

Assessment of Adjustment Problems in Persons with Spinal Cord Injury

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Received: 30-10-2021 / Revised: 04-12-2021 / Accepted: 11-01-2022

Abstract

A traumatic injury to spinal cord presents a sudden overwhelming threat to the individual's psychological safety which may create many adjustment problems. The early adjustment to traumatic injury is both adaptive and protective to the patient. He becomes maladaptive only when it begins to interfere with the realistic efforts and plans. It results in a sudden and profound disruption to an individual's life. Person's life and various factors contribute towards the evolution of adjustment problems. The present study was conducted to assess the adjustment problems in spinal cord injured patients. It was hypothesized that significant difference would be found between adjustment of SCI patients and non-SCI controls. Further it was hypothesized that acute patients would have more adjustment problems than chronic patients whereas, no such difference would be found in their respective control groups. For testing the hypothesis, an ex-post-facto research with multigroup design was adopted. A total sample of 80 subjects (SCI=40; Non-SCI=40). The participants of patient group were further divided into two groups of 20 each on the basis of duration of injury i.e. acute and chronic patient group. An equal number of participants, the key attendants of the SCI patients were taken as control group. The sample was selected from District Rehabilitation Centre at Post Graduate Institute of Medical Sciences, Rohtak on availability basis. Dysfunction Analysis Questionnaire (Parsad et al, 1985) which consists of five subscales pertaining to adjustment in five areas, i.e. personal, social emotional, vocational and cognitive was individually administered to all the participants. Data were analyzed by using t-test and Duncan's Range Test. Findings revealed that the patient group had more adjustment problems than the control group. Further, the deterioration in adjustment was more in social and vocational areas than other areas of adjustment. The relevance of including key attendants as control group is discussed in the findings along with the implications of the study.

Keywords: Adjustment, Spinal cord injury (SCI), Acute and chronic, Key attendants, Dysfunction, Rehabilitation.

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Introduction

Spinal cord injury necessitates lot of changes in patients' life depending upon the extent of physical and psychological loss, apart from the immobility imposed by the injury and loss of sensations. Paraplegia and quadriplegia secondary to concomitant traumatic injury to spinal cord is one of the most devastating injury suffered by men. Although, mortality following spinal cord injury (SCI) is low but morbidity is considerably high. There are also other unpleasant effects of injury like impaired sexual functions, incontinence of bladder & bowel and back pain etc. These physical problems result in vocational and social losses and impose great demands on family and relationships. Moreover, the complications like urinary tract infection (U.T.I), pressure sores and septicemia take their own toll and add to the misery. Under the effect of these physical problems one would easily suspect psychological disruption following SCI.

Adjustment problems in SCI patients are natural to occur as a result of stress of injury and it may be influenced adversely by age, low socio-economic status, low education and in male patients with complete cord lesion. The importance of adjustment lies in the fact that it is a very important emotion which is key to rehabilitation of an injured (Tucker, 1980).

Shrinivasan (1981) defined adjustment as "a disability affecting normal growth and development and also adjustment to life over a substantial period, if not permanently." Another term which had gained popularity in research and clinical circles is "dysfunction". Wolman (1973) has precisely defined dysfunction as a failure of an

organismic process, organ or system to work properly. Trauma to spinal cord is one of the major stress factors and due to this traumatic injury there is always some adjustment problems. Most commonly the personal, family and social type of maladjustment occurs. So, during the past, many health care professionals have turned their attention and tried to describe the process of adjustment to traumatic spinal cord injury. Bingley (1990) reports that person with a recent, traumatic severe spinal cord injury is predominantly young, male and action oriented. In the available text the process of adjustment experienced by SCI person is frequently neglected, rather they focused on one's ability to adapt and fit into the changed conditions.

Research demonstrates that psychosocial adjustment outcomes occur along a continuum. It is reported that the majority of people who sustain SCI are able to achieve positive psychological outcomes and generally report a satisfying quality of life (Elliott et al, 2002; Kennedy et al, 2006 & Kennedy et al, 2000). However a minority of people with SCI do not achieve positive adjustment outcomes, with between 25 and 38% experiencing elevated levels of depression and anxiety and reduced quality of life outcomes (Kennedy et al, 2000; Dorsett et al, 2004 & Krause et al, 2000).

