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Original article

Stroke management: Informal caregivers' burdens and strains of caring for stroke survivors



Caleb Ademola Gbiri^{a,b,*}, Olajide Ayinla Olawale^a, Sarah Oghenekewe Isaac^a

^a Department of Physiotherapy, College of Medicine, University of Lagos, Lagos, Nigeria

^b Department of Psychiatry, Faculty of Clinical Sciences, University of Pretoria, Pretoria, South Africa

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ABSTRACT

Background and aims: Stroke survivors live with varied degrees of disabilities and cares are provided largely by the informal caregivers. This study investigated informal caregivers' burden and strains of caring for stroke patients.

Method: This study involved 157 (81 males and 76 females) informal caregivers of stroke survivors receiving care in all secondary and tertiary health institutions with physiotherapy services in Lagos State, Nigeria. Information was collected through self-administered questionnaire during clinic-hours. Data was analyzed using Spearman's Rank Correlation Coefficient.

Result: The patients' age ranged between 20 and 79 (mean = 59.6 ± 14.6 years). Sixty-one had haemorrhagic stroke while 96 had ischaemic stroke. The informal caregivers' age was 39.2 ± 12.8 years (range: 17–36 years). More (60.8%) participants reported moderate objective while 79.2% had mild subjective burdens. The following factors significantly increased ($P < 0.05$) the level of burden and strains experienced by the informal caregivers: closer intimacy with the stroke survivors, fewer number of caregivers for the stroke patient, longer duration since the onset of stroke and more hours of caregiving per day. Caregiving had negative significant influence ($P < 0.05$) on the social, emotional, health and financial well-beings of the informal caregivers.

Conclusion and recommendation: Caring for stroke survivors put social, emotional, health and financial burdens and strains on the informal caregivers. These burdens and strains increase with duration of stroke, intimacy, smaller number of caregivers and length of daily caregiving. Therefore, informal caregivers should be involved in the rehabilitation plan for stroke patients and their well-being should also be given adequate attention.

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1. Introduction

Stroke is one of the major challenges facing healthcare being one of leading cause of death and one of the major cause of disability and dependency in activity of daily living worldwide [1–4]. Stroke rehabilitation has concentrated on patient-focused interventions to reduce severe disability and institutionalization, which has resulted in increasing number of disabled patients being managed at home [5]. Due to its sudden and unpredictable onset, a stroke often meets stroke survivors and their caregivers unprepared to deal with its impact on daily life [6]. Stroke survivors and their caregivers often suffer from various degrees of permanent

disability and sustain impairments that significantly affect their personal, familial, and social well-being [7–9].

Informal caregiver burden or strain is a multidimensional concept including physical, social, psychological and financial factors [10]. The burden varied from objective (financial and quality of assistance rendered for activities of daily living) to subjective (feelings and perceptions associated caregiving) [10]. The needs of a stroke survivor vary from physical (mobility), communication (verbal and nonverbal), nursing (feeding, clothing, toileting), emotional and psychological changes to adapt to the consequences of stroke. The caregiver has to balance a dual responsibility of looking after a dependent stroke survivor as well as making adjustments in his or her lifestyle. Hence, due to its debilitating and chronic nature, caring for stroke survivors often puts considerable burden on their caregivers [7].

Recent years have seen increasing awareness of the role of caregivers in the long-term management of stroke survivors. There

* Corresponding author at: Department of Physiotherapy, College of Medicine, University of Lagos, Nigeria. Tel.: +2348033598072; fax: +27744814995.

E-mail addresses: calebgbiri@yahoo.com, cgbiri@unilag.edu.ng (C.A. Gbiri).

is growing evidence on the caregiving burden, poor caregiver outcomes, lack of caregiver support, and equivocal success, aimed at alleviating the caregiving burden [11]. Despite these overwhelming, little or no attention has been directed towards ameliorating the consequence of caregiving on stroke survivors' caregivers. The emphasis in stroke rehabilitation needs to shift from a patient-focused approach to a combined patient-caregiver-focused approach. This is necessary because caregivers are central in preserving rehabilitation gains and the long-term well-being of stroke survivors [11]. The rising burden of stroke globally will eventually increase the burden on caregivers [10]. Therefore, there is need for sufficient data to prove and advocate for social support to ease out the burden on caregivers. Therefore, this investigated the burden of caring for stroke survivors on their informal caregivers and the perception of the caregivers on the effectiveness of physiotherapy for stroke patients.

2. Methods

This study involved consecutively recruited 157 informal caregivers of stroke survivors, who have been caring for stroke survivors for a minimum of one month after discharge from in-patient care. Informal caregiver were defined as an unpaid person who lives with a patient and/or is most closely involved in taking care of him/her at home and helps with the physical care of coping with the disease [12]. They were recruited from Physiotherapy Out-patient Clinics of all the ten public (government owned) health institutions in Lagos State, Nigeria where there is availability of physiotherapy services. Prior to the commencement of this study, ethical approval was sought and obtained from the Health Research and Ethics Committee of the Lagos University Teaching Hospital, Lagos. Participants were provided with information sheet, which contained detailed information of what the study is all about. Participants consent was also obtained.

