

**EVALUATION OF THE INFORMAL CAREGIVER BURDEN IN
THE CARE OF STROKE PATIENTS AT KENYATTA
NATIONAL HOSPITAL**

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Medicine, Internal Medicine.**

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ABBREVIATIONS

ADL -	Activities of daily living
AIDS -	Acquired Immune Deficiency Syndrome
CI -	Confidence Intervals
CT scan-	Computerized Tomography Scan
DSMIV –	Diagnostic and Statistical Manual 4
ERC-	Ethics Research Committee
HIV –	Human Immunodeficiency Virus
KNH –	Kenyatta National Hospital
MRS -	Modified Rankin Scale
MCA –	Middle Cerebral Artery
PAS –	Power Analysis Software
PHQ9 –	Patient Health Questionnaire 9
PI-	Principal Investigator
QoL –	Quality of Life
TPA-	Tissue Plasminogen Activator
SAH-	Subarachnoid Haemorrhage
SF12 –	Short Form 12 Questionnaire
SPSS -	Statistical Package for Social Sciences
UON –	University of Nairobi
ZBI –	Zarit Burden Interview

ABSTRACT

Background

Stroke is the second major cause of disability after dementia globally. In sub-Saharan Africa the incidence is increasing and occurring at even younger ages. Most stroke survivors return home after discharge and the burden of caring for them largely falls on their families and communities around them. These informal caregivers are directly affected by patients' illness and this can affect their health status. They are at higher risks of mental and physical illnesses. Caregivers experiencing strain are at a higher risk for mortality especially in elderly spouses. The identification of key factors that contribute to the stress of caregivers can help in designing intervention programs that enhance coping skills and improve overall care and wellbeing of the stroke survivors.

Objectives

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

Materials and methods

The study was carried out at Kenyatta National Hospital the main referral hospital in Kenya. The study design was a descriptive cross-sectional study of participants from:

1. Adult caregivers of stroke in the neurology, cardiac clinic and physiotherapy department
2. New caregivers of the patient at discharge from ward

A total of 145 adult informal caregivers were interviewed from clinics. Informal caregivers of patients with confirmed diagnosis of stroke were recruited. Their socio-demographic information was obtained and stroke patient disability status assessed with MRS. Informal caregiver burden was evaluated using ZBI questionnaire. Assessment for level of depression was done using PHQ9 Depression Test Questionnaire. In depth interviews were undertaken on 10 additional stroke caregivers. We identified upon discharge 20 caregivers and explored their knowledge on awareness of stroke and care of the stroke patient.

Data management

Data was analysed using descriptive and chi square statistics with the help of SPSS and PAS software. Factor analysis and multiple regression analysis were used to describe factors influencing burden. The results included describing the overall extent of informal care giver burden and factors contributing to it.

Results

The stroke caregivers constituted of adult offspring at 50.7%, spouses at 24.1% and siblings at 13.8%. Their mean age was mean age was 36.2 years and 54.5% were females. There was high level of moderate to severe depression at 47.6% and 52.4% had mild or no depression. The level of informal caregiver burden was found to be moderate in 58.6% (CI 50.3%-66%) of the caregivers while 40% had mild or no burden. The major factors that contributed to burden were financial, social and psychological. Most stroke patients were cared for by their adult offspring.

The caregiver factors which were significant were relationship to the patient with daughters having significantly more burden, being employed, shorter duration of care giving and depression. The patient factors significantly associated with burden included higher levels of disability, shorter duration of having stroke, lack of health insurance and being single.

Conclusions

The results of our study highlight 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.

There is need to institute measures for preparation and support of caregivers prior to discharge of the stroke patient.

1.0 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).

2.0 BACKGROUND AND LITERATURE REVIEW

Definitions

Stroke is defined by the World Health Organization as a clinical syndrome consisting of rapidly developing clinical signs of focal (or global in case of coma) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin

A caregiver is any person who without being a professional or belonging to a social support network usually lives with the patient and in some way is directly implicated in patients care or directly affected by the patients' health problem (13).

Caregiver burden is defined as physical, psychological, financial and social problems and disruption experienced by the principal caregiver of a family member (14).

Activities of daily living refer to those activities people undertake routinely in their daily life. They can be divided into basic and instrumental activities of daily living. Basic ADLs are those

involving 1) functional mobility – ambulation, wheelchair mobility, bed mobility, transfers and 2) personal care – feeding, hygiene, toilet, bathing dressing.

Instrumental ADLs include activities that enable a person to cope with their environment e.g. shopping, transport, money managing, cooking, housekeeping, medication and use of telephone (15).

2.1 Stroke epidemiology

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 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 (22,23). 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 (24).

2.2 Causes of stroke

A variety of causes have been implicated in stroke.

Modifiable risk factors include diabetes, smoking, high cholesterol and high blood pressure (25-28).

Non modifiable risk factors include age, sex, race, family history among others(29).History of previous stroke is another non modifiable risk factor (3).

In addition patients with migraines have been reported to have an increased risk of ischaemic stroke and this risk is further increased if patient with migraines is on oral contraception (30).

A study done in Nakuru revealed high burden of cardiovascular risk factors especially hypertension 50.1%, obesity 13%, high cholesterol 21.1% and diabetes 6.6%. This burden was found to be higher in the urban dwellers compared to the rural dwellers (31).

2.3 Clinical presentation and types of stroke

The subtypes of stroke are subarachnoid hemorrhage, intracerebral hemorrhage, cerebral infarction and undetermined stroke (32) The main type of stroke found in a study at Nairobi hospital was ischaemic at 85% followed by hemorrhagic at 8% (24).

Stroke patients present in a variety of different ways including but not limited to speech, sight, mobility difficulties and even confusion (3).

Clinical presentation depends on the region of the brain whose blood supply has been compromised. Therefore ischaemic strokes can be discussed according to the vessel that has been compromised.

Anterior cerebral artery.

Strokes in this territory are uncommon accounting for 1.8% of all strokes and 1.3% of all infarcts. The main aetiologies of stroke were cardioembolic 45% , artherothrombotic 29% lacunar 11% and unknown cause 11% (33).

Similar to these findings some authors reported emboli from internal carotid artery as the major cause of infarct in this territory at 63% which was similar to infarcts in the middle cerebral artery territory. Neurologic features included hemiparesis, hemihypesthesia, mutism at onset, transcortical motor aphasia, conflictual tasks impairment, mood disturbances and more uncommonly incontinence, grasp reflex, hemineglect, acute confusional state, and unilateral left apraxia (34).

Short-term outcome is favourable with an in hospital mortality rate of 7.8% (33).

Posterior cerebral artery

Strokes in this territory are not uncommon accounting for about 14% of all ischaemic strokes and can be either superficial or deep (33). Symptoms include homonymous visual field defects, unawareness of visual field defects and visual field hallucinations, speech disorders, spatial judgement disorders and confusion (35). The common aetiologies are lacuna infarcts, artherothrombotic and cardioembolic phenomenon (36).

Middle cerebral artery

The main aetiological factors are cardio-embolic, internal carotid occlusion and dissection(37). They are the majority with an incidence of about 82% of all ischaemic strokes(33). Clinical presentation includes severe neurologic deficits such as hemiplegia and hemisensory deficits in face arms and legs, hemianopia, global aphasia and reduced consciousness. These findings may be found in strokes from occlusion of other cerebral arteries but occur more commonly in MCA territory infarcts (37).

