Original paper

Evaluation of the Informal Caregiver Burden in the Care of Stroke Patients at Kenyatta National Hospital

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Abstract

Background: Most stroke survivors return home after discharge and the burden of caring for them falls on their families. These informal caregivers have higher risks of mental and physical illnesses.
Objective: To determine the level of informal caregiver burden of stroke patients at Kenyatta National Hospital (KNH).
Methods: This was a cross sectional study at the KNH Neurology clinic, physiotherapy unit, cardiac clinic and medical wards. One hundred and thirty five informal care givers identified in the clinic and the wards were interviewed with pretested questionnaire. Informal caregiver burden was evaluated using ZBI questionnaire and depression using PHQ9 Test Questionnaire. It was analyzed using SPSS software version 21.0. Demographic and clinical characteristics of the study sample were summarized using means (standard deviations) or medians (inter-quartile range) for continuous variables and number (percentage) for categorical variables. Descriptive analysis was made to assess knowledge of caregivers and relationships between independent variables in both stroke survivors their caregivers and level of burden. Level of burden is expressed in proportions and distributed between physical, psychological, social and financial burden. Results are presented as numbers and percentages. Relationships between categorical variables (socio-demographics) were analyzed using chi square. Comparison of means (age) used student t-test while medians (duration of stroke and care giving) were compared with Mann Whitney u test. Confidence intervals were 95% with p value <5% being significant
Results: Their mean age was 36.2 years with 54.5% females. The stroke caregivers were: adult offspring 50.7%, spouses 24.1% and siblings 13.8%. 47.6% of the care givers had moderate to severe depression. The level of informal caregiver burden was found to be moderate in 58.6% (CI 50.3%-66%). The major factors that contributed to burden were financial, social and psychological. The caregiver factors were daughters, being employed, shorter duration of care giving and depression. The patient factors were higher levels of disability, shorter duration of stroke, lack of health insurance and single. There was little preparation of caregivers prior to discharge.
Conclusion: There is need to institute measures for preparation and support of caregivers.

Key words: Stroke, Burden, ZBI questionnaire, PHQ9 test questionnaire, Depression, Care giving

Introduction

Neurologic damage accounts for 40% of patients with severe disability who require daily help (1). Stroke was the third most common cause of disability adjusted life years in 2010 (2). Despite numerous advances stroke remains a significant cause of global morbidity and mortality (3). About 85% of all strokes occur in low and middle income countries (4). Caregivers have been described as the second victims of the disease to highlight their level of involvement in care and level of stress they are under. This is because they assume their roles under sudden and extreme conditions with minimal preparation and little support from the healthcare system (5). They feel unprepared to meet the physical and emotional challenges (6). Unfortunately little attention has been given to demands made on these caregivers and its effects (7). Taking care of an ill relative is a draining experience (8). Evidence has shown they are at risk of financial strain, anxiety and depression while adjusting to the new role (9-11). Furthermore they experience restrictions on managing their personal time and daily tasks and this may impact their physical health (6,12). The high level of emotional distress show that there are unmet needs in caregivers which community services can mitigate (7). Female informal caregivers and those caring for patients with higher functional dependency report higher levels of burden (13). Stroke caregiver burden has been described at 20-40% (14). Most caregivers experience moderate to severe burden and the factors that influence the level of burden include disability duration of care and gender of caregivers (15).

Caregiver burden is defined as physical, psychological, financial and social problems and disruption experienced by the principal caregiver of a family member. Stroke is a leading cause of neurological disability in adults globally (16). About 15 million people develop stroke yearly and of these 33% die while 33% remain neurologically challenged. These disabled survivors place significant strain on their families and communities at large. Stroke is one of the most expensive diseases in the elderly and these expenses are expected to rise in the future (3). As a result of progressive ageing in the population the burden of stroke is increasing greatly in low income countries (17). WHO estimates that globally the Disability-Adjusted Life Years (DALYs) lost to stroke (a measure of the burden of disease) will rise from 38 million in 1990 to 61 million in 2020 (3). In Africa stroke is one of the five most common causes of inpatient deaths (4). The peak age of incidence is also ten to twenty years earlier than in developed countries (18). Sub-Saharan Africa has been shown to report shifting stroke pattern to involve younger ages than reported in industrialized countries (19). These findings reflect a dramatic rise in cardiovascular diseases in Africa from a time when they were virtually unknown to now as the leading causes of death in the elderly (20,21). In Kenya a retrospective study at Kenyatta National Hospital of 396 patients between 2004-2008 revealed a mean age of 54.7 years. This peak age incidence was also seen in Nigeria but not in the developed world which was reported at about 67 years (18). A study done at Nairobi Hospital on patients from Nairobi county in 2008 showed in hospital period prevalence of 3042/100000 and mean age of 61.3 years (22).

