

Original Article

Care Burden Correlates with Depression among Informal Caregivers of Stroke Patients: A Cross Sectional Study in Lagos, Nigeria

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Location of this study: Lagos University Teaching Hospital, PMB Lagos, Nigeria

Abstract

Background: Many stroke survivors receive non-professional care from relatives. While these informal caregivers cope with stroke impact on their relatives, increasing demands placed on them result in caregiver burden and depression.

Objectives: We aimed to determine the relationship between the burden of care and depression in informal caregivers of stroke survivors.

Methodology: This cross-sectional study recruited 311 stroke caregivers by systematic random sampling, at Lagos University Teaching Hospital in Nigeria, over six months. A structured questionnaire incorporating the Zarit Burden Interview and Patient Health Questionnaire-9 was used to obtain information on burden of care and depression, besides socio-demographics.

Results: Females constituted 57.6% of the informal caregivers, whereas males accounted for 42.4%. 75.2% of the caregivers had significant level of burden, and 59.5% had depression, with demonstrable association between the two conditions ($\chi^2 = 99.3$, $p < 0.001$). There was a positive correlation between the scores for caregivers' burden and depression ($r^2 = 0.75$, $p < 0.001$). The severity of caregiver burden correlated positively with the severity of depression ($r^2 = 0.68$, $p < 0.001$).

Conclusion: Burden of care correlates with depression in informal caregivers of stroke survivors, with the severity of each increasing with an increase in the other. Presence of burden of care in a stroke caregiver warrants a search for co-morbid depression, and vice versa. Stroke rehabilitation efforts should incorporate promotion of caregiver wellness.

Key words: Caregivers, burden of care, depression, stroke

Introduction

Stroke survivors experience varying degrees of disabilities, which limit their functional and cognitive capacities and affect their Activities of Daily Living (ADL) and instrumental activities of daily living (IADL) (Kamel, Bond & Sivarajan 2012). It is estimated that 25-74% of

stroke survivors require help with ADL/IADL from informal caregivers. An informal caregiver is defined as an unpaid person that assists an individual with at least one activity of daily living or instrumental activity of daily living but not necessarily living with them (Heejung et al 2012; Jen-wen et al 2012; Kamel, Bond & Sivarajan 2012; Lopez et al 2016). These

informal caregivers could be the spouse, children, children-in-law or close friends. In Nigeria like in other developing countries, the increase in the percentage of stroke survivors requiring help with ADL/IADL can be attributed to a lack of specialized long-term stroke healthcare services. Therefore, home care of the patient with stroke falls on family members, who are often ill-prepared to handle such issue (Lalit et al 2004; Bergstrom et al 2011; Heejung et al 2012; Jen-Wen et al 2012; Kamel, Bond & Sivarajan 2012). Informal caregivers who were in poor health or from low-income countries like Nigeria or dysfunctional families might have the most limited capacity to provide needed care for their patients (Akosile et al 2013).

While these informal caregivers themselves have to cope with the devastating effects that stroke had on their relatives, an increasing amount of demands is made on them resulting in caregivers' burden and depression. Stroke informal caregivers also report more physical and psychological symptoms and use more frequent prescription medications and healthcare services than comparable non-caregivers (Brodaty & Green 2002; Schulz et al 2004; Serrano-Aguilar et al 2006).

The caregiver burden refers to a psychological state that ensues from the combination of physical work, emotional and social pressure involved in caring for an ill patient (Adeosun 2013). Informal caregivers frequently suffer from depression similar to patients and greater than the general population, with an increased risk of suicide, homicide, and violence directed at the care recipients (Ursula 2007). Studies have identified caregiver burden and depression to be among the most frequent adverse outcomes of caring for chronically ill persons (Reinhard et al 2008).

Our hypothesis in this study is that there is a relationship between caregiver burden of care and depression among caregivers of stroke survivors. The study set out to determine the relationship between the burden of care and depression among informal caregivers of stroke survivors in the outpatient clinics of Lagos University Teaching Hospital.

Methods

Study site : We conducted this study at the Neurology and Physiotherapy clinics of Lagos University Teaching Hospital located within the

cosmopolitan city of Lagos in Nigeria; with a population of 17,552,942 from the last national census (National population commission 2010).

