

# A STUDY ON EMOTIONAL ASPECTS OF SPINAL CORD - INJURY

N.M.RATH, S.BAG, P.SAROJINI DASH

## SUMMARY

*Spinal Cord Injury, as an illness, is catastrophic, chronic and at times terminal, leading to overwhelming psycho-social decompensation. One is concerned with physical realities, pain, paralysis, and impotency as well as with tasks and goals in patients' life. A study of psychological consequences and mental morbidity was observed in twenty persons affected with spinal cord injury over three months to twelve years. Eight of twenty patients presented with neurotic disorders, five with intense depression, four with depersonalization, and four with paranoid states in various phases. Impaired social adjustment was observed in five patients. Like the fabulous 'Phoenix' rising out of its own ashes, three patients turned supportive to others in similar situations transcending emotional, physical and social disability.*

## INTRODUCTION

As an illness, spinal cord injury is both catastrophic, chronic, and often terminal in our setting. It leads to overwhelming psychosocial decompensation. Abnormally severe and prolonged psychological stress is encountered. The manner in which a patient with quadriplegia / paraplegia and associated complications approaches the dependent state, preterminality and death defies conventional psychiatric 'rubrics and pigeon holes'. One is concerned with physical realities - pain and paralysis, bowel and bladder incontinence, prolonged traction and immobility, complications such as pressure sores, indwelling catheters, systemic injections of antibiotics and impotency, as well as the disruption of tasks, goals, and dreams of the patient. In a great majority cases, life in a wheel chair begins suddenly - a car accident, a dive into shallow water, even an awkward fall - anything that causes a break in the spinal cord. The extent of paralysis, loss of feeling and movement will depend on the location of the break: the higher it is, the greater the extent of paralysis. When the spinal cord is broken, the nerves controlling bowel, bladder and genital functions and sensations are cut off from the brain. Prolonged dependency, medical management and residual deficits all turn stressful. The emotional impact of spinal cord injury thus overwhelms the boundary between distress and disease; empathy and introspections are more revealing than clinical signs in the 'spinal' person. Psychosocial decompensation in twenty such persons were observed over periods ranging from three months to twelve years, and their findings are reported.

## MATERIAL AND METHODS

Patients were observed in hospital, family and social settings and unstructured interview of patients, key relations and attendants were carried out. Psychological decompensation was clinically noted as per ICD-9. In evaluating the results of surgical invention and management in spinal cord injury, the study was restricted to the outcome as it relates to the long motor and sensory pathways as well as sphincteric and sexual functions. Overall clinical improvement was adjudged 'best' when the

patient was ambulating independently with / without braces or any type of crutches and managing bowel / bladder functions independently. It was judged 'intermediate' when the patient was dependent on a wheel chair with or without supporting attendant and without infective complications and the prognosis was worst when the person was bedridden with systemic infections / bedsores and other complications.

Exact means of gauging psychosocial and occupational impairment in persons with spinal cord injury is non-existent. As such, any catastrophic and chronic illness should be viewed as a new and difficult life situation, loaded with specific stresses and tasks. How a person copes or breaks down with a catastrophic illness and permanent disability depends on many variables - the type, location, onset, progression, degree of potential reversibility, medical, familial, financial, and larger social support available. Key family members, spouse, previous adaptability in job and attitude to life and total life situation all contribute to the outcome. In the present study, managing self in a previous or new job, maintaining self in the same family were judged to be better adjustment. Availability of adequate support system or not also affects the psychological consequences of spinal cord injury. The roles of the spouse, friends, family members, key relations and society in general influence psychosocial recovery. The quality of medical care extended and rehabilitation provided - physical, sexual, familial, occupational and social, are all reflected in the mind of the 'Spinal Man'. Equating 'distress' with 'disease', the present study of the affected persons with spinal cord injury was carried out. Some patients survive the trauma of the illness and often become stronger persons in the process. They share concern with others in the same situations and turn supportive. For such positive transformations, the term 'Phoenix phenomenon' is coined by the authors in the study.