Broad objective: To evaluate the level of burden on informal caregivers of stroke patients.

Specific objective: To determine the level of informal caregiver burden of stroke.

Secondary objectives: Determine correlation between informal caregiver burden and both patient and caregiver factors.

(i) *Caregiver factors:* Duration of care, presence of secondary caregivers, depression in caregivers , socio-demographics, awareness of stroke care
(ii) *Patient factors:* Duration of stroke, level of disability, gender, socio-demographics

Materials and methods

The study was conducted after approval from the Kenyatta National Hospital (KNH) ethical review board and adhered to their recommendations.

Cross-sectional descriptive survey at KNH from 2015-2016 at Kenyatta National Hospital. Informal caregivers of stroke survivors were interviewed from the Neurology and Cardiac Clinics, Physiotherapy Department and new caregivers upon discharge from wards.

An estimation of the sample size has been done using the formula below.

Population size (for finite population correction factor or fpc) (N):x(Total patients in the specified outpatient departments)	7000
Hypothesized % frequency of outcome factor in the population (p):(15) (study of Salma Begum, *et al*)	90%+/-5%
Confidence limits as % of 100 (absolute +/- %)(d):	5%

Np(1-p)

d^2/Z^2x(N-1)+p(1-p)

n=135

In this study the sample size for the determination of the burden of informal stroke caregivers was estimated to be 135 patients. A sample size of 135 was generated using an expected prevalence of 90% at 95% confidence level with a 5% two sided confidence limits using an estimated finite population (sampling frame) of 7000. This number was arrived as the total number of patients seen in the cardiac, neurology, physiotherapy clinics and medically discharged obtained from the Kenyatta National Hospital records department.

The principle investigator with a research assistant administered the questionnaires. The principle investigator also conducted the in-depth interviews. Tools used were;

(i) Zarit burden interview questionnaire
(ii) Socio-demographic study proforma
(iii) PHQ9 depression test questionnaire
(iv) Modified Rankin score
(v) In depth interview