Study Design : We used a cross-sectional descriptive design in this study

Study population: Informal caregivers of stroke survivors who presented in the Neurology and physiotherapy outpatient clinics of Lagos University Teaching Hospital (LUTH) were recruited upon meeting the study eligibility criteria.

The following were the inclusion criteria for the study:

- Informal caregivers of stroke patients, who had no chronic or limiting illness
- Those that were up to 15 years of age and above.
- Those that had been on the caregiving job for at least two weeks
- Those that had not been formally trained in the act of caregiving
- Those who gave informed written consent.

The exclusion criteria for the study were as follows:

- Those providing caregiving services to other chronically ill patients
- Those that were on an antidepressant or other medications for chronic illness before taking up the care-services
- Those who did not give consent for the study

Sample size

The sample size for this study was obtained using the formula: $n = z^2 pq/d^2$ (Araoye 2003).

Where; **n** is the desired sample size; **z** is a constant set at 1.96, corresponding to 95% confidence level; **p** represents the prevalence of burden of care/depression in informal caregivers. A study on depression among informal caregivers of stroke survivors reported a prevalence of 24.3% (Fatoye et al 2006). A value of 0.757 for q was derived by subtracting the prevalence rate from one, and **d** which represents the degree of accuracy was set at 0.05. Thus the computed minimum sample size for the caregivers, to the nearest whole number, was 283. However, to give an allowance of 10% for possible non-responders, missing data or

incomplete data, the sample size was adjusted to $283/10 = 28.3 + 283 = 311$

Sampling method: The participants were recruited by a systematic random sampling method. A sampling interval of two was obtained from the ratio of the estimated number of informal caregivers accompanying stroke survivors to the estimated number of informal caregivers of stroke survivors to be recruited in the clinics per week: The data obtained from the health record department of LUTH showed that an average of sixty (60) stroke survivors accompanied by their informal caregivers presented in the outpatients' clinics per week. It was estimated that in six months period, 720 stroke survivors and their informal caregivers were seen in the outpatient clinics. To recruit 311 informal caregivers of stroke survivors in 6 months about 12 caregivers of stroke survivors who met the inclusion criteria were recruited weekly from neurology and physiotherapy clinics.

Data collection: This study was done for over six months. The starting point or the first client was randomly selected by balloting among the first two patients who presented in the neurology and physiotherapy clinics. Subsequently, in order of their arrival in the clinic, every second patient that met the inclusion criteria and consented to participate in the study was selected until up to thirteen informal caregivers' were recruited per week. A well-structured interviewer-administered questionnaire consisting of four sections was used to obtain the relevant information. The first section obtained socio-demographic characteristics of the informal caregivers of the stroke survivors. The relationship with the stroke survivors was also included in this section. In the next sections, the burden of care and depression were assessed using the Zarit Burden Interview (ZBI) standard version of 22 items with two factorial subscale-personal strain and role strain, and the Patient Health Questionnaire (PHQ-9), respectively.

Assessment of the burden of care: The Zarit Burden Interview (ZBI) is a 22 item self-reporting inventory that examines the burden associated with functional/behavioral impairments and home care situations. Each question was scored on a 5 point Likert scale ranging from never to nearly always present. The total score ranges from 0 (low burden) to 88 (high burden): a score of 0 – 20 (little or no

burden), 21- 40 (mild to moderate burden), 41- 60 (moderate to severe burden) and 61- 88 (severe burden) (Berg 2009, Higginson et al. 2010, Mosquera et al 2016). In this study, the aforementioned levels of the burden of care were assigned ordinal numerical values of 1, 2, 3 and 4, respectively. The burden of care was regarded to be present when there is at least a mild degree of burden (ZBI score ≥ 21).