Subarachnoid hemorrhage

Their incidence is about 5% of all strokes . The aetiology is aneurysmal bleed in 85% (38). Other causes are non aneurysmal perimesencephalic bleed in 10% and rare conditions in 5%. They occur commonly in those less than 60years and the cardinal feature is a sudden explosive headache. Case fatalities are 50% and one third remain dependent(39). One in eight patients dies outside hospital. The major complication is re-bleeding therefore occlusion of aneurysm is paramount in management. Delayed cerebral ischaemia may also occur and the risk is reduced by nimodipine. Diagnosis is by CT scanning and carefully planned lumbar puncture .Hydrocephalus may occur within the first few hour or days and is managed by performing lumbar punctures or ventricular drainage (38).

Intracranial Haemorrhage

The global burden of hemorrhagic stroke [intracerebral hemorrhage and subarachnoid hemorrhage] has increased between 1990 and 2010 by 47%, as demonstrated in a systematic epidemiological review of 119 studies. This is attributed to worldwide ageing of the population, overall population growth, reduced stroke case-fatality and epidemiological transition in low-income and middle-income countries, resulting in increases in the prevalence of stroke risk factors, which may have led to increases in the number of incident strokes, stroke survivors, and DALYs lost (40).

Bleeding into the brain parenchyma accounts for 9-27% of all strokes worldwide (40). The prognosis of this type of stroke is poor with a case fatality of 40% at one month and 54% at 1 year. Less than a third survive to 5 years (41,42).

These different stroke types have unique presentations and impact each patient differently. The type of disability will determine the overall functionality of the patient and impact on the level of informal caregiver burden.

2.4 Recovery after stroke

To improve recovery time after ischaemic stroke several strategies have shown success. Acute de-occlusion of the artery restores flows and improves recovery. Intravenous TPA administered to selected patients within 4.5hours after onset of ischaemic stroke is currently the only validated treatment of acute phase ischaemic strokes. Other treatments being tested include use of monoaminergic drugs that cause cortical excitability, cortical stimulation that balances cortical inner functional balance. Others under study are use of stem cells growth factors and small molecules (43).

Recovery neurologically and functionally depends on several factors like volume of penumbra initial stroke severity, body temperature and blood glucose in the acute phase (44,45). Additionally stroke in progression and treatment and rehabilitation in a good stroke unit contribute to the rate of recovery. The performance of activities of daily living is reduced initially in 75% of patients especially ability to change clothes and walk. Following completion of rehabilitation severe disability is reduced by 25% and in those with mild or no disability their functionality is increased by 25%. Although the prognosis of those with severe strokes is poor 33% will be discharged home with mild or no disability if rehabilitated with consistent follow up in a good stroke unit. They achieved functional recovery in 5 months from onset. Functional recovery is preceded by neurological recovery by about two weeks (46).

2.5 Importance of caregivers

Family caregivers provide the bulk of care to these patients and must be recognized as part of the treatment team. Acknowledgement of their role validates them and gives them confidence in caring for their loved ones. They reduce societal costs of chronic care and improve wellbeing and survival rates of patients (47).

2.6 Factors affecting Caregiver Burden

Various factors have been identified in putting caregivers at risk of adverse outcomes.

Patient Factors such as anxiety and mood. Caregiver Factors such as anxiety levels and mood, advancing age, gender and participation in training were identified as contributors at 3 months. At 1 year patient dependency and family support were factors (48,49). Studies have shown that caregiver mental health and time and effort required of caregiver as significant in increasing burden (50).

In the past any evaluation of caregivers has been in order to incorporate them into the care plan of the care recipient. Little about the caregivers specific needs and issues was assessed. Therefore there was a need to assess caregivers in order to give the practitioner an understanding of the everyday experience of the caregiver and validate the effort put in. This enables risk stratification of caregivers and planning of social service interventions accordingly (51).

The level of caregiver burden remains elevated for an indefinite period following stroke (50).

Informal Caregivers knowledge level

Most information about stroke is obtained from popular media and life experiences rather than from professionals (52). Most Americans had received their information from television magazines and newspapers (53). The lack of information about stroke and its care can increase the burden to caregivers. Evidence has shown that empowering caregivers with knowledge reduces psychological stress (54). Carers expressed dissatisfaction in information received about services needed while patient was discharged (55). Preparing them with individualized health education and home visits improves their preparation and satisfaction of needs during the discharge transition (56). Due to scarcity of health care workers in the community caregivers adopt this role and could be trained to be more active in the rehabilitation process (57). A population study done in Uganda revealed an extremely low level of knowledge of stroke and they did not feel that stroke had any personal relevance to them. Primary health care workers were not a major source of stroke information (58).

Needs of caregivers

Emotional support to informal caregivers is important as well respite from care in order for them to be successful in their new role (59). Bakas et al established 5 common caregiver needs; Informational needs about stroke care, physical care needs, personal responses to caregiving, emotions, behaviours and instrumental care (60).

A comparative study between Kenya and Scotland looking at needs of patients with terminal illnesses and their caregivers reported differences in needs. In Kenya needs were mainly pain control and financial while in Scotland they involved the emotional pain of facing death. This showed the influence of culture on needs (61).

2.7 Impact of Care on the Informal Caregiver

The large burden of stroke is worsened by the limited access to specialists who are few and based in Nairobi(62).This leaves the care of stroke patients mainly in the hands of family members in a home based set up. Due to the abrupt onset of illness caregivers are usually unprepared on how to handle the illness and must adapt quickly to care for their relative (6). Moreover there is an associated increase in family conflict (63). During the first month of stroke the main problems reported are safety, difficulties in managing activities of daily living and behavioural, cognitive and emotional changes in stroke survivors (60). Spouses experience strain when their role changes from partner to caregiver thus changing the dynamics of the marriage (64). Financial implications of the event relate to lost earnings and inability of stroke survivor to contribute to household expenses (65).Caregivers have been shown to suffer psychologically and have increased incidences of depression, anxiety and feeling alienated due to lack of social support (66-69). There have also been increases in physical illnesses including anemia, peptic ulcers diabetes and arthritis (70).The general health of caregivers is negatively impacted in the 3 months following stroke especially due to lack of professional advice and feedback regarding homecare management (71). Some caregivers better appreciated their lives and had positive feedback from caregiving (72).

Research has shown that the most desired information from caregivers regarding home based care is knowledge on how to reduce the chance of stroke reoccurring and information on coping mechanisms (73).

2.8 Depression among caregivers

Little attention has been given to depression in caregivers compared to the stroke survivors yet they have higher levels in comparison. Factors found to increase their level of depression include older age of the patient and stroke severity during the early post-stroke period (11). Depressive symptoms are quite common. They are influenced by sociocultural factors with manifestations that are largely somatic. The depressive symptoms are based on interpersonal relationships and may also be spiritual in nature which may make them difficult to detect. However if symptoms are sought they are easy to elicit (74). Worse emotional distress among caregivers was associated with female gender of caregiver and presence of depression in stroke survivor. Therefore early

detection of caregivers with adverse emotional outcomes can help in designing interventions to mitigate their distress (75).

2.9 Tools to assess level of Informal Caregiver Burden

A number of questionnaires have been used to assess caregiver burden. The Caregiver Strain Index was developed to assess informal caregivers of recently hospitalized patients of an elderly family member. It is a 13 item brief and easily administered tool with responses restricted to 'yes' or 'no'(76). It has been used in stroke caregivers (77). The Modified Caregiver Strain Index includes a third option for 'sometimes' which proved to have slightly better internal reliability (78). It has been used in schizophrenia caregivers (79). Another tool is the Caregiver Reaction Assessment to assess the reactions of family members caring for elderly persons with physical impairments, Alzheimers disease and cancer (80). It has been used to test positive and negative reactions to caregiving among partners of patients with cancer (81).