Participants were included if they had been an informal caregiver taking care of the stroke survivors for at least one month after discharge from in-patient hospital care, relatives (spouse, children, brother, sister or other family relations) to the patients and are not being paid for their caregiving roles, and the stroke survivors they are caring for had been coming from home to access physiotherapy services for stroke rehabilitation on out-patient basis for at least one month after in-patient hospital discharge.

Data was collected through a self-administered questionnaire that was cross-culturally adapted from two existing questionnaires: Modified Caregiver Strain Index [13] and Burden Interview [14]. The questionnaire has three sections: socio-demographic, caregiver strain index (for objective burden and strain), and perceived burden (for subjective burden and strain). The objective aspect consists of thirteen questions to measures strain related to care provision in respect of employment, finance, physical involvement, social life and time commitment. The score on the objective burden ranged between 13 and 26. Score 13 to 17 indicate mild burden and strain, 18 to 22 indicate moderate strain while score of 23 and above indicate severe strain. In the subjective burden, the score ranged between 0 and 88. Scores of 20 or less indicate no burden, 21 to 40 indicate mild burden, 41 to 60 indicate moderate burden, score of 61 and above indicate severe burden.

The content validity of the modified questionnaire was determined through a focus group discussion in two stages. The first stage involved two physiotherapists, three stroke survivors, and four informal caregivers of stroke survivors, two clinical psychologists and four nurses. The second stage involved a panel of five experienced physiotherapists academics and clinicians in the field of stroke rehabilitation. The final questionnaire was

pre-tested among 30 informal caregivers (who were from a separate hospital different from those who were involved for the final study and who did were not part of the final sample size for the real study) of stroke survivors and the items with ambiguity were either removed or re-phrased. The test-retest reliability of the questionnaire was determined among the informal caregivers and it has *r*-value of 0.91. The participants were consecutively recruited as they became available at the physiotherapy out-patient clinics of all the hospitals involved. The questionnaire was self-administered to them (relatives in charge of the stroke survivors). The questionnaire was given to each of the participants as they get to the clinic and they were told that they will be required to return it before they leave the clinic for that day. The questionnaires were retrieved at their earliest convenience time during the clinic-hours.

2.1. Data analysis

Data collected was summarized using descriptive statistics of mean and standard deviation, percentages, frequency. Spearman's Correlation Coefficient was used to explore the relationship among the variables. Mann Withney *U* test was used to find the gender variation among the participants ($P \leq 0.05$).

3. Results

All the 157 (81 males and 76 females) questionnaires administered to the participants were returned and were valid for data analysis giving return and validity rate of 100%. Their age ranged between 17 and 74 years with a mean age of 39.2 ± 12.8 years. One hundred and sixteen (73.9%) were Christians while 41 (26.1%) were Muslims. Ninety-five, 60 and 2 were married, single and widowed respectively. Seventy-five, 45, 21 and 16 were children, spouses, siblings and other significant others respectively. Majority of the participants were employed (66.9%) with more than half (36.3%) of them being self-employed. More (58.6%) of the participants lived in rented while 41.4% were the owner of their accommodations. Other information on the socio-economic characteristics of the participants is provided in Table 1. Sixty-one of the stroke survivors had haemorrhagic stroke while 96 had ischaemic stroke. One hundred and thirteen of them had lesion located in the cortex while 44 had sub-cortical stroke. Other socio-demographic and clinical variables of the stroke survivors were represented in Table 2.

Majority (92.2%) of the survivors have at least more than one caregiver (Table 3). More of the participants (60.5%) spent more than six hours caring for the stroke survivor daily (Table 3). Less than one-third (30.6%) of the participants rendered both self-care and shouldered the financial burdens of the survivors while more (45.2%) of them cared in multiple ways including grooming, financial, mobility and other assistance (Table 2). Above one-third (35.5%) of participants spent at most 50,000 Naira (230 Euro) on a monthly basis caring for the survivor, (26.7%) spent between 50,000–100,000 Naira (230–460 Euro), (1.3%) spent above 100,000 Naira (460 Euro), while 36.3% of the participants were uncertain about how much they spend on caring (note: a Naira is equal to 0.0046 Euro [XE Currency Converter]).

In the objective axis, 47, 96 and 14 reported mild, moderate and severe burdens respectively while in the subjective axis, 1, 125, 29 and 2 reported little, mild, moderate and severed burdens in that order. The total perceived burden showed that 80, 75 and 2 were mildly, moderately and severely burdened respectively (Table 4). There was significant relationship between each of type of relationship, number of caregivers, hour of caregiving, duration of stroke and perceived burden expressed by the participants. There was no significant relationship between age and gender of the participants and burden of caregiving (Table 5). Caring for the

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