Original research article

Unmet needs of care and associated factors among stroke survivors followed up at the Neurology Clinics, National Hospital of Sri Lanka

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Abstract

Background

Stroke was the leading cause of hospital deaths in government hospitals in the year 2010. The disability and dependency due to the stroke have a significant impact on the individual, family and the community.

Objective

To assess perceived unmet needs of care and associated factors among stroke survivors followed up at the neurology clinics, National Hospital of Sri Lanka

Methods

A hospital-based descriptive cross sectional study was carried out among 270 first ever post-stroke survivors, at six-month follow-up. Data were collected via pre-tested interviewer administered questionnaire on health characteristics: cognitive status, disability, emotional status, perceptions on the general health and 'unmet needs of care' under 5 domains: medical/clinical support, risk factor control, rehabilitation therapy, social support, emotional support.

Results

Two third of the participants were males with median age 56 years (IQR 48 - 64 years). Overall 98.9% (n=267) reported having unmet needs of care (median 7.5; IQR 5.0-10.25) across all 5 domains, and highest for emotional support (90.4%, n=244). Individual unmet needs were high for physiotherapy (81.2%), diet (75.9%), transport (73.8%) and stroke information (72.8%).

Unmet needs were significantly ($p<0.05$) associated: in medical/clinical support with ethnicity other than Sinhalese, impaired cognitive status, having possible depression; emotional support with ethnicity other than Sinhalese, having possible depression; in risk factor control with bad perception on general health; in rehabilitation therapy with severe disability.

Conclusion

High level of unmet needs emphasizes the need of implementation of post-stroke care strategies at the community level.

Key words: stroke, stroke survivors, unmet needs of care participatory role

Introduction

Global stroke burden in Disability Adjusted Life Years (DALYS) is projected to rise from 38 million in 1990 to 61 million in 2020. The disability and dependency due to the stroke have a significant impact on the individual, family as well as the community. The quality of life is affected due to the difficulties in performing activities of daily living. Stroke is a costly disease; economic consequences are due to the cost of care for stroke victims and the loss of productivity due to disability (1).

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In Sri Lanka, there is an increasing trend in the number of admissions (from 16,406 in 1998 to 35, 067 in 2010) due to stroke in the government hospitals. Stroke was the leading cause of hospital deaths in the year 2010 (2). The community prevalence of stroke was estimated as 1.6 per 100 population (3). Stroke was reported as the most important cause of adult disability in Sri Lanka, with half the survivors fully dependent on others for their daily activities (4).

With Sri Lanka's projected peak population of 21.9 million in 2031, and 20.7% being over 60 years, the burden of stroke will be on the increase (5). Having managed the acute condition, the majority of the stroke survivors are discharged to the community and reviewed regularly in the medical clinics. Unlike in developed countries, there are no comprehensive services or post-event care plans available for stroke survivors which would help them to lead independent lives despite the functional impairment (4).

Stroke survivors need medical, social and emotional support for the rest of their lives. Medical support mainly includes continuing drug treatment, control of risk factors, rehabilitation therapies and other aspects of clinical care. Having a care giver, maintaining mobility, engaging in activities of daily life and leisure time activities, providing transport, accommodation and finances are the main social support needed. Emotional support mainly includes management of problems related to sleep, mood changes, memory and concentration (6). 'Unmet needs of care' are the requirements of the stroke survivors which are not met by the services, which may vary depending on the person's needs and the services available (7).

Evidence based post-stroke care is imbalanced in most countries despite many published studies to assess the long term needs for stroke survivors (8). There are no published studies in Sri Lanka on unmet needs of care of stroke survivors.

Objectives of this study was to describe the perceived unmet needs of care and associated factors among stroke survivors followed up at the neurology clinics, National Hospital of Sri Lanka.

Methods

A descriptive cross-sectional study was carried out from July to December in 2011 among first ever stroke survivors, six months after discharge, followed-up at the neurology clinics National Hospital of Sri Lanka (NHSL). Those with expressive aphasia were excluded. Sample size was calculated using the formula, $N= Z^2 p (1-p) / d^2$ (9) with the expected proportion prevalence of unmet needs of care of stroke survivors 0.59 **(7)**, an alpha error of 0.05 and the precision (d) 0.06 (10). After adding a non- response rate of 5% the final sample size was 270.