2.9.1 Zarit Burden Interview Questionnaire

The level of perceived burden is measured using the Zarit Caregiver Burden Inventory scale which was originally used for caregivers of dementia and initially a 29 item questionnaire (14). The 22 item tool is either self-administered or interviewer administered. Zarit Burden Interview tool has high internal consistency and test-retest reliability with cronbach alpha coefficient of 0.92.Scores were unrelated to age, gender, locale, language, living situation, marital status or employment status indicating its appropriateness in a variety of populations (82). It has been used widely to study caregivers (83). The tool is commonly used to evaluate burden in caregivers of patients with alzheimers (84). It has been translated into French and Japanese (82,85).

In Africa the tool has been used to asses caregivers of cancer patients in Nigeria (86). In South Africa a short 12 item burden interview was used to asses burden of caregivers of orphaned HIV children (87). The tools reliability and face validity was established in Nigeria (88).

In Kenya the 22 item version was used to asses burden in female caregivers of family member living with HIV/AIDS (89). In this study we shall use the 22 item version. It is a five point likert scale in which the sum of burden is arrived at by adding all the scores to a total range of between 0-88. Higher values indicate more burden (14).

2.9.2 Summary of informal caregiver burden studies

Study	Study Design	Tools Used	Outcomes	Contributors To Burden
Jaracz et al 2014 Poland	Crossectional n=150	Caregiving burden scale(lund university) Barthel index	47% of caregivers reported severe or moderate burden at 6mos	caregiver time spent and anxiety, time spent caregiving, social support Patient – functional status/disability, gender
choi-kwon etal 2005 (S.Korea)	Crossectional n=147	Sense of competence questionnaire. MRS	Overall high burden score (2.3±0.6)(2-4)	Caregiver -female(daughter inlaw),unemployment,depression, long hrs Pt. -unemployment, cormobidity, disability, depression
Bartolo et al 2009 Italy	Crossectional n=118	Caregiver burden inventory, beck depress invento, Euro Qol 5D, barthel and minimal	Mean score 11.37± 7.88 ie little or no burden	Patient -Functional independance, patients quality of life reduced burden while caregiver -depression increased burden
Begum salma 2014 (India)	Crossectional n= 151	Caregiving burden scale (22 item version lund university)	78.8 overall moderate burden 16% high burden	caregiver age, sex(female), income, relationship, duration of care
T. Morimoto 2003 Japan	Crossectional n=100	Zarit burden interview, geriatric depression scale, SF12	Mean burden mild (mean score 28)(0-88)	Caregiver -Depression, decreased social functioning and QoL
Rigby et al 2009	Prospective study n=155	Relative stress scale, bakas caregiver outcome scale	14(7-22) –low risk of psychiatric morbidity.	Patient factors - age, males, disability, and poor mental health.

2.10 Assessment of Factors Influencing Informal Caregiver Burden

2.10.1 The Patient Health Questionnaire 9 Depression Scale

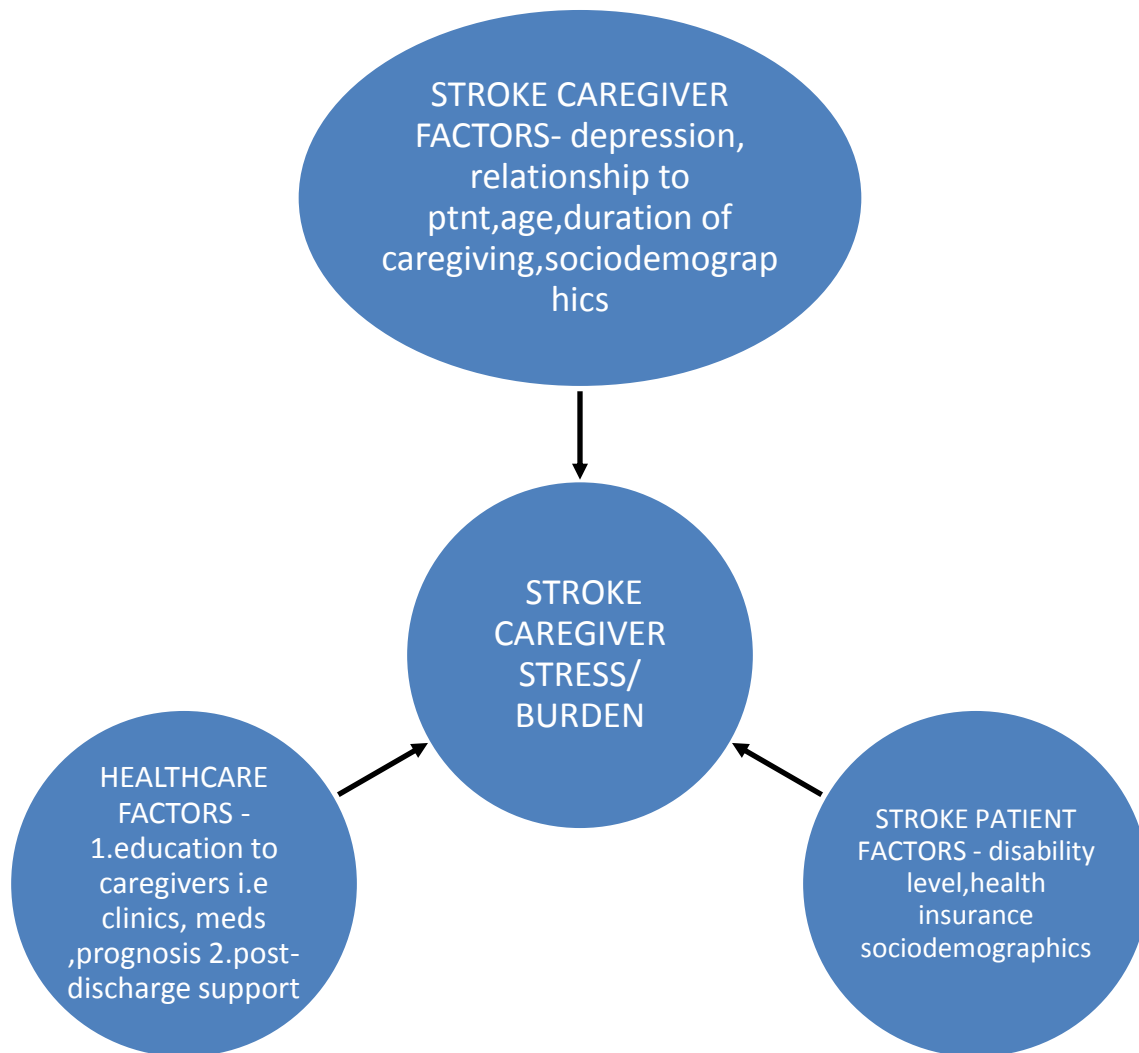
In order to assess depression in our caregivers we will use the above questionnaire. This is a 9 item instrument used in making criteria based diagnosis of depression in the primary care setting. The PHQ9 is the depression module of the Patient Health Questionnaire which includes the 9 categories upon which DSM IV criteria diagnoses depressive disorders. The tool has the advantage of being able to establish the presence of a depressive disorder and also grade its severity. A PHQ9 score greater than 10 has a sensitivity and specificity of 88% for major depression. Depression is classified as none, mild, moderate, moderately severe and severe depending on how high the score is (90).

It has been validated in sub-Saharan Africa and Kenya in particular. It is also brief and can be either self-administered or interviewer administered(91,92). This is an advantage in our resource constrained settings (93) .The tool has been translated into Swahili with good test retest reliability and internal consistency (92).

2.10. 2 Knowledge of stroke questionnaire

This tool to assess knowledge is a self-administered or interviewer administered questionnaire that was pretested and standardized with options for multiple responses. It was constructed from research done in Australia on stroke knowledge. Additional input was gathered from Nigeria among the general population and hospital workers as well as input from studies done on the general population of Iran (94-97). The tool was used to assess stroke knowledge in the general population in Uganda (58). Their knowledge level was assessed based on a number of risk factors and warning signs they could identify. Those with good knowledge identified 5-10 warning signs/risk factors. Those who could identify 2-4 signs or risk factors had fair knowledge and caregivers had poor knowledge if they could only identify 1 warning sign/risk factor (94-95).

