

Needs of Persons with Neurological Disorders

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ABSTRACT

Background: In India, many persons with neurological disorder (PwND) get discharged from several hospitals with significant unmet needs. **Aim:** To assess the needs of persons with neurological disorders in a tertiary care hospital, Bangalore, India. **Method and Materials:** It was a cross-sectional descriptive study where thirty PwND availing the in-patient services at NIMHANS, Bangalore were selected through purposive sampling. Camberwell Assessment of Need – Research version was used. **Results:** Large majority (90%) of the respondents have unmet needs in daytime activities, psychological distress, information about illness and sex. Majority (70%) have unmet needs in job, self-care, medicines, mobility, child care. Half (50%) of the respondents have unmet need in accommodation, intimate and social relationships, finance. Three-fourth revealed that their need for food, safety and social welfare needs have been met. **Conclusion:** Patients from lower economic, educational status and urban domicile have more service needs. Present study attempts a systematic need assessment which has implication in addressing the unmet needs of PwND to improve their quality of life.

Keywords: Need assessment, neurology, discharge planning

INTRODUCTION

It is estimated that more than 30 million people suffer from common neurological disorders in India. Epilepsy, headache, febrile convulsions and cerebrovascular disorders together comprise 80% of all neurological disorders. Neurological disorders affect all age-groups, prevalence were more in rural population.^[1]


Most persons with neurological disorders (PwND) get discharged with significant unmet needs and without adequate discharge planning from several hospitals in India. Assessment of needs is an essential step in planning, developing and evaluation of clinical social

work services in neurological settings, to meet the requirements of PwND and to enable them to achieve, maintain or restore an acceptable or optimal level of functioning and quality of life. PwND share unique need in the areas of treatment, rehabilitation and environmental support. In recent years assessing the needs are given more importance as a part of standard operating procedures in clinical social work.

Needs of persons with common neurological disorders

Epilepsy: Women with epilepsy have unique needs such as educational, vocational, marital, child-rearing needs and informational needs regarding pregnancy, breast-

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feeding and motherhood.^[2] Mental health needs of children with epilepsy such as anxiety, depression and behaviour problems were largely unaddressed. They have 3-6 times increased risk for developing mental health problems than normal children.^[3] Parents of children with epilepsy expressed strong need for information about epilepsy diagnostic procedures, treatment and management at home and school. Psychosocial care needs were associated with family history of epilepsy and number of medicines used by children but not for other socio-demographic factors.^[4] Pregnant women with epilepsy reported need for information about medicines has been met due to long-standing use of anti-epileptic drugs.^[5] Special needs of adolescent such as matching the medicines for adolescent with epilepsy must be considered to optimize treatment, as they were considered a group of patients with special needs owing to their developmental trajectories during adolescence.^[6]

Stroke: Systematic review on needs of persons with stroke and their caregivers revealed that they need knowledge about stroke, treatment, recovery and its prevention. Often these needs were unmet. Most common felt needs of caregivers were mobility in terms as moving and lifting, exercises, psychological and nutritional issues.^[7] Most stroke survivors have long-standing unmet needs such as daily living, financial need, health, leisure, social support, social participation, mobility aids, transport, home adaptation, housing, rehabilitation and employment.^[8,9,12] Age, duration of stroke, more disability were the factors associated with long-term unmet needs of stroke survivors^[9]. Stroke survivors have unmet rehabilitation needs such as acceptance of stroke, access to physiotherapy and occupational therapy, transportation, follow-up service, home visit, emotional support from care giver, domestic help, house modification.^[10]

Family of persons with stroke different needs during hospitalization and after discharge. Common expressed needs were health information, professional support, and community networks. Patients' clinical condition, length of hospital stay and physical dependence determines the needs of caregiver of persons with stroke.^[11] Overall family caregivers need decreased as the illness duration increased and their needs differed

significantly at different point of time. There was an association between caregiving experience and unmet needs of stroke patients. One-third of them have unmet financial and daily living needs. One-fourth of the caregivers need adequate social support for their caregiving role, want to avail respite care and need accessibility for the same.^[12]