Unmet needs of care are the requirements of the stroke survivors which are not met by the services, which may vary depending on the person's needs and the services available (7). A pre-tested interviewer administered questionnaire (IAQ) was developed based on the GM-SAT; Greater Manchester Stroke Assessment Tool (6) to assess the perceived unmet needs of care. The judgmental validity was assessed by a panel of experts in Community Medicine, Neurology, Sociology, Psychology and Rehabilitation. The tool was translated into Sinhala and Tamil and back translated into English. The IAQ was restructured after pre-testing, to ensure better understanding of questions by the respondents.

The 'Unmet Need of Care-Stroke Assessment Tool' assessed perceived unmet needs of care after 6 months of discharge from hospital under 5 domains: medical support (10 items), risk factor

control (7 items), rehabilitation therapies (3 items), social support (8 items), and emotional support (9 items). Stroke survivors were first inquired by the principal investigator to see whether there was a specific need for a service and then assessed as to whether they were getting the available services. If the specific need was not met with the available services it was identified as an unmet need of care. Data were collected by a trained pre-intern Medical Officer who was fluent in all three languages.

Ethical clearance was obtained from the Ethics Review Committee of Faculty of Medicine, Colombo. Administrative approval was obtained from the Director, NHSL and the Consultants of the clinics.

Stroke survivors attending their follow-up, six months after discharge from the hospital were identified from the Clinic Registry and were verified by scrutiny their Diagnosis Cards. Consecutive clinic attendees who met the inclusion criteria and gave their consent were recruited until the required sample size of 270 was achieved.

Stroke survivors were assessed for their physical and mental health status. Cognitive status was assessed using the Mini Mental State Examination (MMSE) form which has been validated for Sri Lanka in Sinhalese (11) and re-translated into English and Tamil by principal investigator. Those with MMSE score =24 were categorized as cognitively impaired. Level of disability was assessed using the modified Rankin's Scale (mRankin's scale). It is a validated tool with 6 items, widely used internationally to assess a person's degree of disability or dependence in performing daily activities; those with mRankin's scale < 3 were categorized as absent /mildly disabled and ≥3 as severely disabled. Possible depression was assessed using the Abbreviated Wimbledon Self Report Scale which reflects the patients' feeling over the previous week. Those with a score of 5-10 were identified as having possible depression. Perception on their general health status was assessed using a visual guide (good, bad, no comments) prepared by the principal investigator. Presence of unmet care was marked as '1' and absence as '0'. Those who were identified as having unmet needs were referred to obtain the available services.

Statistical analysis was done using statistical package of social sciences (SPSS) version 17.0 Univariate analysis was carried out to describe the socio-demographic-economic factors and health characteristics. The proportions with unmet needs of care were calculated for the five domains. The association of socio-demographic-economic factors and health characteristics (cognitive status, disability, emotional status, perceptions on the general health) with the unmet needs of care were analysed for significance using chi squared test.

Results

Total of 270 stroke survivors were interviewed during the study period with less than 3% non-response rate. Two third of them were males (n= 179). The median age of the participants was 56 years (IQR 48-64) with the range of 15-81 years. Of the participants 84.1% (n=227) were Sinhalese and 83% (n=224) were married or living together. Only 3.7% (n=10) had not attended school. Two third (n= 178) of stroke survivors were earning a livelihood at the time of the event and 97.8% (n=174) of them were the breadwinner of the family. The current monthly family income was less than Rs 10,000.00 in 43.7% (n= 118) of the sample.