It is important for a person with SCI to accept his/her limitations to maximise rehabilitation outcomes (Garske et al, 1998; Trieschmann et al, 1988 & Martz et al, 2005). Indeed, recent findings suggest that contrary to the traditional perspective, high hope, even false hope, is associated with lower levels of depression, greater acceptance of disability, increased life satisfaction, less perceived stigma, increased mobility and fewer participation restrictions (Elliott et al, 2002 & Elliott et al, 1999).

An important lacuna in the existing literature on adjustment appears to be that in earlier work adjustment as a whole was studied. However, there may be individual differences in sensitivities and adaptations, owing to which different individuals may exhibit varying

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levels of adjustment difficulties in different areas of life. Research attempts needs to be more precise to point out the specific areas for which intervention efforts should be emphasized. An adjustment inventory has been introduced by Parsad, Verma, Malhotra (1985) which not only incorporated the concept of dysfunction for adjustment but also measured adjustment with reference to premorbid levels. An additional advantage of the scale is that it encompasses scales for number of areas of adjustment and renders separate scores for each. In earlier studies either an overall index of adjustment of the patient was investigated or personal adjustment was emphasized. However, the impact of such a sudden, traumatic injury is not only devastating for the individual's personal life but also for total life. Therefore, there is a need to make a formal and systematic assessment of adjustment in various areas of life. Adjustment to SCI has generally been examined in the literature solely from the view point of the injured person. Little attention has been focused on the family, although several researchers had highlighted the importance of strong family support as being a major factor in the process of adjustment. Adjustment to sudden traumatic SCI is often more difficult for other family members than for injured person himself. Richmond (1990) stated that spinal cord injury occur not just to the individual but to the entire family. Same had been pointed out earlier by Oliver (1981) and Butt (1989). Judd et al (1988) based on their researches further reported that those families of injured patients who adapted well to the needs of an injured person and closely integrated with patients after injury exhibited low adjustment problems both for family and patient. He further supported this finding with low rate of divorce in injured where wives/spouse were showing major adaptive changes to the needs of the patients.

Chan (2000) also studied this phenomenon in Hong Kong and find that spouses of persons with spinal cord injury suffer emotional stress that is comparable to or greater than those of the injured partner. In one another study, Hadrys et al (2011) investigated the frequency of psychological problems in the caregivers of patients with SCI and mental disorders respectively. They reported that care giving can have a negative effect on the mental health of these persons and claim that depression and anxiety are highly prevalent among them.

Further, Ebrahimzadeh, Shojaei and Golhasani-Keshtan et al. (2013) stated that the burden of care giving can impact the quality of life of care givers and cause health problems. These problems can cause limitations for care givers spouses and it can lead to a decrease in the quality of given care. Various items can influence the quality of life (QOL) among the caregivers or spouses of patients with a chronic disease like spinal cord injury. The chronicity of the problem can negatively affect the life of these caregivers as well as their QOL.

Literature reveals that attention being focused only to the patient at the cost of neglect of reactions of the family members to the problems faced by them. Problems like adjustment should have been studied in a broader context than restricting them to the individual patient only. The present study is an attempt in the same direction. It is generally assumed that human nature is resilient and with the passage of time victims come to terms with the loss. However, Hancock et al. (1993) pointed out that in SCI patients adjustment process goes along

