

## Burden, coping and functionality of the patients with neurological disability availing treatment at neuro rehabilitation ward

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### Abstract

Neurological conditions are the one where Rehabilitation place a major role because of its magnitude, manifestation and long term impact on the person and his/her family as whole. Neurological conditions pose great threat to public health as it contributes to 6% of the global burden of diseases effecting individuals functioning and resulting in long term disability.

**Objectives:** To assess the burden, coping and functionality of patients with neurological disability through standardized instruments and semi structured proforma to study socio demographic data and other illness related details.

**Results:** There were 33 patients admitted to neuro rehabilitation ward, majority of them belong to low socio economic group, males were more than females, there was no rural and urban difference, female caregivers of patient had mean score of higher burden, lesser coping, and social support compare to male caregivers.

**Keywords:** Neurological Disability, Burden, Coping, Social support.

### Introduction

The World Health Organization (WHO) has declared 2001 as the year for mental health in recognition of the burden that mental and brain disorders pose on people and families affected by them. Neurological, and developmental disorders account for a significant proportion of the global burden of disease. Growing recognition of the prevalence of brain disorders, as well as the availability of cost-effective treatments, may now lead to the adoption of measures designed to achieve significant reductions in the disease burden due to these disorders.

Neurological disorders encompass a wide range of disabling conditions, including epilepsy, stroke and degenerative disorders as the most common and severe. It is estimated that currently 1.5 billion people worldwide are affected by the disorders of the brain – a number that is expected to grow as life expectancy increases. Most of the disorders result in long-term disability and many have an early age of onset; measure of prevalence and mortality vastly understate the disability they cause.

Social isolation and stigma is often added to the medical and financial burden borne by patients and their families. Families are an integral part of the care system for persons affected with chronic and debilitating illness. The caregivers of neurological disorders are exposed to high levels of burden and distress. The five components of family structure like cohesion, family values, communication, organization and relationships with the society (Siert 2000) change radically after the onset of illness. The cohesiveness of the family may be disrupted often because the needs of the person affected will take the first priority and the common rituals and jobs that bring the family together as a unit might be disturbed.

Families as caregivers experience a feeling of loss and grief. They are confronted with uncertainty and emotions of shame, anger and guilt. Like the patient, they feel stigmatized and socially isolated (Wahl and Harman, 1989). The care giving role to the already existing family roles may become stressful, both psychologically and economically (Schene et al, 1996). Family members experience a loss of value or a sense of demoralization. They may withdraw from their contacts with other people and with the society. Disability (resulting from impairment) as defined as any restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being. Disability reduction primarily depends on the qualitative intervention of medication and allied therapeutic interventions as well as psychosocial therapeutic inputs.

Disability is performing socially defined role and tasks expected of an individual within a socio-cultural and physical environment of the person affected. These roles and tasks are organized in spheres of life activities such as those of the family or other interpersonal relations; work, employment, and other economic pursuits; and education, recreation, and self-care. Not all impairments or functional limitations precipitate disability, and similar patterns of disability may result from different types of impairments and limitations in function.

The nature of the illness and its course and prognosis, and the time at which the intervention has been explained the disability levels of the person affected. A person affected with stroke, with acute onset, who is brought immediately to the hospital and treatment has been initiated will have physical complications in spite of this, because of the nature of the illness and may have

high disability levels. In the current study all these factors are explored.

### Materials and Method

**Sample:** The study was carried out in Neurological Rehabilitation Ward, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore. NIMHANS is a premier institution in India and South East Asia, recognized for its contributions in service, training and research in the area of Mental Health and Neuro Sciences, and also Traumatic Spinal Cord Injuries. A multidisciplinary integrated approach is the mainstay of this institute. The institute runs in Neurological Rehabilitation Ward, which provides continuous care for spinal cord injury patients in IP care. On an average there by 200 patients are admitted in Neuro rehabilitation ward per year. For the current study, 33 patients who got admitted with neurological and neurosurgical problems were recruited using purposive sampling. Patients with neurological and neurosurgical problems without history of head injury were included for the study. Those patients with focal deficit were excluded from the study. Patients with co-morbid psychiatric problems, intellectual or memory deficits including dementia were excluded.

### Measures

**Socio Demographic Data Sheet:** The researchers prepared socio demographic data sheet to collect background information of the subject and their family members. Apart from this checklist was prepared to understand difficulties of the patients due to neurological problems and also their understanding of neurological disability, available community support and services, and experience of caregivers in care giving and their need once the patients get discharged from the neuro rehabilitation ward.