## RESULTS

Twenty patients with spinal cord injury were studied; age range was from eighteen to sixty two years and there were eighteen male and two female patients. In the majority of patients [12/20], injury was due to motor-vehicular accidents. Two each were injured in domestic

accidents, gun-shot injury, house collapse and fall from high places / trees.

Three patients had injury at the cervical level. Six patients had compression in upper thoracic level (T4-T7) and nine at the lower thoracic level (T8-T10); two had cord involvement at the T11 level and below. Three patients were encountered in quadriplegia and seventeen in paraplegia. Associated head injury was observed in one and other orthopaedic affection in three of the patients. Management in form of surgical decompression was carried out in twelve out of twenty patients. Six of the patients were under conservative management for spinal cord injury. Two of the patients were under general care only.

For follow up at the end of three weeks, all the twenty patients were available; at the end of three months, fifteen of them were available and at the end of one year, twelve patients were available. The first three weeks were called the acute phase; from the fourth week to the end of the third month: subacute phase and the fourth month and beyond was designated to be the chronic phase for clinical observations.

Clinical improvement as per observation was 'best' in four, intermediate in 'five' and worst in six of the patients. Five patients died while under observation. Of the twenty patients, eleven hailed from villages and nine from urban areas. Half of the patients were literate. Four were from an upper socio-economic status, i.e., income tax payees. Seven of the patients were from economically backward families or lower group whose income was below rupees ten thousand per annum. The remaining nine patients were from the middle income group. Regarding employment, one of the patient was in Government service, seven of the patients were self-employed, and eight of the twenty patients had irregular employment as seasonal agricultural workers or migrant land laborers. Four were unemployed; thirteen patients were married.

Twenty patients were under observation in the acute phase (the first three weeks). The predominant symptom observed was an acute reaction to stress in eighteen of the twenty patients, in the form of denial among six, general anxiety among eight and secondary depression in four. Two patients had a post-concussional syndrome.

Fifteen patients were under observation in the subacute phase [from the fourth week to the end of three months]. In eight of them, of more neurotic symptoms were observed, of whom five had 'depersonalization' and three had phobic symptoms. An intense depressive reaction was observed in five of these fifteen patients and psychogenic paranoid psychosis was encountered in two.

In the chronic phase [from the beginning of the fourth month and beyond], twelve patients were under observation. Depersonalization was observed in four, paranoid state in four and prolonged depressive reaction in three of these patients. Personality deterioration occurred in one, observed in the form of turning avoidant, dependant, passive and aggressive at different times.

Twelve patients were observed after one year of spinal cord injury for occupational adjustment; four patients had

returned to their previous work and two had readjusted by changing to other professions, while six others remained unemployed.

Three patients had social and family interactions at the previous level and they took part in social activities satisfactorily. Impairment in adjustment occurred in five patients in form of social withdrawal, marital problems and altered familial interactions. Severe disruptions in form of spouse living away from the patient, desertion or divorce, occurred in four of the patients.

Impotency of various degrees was marked in eleven of the eighteen male patients. Neurogenic impotency was found in five of these and psychogenic in six. Of the female subjects in the study, one aged twenty three was unmarried and the other was aged fifty eight and had attained menopause. They denied any sexual activity when asked about psychosexual response. They expressed feeling 'asexual' and changed 'body-image' and opined that spinal cord injury did affect their 'mental-image' of womanhood, which is so much entwined with sexuality.