throughout the period of injury and after. Therefore, studying deterioration index of adjustment overtime in terms of duration of injury, i.e., chronic and acute patients seemed relevant. Besides, adjustment is a very important emotion in the rehabilitation of an injured (Tucker, 1980; Worrell and Reynolds, 1994). Nordholm and Westbrook (1986) reported that the SCI persons who assumed responsibility for their injury made better adjustment to their disability following discharge. In past, the adjustment was considered to the problem only for patient but recent research evidences show that adjustment affects family and society too. Another study that the problem focused coping strategies (e.g. coping strategy of acceptance i.e. modifying life values and arranging latest priorities) were highly connected with better adjustment and well-being among SCI patients (Elfstrom et al, 2006). In earlier researches it was pointed out that psychological consequences in SCI patients remains neglected by researchers which may actually be contributing to the rate of outcome (Somasundram et al, 1992 and Noor et al, 2016). In the present study an attempt would be made to include those relatives or key attendants who were also exposed to stressful situation similar to that of the patient but in methodological and technical term they may not be pure controls. This is particularly done to add to the literature the evidence that it is not only the patient who suffers from the reaction of various problems, but also, the individuals around him/her. The findings of the study may help in differentiating those. The often cited role of family as a social support system in literature from that of the one exposed to an equal amount of distress. These findings would have relevance in planning of intervention, particularly rehabilitation. So that the rehabilitation programme involve not only the patient but also the key attendants and family members of the patient. Keeping all these factors in view the study was designed with following hypotheses:

- There would be a significant difference in the level of adjustment between SCI and non-SCI groups.
- Acute patients would have more adjustment problems than chronic patients, whereas, no such difference would be found in their respective control groups.

Method and Material

Design

The present study was conducted following a multigroup ex-post-facto design.

Sample

The sample consisted of 80 participants (SCI patients and their key attendants). Subjects were drawn from outdoor department as well as those admitted in District Rehabilitation Centre at Medical College and Hospital Rohtak. Criteria for inclusion of case was as under:

The patient group comprised of those who were affected with injury and these were divided into experimental groups on the basis of duration of SCI. In group I, the criteria for inclusion was injury of less than two weeks and this was designated as acute patient group. Likewise, group II, comprised of patients with injury of more than 12 weeks. This group was designated as chronic patient group. Group III and IV comprised of the key attendants of the acute and chronic patients respectively. These formed the control group of the study.

Table 1: Distribution of the Sample

Sample (N=80)

Patient Group (N=40)		Control Group (N=40)	
Acute Patient Group (N=20) (Group-I)	Chronic Patient Group (N=20) (Group-II)	Acute Control Group (N=20) (Group-III)	Chronic Control Group (N=20) (Group-IV)

Only patients with paraplegia and quadriplegia following spinal cord injury were included in the present study. Both males and females between the age of 18-45 years were included in the sample after taking informed consent. Although this type of injury can be seen in any age group but it is more common in patients who were actively involved in outdoor activities and manual labour. Patients with chronic medical illness like cushing syndrome, hyper or hypothyroidism, multiple-sclerosis, chronic infective states and malignancies were excluded. Similarly, patients with history of schizophrenia, chronic alcoholism and other psychiatric disorders

were also not included. For the two control groups key attendants (close relatives i.e., parents, brothers and sisters, spouse and close-friends) were selected for the acute (group III) and chronic (group IV) control groups.

Material

Unstructured interview and Dysfunction Analysis Questionnaire (Parsad, Verma, Malhotra & Malhotra, 1985) were used.

Unstructured interview-Each subject was interviewed personally by the interviewer with the aim of establishing rapport and for obtaining

socio-demographic background information and their personal and illness history.

Dysfunction Analysis Questionnaire(Parsad et al, 1985)

DAQ is a standardized measure of dysfunction in simple spoken language. It is a 50 item questionnaire. The items are related to five areas of functional states viz. social, vocational, personal, family and cognitive. Each area contains 10 items measured on a five point scale in comparison to the premorbid status. Percentage score of 40 in each sub scale would demonstrate no dysfunction compared to premorbid level. A score higher than this would be indicative of dysfunction while the score lower than this would mean better functioning than premorbid level. The possible range of percentage score thus would be 20 to 100. Standardized data revealed highly satisfactory test-retest reliability which ranged from 0.77 to 0.97 and high validity.