Statistical analysis

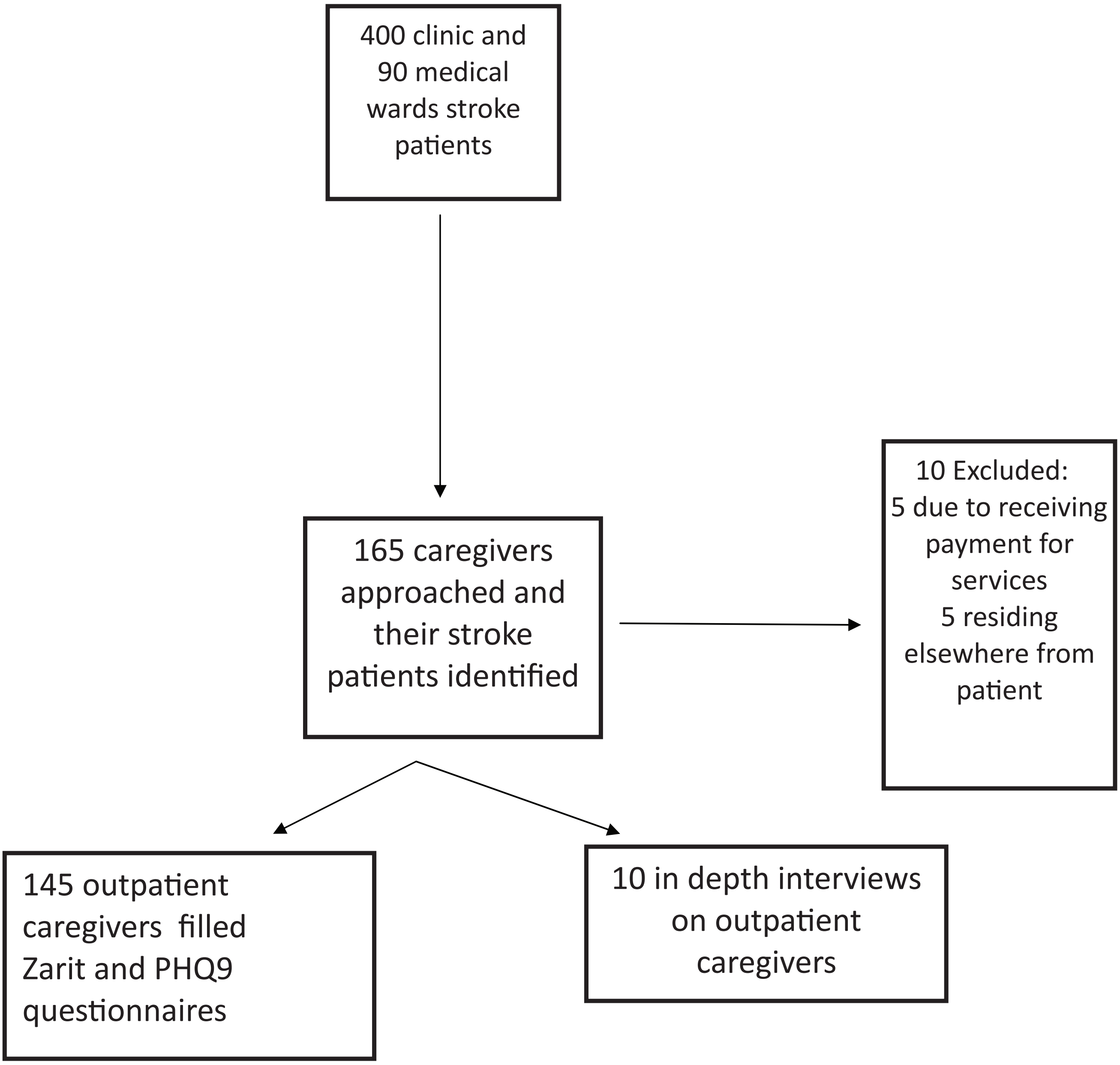
The research assistant was trained on how to collect the data and administer the questionnaire as well as how to select patients from clinic and ward. Data obtained from caregivers was fed into a data extraction form. The data was stored in a secure location (offsite) and was only accessible to the Principal Investigator (PI). Participants who scored adversely in the questionnaires were referred for counseling intervention. Data was collected and kept in a safe area locked by the PI. The data was verified every day for completeness. It was analyzed using SPSS software version 21.0. Demographic and clinical characteristics of the study sample were summarized using means (standard deviations) or medians (inter-quartile range) for continuous variables and number (percentage) for categorical variables. Descriptive analysis was made to assess knowledge of caregivers and relationships between independent variables in both stroke survivors their caregivers and level of burden. Level of burden is expressed in proportions and distributed between physical, psychological, social and financial burden. Results are presented as numbers and percentages. Relationships between categorical variables (socio-demographics) were analyzed using chi square. Comparison of means (age) used student t-test while medians (duration of stroke and care giving) were compared with Mann Whitney u test. Confidence intervals were 95% with p value <5% being significant.

Qualitative data in the form of in-depth interviews were recorded using Smart Voice Recorder and stored securely for later transcription by the principal caregiver. Ten caregivers underwent one on one in-depth interviews to capture information not obtained in questionnaire selected via convenience sampling. This was for a detailed perspective of their experiences using appropriate probes and question guides to capture information not obtained from the questionnaire. Emerging recurrent themes were highlighted from the interviews until a saturation point was reached where no new themes arose. They were recorded using smart voice recording software for later transcription. Recurrent themes and emergent trends were highlighted.

Level of burden was expressed as a percentage

(i) Dependent variables – level of burden
(ii) Independent variables: (a) patient factors – duration of stroke, level of disability (Modified Rankin Scale), socio-demographics (b) Caregiver factors: Presence of secondary caregivers, duration of care giving, depression level, socio-demographics

Figure 1: Recruitment process



Results

The study findings in Table 1 shows that the mean age of caregivers was 36 years. Majority of caregivers were female at 54%. Those who were employed fulltime were more than half at 53% and half of the caregivers were married. The caregivers had formal education comprising 96% of whom 24% had tertiary education.