Parkinson Disease (PD): Persons with PD reported that need for information on dealing with fear about future, marital relationships, programs for promoting sense of well-being, maintaining driving license, financial assistance, transportation, managing government paper work, informed participation in health related decisions, managing non-motor symptoms, need for adaptive technologies for activities of daily living, information on home activity programs, parkinson's symptoms, side effects of medications and its management, information on relationship between diet and medication.^[13] Informal caregivers of persons with Parkinson disease need respite care, financial, social and emotional support, and coordination of continued multidisciplinary care. Treating team seldom address these needs.^[14]

Multiple Sclerosis (MS): One-third of multiple sclerosis (MS) patients mentioned psychological support as their common unmet need.^[15,18] Forty-eight needs were identified among adults with severe multiple sclerosis who were living at home. These patients had difficulty in expressing their needs; informational need, access to services and need for home care were highest in them.^[16] Home visit, permanent neurologist and emotional support from nurse were the palliative care needs of persons with severe MS.^[17] Multiple sclerosis patients expressed physiotherapy as their most unmet need.^[19,20] Perceived needs significantly differed between moderately and severely disabled MS patients.

Most MS patients have minimum one unmet health or social needs. Most prevalent social care need was transport assistance. More male MS patients have employment needs than female patients. More women MS patients cited a need for psychosocial support, counselling to greater extent than men.^[21] There was relationship between unmet health needs and disease duration, phase, amount of disability among multiple sclerosis patients. Presence of more unmet needs were

related to clinical factors (disease subtype, illness duration) and demographic factors (rural residence, being older, unmarried).^[20,22] Patients' needs increase when disease progresses and symptom worsens^[23]. MS patients reported lack of time, poor care coordination among treatment providers, over dependence on drug treatments and inadequate patient self-advocacy were main reasons for not discussing their needs with healthcare providers.^[24]

Delaying progression, providing neuro-protection, delaying and minimizing disability, reducing active symptoms, improving drug adherence, addressing the cognitive disability, reducing adverse effects of drugs, understanding patients priorities, optimizing their ability to be productive, providing psychosocial care along with medical care and developing better treatment for progressive multiple sclerosis were needs voiced by patients, clinicians, caregivers and researchers. Psychosocial needs are inadequately addressed by the health professionals in half of the MS survivors. Many MS patients felt that they were continuing disease modifying therapy without any benefits.^[18] Employment needs, leisure needs, specific resource needs, needs related to interaction with medical community, meaningful daytime activities, accessibility and information were few identified needs of patients with multiple sclerosis and their significant others^[25]. However, few perceived a need for a specific service continuously. There was greater perceived need for almost all the services among MS patients. Severe MS patients perceived environmental support, providing information, enhanced care provision, rehabilitation, psychological support and non-professional care were important to meet their needs.^[26]

Motor Neuron Disease (MND): Nearly one-fourth of the persons with MND reported that health services and social services did not meet their needs.^[27] Patients and carers needs were addressed in the final stages of MND. There appears a need for increased, co-ordinated support from palliative care services to use advance care planning tools.^[28]

Huntington Disease (HD): Persons with Huntington disease and their families need palliative care service in terms of supportive care, practical support, providing essential information, reducing the fear of future, coping

with illness, individualized care and bolstering their spirit.^[29,30]

Multidisciplinary disciplinary approach: Multidisciplinary approach is considered effective in addressing the patients' needs and their family needs. NIMHANS is a multidisciplinary institute for patient care in the field of mental health and neurosciences. Multidisciplinary team in neurology consists of Neurologist, Neuropsychologist, psychiatric social workers, nurse, physiotherapist, occupational therapist, clinical neurophysiology technicians and support staff. This approach found to be effective reducing the needs of MS patients.^[31] Persons with severe multiple sclerosis reported that they need physiotherapist, occupational therapist, general physicians more frequently than neurologist. Majority of MS patients perceived a need for rehabilitation, assistive devices, transportation service, psychosocial support, counselling and information on social insurance, vocational rehabilitation which requires multidisciplinary inputs.^[32]

METHOD AND MATERIALS

Aim: To assess the needs of persons with neurological disorders in a tertiary care hospital, Bangalore.