2.10.3 CONCEPTUAL FRAMEWORK



3.0 STUDY JUSTIFICATION

There is an increasing burden of non-communicable diseases yet little literature in Africa available about the caregivers of these patients and little literature reference about the burden of stroke.

Due to the change in the society with urbanization, care of a sick member of the family is concentrated on the nuclear family units rather than on the community at large as was the case in the past. The impact of burden on informal caregivers has been shown to have adverse effects on their mental, emotional and physical health which ultimately impacts negatively on the care of stroke patients.

This study aims at providing clinicians with an insight into the burden on stroke caregivers and will assist in addressing unmet caregiver needs.

The identification of factors that increase level of strain in caregivers and those caregivers at higher risk of developing psychological and physical symptoms can help in designing interventional packages to reduce this strain and improve quality of life of caregivers and overall care to the stroke survivor. These packages may be instituted at discharge and assist in policy formation for organized rehabilitation facilities.

4.0 RESEARCH QUESTION

What is the care giving burden on informal caregivers of patients with stroke at the Kenyatta National Hospital?

5.0 OBJECTIVES OF THE STUDY

Broad objective

To evaluate level of burden on informal caregivers of stroke patients.

Specific objectives

To determine the level of informal caregiver burden

Secondary objectives

Determine correlation between informal caregiver burden and both patient and caregiver factors.

- a. Caregiver factors - duration of care, presence of secondary caregivers, depression in caregivers, socio-demographics, awareness of stroke care
- b. Patient factors – duration of stroke, level of disability, gender, socio-demographics

6.0 STUDY DESIGN AND METHODOLOGY

6.1 Study design

Cross-sectional Descriptive Survey at KNH.

6.2 Study location

The study was conducted at the neurology clinic, cardiac clinic, physiotherapy department and wards in KNH. The clinics run once weekly on all week days excluding public holidays and weekends. The physiotherapy department runs all weekdays except public holidays and weekends.

6.3 Study population

Informal caregivers of stroke survivors at neurology and cardiac clinic, physiotherapy department and new caregivers upon discharge from wards.

6.4 Case definition

An informal caregiver is an adult who lives with the patient and assists in at least one activity of daily living.

Activities of daily living are activities people undertake routinely in their daily life i.e.: functional mobility and personal care and activities that enable a person to cope with their environment

6.4.1 Inclusion criteria

1. Must be over 18years
2. Has given informed consent
3. Lives in informal setup of home based care
4. Is caring for stroke survivor whose diagnosis is confirmed on imaging.
5. Care giving duration for at least 1 month in participants coming to the outpatient.
6. If more than one caregiver present then the order of preference is spouse, children, siblings, parent, extended family.

6.4.2 Exclusion criteria

1. Receiving payment for services
2. Has received professional training on care of stroke survivor.
3. Is living in a different residence from stroke survivor

6.5 Sample size calculation

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 Pts in the specified outpatient departments) 7000

Hypothesized % frequency of outcome factor in the population (p): 90%+/-
5%

Confidence limits as % of 100(absolute +/- %)(d): 5%

Z score for 95% confidence intervals 1.96

$$\frac{Np(1-p)}{d^2/Z^2x(N-1)+p(1-p)}$$

$$n=135$$

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.

6.6 Sampling method, Recruitment and consenting procedures

Outpatient Recruitment of Informal Caregivers

The PI scrutinized files of patients with stroke and recruited participants via consecutive sampling. Those who had given written informed consent and who met inclusion criteria to participate in study were recruited. If the principal caregiver had not accompanied the patient then an option was availed to have them come for the next clinic which was scheduled at the soonest possible date convenient to them within the month. Telephone calls using next of kin contacts were used to remind them of this. If the principal caregiver could not avail themselves to attend any clinic then they were excluded from participating in the study. The aims and objectives of the study were explained to study participants.

Informal caregivers of stroke survivors filled in the 22 item Zarit Burden Interview questionnaire which took about 10minutes and PHQ9 depression questionnaire took 6minutes.

If the participants were unable to read the PI administered the questionnaire verbally. Any participant with high burden or depression scores was referred for counseling in the psychiatry clinic.

10 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.

Patients attend clinic visits after a variable duration of time depending on their severity of illness and how closely they need to be monitored. The interval ranges from 1 week to 1 year.

Patients were not reimbursed as they were recruited during their normal clinic visits and if they were required to be seen again telephone contacts were obtained and information was gained via calls or upon return for their next clinic visit.

Inpatient Recruitment of New Caregivers upon discharge of Stroke Patient

An exploration into awareness of stroke and its care on new caregivers of discharged first occurrence of stroke patients was carried out. This was to determine what information the caregivers had received about stroke prevention and follow up at discharge. They were identified by reviewing the files in the wards and those who gave written informed consent were recruited via convenience sampling.

This was an exploration into possible gaps in the healthcare system at level of discharge in equipping new caregivers with information of stroke and its care.

7.0 DATA COLLECTION

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

1. Zarit burden interview questionnaire
2. Socio-demographic study proforma
3. PHQ9 depression test questionnaire
4. Modified Rankin score
5. In depth interview

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. Participants who scored adversely in the questionnaires were referred for counseling intervention.

7.1 Data Variables

Level of burden was expressed as a percentage

- a. Dependent variables – level of burden
- b. Independent variables : (1)patient factors – duration of stroke, level of disability (Modified Rankin Scale) , socio-demographics (2)Caregiver Factors: Presence of secondary caregivers, duration of care giving, depression level, socio-demographics

8.0 ETHICAL CONSIDERATIONS

Ethical approval was obtained from the Department of Clinical Medicine and Therapeutics in the University of Nairobi and the Ethics and Research Committee (ERC) KNH/ UoN. Results and final book was to be presented to the ERC within one year of approval.

Consent obtained was informed and written. This study was explained to every participant and they were allowed to ask questions and seek clarification.

Personal unique study numbers were assigned to the patients. The information obtained was strictly confidential. Participants were allowed to opt-out from the study without prejudice. After completion of the study, all raw data will be stored for 5 years or as will be advised by the ethical committee.

The results of this study will be disseminated to the primary health care providers, the department, and all relevant decision making bodies