Table 1: Socio-demographic characteristics of informal caregivers

Characteristic	Caregiver variable (absolute/percentage)
Mean age (years)(standard deviation)(range)	36.2 (12.0)(18-72)
Gender	
Male	66 (45.5)
Female	79 (54.5)
Current employment status	
Fulltime	77 (53.1)
Self-employed	32 (22.1)
Housewife/husband/unemployed	24 (16.6)
Part-time	9(6.2)
Retired	3 (2.1)
Marital status	
Married	78 (53.8)
Widowed	34(23.4)
Separated	17(11.7)
Single	16(11.0)
Education level	
Secondary	65 (44.8)
Primary	37 (25.5)
Tertiary	35 (24.1)
None	8 (5.5)

Table 2: Relationship to patient

Relationship	No. (%)
Son	39 (26.9)
Daughter	36 (24.8)
Wife	26 (17.9)
Sister	11(7.6)
Husband	9 (6.2)
Brother	9 (6.2)
Daughter in law	4 (2.8)
Mother	2 (1.4)
Nephew	4 (2.8)
Grandson	1 (0.7)
Cousin	3 (2.1)
Niece	1 (0.7)

On evaluation of the stroke patients characteristics in Table 3 the median duration of care was 6 months and median duration of stroke 24 months. Majority of strokes were infarcts at 64% and when their level of disability was evaluated 75% were moderately disabled according to modified Rankin score.

Table 3: Stroke patient characteristics

Variable	Frequency (%)
Duration of care in months	
Median (IQR)	6.0 (5-18)
Min-Max	1-264
Duration of stroke in months	
Median (IQR)	24.0 (12.0-36.0)
Min-Max	1-264
Type of stroke	
Infarct	93 (64.1)
Bleed	52 (35.9)
Level of disability - modified Rankin Score	
Low MRS (0-2)	36(25%)
High MRS (3-5)	109(75%)

The proportion of informal caregivers with burden in Table 4 was in the moderate range amounting to 58.6% at 95% confidence interval (50.3-66.9) using the Zarit Burden Interview Questionnaire.

Table 4: Burden of disease frequency in informal caregivers

Variable	Frequency (%)	95% CI
Zarit score		
Little/no burden (0-20)	29 (20.0)	13.1-27.6
Mild burden (21-40)	30 (20.7)	14.5-28.3
Moderate burden (41-60)	85 (58.6)	50.3-66.9
Severe burden (61-88)	1 (0.7)	0.0-2.8

On analysis of caregiver depression in Table 5 , 40% caregivers had moderate depression at 95% confidence interval (37.8-55.1).

Table 5: Caregiver PHQ9 depression scores

PHQ9 Depression score	Frequency (%)	95% CI
No - Minimal depression	46(31.7)	16.5-31.5
Mild depression	30 (20.7)	37.8-55.1
Moderately- severe depression	69 (47.6)	

Table 6 represents the odds ratio of burden in informal caregivers in the nuclear family compared to others who are not in the nuclear family. Most of the informal caregivers were burdened especially those in the nuclear family. Eighty six percent of daughters, all of the siblings and 80% of the spouses to the stroke survivor experienced burden. The informal caregivers who were daughters had the highest odds ratio of burden which was statistically significant.

Table 6: Odds ratio of burden among different informal caregivers

Variable	Burden	No burden	OR (95% CI)	P value
Relation with the patient				
Wife/husband	28 (80.0%)	7 (20.0%)	3.5 (0.9-13.0)	0.061
Daughter	31 (86.1%)	5 (13.9%)	5.4 (1.4-21.7)	0.017
Son	29 (74.4%)	10 (25.6%)	2.5 (0.7-8.8)	0.142
Brother/sister	20 (100.0%)	0 (0.0%)	-	0.998
Other	8 (53.3%)	7 (46.7%)	1.0	

The highest frequency of moderate to severe burden was reported in caregivers who were siblings at 85% as shown in Table 7. Daughters also experienced higher levels of burden with 72.2% having moderate to severe burden. Other caregivers included daughters in law, cousins and nephews. Their level of burden was evenly distributed between little burden and moderately severe burden at 46% each.

Table 7: Distribution of burden in relation to type of informal caregiver

Variable	Little/no burden	Mild burden	Moderate/ severe burden	P value
Relation with the patient				
Wife/husband	7 (20.0%)	14 (40.0%)	14 (40.0%)	0.002
Daughter	5 (13.9%)	5 (13.9%)	26 (72.2%)	
Son	10 (25.6%)	7 (17.9%)	22 (56.4%)	
Brother/sister	0 (0.0%)	3 (15.0%)	17 (85.0%)	
Other	7 (46.7%)	1 (6.7%)	7 (46.7%)	

The analysis of the correlation between caregiver socio-demographics and caregiver burden in Table 8 was done using the categorical variable of burden (presence or absence) rather than the continuous variable i.e mild, moderate or severe and findings were similar. Any amount of burden indicated from the questionnaire whether mild-severe was classified as present as opposed to lack of any burden from questionnaire records.