Assessment of depression: Patient Health Questionnaire (PHQ-9) was used in the assessment of depression. It was developed in 1990 from PRIME-MD. PRIME-MD was originally developed to detect five common mental disorders in primary care: depression, anxiety, alcohol abuse, somatoform disorder and, eating disorder. It is a self-report questionnaire that assesses the level of depression on the nine key symptoms (each rated from 0-3). The score on the questionnaire ranges from 0 to 27: a score of 0 (no depression), 1- 4 (minimal depression), 5-9 (mild depression), 10-14 (moderate-depression), 15-19 (moderate severe depression) and 20-27 (severe depression) (Zuihoff et al 2010). In this study, the aforementioned levels of depression severity were assigned ordinal numerical values of 0, 1, 2, 3, 4 and 5 respectively. Depression was regarded to be present when there is at least a mild degree of depression (PHQ9 score ≥ 5).

Ethical consideration: Ethical approval for the study was obtained from the Health Research and Ethics Committee of Lagos University Teaching Hospital with assigned no: ADM/DCST/HREC/2055. This study was conducted in compliance with the Helsinki declaration of 1975 as revised in 1983 and 2013.

A formal introduction of the research and assurance of confidentiality was made to the informal caregivers of stroke survivors recruited in the study. This was followed by obtaining informed consent from each of them. After completing the questionnaire, caregivers with mild to severe burden of care (ZBI score of ≥ 21) and those with mild to severe depression (PHQ-9 score of ≥ 5) were counseled and referred to the mental health team for further evaluation and management.

Data analysis : This was conducted with version 20 of the statistical package for social sciences (SPSS) software. Descriptive statistics were generated. Continuous variables were presented as means and standard deviations, and

categorical variables reported as proportions. Chi-square test and Pearson correlation were used to determine the association and correlation, respectively, between the burden of care and depression among the informal caregivers of stroke survivors. Kappa analysis was used to determine the level of agreement between the occurrence of the burden of care and depression. Microsoft Excel, 2010, was used to generate the graphs of correlation analysis. There were no missing data. Two-tailed P values were computed, with the level of statistical significance set at P-value < 0.05.

Results

A total of 311 informal caregivers of stroke survivors took part in this study. The ages of the participants ranged from 18 to 75 years, with a mean age (SD) of 41.1 years (15.3). Females

accounted for 179 (57.6%) of the participants, whereas 132 (42.4%) were males; giving a Male to Female ratio of 1:1.4. Two hundred and thirteen (68.5%) of the informal caregivers were married, fifty-two (16.7%) were single, twenty-eight (9.0%) were separated and eighteen (5.8%) were divorced. Two hundred and fifty-seven (82.6%) of the caregivers live with the stroke survivors whereas 54 (17.4%) of them do not live in the same house with the stroke patients. A hundred and twelve (36%) of the caregivers had offered their services to the stroke survivors for a period of one to three months; 26 (8.3%) for 4 to 6 months; 22 (7.1%) for 7 to 12 months; 32 (10.3%) for 13 to 24 months; and 119 (38.3%) for more than 24 months. The nature of the relationship of the stroke survivors with the caregivers is as shown in Figure1.

Figure1. The relationship of stroke survivors (care recipients) with informal caregivers

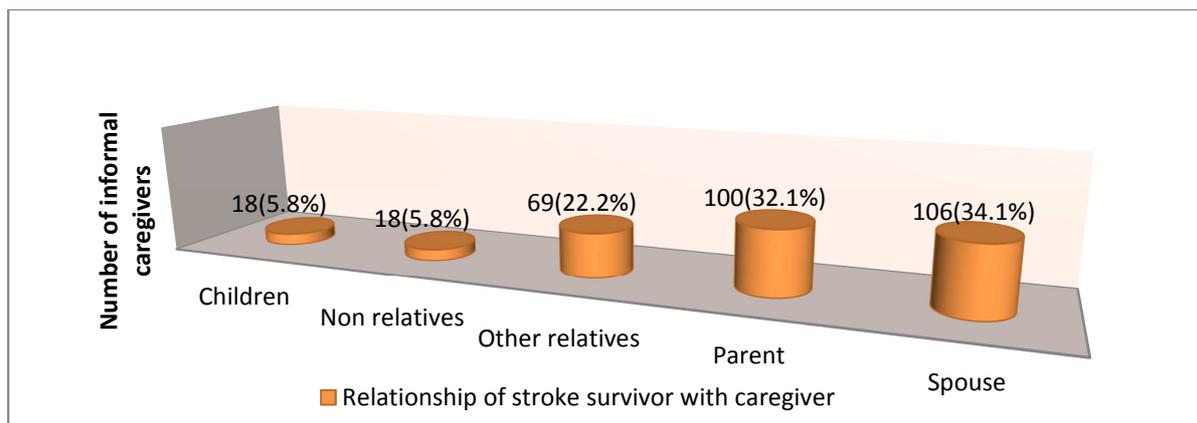


Table1. Distribution of the Zarit Burden Index (ZBI) and Patient Health Questionnaire (PHQ9) scores of the participants