9.0 DATA ANALYSIS, MANAGEMENT AND QUALITY ASSURANCE

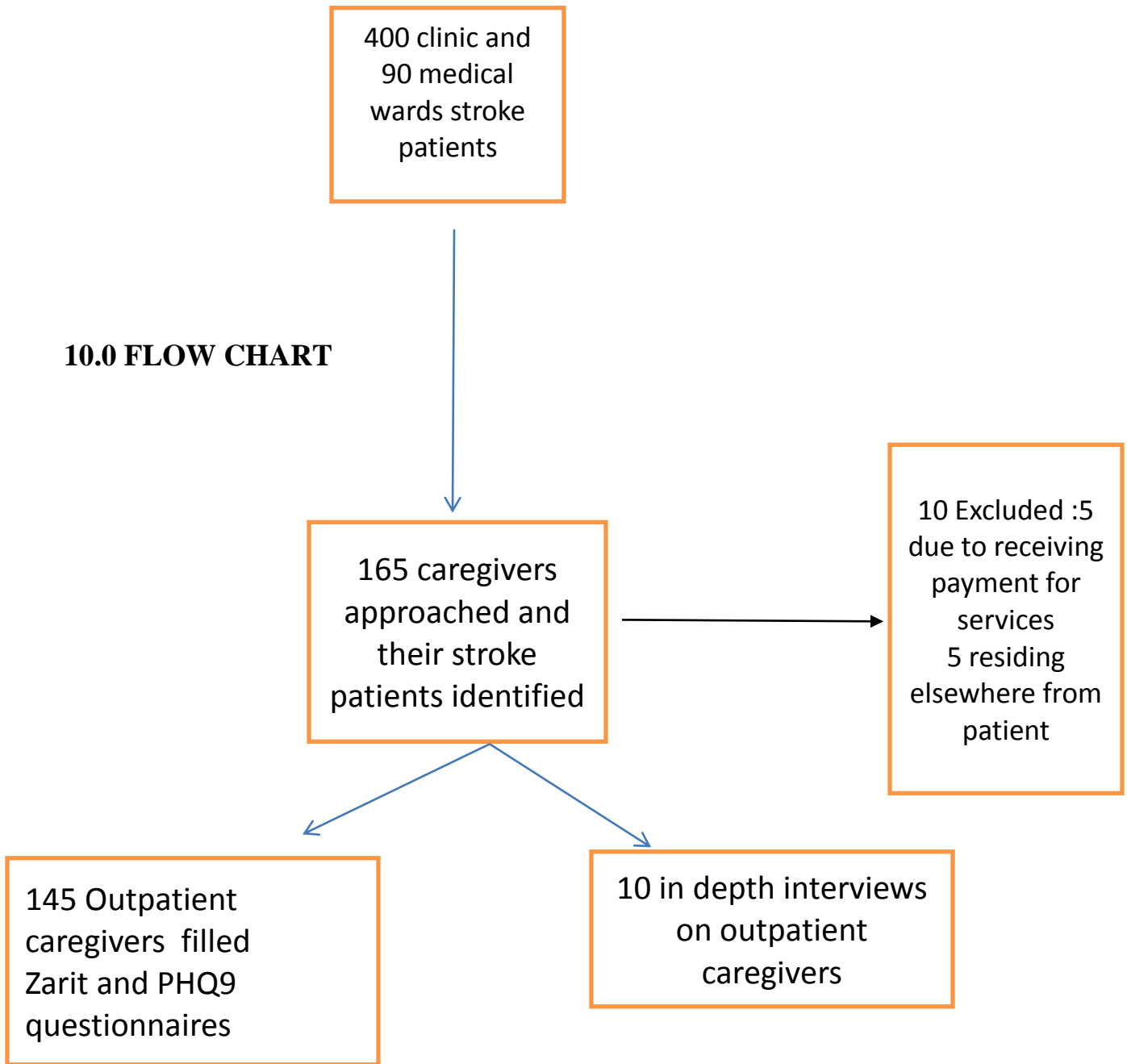
Data was collected and kept in a safe area locked by the PI. The data was verified everyday for completeness. It was analyzed using SPSS software version 21.0. Demographic and clinical characteristics of the study sample were summarized using means (standard deviations) or medians (inter-quartile range) for continuous variables and number (percent) 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 caregiving) 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. Recurrent themes and emergent trends were highlighted.

10.0 FLOW CHART



11.0 RESULTS

This chapter presents findings from the research. The results are analyzed per the objectives of the research and covers demographic data and results on levels of burden of informal caregivers of stroke patients

Table 1 Socio-demographic characteristics of informal caregivers

Characteristic	Caregiver variable
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)

The study findings show 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.

Relationship To patient

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)

The majority of caregivers were sons to the stroke survivors at 26.9% followed by daughters at 24% and wives at 17%.

Table 2 Residence of caregivers

Residence county	
Nairobi	100 (69.0)
Kiambu	15 (10.3)
Muranga	1 (0.7)
Nyandarua	3 (2.1)
Makueni	9 (6.2)
Narok	6 (4.1)
Kisii	3 (2.1)
Kericho	1 (0.7)
Nakuru	2 (1.4)
Kakamega	1 (0.7)
Kitui	3 (2.1)
Kajiado	1 (0.7)

The participants of the study were majorly from Nairobi county and its environs comprising over 70%.

Table 3 socio-demographic characteristics of stroke survivors

Variable	Survivor
Mean age (years)(range)	54.7 (14.3)(3.5-90)
Gender	
Male	77 (53.1)
Female	68 (46.9)
Current Employment status	
Retired	42 (29.0)
unemployed	37(25.5)
Fulltime	25 (17.2)
Self employed	19(13.1)
Part-time	11 (7.6)
Housewife/husband	11 (7.6)
Marital status	
married	117(80.7)
Single	24 (16.6)
Separated	1 (0.7)
Widowed	3 (2.1)
Education level	
Tertiary	78(53.8)
Primary	15 (10.3)
Secondary	49 (33.8)
None	3 (2.1)
Insurance	
Absent	74 (51.0)
Present	71 (49.0)

Secondary Caregivers(Assistant caregivers)

None	115 (79.3)
Unpaid	11 (7.6)
Paid	19 (13.1)

The mean age of the stroke survivors was 54 years and majority were men who were 53%. The stroke survivors who were retired were 29% and those unemployed were 25%. Over three quarters of them were married and 93% had some form of formal education with 53% having tertiary education. Only about 20% of the stroke survivors had secondary caregivers. They provided part time assistance to the principal caregiver in caring for the stroke patient. Over half of secondary caregivers were paid.

Table 4: 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%)

On evaluation of the stroke characteristics 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 5: 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

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

Table 6 Caregiver PHQ9 depression scores

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

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

Table 7 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 above table 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. 86% 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 8 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 highest frequency of moderate to severe burden was reported in caregivers who were siblings at 85%. 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 9: 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	0.068
Secondary	43 (87.8)	6 (12.2)	3.6 (0.9-14.1)	
Tertiary	60 (76.9)	18 (23.1)	1.7 (0.5-5.5)	
None	3 (100.0)	0	-	
Insurance				
Absent	64 (86.5)	10 (13.5)	1.0	0.050
Present	52 (73.2)	19 (26.8)	0.4 (0.2-1.0)	
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)	
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)		
Moderate –severe depression	69 (100.0)	0		

The analysis of the correlation between caregiver socio-demographics and caregiver burden 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.

85% of those who were employed had burden with an odds ratio of 4.8 (p0.001). 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 (p0.001) . Higher scores of depression in caregivers correlated with burden and an odds ratio of 38 in those with mild depression compared to those with no depression (p0.001).

Table 10: 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	

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 ($p < 0.001$). 61.1% 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 $p < 0.001$. 56% of Caregivers of stroke survivors who were single experienced burden ($p = 0.041$).

Table 11. Education level of stroke survivors and severity of caregiver burden

Variable	No burden (%)	Mild (%)	Moderate (%)	Severe (%)	P value
Education level					
Primary	9 (24.3)	7 (18.9)	21 (56.8)	0	<0.001
Secondary	3 (4.6)	10 (15.4)	51 (78.5)	1 (1.5)	
Tertiary	16 (45.7)	10 (28.6)	9 (25.7)	0	
None	1 (12.5)	3 (37.5)	4 (50.0)	0	

Almost half of caregivers of stroke survivors (45%) who had attained tertiary education had no burden while 78% of caregivers of those who had attained secondary education had moderate burden ($p < 0.001$).