Eighty five percent of those who were employed had burden with an odds ratio of 4.8 (p 0.001). The proportion of informal caregivers whose duration of care was longer (median of 24 months) who reported no burden was higher than that of those with shorter duration of care of median six months (p 0.001).

Table 8: Associations between caregiver factors and caregiver burden

Variable	Burden (%)	No burden (%)	OR (95% CI)	P value
Gender				
Male	52 (78.8)	14 (21.2)	0.9 (0.4-2.0)	0.739
Female	64 (81.0)	15 (19.0)	1.0	
Employment status				
Employed	101 (85.6)	17 (14.4)	4.8 (1.9-11.9)	0.001
Unemployed	15 (55.6)	12 (44.4)	1.0	
Marital status				
Single	19 (79.2)	5 (20.8)	0.9 (0.3-2.8)	0.895
Separated/Widowed	3 (75.0)	1 (25.0)	0.7 (0.1-7.4)	0.793
Married	93 (79.5)	24 (20.5)	1.0	
Education level				
Primary	10 (66.7)	5 (33.3)	1.0	
Secondary	43 (87.8)	6 (12.2)	3.6 (0.9-14.1)	0.068
Tertiary	60 (76.9)	18 (23.1)	1.7 (0.5-5.5)	0.402
None	3 (100.0)	0		0.999

Variable	Burden (%)	No burden (%)	OR (95% CI)	P value
Insurance				
Absent	64 (86.5)	10 (13.5)	1.0	
Present	52 (73.2)	19 (26.8)	0.4 (0.2-1.0)	0.050
Presence of secondary caregivers				
None	92 (80.0)	23 (20.0)	1.0	0.216
Unpaid	7 (63.6)	4 (36.4)	0.4 (0.1-1.6)	0.336
Paid	17 (89.5)	2 (10.5)	2.1 (0.5-9.9)	
Duration of care in months, median (IQR)	6 (4-10.5)	24 (12-72)	-	<0.001
No - minimal depression	30 (65.2)	16 (34.8)	38.7 (4.6-325.2)	0.001
Mild depression	29 (70.6)	1 (29.4)	-	0.997
Moderate –severe depression	69 (100.0)	0		

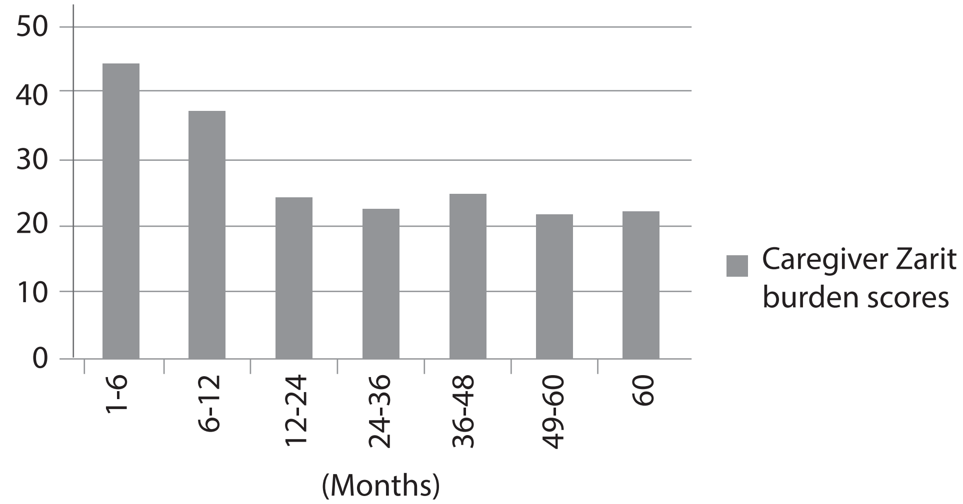
The proportion of caregivers of stroke survivors who had a median duration of stroke of 36 months who had no burden was higher than that of those with a median duration of 24 months (p<0.001) as shown in Table 9. The variable is continuous and was not converted to categorical. It has measured median values. Sixty one point one percent of caregivers of patients whose level of disability according to Modified Rankin Scale was low reported lower burden scores. High disability scores resulted in caregiver burden p 0.001. Fifty six percent of caregivers of stroke survivors who were single experienced burden (p 0.041).