Results and Discussion

The aim of the present study was to assess adjustment problems in persons with spinal cord injury. The data was collected with the help of standardized scales and the scores obtained by the subjects in the various groups form the raw data. The raw data was primarily operated upon Duncan’s range test (DRT) for multi group research design. It is considered to be a suitable analysis tool which, with the advantage of getting information about all the possible combination of groups. It is considered to be a very effective substitute for one way ANOVA and at the same time it is less cumbersome. In addition to DRT, ‘t’ test was also applied to compare the two primary groups, i.e., patients and controls. The five specific areas as well as total adjustment were analyzed by employing separately Duncan’s Range Test (DRT). The results are presented in Table 2&3 and Fig. 1 & 2.

Table 2: Summary of Duncan’s Range Test (DRT) for Five Specific Areas and Total Adjustment Scores

Adjustment areas	Groups			
	4. Chronic Control Group	3. Acute Control Group	2. Chronic Patient Group	1. Acute Patient Group
Social	30.25	31.85	33.75	38.05
Vocational	32.30	33.20	37.95	39.95
Personal	26.75	29.35	33.50	33.60
Family	28.30	30.95	32.35	34.55
Cognitive	21.20	21.50	23.85	28.15
Total/Overall	138.50	145.25	162.25	174.35

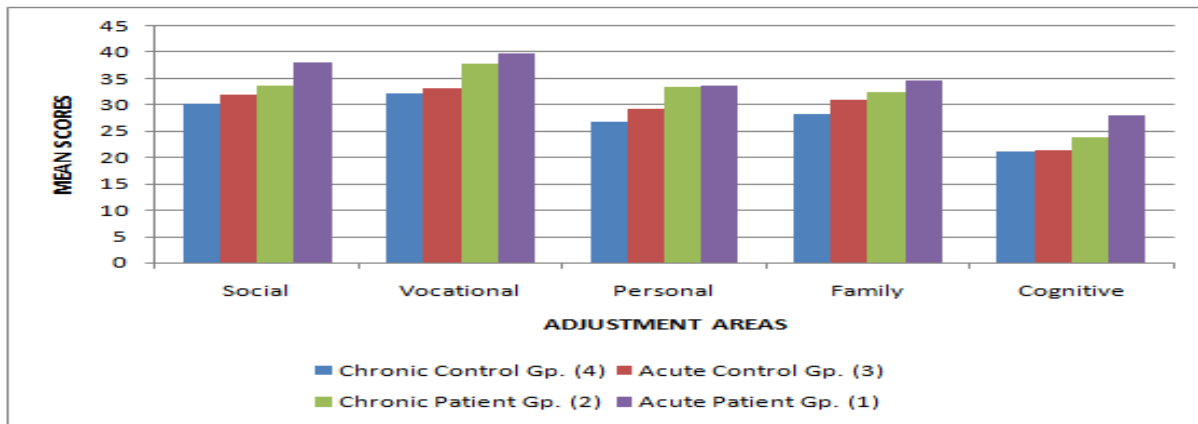


Fig 1: Mean Adjustment Scores of Four Groups in Five Areas

Table 3: ‘t’ test between Patient and Control Groups on Overall Adjustment

Groups	Mean	‘t’ value
Patient	168.3	3.6**
Control	141.0	

**p<0.01

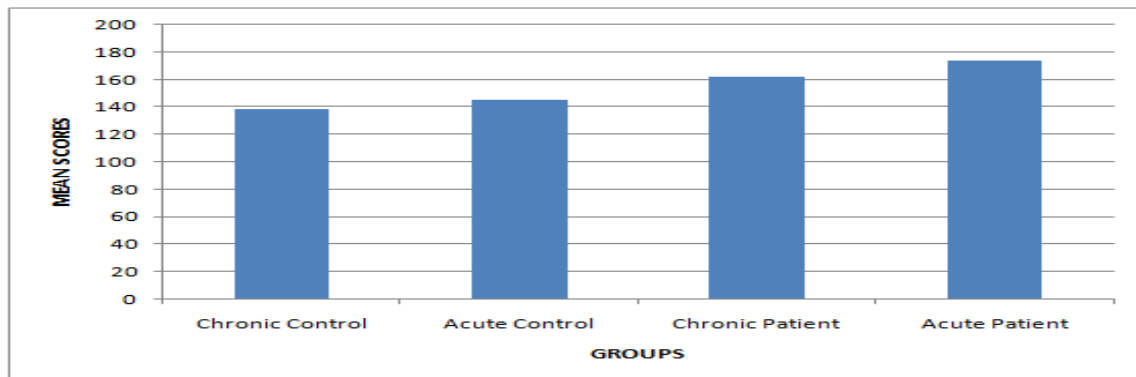


Fig 2: Mean of Total Adjustment Scores of the Four Groups

Social Adjustment

As measured by DAQ, social adjustment consists of ability to mix up with other persons, participate in outdoor activities and attending social functioning and parties etc. DRT was applied to find out the difference between the four groups of social adjustment (Table 2). The findings in Table 2 depicts that difference between chronic patient and acute patient group was 4.3 which is significant at $p < 0.05$. The result has also depicted the difference between controls of both acute and chronic patient group which was 1.6 and that was not significant. The difference between both patient group i.e. chronic and acute and their respective key attendants was significant. From the finding it is highlighted that in the area of social adjustment, the problem was more in acute patients than chronic patients. The attendants of the patients in both groups faced about similar adjustment problems. They had to spend most of the time with the patients due to which they could not maintain their social life. The impact of SCI on the family has been emphasised in earlier researches. The attendants of the patients in both the groups faced about similar adjustment problems, due to the increased demand of their time, money and attention by the patients (Fig. 1). The impact of SCI on family has been emphasized in some studies (Judd et al, 1988; Oliver et al, 1988). It was pointed out that SCI not only shatters the physical and psychological integrity of the patient but also leads to disturbances in societal structure. The social adjustment index revealed more than 60% deterioration in patient groups, which is a significant loss. Paraplegia incapacitates the patient's interpersonal life due to confinement leading to substantial reduction in exposure to social life. Social adjustment is affected in case of paraplegia because of the inability of the patient to carry out the interpersonal roles effectively. The life become too restricted and the patient is subjected to confinement. There is substantial decrease in exposure to social life.