**Multidimensional Scale of Perceived Social Support (MSPSS) by Zimet, et al, 1988:** The MSPSS is a 12 item instrument designed to measure perceived social support from three sources: family, friends, and a significant others. It assesses the extent to which respondents perceive social support from each of those sources and is divided into three subscales: family, friends and significant other. Higher scores reflect higher perceived support.

**Brief Cope by Carver, 1997:** The Brief Cope is the abbreviated version of the COPE Inventory. Brief COPE, consists of 28 items, eliciting 14 different methods of coping. The COPE Inventory was developed to assess a broad range of coping responses, several of which had an explicit basis in theory. The domains of the scale are as follows: self-distraction, active coping, denial, substance use, use of emotional support, use of instructional support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self- The scale has good validity and reliability.

**WHO-Disability Assessment Schedule 2.0(2000):** WHODAS 2.0 is a practical, generic assessment instrument that can measure health and disability at population level or in clinical practice. It was developed from a comprehensive set of International Classification of Functioning, Disability and Health (ICF) items that are sufficiently reliable and sensitive to measure the difference made by a given intervention. WHODAS 2.0 captures the level of functioning in six domains of life including Understanding and communicating, Getting around, Self-care, Getting along, Life activities and participation in society. The full version has 36 questions which relate to functioning difficulties experienced by the respondent in the six domains of life during the previous 30 days. WHODAS 2.0 has excellent psychometric properties. Test-retest studies of the 36-item scale in countries across the world found it to be highly reliable.

**Burden Assessment Schedule:** The Burden Assessment Schedule (BAS) by Sell *et al.* The scale has 20 items. Each item is rated on a 3-point scale (not at all, to some extent and very much). The items of the schedule are categorized under five factors, i.e. impact well-being, marital relationships, appreciation for caring, impact on relationships with others, and perceived severity of disease. The scale measures the extent of subjective burden of caregivers and has been proven to have good inter-rater reliability and criterion validity.

### Results

**Socio Demographic Details:** The majority 75.8% were male, belonged to Hindu Religion. 54.5% of the patients were married. Majority 42.4 % of the patients were daily wage earner and 60.6% of the patients were breadwinner of the family and belonged to below poverty line income group. Majority of the patients were suffering from spinal cord injury 15%, GBS, TBI and Stroke were 12%, other condition were transverse mellitus 9%, Paraplegia 9%, Meningitis 9%, Toxic Myelopathy 3.03%, D4 D6 9%.

All most all the patients are dependent on the caregivers for the daily activities. Majority of them have bowel and bladder dysfunction, either they complain of urinary hesitance, urgency or retention, frequent urinary incontinence or the caregivers assist them in manual compression to evaluate bladder or finger evacuation of stool. The other problems faced are sexual dysfunction, motor problems and speech deficit for which speech therapy, physiotherapy and occupational therapy are referred. The Barthel Index is routinely measure of daily living index, used as a measure to assess feeding, bathing, grooming, dressing, bowel, bladder, toilets use, transfer from bed to chair and back. Most of our patients are able to do with moderate assistance. A patient's performance should be established by using best available evidence, asking the patients, friends, relatives and nurses are the usual source, but direct observation and common sense are also important. In eliciting sexual

dysfunction- confidentiality and privacy should be maintained as it may lead to inhibition and guilt feelings. **Knowledge and Neurological Disability:** Majority 80% of them did not have any information about neurological disability, visiting temples, prayers and fasting finally leading to visit the general practitioners and may be cured within short time after medication they felt the prognosis to be good, they were shocked to know about the nature of illness. Majority of them had family members who would help them in running the household work. They would also give their some financial help for medical expenses, and travels to the hospital. The caregivers who were spouses (wives, mothers) spent long hours in care giving. Male caregivers had requested their employers to be more flexible in work schedule, at times when it was not possible they have given up their job. The family is not aware of any community support

or service; they have not asked any philanthropy or medical camps for help, nor any government schemes, they have relied primarily on family members for support. They have invested family resources, borrowed small loans from relatives. Caregivers are tired and exhausted of long hours of care giving. Their health has been affected, they have ignored timely meals, snacks etc... hardly celebrate festivals, buy clothes, socialize with friends. All their time is centred around care giving of patient.

**Expectations:** When it comes to expectations of the caregivers, the caregivers need after discharge is to see that patient lives independently, able to get back to work, earn his livelihood, and focus on education / marriage of children. Caregivers feel that patient being female is enough if she relax at home and do household work.