Table 9: Associations between patient factors and burden

Variable	Burden (%)	No burden (%)	OR (95% CI)	P value
Gender of patient				
Male	63 (81.8)	14 (18.2)	1.2 (0.6-2.9)	0.561
Female	53 (77.9)	15 (22.1)	1.0	
Duration of stroke in months, median (IQR)	24 (8-36)	36 (24-120)	-	<0.001
Level of disability				
Low (MRS 0-2)	14 (38.8%)	22 (61.1%)	-	<0.001
High (MRS 3-5)	107(93.6%)	7 (6.4%)		
Employment status				
Employed	41 (74.5)	14 (25.5)	0.6 (0.3-1.3)	0.586
Unemployed	74 (83.3)	15 (16.7)	1.0	
Marital status				
Single	9 (56.3)	7 (43.8)	0.3 (0.1-1.0)	0.041
Separated/Widowed	43 (86.3)	7 (13.7)	1.4 (0.6-4.0)	0.418
Married	63 (80.8)	15 (19.2)	1.0	
Education level				
Primary	28 (75.7)	10 (24.3)	0.4 (0-4.1)	0.475
Secondary	62 (95.4)	3 (4.6)	3.0 (0.3-32.4)	0.375
Tertiary	19 (54.3)	16 (45.7)	0.2 (0-1.5)	0.114
None	7 (87.5)	1 (12.5)	1.0	
Insurance				
Absent	66 (90.4)	7 (9.6)	4.2 (1.6-10.5)	0.003
Present	50 (69.4)	22 (30.6)	1.0	
Type of stroke				
Infarct	78 (83.9)	15 (16.1)	1.9 (0.8-4.4)	0.123
Bleed	38 (73.1)	14 (26.9)	1.0	

A higher level of burden was found in caregivers with shorter duration of care compared to those who had provided care for a year or longer as illustrated in Figure 2.

Figure 2: Duration of caregiving and Zarit burden scores



In depth Interviews recurrent themes

(i) *Time constraints*: Performing normal duties plus caring for patient
(ii) *Coping with patient behavioural changes*: irritability, insomnia of patient
(iii) *Knowledge gap in patient care*: Changes in diet and where to get physiotherapy
(iv) *Financial constraints*: Lacked funds for clinics, physiotherapy, speech therapy
(v) Difficulties in attending social engagements

Discussion

Characteristics of stroke caregivers: Stroke is one of the diseases associated with high burden in society. In this study we report the high burden on care givers of stroke patients. It is one of the few studies which has looked at the burden of disease on caregivers. We found adult offspring were the caregivers of most of the stroke patients and here was a high level of moderate to severe caregiver burden. While most of the caregivers in this study were offspring of the stroke patient, in other chronic disorders like mental illnesses either the parent or sibling was the main caregiver (23). Informal caregivers in southern Europe were reported to be spouses or homemakers while those in northern European countries were majorly employed informal caregivers (24). This study found 58.6% moderate to severe caregiver burden. Similarly in 2005 Visser-meily *et al* (25) studied burden in Netherlands on 187 spouse caregivers one year post stroke using the caregiver strain index. They found 54% had high burden and most caregivers were a spouse to the patient (25). In 2006, Kimemia (26) did a study on caregiver burden of females who were the primary care givers of a family member living with HIV/AIDS. She found that the main caregiver was either a sibling or a parent. Female caregivers are at higher risk of depression and thus the added strain of care giving may result in worse outcomes in the female members of the immediate family (27). In contrast to this McCullagh *et al* (28) who studied determinants of 232 stroke caregivers' burden and quality of life found no correlation between caregiver burden and relationship to patient. This may have resulted from the training of caregivers.

Factors contributing to burden: We attribute the high burden in our study to multiple factors. The high percentage of stroke patients who were significantly disabled was at 75% using the MRS. High level of disability increased caregiver burden because more assistance in activities of daily living is required (29,30). Furthermore higher levels of disability result in more disruption of the caregiver's social life and employment. However recruitment of the participants in our study was from a large tertiary referral hospital hence this may have over-represented the severity of disability. Rigby *et al* (31) in Canada who carried out an outpatient study on 155 caregivers of stroke survivors reported mild levels of burden with lower levels of disability. He also found that stroke survivor characteristics are more strongly predictive of caregiver burden than caregiver characteristics.