11.1 In Depth Interviews recurrent Themes

1. Time Constraints – Performing normal duties plus caring for patient
2. Coping with patient behavioural changes – irritability, insomnia of patient
3. Knowledge gap in patient care – Changes in diet and where to get physiotherapy
4. Financial constraints – Lacked funds for clinics, physiotherapy, speech therapy
5. Difficulties in attending social engagements

Table 12 Duration of caregiving and Zarit Burden Scores

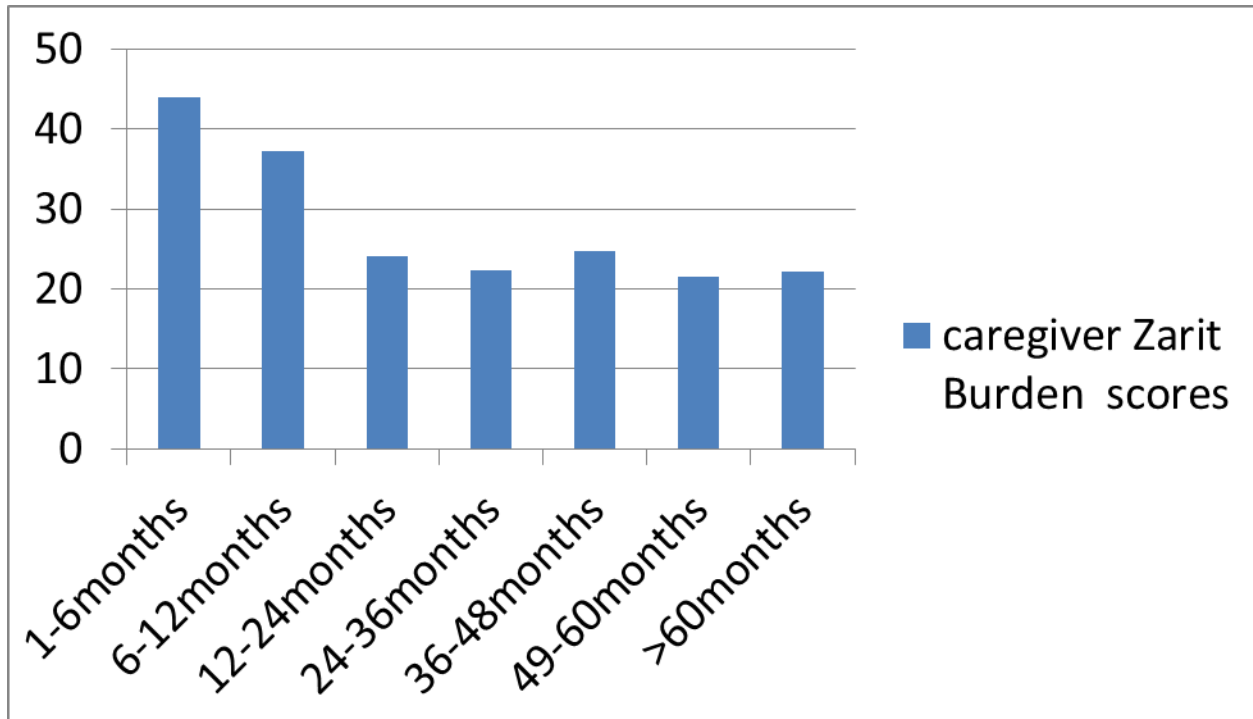


Table 13 Knowledge of informal stroke caregivers at patient discharge in the ward n=20

Variable	Frequency (%)
Knowledge on risk factors	
Good	4 (20.0)
Fair	10 (50.0)
Poor	6 (30.0)
Knowledge on warning signs	
Good	6 (30.0)
Fair	12 (60.0)
Poor	2 (10.0)
Is stroke preventable?	
Yes	9 (45.0)
No	2 (10.0)
Don't know	9 (45.0)
Can a person have stroke more than once?	
Yes	8 (40.0)
No	4 (20.0)
Don't know	8 (40.0)
Planned response to stroke	

Go to hospital	8 (40.0)
Go to hospital & Call relative	9 (45.0)
Go to hospital & Call family doctor	1 (5.0)
Call family doctor	1 (5.0)
Call relative	1 (5.0)
Source of information on stroke care	
Friends/relatives	14 (70.0)
Healthcare workers	3 (15.0)
Friends/relatives & healthcare workers	2 (10.0)
Radio	1 (5.0)
How to prevent second stroke at discharge	
Diet awareness	8 (40.0)
Medication awareness	19 (95.0)
Knowledge on physiotherapy sessions	
Importance	15 (75.0)
Place where sessions are given	5 (25.0)
Frequency of sessions	3 (15.0)
Perception of Prognosis of stroke-good	17 (85.0)
Knowledge of importance of clinic attendance	15 (75.0)

12.0 DISCUSSION

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 there 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(104). Informal caregivers in southern Europe were reported to be spouses or homemakers while those in northern European countries were majorly employed informal caregivers (105).

Our study found 58.6% moderate to severe caregiver burden. Similarly in 2005 Visser-meily et al studied burden in Netherlands on 187 spouse caregivers 1 year post stroke using the caregiver strain index. They found 54% had high burden and most caregivers were a spouse to the patient (122).

In 2002 Kimemia 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 (89). Members of the immediate family have been found to report higher levels of caregiver burden compared to those in the extended family (110). Our study found 66% of the caregivers were members of the immediate family. The highest levels of burden were experienced by daughters and siblings. These findings were in agreement with findings from Nigeria where Akosile studied burden of 91 community dwelling Nigerian stroke caregivers. He found females in the immediate family had the highest burden (110). 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 (109). In contrast to this McCullagh et al 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 (48)

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 (98,107). 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 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 (50).

Our study reported high levels of caregiver depression of 47% using PHQ9. Jaracz et al 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 (100). Consistent with findings from Berg et al who studied 100 caregivers of stroke out-patients in Helsinki, higher levels of caregiver depression led to more burden (11). 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 Salma et al who studied 151 outpatient stroke caregivers in Bangladesh and found 60% of them were highly disappointed by the change in their personal lives (99). Bartolo et al 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 (49).

Another factor that may have led to this high burden is the shorter duration of caregiving. 48% of caregivers had given care for less than six months and this finding was similar to Salma et al 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 (99). 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 (111,112). However Anderson et al 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 (7).

Scholte et al 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(98). 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 Salma et al 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 (99). 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 (48).

Studies in developing countries have reported relatively high levels of burden in comparison to studies carried out in developed countries(49)(101). 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 (102)(103).

12.1 Factors Affecting Burden

Caregiver factors

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 in a study of 20 female caregivers of stroke found occupational loss reduced quality of life of caregivers in Washington (106,107). Training of caregivers has been shown to reduce caregiver burden (57).

Patient Factors

While gender of the patient did not significantly impact caregiver burden in this study Akosile et al in 91 Nigerian stroke caregivers found that caregiver burden is increased in those caring for female stroke survivors compared to male stroke survivors (110).

12.2 Sociodemographics of Caregivers

The majority of caregivers in this study were the adult offspring constituting 51% compared to spouses who were 23%. This was due to the cultural norms in Africa where an individual's descendants take care of them as they age or during periods of ill health. Akosile et al in 91 Nigerian stroke caregivers reported similar findings where 61% of caregivers were adult children and grandchildren of the patient (110). Contrary to this Salma et al in 151 caregivers at a rehabilitation center in Bangladesh found 44% were spouses (99). Rigby et al in a Canadian outpatient stroke caregiver study of 155 reported 63% of caregivers were a spouse and 25% were daughters(50). Furthermore Bartolo in a study of 118 caregivers of chronic neurological illnesses in a neuro-rehabilitation center found the majority of caregivers at 72% was also either a

husband or wife. Offspring were only 12% (49). Consistent with these studies Hughes et al who looked at relationship between caregiver burden and Health related quality of life among 1594 caregivers of veterans found that 55.3% were spouses and 17.5% were their offspring (113). Mackenzie et al studied caregivers in China and reported that the stroke caregivers who were spouses were 57% while daughters were 19% and sons 5%(114).