Operational Definition of Need: There is lack of consensus in defining 'need' owing to the inherent complexity in it.^[33] In this study, 'need' refers to requirement of individuals to enable them to achieve, maintain or restore an acceptable level of functional independence to have a better quality of life.^[34] Bradshaw^[35] defines Felt needs are wants, wishes, desires. Expressed needs are demands or felt needs which are articulated. Normative needs are those assessed by health professionals, administrators or experts in relation to norms or a desirable standard. Rehabilitation needs may be defined as a need arises out of resource constraint between individual abilities and disabling situations in his/her environment as compared to desirable level.

Descriptive research design was used for the study. PwND availing the in-patient services at NIMHANS, Bangalore were considered as universe of the study. Sample Size: 30 respondents were selected through purposive sampling. Data was collected from male medical ward, female medical ward, stroke ward, step-

down ward from neurology in-patient services at NIMHANS, Bangalore. NIMHANS is a tertiary care hospital and provides multidisciplinary care. Sample of the study consisted of persons with Stroke, GB syndrome, Parkinson disease, Wilson disease, uncontrolled seizures. The study was carried out during Sept 2004 – May 2005 as a part of partial fulfilment of M.Phil degree in Psychiatric Social Work. The study was cross-sectional in nature. Inclusion criteria: Inpatients with neurological disorders aged between 16 years to 65 years. Those who have family members during the time of study and those who speak Tamil, Kannada, Telugu and English were included in the study based on the researcher's language fluency. Patients who were in Neurology ICU and receiving out-patient services were excluded. Ethical Consideration: The study was approved institutional ethics committee.

Universe: Presently NIMHANS has 393 beds for both neurology and neurosurgery (293 beds for IP care and 100 beds for emergency and casualty services). Neurology department has eight wards such as male medical ward (24 beds), female medical ward (22 beds), paediatric neurology ward (18 beds), neurology ICU (6 beds), neurology emergency ward ICU (6 beds), stroke ICU (5 beds), stroke ward (5 beds), step-down ward (4 beds), neuro-infection ward (6 beds) and special wards (27 beds), neurology short stay ward (25 beds) and neuro-rehabilitation ward (22 beds).

Table 1 shows the increasing trend in number of availing neurology consultation in the last five decades. Every decade the number of people seeking consultations gets doubled.

On an average 18 persons get admitted and 12 persons

get discharge per day in neurology. At any given point of time approximately 150 patients stay and bed occupancy is more than 85%. Average length of stay at neurology ward is 7-10 days. Few patients stay for minimum 3 days to maximum one month, depends upon the severity and nature of the neurological disorders. In the last 67 years, 821000 persons availed neurology and neurosurgery consultations which excludes screening.

Tools used: Camberwell Need Assessment-Research version^[36] was used in this study. This tool was primarily developed to assess the needs of persons with psychiatric disorders. It was used in this study to assess the health and social needs of PwND. It assesses both met and unmet needs. It incorporates the views of both service users and staff about met and unmet needs. The adult version was used in the study as it covers the age from 16-65, original version has 22 items and five domains such as basic need, health need, functioning, social need, and service needs. Two items such as need for job and medicines were added after the pilot study. Tool can be completed within 30 minutes, suitable for both routine clinical practice and research. *Scoring procedure:* Scoring of each item is coded by '0' means no serious problem (no need), '1' means moderate need after addressing the need (met need), '2' means serious problem in the need which is unmet, '9' means not known. *Method of data collection:* Interview schedule was used to collect participants' socio-demographic data, illness related information and their needs. Informed consent was obtained from participants and their family. *Statistical analysis:* frequency distribution, mean, t-test were used to analyse the data.