Table 1: Distribution of health characteristics among stroke survivors (n= 270)

Health characteristics	Number	Percent (%)
Cognitive status		
Normal	153	46.7
Cognitively impaired[1]	117	43.3
Disability status		
Absent or Mildly disabled	197	73.0
Severely disabled[2]	73	27.0
Emotional status		
Normal	198	73.3
Possible depression[3]	72	26.7
Perception on the general health status[4]		
Good	162	60.0
No comments	67	24.8
Bad	41	15.2

1. Mini Mental State Examination Score < 24
2. modified Rankin's scale 3 and more
3. Abbreviated Wimbledon self reported depression scale 5-10
4. Assessesd by visual guide

Table 1 shows the distribution of health characteristics among stroke survivors, of the stroke survivors 43.3% (n=117) were cognitively impaired (MMSE score <24.), 27% (n=73) were severely disabled (modified Rankin's Scale 3 an more) and 26.7% (n=72) had possible depression (abbreviated Wimbledon Self Report Scale 5-10). Sixty percent (n= 162) of them perceived their general health as good.

Overall 98.9 % (n=267) participants reported having unmet needs of care. The median number of unmet needs was 7.5 (IQR 5-10.25) with a range of 0 to 22 across the 37 items. The highest (n=244, 90.4%) unmet need of care was reported for the emotional support domain and lowest (n=85, 31.5%) was reported for the rehabilitation therapy domain, while medical/clinical support was 68.5% (n=185), risk factor control 82.2% (n=222), social support 84.8% (n=229).

Table 2: Distribution of individual unmet needs of care among stroke survivors

Unmet Needs of Care*	Number	Percent (%)
Medical/Clinical support (N=185)		
Medicine management	74	40.0
Vision	36	19.5
Hearing	47	25.4
Communication	46	24.8
Dysphagia	10	5.4
Nutrition	36	19.5
Continence	10	5.4
Pain	68	36.8
Headaches and migraine	31	16.8
Seizures	1	0.5
Risk factor control* (n=224)		
Blood Pressure control	11	4.9
Cholesterol control	64	28.6
Glycaemic control	2	0.9
Alcohol	34	15.2
Diet	170	75.9
Smoking	15	6.7
Exercise	120	53.6
Rehabilitation therapies (n=85)		
Physiotherapy	69	81.2
Occupational therapy	34	40.0
Speech therapy	33	38.8
Social support (N=229)		
General transport and travel	165	73.8
Activities and hobbies	4	1.7
Employment	36	15.7
Benefits and finances	119	52.0
House and home	38	16.6
Care and supporter need	57	24.9
Activities of Daily Living	11	4.8
Mobility	49	21.4
Emotional support (n=224)		
Anxiety	124	55.4
Emotionalism	79	35.3
Personality changes	61	27.2
Sexual health	49	21.9
Sleep pattern	10	4.5
Fatigue	88	39.3
Memory	75	33.5
Concentration and attention	127	56.7
Stroke information	163	72.8

*Multiple responses allowed

Table 2 shows the distribution of total and individual unmet needs of care under the five domains. Proportion of individual unmet needs was highest for medicine management (40%), and diet (75.9%) in the risk factor control domain; physiotherapy (81.2%) in the rehabilitation therapy domain, transport (73.8%) in the social support domain, information regarding stroke (72.8%) in the emotional support domain. Unmet need was reported low (<10%) for seizures (0.5%), dysphagia (5.4%), continence (5.4%) in the Medical/clinical support domain, glycaemic control (0.9%), smoking (6.7%) in the risk factor control domain, activities and hobbies (1.7%), activities of daily living (4.8%) in the social support domain and sexual health (4.5%) in the emotional support domain.

The unmet needs of care related to medical/clinical support was significantly higher among stroke survivor with ethnicity other than Sinhalese (x^2=5.356,df=1, P= 0.021), with impaired cognitive status (x^2=5.456, df=1,P=0.020) and with possible depression (x^2=3.902, df=1,P=0.048). Stroke survivor with ethnicity other than Sinhalese (x^2=10.912, df=1, P=0.001) and having possible depression (x^2=10.462, df=1, P=0.001) had significantly higher unmet need related to emotional support. Unmet needs related to risk factor control was significantly higher among those with bad perception on general health status (x^2=10.526, df=2, P=0.005). Stroke survivor with severe disability status (x^2=5.596, df=1,P=0.018) had significantly higher unmet need related to rehabilitation therapy.