The low percentage of caregivers who were a spouse in KNH may have been because most patients were moderately disabled and middle aged thus were not fully mobile. They had to be transported by their children from their rural homes.

Only half of the caregivers were married at the time of the study at 54% compared to stroke caregiver studies in USA and South Korea which had higher rates of 70-90% (50,90,107). This may be explained by the finding that most caregivers were adult offspring and not their spouses. Our findings showed that 24% were widowed while 11% separated. They may have been more willing to take in their ailing relative due to loneliness and less marital commitments.

Majority of caregivers were female 54% and males were 45%. This majority was also seen in other studies in USA and Europe in which female caregivers were reported as 50%-80% (7,114,49). This is because females especially daughters are able to relocate to their relatives residence to care for them more easily than males. Additionally strokes occur at higher incidence in men resulting in their wives becoming the principle caregivers (18).

However contrary findings were reported Onabjo et al in Nigeria who studied caregivers of community dwelling stroke survivors. He found most caregivers were males at 55.9% providing care for their parents with stroke (115). The mean caregiver age was 36years which was in agreement with Akosile et al in Nigerian stroke caregivers of 34 years (110). Other reports in the west found that caregivers were older with the ages ranging from 30-80 years with a mean of 55-70years (7,116,107,49). Anderson et al who carried out a population based study on impact of caregiving for stroke survivors reported similar findings of older caregivers ranging from 63-79 years with a mean age of 73years (7).The reason for our lower age may be attributed to the caregivers being offspring of the stroke survivors and also the earlier onset of stroke in Sub-Saharan Africa hence younger spouses for the stroke survivors.

This study reported that three quarters of caregivers were employed and this is explained by the fact that they were financially able to take care of their relative as well as themselves. The findings are different from Chow et al who studied Coping and caring: support for 47 family caregivers of stroke and where 58% of caregivers were housewives and 67% were unemployed (99,117).The mean duration of care giving was 6 months ranging from 1-264 months similar to Salma et al who studied 150 outpatient stroke caregivers and showed that most caregivers were providing care for 1-5 months with mean duration 11 months (99). Kamel et al carried out an outpatient study on caregiver depression and burden in 116 Jordanian stroke patients. He reported a mean duration of care of 12 months with a range of 3-96months (118).

12.3 Sociodemographics of stroke survivor

Majority of stroke survivors were male at 53% and this is may be explained by the epidemiology of stroke being higher in males than females (18). Studies in outpatient stroke caregivers in Bangladesh, USA, Nigeria and Taiwan have been reported by other authors who found the proportion of males was 50-70% (99,113,110,119) .

Regarding the age of stroke survivors the median age was 54years and this was slightly lower than other reports in the first world countries of between 60-80years(49,50,113). This may be due to the lower age of occurrence of cardiovascular events including stroke noted in sub-Saharan Africa(19). Furthermore higher life expectancy is seen in first world countries(120). In Nigeria Akosile et al in 91 community dwelling stroke caregivers found the median age of the stroke survivors was 60years (110) .

The stroke survivors who were retired were 29% and unemployed 25% which was consistent with the reasoning that the illness may have led to early retirement or loss of employment. This was in agreement with Suh M. et al who carried out a cross-sectional survey on stroke caregiver burden and depression in which stroke survivors who were not working were 70% (121) .

The reported number of married stroke survivors was 80% which was consistent with findings from outpatient stroke caregiver studies in Italy, Canada and Bangladesh of 70-90% (49,50,99).

Regarding secondary caregivers 79% had none. This was explained by the cost implications and the greater amount of care required by the stroke survivor thus creating a challenge for theses secondary caregivers. This was also noted by Bartolo et al in Italy who reported that less than half had additional help (49). However other findings reported that 53% of stroke survivors had secondary caregivers (117).

The median duration of stroke was 24 months and this was longer than studies from India by Salma et al of 1-5 months and Suh M. et al who studied Caregiver's burden and depression of 225 stroke caregivers in Seoul of 11.8 months (99,121).

Conclusions

The results of our study highlight 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.

Recommendations

A better understanding of the aspects of caregiver burden can help in the implementation of psychological and social support systems for the caregiver thus minimize the burden.

Pre-discharge as well as post discharge packages may reduce caregiver burden.

The health financiers can assist by insuring home based interventions including physiotherapy and occupational therapy.

The role of a community social worker to visit the homes of stroke survivors and assess the caregivers and the patients periodically and advise them accordingly.

Clinicians managing stroke should go beyond managing the individuals with stroke to assessing the level of burden in each caregiver and finding strategies to help individuals cope with the burden of caring. The ability to predict caregivers at higher risk of adverse outcomes has important implications in practice. Caregiver burden is a significant health care concern and the adverse effects may be diminished through primary and secondary prevention programs. The findings may also provide a useful resource for defining structured interventions geared at assessing, preventing or managing problems related to stressful care giving situations

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.

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14.0 APPENDICES

APPENDIX A: INFORMED CONSENT

Informed consent form for caregivers of stroke patients at Kenyatta National Hospital

Information sheet

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Department of clinical medicine and therapeutics

Resident

University of Nairobi

Evaluation of caregiver burden on caregivers of stroke at Kenyatta national hospital

Introduction

I am undertaking a study on care giving burden to those who care for stroke victims. This form is to give you the information you need before deciding if you want to participate in this study. As you read this form you may ask any questions of what you do not understand.

Purpose of Research

Usually after one suffers from a stroke they are admitted for a short time then when they are stable are discharged into the care of relatives and family. These relatives may not be aware about how to take care of them so we want to carry out research to understand how burdened caregivers are and the factors which increase their level of strain or distress.

Procedures involved

1. Sign a consent form
2. Fill a form with information on socio-demographics, depression questionnaire, burden questionnaire, knowledge of stroke questionnaire may take maximum 30minutes or
3. Participate in an audio recorded in depth interview lasting 40minutes maximum

Your rights

- i) Your participation in this research is voluntary.
- ii) You will not be victimised if you refuse to participate in this study.

- iii) If you choose to participate and not answer certain questions, you are free to do so.
- iv) You are free to terminate the interview and withdraw from the study at any time.
- v) You are free to ask questions before signing the consent form.
- vi) All the results will remain confidential. Your individual responses will be stored in a locked place under my control and will only be seen by my statistician and me.

Risks and costs

There are no risks or costs to be incurred.

Benefits

Information obtained will improve knowledge to health care givers on stressful factors that increase strain to caregivers and

Assist them in making decisions on trying to reduce the distress of caregivers.

If you have any questions later contact:

1. Dr. Louisa W Mahinda.

Tel 0722604689

2. The Chairman, KNH/UON – Ethics and Research Committee

Hospital Road along Ngong Road

P.O BOX 20723, Nairobi (CODE 00202)

Telephone number (+254-020)2726300 ext 44355

Chairperson: Professor K.M. Bhatt

Contact person: Esther Wanjiru Mbuba

Email: uonknh_erc@uonbi.ac.ke

CERTIFICATE OF CONSENT

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant _____

Signature of Participant _____

Left thumbprint of subject _____ **Date** _____

Date _____

Day/month/year

INVESTIGATOR'S STATEMENT:

I, the Principal Investigator, have fully informed the research participant on the purpose and implication of this study.