Table 1: No. of Persons availed neurology consultations in the last five decades

Neurology consultations	1950	1965	1975	1985	1995	2005	2016
Registrations	350	860	7246	5879	8878	13456	17664
Admissions	350	730	1374	2321	1972	2883	3840
Discharges	300	690	1340	2300	1870	2802	3648
Follow-up	500	4302	1649	24204	63300	54166	77400
Emergency consultations	300	950	763	4120	8623	10685	21084

(Source: Annual Reports, NIMHANS)

RESULTS

Socio-demographic details of the study participants

Mean of age of respondents was 35 years (S.D=11). Majority were (63%) male. Half (50%) of them were illiterate. One-third (36%) had primary education. Nearly one-fifth were housewives and 43% were farmers. Majority (82.5%) were Hindus, 69% belong to lower socioeconomic status. Majority (69%) were married, hailing from nuclear family (59%). Majority (69%) were from rural areas. Majority (62%) were from Karnataka, out of which 21% were from Bangalore. Nearly one-third (28%) were from Tamil Nadu. One-third (35%) were having family size of 3-6.

Needs of persons with neurological disorders

Table 2 reveals the needs of the persons with

neurological disorder. *Basic needs:* Half of the respondents 50% have unmet need for accommodation at home, 63% have unmet need for food, large majority (93%) have need for daytime activities. Health needs: Nearly half of the respondents (47%) have moderate, and 50% have severe physical health need. Large majority (90%) have psychological distress and need information about illness. One-third has mild to moderate problem in alcohol (29%) and drug use (13%) *Social needs:* Majority(63%) have problem in intimate relationships, 60% in social relationships and more than half of them (52%) have problem in sexual need and among one-third (33%) sexual need were not known and for 10% of sample sexual need domain was not applicable. *Functional needs:* Large majority (80%) of them have problem in looking after home, 87% have

Table 2: Needs of Persons with Neurological Disorders

Sl. No	Needs	Unmet Need f (%) N=30	Unmet Need Mild (%)	Unmet Need Moderate (%)	Unmet Need Severe (%)
	Basic Needs				
1	Accommodation	15 (50%)	43	3.3	3.3
2	Food	19 (63%)	47	13	3
3	Day time Activities	28 (93%)	16.5	60	16.5
	Health needs				
4	Physical Health	29 (97%)	3.3	47	50
5	Psychotic Symptoms	02 (7%)	7	-	-
6	Psychological Distress	27 (90%)	30	50	10
7	Information about Illness	27 (90%)	23	47	19
8	Safety to Self	0	0	0	0
9	Safety to Others	02 (7%)	7	-	-
10	Alcohol & Drug use	09 (30%)	13	17	-
	Social Needs				
11	Intimate relationship	19 (57%)	40	7	10
12	Social Relationship	18 (60%)	37	20	3
13	Sexual Needs	15 (50%)	13	20	17
	Functional needs				
14	Looking after Home	24 (80%)	63	10	7
15	Self-Care	22 (72%)	13	46	13
16	Child Care	26 (87%)	26	13	3
17	Job	24 (80%)	30	40	10
18	Financial need	20 (66%)	33	23	10
	Service needs				
19	Transport	24 (79%)	53	13	13
20	Social welfare Benefits	11 (37%)	37	-	-
21	Medicines	21 (70%)	53	10	7

Table 3: Difference between Need and respondents' demographic variables

Need	Demographic variables	Mean	S.D	't' value	p value
Total Need Score	Male	51.89	10.72	0.79	0.42
	Female	50.13	10.17		
	Literate	50.63	10.09	0.48	0.63
	Illiterate	51.75	11.16		
	Middle SES	49.61	9.45	1.12	0.26
Lower SES	52.11	11.10			
Rural	Urban	49.97	10.31	0.85	0.39
	Urban	51.88	10.56		

problem in self-care, 38.5% problem with childcare, 80% have problem in vocation, 67% have problem in financial need. Service Needs: Large majority (79%) have mobility/transport needs, for 73% their social welfare need was met and 70% have unmet need for medicines.

Table 3 shows the difference in need between gender, educational status, economic status and domicile. Independent sample 't' test results showed that there was no statistically significant difference in overall need score between male and female, literate and illiterate, middle and low economic status, rural and urban patients. It may be inferred that needs of PwND have similar across different demographic factors. However, there was trend showing that male patients, illiterates, persons from LSES and urban have more needs than their counter parts.