In one another study, Lustig (2005) investigated the role of sense of coherence (SOC) in adjustment to SCI. Described as a belief that the world is manageable, meaningful and comprehensible, SOC was investigated in a sample of 48 SCI patients when grouped according to the SOC strength post-injury. Results found that weakened SOC was positively correlated to nonadaptive strategies, such as anger and hostility, and negatively associated with adjustment. Strong SOC scores, conversely, were associated with adaptive strategies and positive adjustment. The present findings are indicative of deterioration in current adjustment with reference to their past findings both statistical and figure (Fig.1) reveal a substantial deterioration in all the four groups. The deterioration level was as long as 60% and even above in the case of the patient groups.

Vocational adjustment

Vocational adjustment consists as measured by DAQ interest of the person in occupational work, cooperation with co-workers and seniors, ambitions and promotion and praise and income resources etc., in comparison to the pre-morbid level. Table 2 shows the mean value of all four groups for vocational adjustment along with the significance of their differences. It indicates that the difference between chronic patient group and acute patient group was 2.0 which was not significant. Likewise, the findings between both control groups were not found to be significant. However, the difference between chronic control groups and chronic patient group was significant. Comparing acute patients with their controls revealed insignificant findings. The findings have been presented in Table 2 and Fig.2 and the size of bars also show the same results.

Vocational adjustment remains to be the most affected aspect in one's life following SCI. Analysis of deterioration index seems to be more revealing. As expected both the patient groups reported greater deterioration than their control group counterparts. Patients reported nearly 80% loss and attendants at 64% to 66%. In one study by Hampton, 2004 also reported that youth and higher income were the only demographics reported to be significantly related to well-being, with other factors, such as positive perception of health, high efficacy and high social support showing significant relationships. Self-

efficacy, social support, perceived health and age at time of injury were identified as major predictors of the variance in well-being, accounting for 36% of the variance. Therefore, the implications could be serious. Unfortunately, the victim is the young and the working individual, at times the only, in the family so the whole family is exposed to economic crisis. The injury vocationally handicaps a person, more often, for the whole life. Such a high level of deterioration in this area is justified and requires greater attention in rehabilitation.