In our study both these characteristics were found to be significant. Our study reported high levels of caregiver depression of 47% using PHQ9. Jaracz *et al* (32) in Poland studied 150 stroke caregivers and found that lower levels of burden were reported by caregivers who were less depressed using Hospital Anxiety and Depression Scale. Consistent with findings from Berg *et al* (9) who studied 100 caregivers of stroke out-patients in Helsinki, higher levels of caregiver depression led to more burden. These high levels of depression were due to multiple factors. At discharge we found only 50% caregivers had received any information on post stroke care. This showed there was little preparation prior to discharge. Other factors that contributed included impact on time management and difficulty in allocating enough time to attend to the needs of the stroke patient. The caregivers reported that they felt their efforts at caring for their patient were inadequate as they had to attend to prior employment activities. Caregivers in KNH also reported financial strain due to repeated outpatient clinic visits that included physiotherapy, medical outpatient clinic, occupational therapy and speech therapy. This was in addition to drugs and further work up required of them during these visits (6). Caregivers reported high levels of psychological burden in 70% of the cases including lack of time for personal activities. This was consistent with findings by Begum (15) who studied 151 outpatient stroke caregivers in Bangladesh and found 60% of them were highly disappointed by the change in their personal lives. Bartolo *et al* (33) who studied 118 caregivers' burden and needs in community rehabilitation reported 34% of the caregivers had time constraints. This was due to burden of care giving and 25% felt they had been left behind socially and were unable to enjoy the same activities as their peers (33). Another factor that may have led to this high burden is the shorter duration of caregiving. Forty eight percent of caregivers had given care for less than six months and this finding was similar to Begum (15) who studied 151 community stroke caregivers in India. He found that most had given care for less than 6 months and his study reported high levels of burden. A shorter care giving duration was associated with more burden and this could be explained by the lack of adjustment to their role as well as their patients being less functionally able compared to later on in their illness (34,35). However Anderson *et al* (7) who carried out a population based assessment on burden of stroke caregiving indicated that prolonged duration of care correlated with more burden. This was due to the prolonged disruption on their social activities and leisure time.

Stroke patient characteristics contributing to burden: Scholte *et al* (29) who studied the assessment of burden in 166 partners of stroke patients in Netherlands observed that care giving burden is generally higher in older patients than younger patients. The median age for stroke survivors was at 54 years which may have contributed to the high level of burden in this study. In 2015, Begum (15) using the Caregiver Burden Scale in 151 caregivers in Bangladesh found a prevalence of 94% of moderate to severe burden. This high burden was because the mean duration of stroke in Bangladesh was 12 months while in KNH it was 24 months. The stroke survivors in Bangladesh had undergone the illness for a shorter duration and they still had high anxiety and disability levels which translated to more caregiver burden (15). Longer duration of stroke was associated with less burden due to the improvement in patient functional status over time. Additionally there were less requirements for assistance as well as reduction in patient and caregiver anxiety over time (28). Studies in developing countries have reported relatively high levels of burden in comparison to studies carried out in developed countries (33,36). This is because in most western countries more than 20% of caregivers use a support service that helps in developing coping mechanisms and reducing caregiver burden. While in developing countries post stroke care for the survivors and caregivers is very limited (37,38).

Caregiver characteristics contributing to burden: Being employed was found to increase caregiver burden. This was because those who were employed did not have enough time to spend with the stroke survivor attending to their needs and attending regular clinics, physiotherapy and occupational therapy services. Contrary to this Kniepman *et al* (39) in a study of 20 female caregivers of stroke found occupational loss reduced quality of life of caregivers in Washington. Training of caregivers has been shown to reduce caregiver burden (40).

Conclusions

The results of our study highlights the heavy burden borne by caregivers. It draws attention to their often unmet needs. Most stroke patients were cared for by their adult offspring. There was a high level of caregiver depression. Moreover there was little preparation of caregivers prior to discharge of their patient which may have led to high caregiver burden.

Limitations

The assessment of caregiver burden was done only once and serial follow up studies are required to understand the changing nature of caregiver burden. We did not conduct home visits to corroborate the questionnaire findings. There was language barrier where some participants could only communicate in their native language.

Declaration: A dissertation submitted in partial fulfillment for the degree of Master of Medicine, Internal Medicine by Dr. Louisa W. Mahinda.

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