Sub-domain analysis revealed that urban patients (mean=10.3 vs 8.6, t=2.81, p=0.01) illiterates (10.4 vs 9.0, t=2.11, p=0.03) patients from lower economic status (10.2 vs 8.6, t=2.54, p=0.01) have significantly more service needs such as need for social welfare benefits, assistance in transport/ mobility, need for medicines.

DISCUSSION

Mean age of the patients in neurology ward is 35 years. More neurology patients were in the reproductive age group 26-35, they are more skilled. The younger age group indicates productive age group. Hence focus should be on skill intervention, independent living and disability management. More than one-third (35%) were illiterate which indicates psychoeducation should be planned for them during hospitalization as per their level of understanding and to educate them in their own

language as far as possible.

Nearly half of respondents (43%) and around one-fifth (19%) have moderate and severe level of informational need about their illness respectively. This finding was in accordance with previous studies.^[7,16,29] Providing essential information about palliative care service was felt by family as well patients.^[29] Most MS persons had perceived need for information on social insurance.^[26] Information about illness is invariably found not reaching the patient and their family members across studies. This may be attributed to more patients from lower educational status, professionals' limitation in converse in vernacular languages to people who seek treatment from diverse cultures.

Large majority (90%) need relief for their psychological distress. This finding was similar to unmet needs of stroke patients.^[7] MS persons reported need for emotional support specifically from nursing care.^[17] Psychological support was most cited health need in MS patients.^[20,23] Review on unmet needs of MS patients revealed that providing psychosocial care along with medical care as their essential need.^[18] There was greater perceived need for all services among MS patients.^[26] Persons with Huntington disease revealed supportive care as one of their prime need^[30]. Whereas support from professionals as most frequently expressed family needs of stroke patients.^[11] More women with MS reported need for psychosocial support than men. There was no significant difference between men and women regarding need for psychological support.^[21]

Transport need in mobility and to access the health care services were felt by 80% of the hospitalized patients. This finding was in concordance with earlier studies. Families and patients need assistance in mobility for exercise, bathing, moving, lifting is more prevalent in stroke^[7] and multiple sclerosis.^[26,20,22]

In this study, 40% have moderate and 10% have severe need in vocation. This result was comparable to previous study^[9] where 60% of stroke patients had unmet need in work, whereas in MS patients, more male (23%) had employment needs than female.^[2] Majority (67%) had financial need in this study. This finding was parallel to previous studies.^[14,26]

Recommendations

Although, this study did not assess the emerging needs in the literature such as need for palliative care the researchers felt neurology patients have unique palliative care needs such as death place preference and advance care planning/ directives. Hospital deaths are common in neurological disorders. Many patients prefer to die at their own home than in hospital.^[37] In India, very few patients may be aware of advance directives. Patients who received more tailored made interventions and palliative care services; most of their need were satisfied.^[38] Despite the fact that palliative care emerged as an alternative care in the management of patients with terminal cancer, recent developments in the field of palliative care medicine suggest that palliative care may be suitable for any patient at any age and at any stage living with chronic, life-threatening, progressive, disabling illness.

During the study, there were no standardised tool specifically available for assessing the needs of PwND. Presently few tools available to measure needs of persons with neurological disorders such as Needs Questionnaire for women with epilepsy,^[2] Needs provision complexity scale for long term neurological conditions,^[39] The Northwick park care needs assessment,^[40] Multiple sclerosis need assessment tool,^[41] Psychosocial care need scale for children with seizure.^[42] These tools may be considered for future studies.

Limitations

Generalization of the study finding is limited owing to small sample size. The study did not assess the emerging needs in the literature such as need for palliative care, hospice care, respite care, home based care, rehabilitation needs such as skilled nursing needs, basic care support needs, equipment needs, behavioural and cognitive needs, therapy needs from different disciplines (frequency and intensity), advocacy needs and spiritual needs of PwND. The study did not compare the needs of persons with different neurological disorders because of limited sample.

CONCLUSION

Large majority hospitalized persons in neurology have significant unmet need in day time activities,

psychological distress, information about illness, looking after home, child care, vocational needs, assistance in self-care, transport, subsidized medicines, financial needs and need for intimate and social relationship. Present study implies a systematic need assessment in addressing these unmet needs among PwND to improve their quality of life.

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