Personal Adjustment

It consists as measured by DAQ, the physical health, mental health, habits, personal hygiene and sexual activities of the individuals. The findings based on DRT are presented in Table-2. The difference between the two patient groups as well as between the control groups was not significant. Among both the acute and chronic patients, the deterioration in personal adjustment was of same level. However, the difference between control group was 6.75. It is significant at $p < 0.05$ level. The comparison between acute patient and control group was 4.25 which was found significant at 0.05 level. Since the disabilities caused by SCI are of long-term nature, the patients, even with the passage of time, remain unable to carry out their personal life effectively. They need constant help from their attendants which, in turn, affect the later's personal adjustment too.

MacLeod, 1988 and Lazarus, 1984 suggested that problems with adjustment are linked to self-neglect, which can in turn impact on the physical well-being and increase the likelihood of the onset of secondary complications. Difficulties have also been linked to substance abuse and which may contribute to further health problems. Therefore, irrespective of the acute and chronic condition there was consistent deterioration in both the patient groups and their respective controls (Fig. 1). However, comparison between the patient and control groups revealed significant differences, patient groups suffered greater deterioration in personal adjustment following as life is drastically changed for them.

Family Adjustment

It consists interacting with the family which involve participating in family affairs and decision making, mixing up with family members, fulfilling family responsibilities, playing with children etc. Overall it also deals with general behaviour with the family members. The trends revealed by DRT between the four groups were exactly same (Table-2) as observed in personal adjustment. The differences between the four groups as revealed by Fig. 1 indicated that it's not the patient alone who suffered the injury but the whole family. The deterioration in patients was approximately 69% and 64% respectively for group I and group II, whereas, in both the acute and chronic control groups it was 61% and 56% respectively. Although the differences between both the patient and control groups was significant (Table-2), yet the deterioration index indicated considerable loss in family adjustment compared to the pre-morbid levels in all the four groups. In earlier studies too, loss in family adjustment has been reported (Richmond, 1990; Oliver, 1981). The impact on family was also supported by the present findings.

Family and friends of people with a SCI who have a caring role (carers), are often emotionally affected and may have to make adjustments. Chan et al (2000) as well as Hadrys et al. (2011) investigated the frequency of psychological problems in the caregivers of patients with SCI and mental disorders respectively. They reported that caregiving can have a negative effect on the mental health of these persons. Further, the chronicity of the problem can negatively affect the life of these caregivers as well as their QOL. Rahimi-Movaghar et al. (2010) who found a high burden for SCI, we assumed a lower quality of life among the caregivers of SCI individuals due to the high work load.

Cognitive adjustment

As measured by DAQ, it consists of thinking, reasoning, concentration, tension in memory. The DRT values as shown in Table 2 indicate that except for the two control groups all other comparisons were exactly significant. The trends in Fig. 1 revealed that the scores

were higher in the two patient the four groups as compared to the control groups. Further, the mean was greater in case of acute patients than their chronic counterparts. Lindman (1944) and Kubler Ross (1969) reported stage theory of adjustment which explains that the person cognition changed by different individual factors like personality and coping styles etc. As a result acceptance of disability and it is overcome gradually by different natural supporting factors. Trieschmann (1992) in his work it has been reported that the new SCI gets depressed in order for adjustment to occur. Depression was more in the acute phase than the chronic phase in which it resolved within a few weeks, due to the various types of interventions as well as activation of one's coping capacities.

In one another study that the problem focused coping strategies (e.g. coping strategy of acceptance i.e. modifying life values and arranging latest priorities) were highly connected with better adjustment and well-being among SCI patients (Elfstrom and Kreuter, 2006). As such in SCI patients there is no organic loss in cognitive functioning, but due to over all psychological imbalance a temporary loss in this area may be suffered which was indicated by the present findings. Chronic patients reported significantly less deterioration than acute patients, with the passage of time they seem to have overcome the loss. When he compared to other areas of adjustment, this appears to be least affected area. In earlier studies on cognitive adjustment little attention has been paid to this area.

