationship to the quality of life for individuals with spinal cord injury.

The theory and practice of vocational rehabilitation, now commonly known as rehabilitation counseling, has its historical roots in rehabilitation efforts to restore impaired individuals to mobility and gainful employment (Krause, 2003). The term vocational assessment/evaluation has been used over the years to describe the process of gathering data and determining a person's potential for work activity. Deutsch (1994) reported on a project where counselors conducted a comprehensive analysis of each client's education, biographical and social history, work history, medical history, and other pertinent records to determine the

client's vocational potential. In this study, occupational therapy was directed toward returning the individual to the maximum degree of mobility possible and instilling a motivation to return to work (Deutsch, 1994). Helping people with severe impairments regain and maintain satisfying employment that is expected to improve their quality of life is a high priority for vocational rehabilitation counseling. Life care planning development and recognition is important in this regard. Three critical factors that most people incorporate into thinking about the meaning of work are a) social contacts, b) self-image, and c) financial income (Florian, 1984). Of these three factors, Florian (1984) believed that social contacts were the most important. This could explain why some individuals with spinal cord injuries become lonely and easily depressed shortly after experiencing an injury. The threat of losing their financial income and the resulting loss of self-esteem that often accompanies the inability to work can be depressing and overwhelming for some individuals (Krause, 1998). Fabian (1991) collected data from personal interviews of 100 persons with spinal cord injuries. Notable among his findings were feelings of loneliness and healthiness in the lower quality of life ratings associated with the greater severity of disability. Fabian's study in 1991 indicated that socialization issues warrant priority in the rehabilitation effort and that rehabilitation specialists may need to explore and facilitate participation in social activities as soon as possible as a way to improve an individual's quality of life.

The role of depression among individuals with spinal cord injuries and quality of life has also received increased attention over the years, and increased depression has been found to be likely related to the perceived loss of social contacts and a loss of self-esteem (Carins, 1993). Carins (1993) states that objective, psychological testing shows that acute injury results in a frequency of major depression in at least 20% of the population of individuals with spinal cord injury. Further, Carins' study (1993) states that specialists must accept the patient's emotional expressions as genuine and relevant instead of interpreting them as denial, depression, anger or some other transient emotion. Full acceptance and constructive intervention is a prerequisite to overcoming depression and reestablishing motivation to address basic need for social contacts, improved self-esteem and working towards self-reliance (Fabian, 1991), all ingredients for improved quality of life following spinal cord injury.

Method

This study investigated the relationship between quality of life and the demographic values of age, gender, marital status, ethnicity, educational level, work status, and year injury occurred, as well as the individual self-rating of his or her quality of life in relation to the financial settlement awarded.

This was a non-experimental study described by Best and Kahn (1998) as a form of descriptive research which "seeks to find answers to questions through the analysis of variable relationships" (p. 129). Best and Kahn (1998) state that because it is often impractical or unethical to arrange occurrences, an analysis of past events, or of already existing conditions, may be the only way to study causation. Heppner, Kivlighan and Wampold (1999) further indicate that in a descriptive study design, the events being analyzed have already occurred and a researcher studies the existing data in detail to identify and explain causes, relationships, or meanings that can be deduced from the data. Isaac and Michael (1995) indicate that this type approach stands in contrast to an experimental study, which collects its data under controlled conditions in the present. This research was approved by a research review committee for protection of human subjects' research concluding that informed consent was not necessary.

Independent and Dependent Variables

In this study, the participants' demographic values and their self-rating of quality of life in relation to the financial settlement awarded were the independent variables. It is noted that the independent variables could not be manipulated. The multi-dimensional adjustment profile (MAP), a quality of life measure developed by Dr. James Krause, served as a dependent variable. A correlational analysis was used to assess the relationships between the independent and dependent variables in the study. There were 21 individuals with spinal cord injuries, in varying degrees of recovery, that participated in this study. These individuals lived in a geographically dispersed area in the Southeastern United States and volunteered to be in this study. The participants varied according to gender, race, age, and ethnicity. Participants selected for the study had previously received evaluations and life care plan assessments from a well-known rehabilitation consultant and life care planner in the Southeast with over 30 years of experience working with individuals with spinal cord injuries.

Research Question

The research question for the study was:

- What is the relationship between quality of life issues for individuals with spinal cord injuries as measured by the MAP and specific demographic variables following treatment for their spinal cord injury?

The hypotheses tested whether there is a relationship between quality of life and issues of age, gender, educational level, marital status, year injury occurred, ethnicity, work status, and financial award for individuals with spinal cord injuries following treatment for their spinal cord injury.