**Table 1: Comparison between Burden Assessment Scale (BAS), Brief Coping Scale, (BC) Multi-Dimensional Social Support Scale (MDSS) and WHODAS Overall Scores of Patients with Neurological Disability and Background Variables**

Background Variables		Overall Burden		Overall Coping		Overall Social Support		Overall Disability	
		Mean & SD	Level of Significance (2-tailed)	Mean & SD	Level of Significance	Mean & SD	Level of Significance	Mean & SD	Level of Significance
Gender	Male (N=25)	85.38 (5.52)	(0.37)	68.68 (7.49)	(0.95)	59.22 (9.085)	(0.44)	84.68 (25.11)	NS 0.57
	Female (N=8)	88.72 (15.89)		68.25 (18.29)		62.43 (11.70)		90.00 (14.44)	
Residence	Urban (N=14)	91.93 (15.72)	0.162	64.93 (11.87)	0.094	58.85 (7.38)	0.586	85.86 (26.47)	NS 0.981
	Rural (N=15)	84.95 (12.33)		71.26 (9.24)		60.82 (11.21)		86.05 (20.62)	
Marital Status	Single (N=18)	84.94 (11.80)	0.189	70.72 (8.52)	0.213	59.27 (7.93)	0.698	76.67 (16.39)	S 0.008*
	Married (N=15)	91.47 (16.09)		66.00 (12.75)		60.67 (11.33)		97.13 (25.02)	

NS-Not Significant; Significant\* P<0.00

The Table 1 shows comparison between Burden Assessment Scale (BAS), Brief Coping Scale, (BC) Multi-Dimensional Social Support Scale (MDSS) and WHODAS Overall Scores of Patients with Neurological Disability and Background Variables such as gender, residence and marital status of the caregivers. The results showed female caregivers of patients had mean score of higher burden, lesser coping social support and higher disability of patients compared to male. However, the results were statistically nil significant. With the comparison of residence of caregivers of patients, those from urban residence had higher mean score burden, lower mean score coping and lower social support compared to caregivers from residing from rural area. However, the results were statistically nil significant. The married caregivers reported of patients having significantly (p<0.00) higher overall disability compared to single.

**Table 2: Relationship between Burden Assessment Scale (BAS), Brief Coping Scale, (BC) Multi-Dimensional Social Support Scale (MDSS) and WHODAS**

Correlations			
Variables		Social support(MDSS)	WHODAS
Burden(BAS)	Pearson Correlation	0-.270	0.460**
	Sig. (2-tailed)	0.149	0.007
	N	30	33
Coping (BC)	Pearson Correlation	0.305	0-.064
	Sig. (2-tailed)	0.102	0.721
	N	30	33

\*\* . Correlation is significant at the 0.01 level (2-tailed).

Table 2 shows relationship between burden, coping, social support and disability. The results revealed that BAS was positive correlated with WHODAS. The results revealed higher the burden higher the disability of the patients with the neurological disability.

## Discussion

This study is a first attempt to describe care burden, coping social support, disability and needs of those caring of individual affected by chronic neurological disorders availing services at neuro rehabilitation facility at tertiary care. In the current study majority of patients had bowel and bladder dysfunction, motor and speech deficits and sexual dysfunction. In eliciting sexual dysfunction- confidentiality and privacy should be maintained as it may lead to inhibition and guilt feelings.

When it comes to difficulties needs of the caregivers in care giving of person with neurological disability, majority had financial problems, loss of income due to absent from work due prolonged hospitalization, lack of social support, difficulty in coping and reported severe burden. The finding of the present study is concordance with other studies where caring for a disabled person to be stressful and burdensome experience (Schulz and Shewood, 2008; Bartolo et al, 2010). Female caregivers reported more burden and poor coping compared to male counterparts. Disability is more in married than single patients, there was no rural and urban difference. Caregiver's burden was positively correlated with level of disability of patients. Higher the disability higher burden reported by the caregiver which similar to existing studies (Bartolo et al 2010, Salter, Foley and Teasell, 2010).

From the current study when it comes to need of care giver they wanted emotional support, information about different phases of management of patients, financial aid, community resources to manage the patients back at home. When planning for intervention multi-disciplinary team should plan comprehensive care at individual, family and community level to prevent further disability of patients, reduce caregiver's burden, social support to enhance over all well-being. The study was done in one centre and generalizations of the finding may not be possible. There is need to replicate the study in other centres as well for planning intervention comprehensively.

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