Total adjustment

Adjustment as a whole consists of the sum total of all the five areas with the scores ranging between 50 to 250. Higher the score, greater the deterioration in adjustment. Total scores were analyzed on the basis of DRT (Table-2) and 't' test (Table-3). Significant findings were obtained between all the possible pairs except for the two control groups (Table-2). It was hypothesized that the acute patient group would suffer more adjustment problems than the chronic counterparts. Findings were consistent with the hypothesis. Acute patients have yet to activate their adaptive resources after resolving the initial shock. They were completely dependent on their attendants even for their personal hygiene and nutritional needs. Chronic patients, with the support of physiotherapy and neurological recovery, able to overcome certain physical disabilities. Acute patient group was most affected followed by chronic patients, the same pattern was observed in their respective controls (Fig.2).

The trends (Fig. 2) revealed that the two control groups were almost equally affected by the injury of the patients. There was significant difference between the patients and controls (Table-3). Patients obtained higher mean scores indicating greater maladjustment, than their control counterparts. Ebrahimzadeh et al. (2013) also reported that the QOL among the caregivers or spouses of patients with a chronic disease like spinal cord injury. The chronicity of the problem can negatively affect the life of these caregivers as well as their QOL. However, with better support and more education, and generally by modifying the contributing factors, we can anticipate a better quality of life for the caregiver spouses and as a result improved care of spinal cord injured veterans.

The purpose was to identify areas of acute adjustment which need to be emphasized in intervention and rehabilitation. Although the personal, social and family mal adjustment were found but the maximum problem was invocational adjustment and minimum in cognitive. The finding were consistent with the hypotheses, existing research evidence as well as the psychological and sociological theories of adjustment (Whalley and Hamme, 1992). The analysis of data in terms of level or scores was more revealing especially in case of overall adjustment as well as social and vocational adjustment not only of the SCI patients; but also their family. High levels of maladjustment reported by attending family members indicated that in such stressful situations the usual role of family as social support network become secondary. Therefore, their reactions to the victims becomes strained with stress, multiplying the impact. Hence, the role of family needs to be explored from a different perspective. Further,

classifying patients on the basis of duration of injury is useful for rehabilitation.

The present findings are consistent with an earlier research (Worrell & Reynolds, 1994) which highlighted the importance of exploring psychological factors for effective rehabilitation. Noor et al (2016) stated that if SCI patient will be aware of regarding biological and psychological consequences of their injury then they will take psychological rehabilitation centres. Finally the utilization of trainings and counseling regarding problem focused coping would be helpful for better adjustment.

The treatment and rehabilitation program of these patients need to have a holistic focus in the sense that, the health professionals have to understand and to manage the psychological reactions of the patient and their family members.

Limitation and Suggestions

The present study was conducted on a relatively small sample due to time constraints. However, the importance of the field calls for a further study on a larger group in order to make the findings more conclusive. In methodology, the control groups were taken as key attendants of the patients which were not pure controls. Further study involving family as well as pure controls from general population would render better comparisons of findings and the main focus was only on the one aspect of the problem i.e. assessment of psychological reactions. Work involving the management and rehabilitation aspects of the patients would be worthwhile.

Conclusion

Spinal cord injured patients under go severe physical, psychological and social stresses and reacts in different way to cope with stress. While doing so they may exhibit psychological disturbances, some of which may interfere with their treatment and rehabilitation. Education and training programmes that demonstrate the value of fostering independence for persons with disability should be provided for individuals, together with family members, neighbors and other relatives. Implication of the study lies in its applied utility. The insight gained by the study has opened new vistas for further researches. Future research needs to be investigated the psycho-social rehabilitation strategies for the lowering negative psychological states. The findings of the present study would have relevance in planning of intervention, particularly rehabilitation with emphasis of family involvement, so that the rehabilitation program will involve not only the patients but also the key attendants & family members of the patients.

Acknowledgements

I would like to extend my deepest gratitude to my teacher and guide late Dr. Ravinder and Dr. Radheeshyam, Professor, Department of Psychology, Ch. Bansilal University, Bhiwani for their guidance and support and patients and their caregivers for their patience and cooperation.

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Conflict of Interest: Nil Source of support: Nil