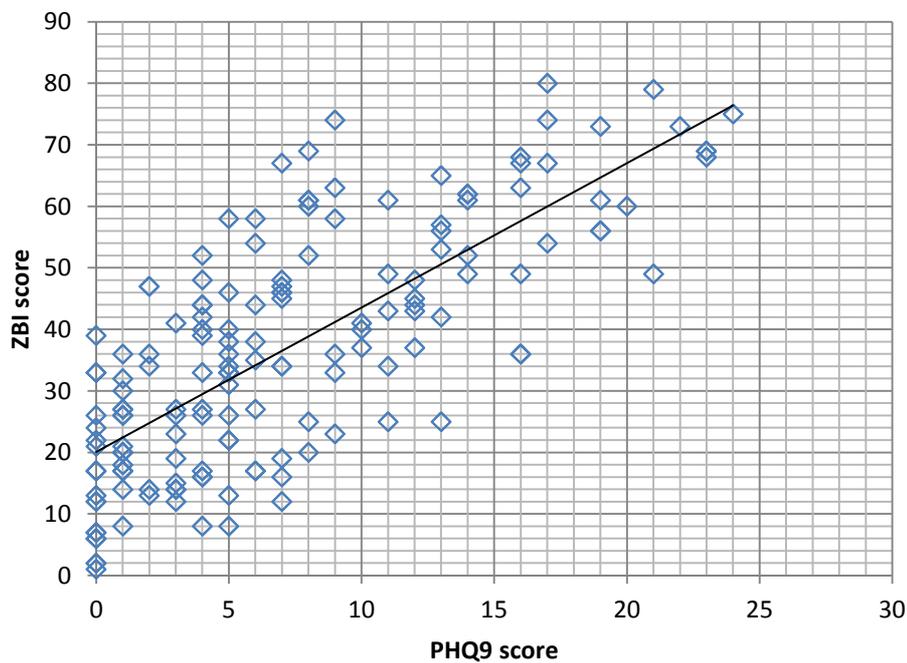
Assessment tool	Mean score (SD)	Scores		
		median	minimum	maximum
ZBI	37.1 (19.39)	36	1	80
PHQ-9	7.3 (6.21)	6	0	24

Table2. Association between burden of care and depression in the stroke caregivers

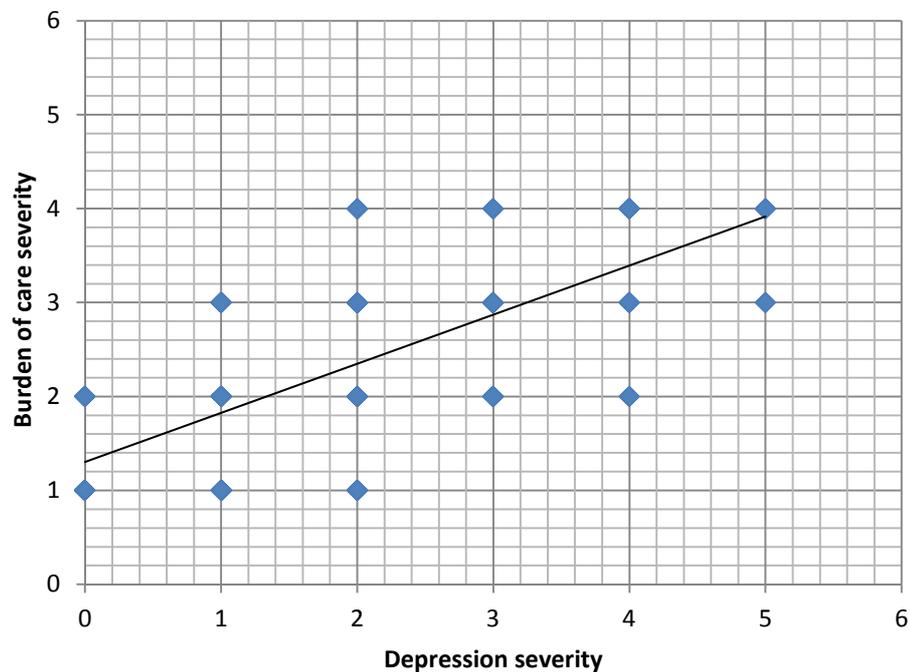
Burden of care	Depression	
	Absent (%)	Present (%)
Little or no burden	61 (79.2)	16 (20.8)
Mild to moderate	50 (47.6)	55 (52.4)
Moderate to severe	15 (19)	64 (81)
Severe	0 (0)	50 (100)