The MAP, a Likert-type scale, was selected as the instrument for use in this study. The MAP is an extended version of the Life Situation Questionnaire (LSQ), which has been widely used over the past 30 years to assess outcomes following spinal cord injury, including one 20-year longitudinal study of Quality of Life perceptions after spinal cord injury. In explaining the need to expand the LSQ, Krause (1998) stated "the LSQ was limited in both the breadth of content coverage and the adequacy of its measurement of content areas" (p. 53).

The Life Situation Questionnaire (LSQ) was initially developed in 1973 to assess objective information on a wide range of long-term, post-spinal cord injury outcomes (Krause, 2003). The instrument assesses biographic status, medical history, employment and educational status, social activities, and self-rated adjustment and life satisfaction. In describing the use of the LSQ, Krause (1995) stated:

"this instrument generated valuable data on life adjustment after spinal cord injury and served as a basis for later instrument refinements. The LSQ was revised during subsequent follow-ups (1984; 1988; 1993; 1998) adding substantial improvements over the original LSQ. These enhancements led to the development of several sets of subjective well-being scales." (p. 1283)

Building on the basic structure and content of the LSQ, Krause and Anson (1996) created the Multidimensional Adjustment Profile (MAP) for use in a study that examined several outcome variables not addressed by the LSQ. This included finances, sex life, and other psychological adjustment issues. All of the original LSQ scales were incorporated into the Multidimensional Adjustment Profile (MAP), which has been used in recent studies.

Since the MAP is a relatively recent instrument in its current form, there is very little

statistical information available on its reliability and validity. However, its parent instrument - the Life Satisfaction Questionnaire (LSQ) - has over 30 years of extended use, during which its face validity and construct validity have been consistently confirmed (Krause, 2003; Krause, 1998a; Krause, 1998b; Krause & Rowe, 1999; Rowe & Krause, 1998).

For purposes of the current study, the MAP was sent to each participant with a letter from the life care planner from whose caseload the participants were recruited and from the principal investigator to explain the purpose of the study and importance of completing the questionnaire. The survey was completely anonymous and participants were asked not to sign any returned documents. Each packet contained a stamped self-addressed return envelope for the participant's use in returning the survey to the researcher. A second and third mailing occurred to maximize responses in 30 day intervals. The results were collected after 60 days from the last mailing, then counted and recorded, and a summary was prepared, so that the data could be generated.

Results

As previously stated, the hypotheses for this study predicted there would be a relationship between quality of life issues for individuals with spinal cord injuries following treatment for their spinal cord injury and age, gender, educational level, marital status, year injury occurred, ethnicity, work status, and amount of financial award. There were no significant relationships between seven of the variables; therefore, the null hypothesis was not rejected. The null hypothesis is proposed to allow for identification when the anticipated relationships between variables do not occur. Therefore, the eighth null hypothesis, the correlation between quality of life issues and financial award, was rejected. One possible explanation for this unexpected outcome may be that individuals who had larger settlements also had more severe impairments as a result of their injury, and since they had more limitations in functioning, their quality of life might be lower despite the size of the award. Potential future research in this regard may be beneficial.

Study Limitations

As with most studies, this current research had limitations. Limitation factors noted in this study were 1) the honesty and matter in which individuals responded to the survey could not be controlled, 2) the study does not account for improvements in quality of life that may be attributed to sources other than those measured by the MAP (an assumption that personality makeup and temperament varies in all individuals), 3) individuals in this study may be more highly motivated toward recovery than others, and financial gains from litigation may not be the primary determining factor in recovery, and 4) given the small sample size, the population survey may not be representative of the larger population of individuals with spinal cord injury.

Discussion and Conclusion

Quality of life issues are crucial elements for individuals with spinal cord injuries. Would personal interviews create a different outcome among participants? Would a description of events followed by a qualitative approach with a narrative format have made a difference? Perhaps the individuality of participants would surface with the qualitative method, creating an expected hypotheses outcome as presented in the study.

This study may be useful for life care planners in their interactions with individuals with spinal cord injuries. It may provide some incentives to individuals with spinal cord injuries when life care planners convey what quality of life issues are essential and portray that financial gains may not imply long-term happiness or stability.

Being aware of quality of life issues may be important in life care planning when psychiatric matters are a concern. Psychotherapy (talk therapy), provided by a qualified professional, may be a consideration for life care planners who might otherwise focus only on medication costs for depression, anxiety, and other psychological sequelae when establishing overall future psychiatric/psychological costs.

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About the Author

Randy Salmons resides in Central Florida, having been self-employed for over 20 years as a Vocational Consultant / Expert. He is certified in several areas of counseling and consultations regarding employment and career choices. Randy Salmons obtained the status of Ph.D. from Barry University in 2007.

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Appendix A

DEMOGRAPHIC SURVEY

Please fill out this demographic survey so that we may obtain some general information about you. Your responses are confidential.

Please write in (where appropriate) or circle the number of your response.