Discussion

Overall unmet needs of care (98.9%) were very high compared to developed countries. Christopher et al, (2011) showed that overall 49% reported having unmet needs with a median of 3 items (range 1 to 13) across a range of different domains (7). The Longer-term Unmet Needs after Stroke (LUNS) study carried out at 3 to 10 months of post-stroke reported a median of 4 unmet needs (range 0-19) out of 22 items (12). However the estimates on unmet needs of long-term stroke survivors may be an imprecise estimate as those not attending the clinic due to severe disability, whose monthly medicines were collected by care giver were not included.

The burden for the patient and the family due to loss of income and the expenses incurred to care for stroke survivors is flagged by the finding that two third of stroke survivors were earning members at the time of the event, 97.8% of them were the breadwinner of the family. Fifty two percent of post stroke survivors had unmet need of care for benefits and finance and 15.7% for employment.

Ethnicity was significantly ($p<0.05$) associated with higher unmet needs related to medical/clinical support and emotional support. Expressing the needs can be influenced by the ethnicity which can be due to inequity in the services or socio-cultural background. A similar finding was found among black and white ethnic groups in the study done by Christopher et al (7) that ethnicity and disability were significantly associated with the reported unmet needs.

Among those who reported unmet need of care for risk factor control (82.2%), the majority were related to advice on diet (75.9%) and exercise (53.6%). A notable percentage were still smoking and consuming alcohol (15.2% and 6.7% respectively), indicating that more targeted rehabilitation programmes may be needed to change the life style of the stroke survivors. However freely available services for monthly checkup of blood sugar and blood pressure may

be the reason for very low unmet needs of care for glycaemic control and blood pressure control (<1% and 5% respectively).

The major unmet needs of care related to social support was general transport and travel (73.8%), which could be explained by the fact there are no facilities for disabled persons in public transport in Sri Lanka, the private transport is also costly especially with the need to be accompanied by another person. High proportions of unmet needs of care reported in relation to stroke information (72.8%) supports the consistently reported dissatisfaction with the provision of information (12-15).

Scholte W J M, et al, 1999 (16) reported, that around 50% of unmet demanders were feeling unhealthy. Nevertheless, 60% of stroke survivors in the present study perceived their general health as good which may be mainly due the supportive family environment prevailing in Asian countries. One quarter of stroke survivors in the present study had possible depression which was less than that reported by most studies (16). Robert G et al, (1982) (17) also reported that one third of stroke survivors had post-stroke depressive disorders. A similar finding (33%) was seen in the pooled estimate of clinically assessed post-stroke depression reported in a systematic review of observational studies (16). The lower percentage found in the present study may be due to under-reporting since depression was assessed through self-reporting. The high percentage of unmet needs for mood and anxiety care (55.4% and 35.3% respectively), were similar to findings of a systemic review by Murray et al, 2003 (8).

Scholte's study supported that emotionally distressed patients and disabled patients were more likely to be unmet demanders for psychosocial support (OR=3.8) (16), similarly the present study observed significant association ($p<0.05$), between emotional status and unmet needs related to medical/clinical support, rehabilitation therapy and emotional status domains implying the need for active interventions for mental health services for stroke survivors. However one of the limitations in the present study is that the tools used to identify possible depression or severity of disability or their cut off values are not validated to Sri Lanka.

Overall 81.2% of stroke survivors reported unmet needs for physiotherapy yet only 27% were severely disabled. The disability status was significantly ($p<0.05$) associated with unmet needs related to rehabilitation therapy implying the need to establish community based rehabilitation services for stroke survivors.

Cognitive status can affect the patients' perception causing under estimation or over estimation of needs. In the present study, 43.3% (n=117) of the survivors were cognitively impaired and it would have influenced the self-reported unmet needs. This proportion was higher than that of reported by Christopher et al (12.2 %) (7), yet only the medical/clinical support was significantly ($p<0.05$) associated with the cognitive status as cognitively impaired patients are invariably looked after by a carer as shown by Scholte W J M, 1999 (16).

Conclusion

The results emphasize the requirement to implement long-term primary care-based strategies to care for stroke survivors. Mood assessments for all stroke patients and detection of post-stroke psychological problems will optimize recovery from stroke. Patient/caregiver information booklet on post-stroke care should be given to all post-stroke survivors on discharge from hospital.

Disclosure of interest

None declared

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