p < 0.001

Figure2. Correlation of Zarit Burden of Index (ZBI) with Patient Health Questionnaire (PHQ9) scores



$r^2 = 0.75; p < 0.001$

Figure3. Correlation of severity of burden of care with the severity of depression

$$r^2 = 0.68; p < 0.001$$

The mean scores of the study tools (PHQ-9 and ZBI) are as shown in Table1. Two hundred and thirty-four (75.2%) of the participants experienced some level of burden of care; the pattern of the burden of care is as follows: Seventy-seven (24.8%) had little or no burden, 105 (33.8%) had mild to moderate burden, 79 (25.4%) had moderate to severe burden and 50 (16%) had a severe burden. A hundred and eighty-five (59.5%) of the informal caregivers were identified to have at least a mild level of depression; as shown in the following details: 126 (40.5%) had none to minimal depression, 93 (29.9%) had mild depression, 48 (15.4%) had moderate depression, 28 (9.0%) had moderately severe depression and 16 (5.1%) had severe depression.

The study demonstrated an association between the presence of burden of care and the occurrence of depression in the participants ($\chi^2 = 99.3$, $p < 0.001$); see Table2. There was a positive correlation between the ZBI scores for the burden of care and the PHQ9 scores for depression among the informal caregivers of

stroke survivors ($r^2 = 0.751$; $p < 0.001$), as shown in Figure2. Similarly, the severity of depression positively correlated with an increasing burden of care in the caregivers ($r^2 = 0.68$, $p < 0.001$), see Figure3. The kappa coefficient for the level of agreement between diagnoses of burden of care and depression among the caregivers was 0.42 ($p < 0.001$).

Discussion

The burden of caregiving is a complex multifaceted construct that may defy a uniformly agreed simple definition. It has been estimated that around 43% of adults aged 51 years and above have surviving relatives putting them at risk of one day having to provide some informal care, and the risk declines considerably with increasing age (Ogunlana et al 2014). The mean age of informal caregivers of stroke survivors in this study mirrors that of Salama et al. who got a mean age of 41.35 ± 8.44 years from his study done in Lower Egypt (Salama & Abou 2012). Some investigators who looked at the quality of life and burden of informal caregivers of stroke

survivors in the Ogun state area of Nigeria reported a similar mean age value of 41.1 ± 14.0 years (Ogunlana et al 2014).

Considering that the stroke survivors were older than their informal caregivers and that the caregivers were mainly females compared to the care recipients who were predominantly males, it is likely that the majority of the caregivers were female spouses who were much younger than their care recipients. This is further corroborated by the reported nature of the relationship of stroke survivors with the caregivers, and the high proportion of the caregivers in this study who were married.

Furthermore, the higher proportion of the female gender among the caregivers could be a result of certain cultural influence as suggested by some researchers in their study on the adverse impact of medically ill elders on the mental health of their informal caregivers (McCusker et al 2007). In most African settings, women are brought up to accept caring for loved ones as a “basic and normal role”. In Nigeria and in some other African countries, domestic work and caregiving roles are primarily considered as women’s work (Akosile, Okoye & Odunowo 2009). This gender distribution pattern is at variance with the study on caregivers’ stress on stroke survivor, by Ain et al in Pakistan, which showed a majority of the informal caregivers (70%) to be of the male gender (Ain et al 2014). This variation could be attributed to the cultural setup in Pakistan where sons are usually responsible for caregiver roles.