1. Your age: _____
 2. Gender: 1. Female
 2. Male
 3. Marital Status:
 1. Single
 2. Married
 3. Separated
 4. Divorced
 5. Widowed
 4. What is your ethnicity?
 1. African-American
 2. Caucasian
 3. Hispanic
 4. Asian
 5. Other: _____
 5. Educational level:
 1. Less than high school diploma
 2. High school diploma
 3. Some college
 4. Undergraduate college degree
 5. Graduate degree (Master's Degree, Ph.D., J.D., M.D., etc.)
 6. Current work status:
 1. Employed/self employed full time
 2. Employed/self employed part time
 3. Retired
 4. Unemployed
 5. Never employed
 6. Other: _____
 7. Year of Spinal Cord Injury Incidence
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Appendix B

MULTIDIMENSIONAL ADJUSTMENT PROFILE**(Quality of Life Survey)**

1. On the Scale below, please rate your **DEGREE OF SATISFACTION** with the following aspects of your present life? (Circle the number that describes your feeling) Note: 1 = Very Dissatisfied; 5 = Very Satisfied

	Dissatisfied		Neutral		Very Satisfied
a. Living Arrangements	1	2	3	4	5
b. Employment	1	2	3	4	5
c. Financial Means	1	2	3	4	5
d. Social Life	1	2	3	4	5
e. Sex Life	1	2	3	4	5
f. General Health	1	2	3	4	5
g. Family Relationships	1	2	3	4	5
h. Recreational Opportunities	1	2	3	4	5
I. Life Opportunities	1	2	3	4	5
j. Emotional Adjustment	1	2	3	4	5
k. The Amount of Control You Have Over Your Life	1	2	3	4	5
l. Your Accomplishments	1	2	3	4	5
m. Relationships with Friends	1	2	3	4	5
n. Activity Level (how active you are)	1	2	3	4	5
o. Physical Appearance	1	2	3	4	5
p. Opportunities	1	2	3	4	5
q. How You Spend Your Time	1	2	3	4	5
r. Availability of Health Care	1	2	3	4	5
s. Home Life	1	2	3	4	5
t. Marital or Relationship Status	1	2	3	4	5

Appendix B

Multidimensional Adjustment Profile (Part 2)

2. On the scale below, with the number One representing No Problem and Five representing a Major Problem, please indicate how much of a problem the following things are for you in your CURRENT situation? (Circle the number that describes how much of a problem you believe it is.)

	No Problem		A Small Problem		A Major Problem
aa. Pain	1	2	3	4	5
bb. Loneliness	1	2	3	4	5
cc. Control over your Life	1	2	3	4	5
dd. Difficulty making new Friends	1	2	3	4	5
ee. Adequate Income	1	2	3	4	5
ff. Boredom	1	2	3	4	5
gg. Adequate Transportation	1	2	3	4	5
hh. Adequate Levels of Independence	1	2	3	4	5
ii. Health Problems	1	2	3	4	5
jj. Depression	1	2	3	4	5
kk. Family Problems	1	2	3	4	5
ll. Conflicts with Attendants	1	2	3	4	5
mm. People's Negative Attitudes toward the Disabled	1	2	3	4	5
nn. Adequate Accessibility	1	2	3	4	5
oo. Alcohol or Drug Abuse	1	2	3	4	5
pp. Stress	1	2	3	4	5
qq. Adequate Employment	1	2	3	4	5
rr. Access to Money	1	2	3	4	5
ss. Being Accepted by People	1	2	3	4	5
tt. Worries	1	2	3	4	5
uu. Spasticity (muscle spasms)	1	2	3	4	5
vv. Sweats or Chills	1	2	3	4	5

Appendix B

	No Problem		A Small Problem		A Major Problem
ww. Skin Sores	1	2	3	4	5
xx. Urinary Tract Infections	1	2	3	4	5
yy. Emotional Pain	1	2	3	4	5
aaa. Sadness	1	2	3	4	5
bbb. Sufficient Number of Things to do that hold your Interest	1	2	3	4	5
ccc. Adequate Job Skills	1	2	3	4	5
ddd. Opportunities to Learn about Things that you want to	1	2	3	4	5

Appendix B

3. Assume there is a relationship between the amount of a litigated financial award (settlement) and the Quality of Life for spinal cord injured individuals. Also assume this relationship can be measured on a scale of One to Ten with One representing the WORST or WEAKEST possible relationship and ten representing the BEST or STRONGEST possible relationship.

Considering the amount of your financial settlement and your personal perceptions of your Quality of Life, please indicate where on the scale below you would rate yourself regarding the relationship between your financial aware and current quality of life.

Circle One:

1 2 3 4 5 6 7 8 9 10

Worst **Best**

Appendix B modified from the original Multidimensional Adjustment Profile, Krause and Anson (1996).