Signed: Date: _____

APPENDIX B: THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel.	Never	rarely	sometimes	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4

6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you	0	1	2	3	4

are caring for your relative?					
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4

18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
Total Score (out of 88)					

Interpretation of Score:

0 – 21 little or no burden

21 – 40 mild to moderate burden

41 – 60 moderate to severe burden

61 – 88 severe burden

APPENDIX C: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF CAREGIVER AND STROKE SURVIVOR STUDY PROFORMA

	Stroke survivor	Informal caregiver
Age stroke survivor and caregiver (years)		
Gender of caregiver and survivor		
Relationship to patient		
Residence(county)		
Duration of caring for patient(months)		
Duration of stroke(months)		
Type of stroke(infarct, bleed)		
Employment status of caregiver and stroke survivor		
Full time		
Part time		
self-employed		
Housewife/househusband		
retired		
unemployed		
Cor-mobidities(chronic illnesses)		
Marital status		
single		
married		
separated		
widowed		
Educational qualifications		
Primary		
secondary		
tertiary		
None		
Insurance status(present or absent)		

Secondary caregivers paid or unpaid		
Modified Rankin scale of stroke survivor		
No symptoms at all	0	
No significant disabilities despite symptoms able to carry out all usual duties and activities	1	
Slight disabilities unable to carry out all previous activities but able to look after own affairs without assistance	2	
Moderate disability requiring some help but able to walk without assistance	3	
Moderate severe disability unable to walk without assistance unable to attend to own bodily needs without assistance	4	
Severe disability – bedridden incontinent requiring constant nursing care and attention	5	
Dead	6	

Appendix D: STROKE KNOWLEDGE QUESTIONNAIRE

1. Do you know any stroke risk factors?

No

Yes

If yes

Old age

Diabetes

Heart disease

Obesity

Stress

Poor hygiene

Cancer

Bad diet

Hypertension

Cigarette smoking

Alcohol

High cholesterol

Genetics (hereditary)

Lack of exercise

Headache or migraine

Tremors

Demons

Witchcraft

God's will

Angry ancestral spirits

2. Warning signs

Do you know any stroke warning signs?

No

Yes

If yes

Dizziness

Headache

Tiredness

Shortness of breath

Nausea/vomiting

Weakness of one side of the body

Paralysis on one side of the body

Numbness tingling sensation or dead sensation of any part of body

Numbness tingling sensation or dead sensation on one side of the body

Blurred/double /loss of vision

Sudden difficulty in speaking/understanding/reading

Fever/sweating

Chest pain/tightness

Weakness of any part of the body

Paralysis of any part of body

Fainting/black out/collapse

Others (specify)

Warning symptoms required yes/no response.

3. Is stroke preventable?

No

Yes

Do not know

4. Can a person have stroke more than once?

No

Yes

Do not know

5. Planned response –

Go to hospital

Traditional healer/herbalist

Call family doctor

Call relative

Self medicate

6. Source of information

Friends/relatives

Healthcare workers

Radio

Television

Internet

6. Secondary prevention of stroke i.e. diet, clinics, medication
7. Physiotherapy sessions where to attend and how often
8. prognosis

1 identified warning sign or risk factor – poor knowledge

2-4 identified warning sign or risk factor- fair knowledge

5-10 identified warning sign or risk factor- good knowledge

APPENDIX E: PHQ 9 QUESTIONNAIRE

Over the last two weeks have you been bothered by any of these problems

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying asleep or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot more than usual
- 9 Thoughts that you would be better off dead, or of hurting yourself
10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people

Score – 0-3

Not at all- 0

Several days- 1

More than half the days- 2

Nearly every day- 3

Total Score Depression Severity

Minimal depression 1-4

Mild depression 5-9

Moderate depression 10-14

Moderately severe depression 15-19

Severe depression- 20-27

KIDODOSI JUU YA AFYA YA Mgonjwa - 9 (P Q - 9)

Katika kipindi cha wiki mbili zilizopita ni mara ngapi umesumbuliwa na matatizo haya yafuatayo?

(Tumia “✓” ili kuashiria jibu lako)

Haijatokezea kabisa (0), Siku kadhaa(1) ,Zaidi ya nusu ya siku hizo(2), Takriban kila siku (3)

1. Kutokuwa na hamu au raha ya kufanya kitu
2. Kujisikia tabu sana au kukata tamaa
3. Matatizo ya kupata usingizi au kuweza kulala au kulala sana
4. Kujisikia kuchoka au kutokuwa na nguvu
5. Kutokuwa na hamu ya kula au kula sana
6. Kujisikia vibaya-au kujiona kuwa umeshindwa kabisa au umejiangusha au kuikatisha tama familia yako
7. Matatizo ya kuwa makini kwa mfano unaposoma gazeti au kuangalia TV
8. Kutembea au kuongea taratibu sana mpaka watu wakawa wameona tofauti? Au kinyume chake kwamba hutulizani na unahangaika sana kuliko ilivyo kawaida
9. Mawazo kuwa ni afadhali zaidi ufe au ujidhuru kwa namna fulani

FOR OFFICE CODING 0 + _____ + _____ + _____

=Total Score: _____

Kama ulitia alama matatizo yoyote, matatizo hayo yamefanye iwe vigumu kivi kwi kwako kufanya kazi yako, kushughulikia vitu nyumbani, au kutangamana na watu wengine?

Sio ngumu hata kidogo, Ngumu kiasi, Ngumu sana , Ngumu zaidi

Imetengenezwa na Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke na wenza wake, na ruzuku ya kielimu kutoka kwa Pfizer Inc. Hakuna kibali kinachohitajika ili kuzalisha upya, kutafsiri au kuonyesha au kusambaza.

APPENDIX F: INDEPTH INTERVIEWS STUDY PROBES

1. Information on stroke including what it is, risk factors, cause, 2^o prevention, prognosis, source of knowledge
2. Major challenges in caring for patients
3. Impact financially
4. Impact on time management and engagement on social activities
5. Level of support from family members
6. Impact on spirituality
7. Impact on sleep
8. Impact on appetite
9. Impact on mood
10. Methods of trying to cope
11. Additional comments or questions

APPENDIX G: ETHICAL APPROVAL LETTER



KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723, 00202 Nairobi

Tel.: 2726300/2726450/2726550

Fax: 2725272

Email: knhadmin@knh.or.ke

Ref: KNH/AD-MED/42B/VOL.1

Date: 27th November, 2015

Dr. Louisa Wanjiru Mahinda
Department of Clinical Medicine & Therapeutics
School of Medicine
University of Nairobi

Dear Dr. Mahinda

RE: APPROVAL TO CONDUCT STUDY IN KNH, MEDICINE DEPARTMENT

Following approval of your study by the KNH/UoN ERC and completion of the KNH study registration form, permission is hereby granted for you to collect data from Medicine Department to enable you complete your study on "*Evaluation of the informal caregiver burden in the care of stroke patients at Kenyatta National Hospital*".

Kindly liaise with the Senior Assistant Chief Nurse, Medicine Department for facilitation. By a copy of this letter, the Senior Assistant Chief Nurse, Medicine Department is informed and requested to facilitate.

DR. ANN WAWERU
ASSISTANT DIRECTOR, MEDICINE

Cc. Senior Assistant Chief Nurse, Medicine

APPENDIX H: KENYATTA NATIONAL HOSPITAL ETHICS & RESEARCH COMMITTEE STUDY APPROVAL



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15 NOV 2015

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Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726900-9
Fax: 726277
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/472

19th November 2015

Dr. Louisa Wanjiru Mahinda
P-58/00170/13
Dept. of Clinical Medicine & Therapeutics
School of Medicine
University of Nairobi

Dear Dr. Mahinda

Revised research proposal: Evaluation of the informal caregiver burden in the care of stroke patients at Kenyatta National Hospital (P559/08/2015)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH-UoN ERC) has reviewed and **approved** your above proposal. The approval periods are 19th November 2015 – 18th November 2016.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal.*)
- Clearance for export of biological specimens must be obtained from KNH-UoN-Ethics & Research Committee for each batch of shipment.
- Submission of an *executive summary* report within 30 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

Protect to Discover