The observation of a large proportion of caregivers with a burden of care in our study is in line with reports from a few other Nigerian studies that demonstrated a burden in 82.4% and 83.07% of informal caregivers, respectively (Akosile et al 2013; Ogunlana et al 2014). In comparison with European studies carried out six months after stroke, this proportion is remarkably high. The figures from some studies in Norway, the Netherlands, Belgium, and Scotland were 25%, 30%, 29%, and 37%, respectively (Krystyna et al 2014). The discrepancies may reflect, on the one hand, methodological differences between the studies, but may also indicate differences in caregiving support systems in Europe. However, the EUROFAMCARE study showed that carers’ use of support services is generally limited throughout Europe, with about 20% of caregivers using support services. This is noticeable in

Germany, Sweden, and the UK, while in Poland fewer than 5% use the support services (Krystyna et al 2014).

The result of this study confirmed an association between caregiver burden and depression, and a positive correlation between the ZBI scores used to assess caregiver burden and PHQ9 scores for depression, in the caregivers of stroke survivors who participated in the study. As mentioned earlier, caregiver burden and depressive symptoms are the most common negative outcomes of providing care for the elderly and chronically ill (Reinhard et al 2008). Studies have demonstrated that caregivers of stroke patients have the highest levels of anxiety and depression (Berg et al 2005; Wilz & Kalytta 2008). Reports on several diseases showed that the odds of caregiver depression increased with an increase in caregiver burden. As caregiver burden increases, it is more likely that caregivers may have depression (Denno et al 2013). Caregivers of patients with neurological disorders have been found to be at higher risk of social isolation, emotional burden and a reduction in quality of life. The burden of care of stroke patients adversely impacts the physical as well as psychological well-being of the caregivers (Balhara et al 2012).

The severity of caregiver burden positively correlated with the severity of depression among the participants. This is in concordance with the study on “Anxiety and depression associated with caregivers’ burden in caregivers of stroke survivors with spasticity” by Denno and his colleagues in which the association was significant (Denno et al 2013). Caregivers of stroke survivors who had high caregiver burden showed significantly worsened depression survey scores when compared with caregivers without high caregiver burden (Denno et al 2013). However, this finding was at variance with the study on the level of caregiver burden in Jamaican stroke caregivers and the relationship between selected socio-demographic variables done by Roopchand-Marthin et al whose study showed a poor correlation between depression and caregiver burden (Roopchand-Marthin & Creary-Yan 2013). Methodological differences between the studies and peculiarities in cultural context could account for the disparity.

We acknowledge that the hospital-based nature of our study poses some limitations to the generalization of our findings. However, the

adoption of a probability sampling method improves the quality of our study. Some confounders like the length of caregiving time and severity of stroke in care recipients, which impact on care burden, could have influenced the observed association between the burden of care and depression. However, these same factors have been linked to depression in caregivers too (Smith et al 2004; Oni et al 2019).

Our study demonstrated that informal caregivers of stroke survivors are prone to suffer the burden of care and depression and that there is a relationship between burden of care and depression in informal caregivers of stroke survivors, with increasing frequency and severity of depression as the severity of the burden of care increases. These findings make it imperative that identification of the burden of care in a stroke caregiver should warrant a search for possible co-morbid depression, and vice versa.

Informal caregivers of stroke survivors should be regarded as hidden patients and encouraged to present for regular check-up alongside with their care recipients. In addition, stroke rehabilitation efforts should extend beyond a patient-focused approach to incorporate the promotion of their caregivers' wellness, so as to reduce the adverse impact of the burden associated with caregiving. Periodic mental health screening of these informal caregivers would be of benefit to identify those with a high burden of care and at risk of depression for immediate intervention. We also recommend further local studies to explore the determinants of caregiver burden and depression among informal caregivers of stroke survivors, with the intent of providing clarifications, in order to enhance judicious utilization of available health resources, especially in resource-constrained settings such as obtained in Nigeria and other developing nations.

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