Positive transformation in form of becoming altruistic and supportive to the handicapped was found in three. Patients expressed their views on 'support' available. All of them felt that family support was available; sixty percent felt that it was adequate and forty percent were overwhelmed by it. Families spent their total savings and sold ornaments, land and utensils to treat them. Forty percent of the patients expressed the opinion that the medical support was adequate and satisfactory while it was meaningless for twenty percent. Cost of treatment was prohibitive for most of them and for forty percent of patients, medical support arrived late. About sixty percent of patients felt a total lack of larger social support. Only ten percent of patients felt that larger social support in form of governmental, non-governmental or charitable organizations was available for them and was adequate. For the remaining thirty percent, it was grossly inadequate.

## DISCUSSION

Emotional impact of the spinal cord injury can be equated with that of the 'Survivor syndrome'. Much of the symptomatology of the survivor syndrome emanates from maladaptive handling of aggression against self and others as projection and somatization, periods of psychotic depression, schizophrenia like symptoms, paranoid attitude and evasiveness (Krystal, 1965). Intense depression, paranoid states and personality disorders as consequences of spinal cord injury were observed.

Somatization disorder is always associated with chronic and pervasive disability (Zoccolillo, 1986). In the present series, a depersonalization syndrome was observed in almost one third of the patients with spinal cord injury; the body image changed, and perception of the self as 'half', 'shrinking', 'degenerating' and phantom-limbs hanging around were common.

The resultant neurogenic bowel, bladder and sexual problems of erectile dysfunction, in addition to physical debility impose serious psychological and emotional

stress on the persons affected. A variety of sexual problems arise following spinal cord injury, with little impairment of sexual interest or desire (Higgins, 1979; Bancroft, 1983). Higgins (1979) who studied sexual response in spinal cord injury stated that in adult males reflex psychic erection is possible depending on the level of injury. After thoracic cord transection, reflex erection can take place at a segmental level enabling many to have vaginal intercourse. Ejaculation and conception are possible if lower thoracic and upper sympathetic connections are intact (Munro et al, 1948).

With desire intact, sexual problems contributed to morbid jealousy which accompanied the paranoid state in the series. Paranoid psychosis was observed in two male patients whose wives conceived after their spinal cord injury.

Intense depression with suicidal ideation or an attempt was observed in about one third of the patients. Lack of larger social support, adequate care system for paraplegics, unemployment, loss of meaning of continuing existence all contributed to a negative attitude to life. Among patients from rural setting and lower social status, leaving the family and turning into ascetics and beggars was observed in a few patients. At the other extreme, positive or altruistic transformation was observed in about 20% of the patients. One patient with post graduate qualification became a teacher and worked in a school for the physically and mentally handicapped. Another on a wheel-chair managed a grocery shop employing the physically handicapped in a bid to support them. One became a social worker organizing a support system and treatment center for spinal cord injury affected persons.

"Rebirth" is a state of being born again. Such a state where intense depression and crippling helplessness gives rise to a firm resolution and motivation to help others in the same difficult situations can be equated with "rebirth". This may be a coping strategy used by patients with chronic illness, so as to share concerns with people similar-

ly affected and do something positive about a totally negative situation. Through such identification and supportive relationships, they tolerate hardships better and a more relaxed and realistic attitude is adopted. For such a positive approach to 'negative' situations, the term 'Phoenix Phenomenon' is suggested (Phoenix: a fabulous Arabian bird said to have lived, burned itself but rose again from ashes; phenomenon: anything appearing / observed in a scientific sense, remarkable, appropriate).

For the person with a spinal cord injury, battling with a changed life situation at an emotional plane is a front without flanks. Inadequate means of gauging psychological consequences, sexual and social interactions do compromise the validity of such a study. Equation of distress and disease has its own limitations. However, this has been an attempt to study emotional, social and psychiatric situations arising from spinal cord injury in our own setting.

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*N.M.Rath MD*, Lecturer in Psychiatry; *S.Bag MD, DM*, Assistant Professor, Dept. of Medicine, V.S.S. Medical College, Burla, Orissa; *P.Sarojini Dash*, Associate Professor & Head, Dept. of Psychiatry, MKCG Medical College, Berhampur, Orissa.

\*Correspondence