Original article

**Stroke management: Informal caregivers’ burdens and strians of caring for stroke survivors**

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1. Introduction

Stroke is one of the major challenges facing healthcare being one of the 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

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http://dx.doi.org/10.1016/j.rehab.2014.09.017
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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 rehabilitation on in-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 ≤ 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 severe 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
stroke survivor had a significant influence on the finances, emotional status, health and the social life of the informal caregivers (Table 6).

4. Discussion

Caregiving is a complex phenomenon having both physical and emotional components. It requires both physical activities and expression of love from the caregivers. Therefore, it will be very important to determine the burden experienced by informal caregivers of stroke survivors especially in an African setting where stroke care have been said to be at sub-optimal level and there is much reliance on the informal care support after hospital discharge. The purpose of this study was to investigate the burden of informal caregiving for stroke survivors in Lagos State, and also to assess the informal caregivers’ perception of effectiveness of physiotherapy rehabilitation on restoring the quality of life and functional performance of the stroke survivors. This study involved 157 informal caregivers of stroke survivors from various Physiotherapy out-patient clinics in secondary and tertiary health institutions in Lagos State.

The findings that majority (60.8%) of the caregivers expressed at least moderate objective burden shows that caregiving for stroke survivor is stressful and can induce health challenges to the informal caregivers. The experience of burden by the informal caregivers maybe associated with their constant need to meet the requirements for functional performance in the stroke survivors. They probably provide support in self-care and other activities, which will pose more challenges to their physical and mental health. His finding corroborates that of Bhattacharjee et al. [10] who had earlier concluded that caregiving for stroke survivors is of great burden and many factors contributed to this burden. Some other studies have also observed that many stroke survivors’ physical characteristics such as age, gender, physical functioning,
neurological functioning and cognitive impairments also contributed to the burden expressed by the informal caregivers [15–17]. Deterioration in survivor physical functioning had been shown to predict worse objective burden among informal caregivers of stroke survivors [17].

The fact that most (79.2%) of the respondents expressed to have a mild subjective burden in contrast to the majority having high objective burden may be attributed to the African social system. Until recently that the African traditional system has been giving way to the western culture, Africans lived in communal system and the family role and association were given great priority [18]. The differences in the objective and subjective report of the participants can be explained by the fact that objective assessment do not always correspond to subjective assessment and that the subjective assessment only reflect societal expectations while subjective report expressed personal experience [19]. The mild subjective burden reported might not be unconnected with the family role and care in the African culture. A previous study had earlier reported that stroke survivors in south-western Nigeria enjoyed the same level of intimacy with relatives and friends as their apparently healthy matched individuals [18]. It has also been observed that stroke survivors who enjoyed family care had faster recovery of functional performance, were unlikely to have emotional disorders and had better quality of life than those who did not enjoy family support [9,20]. This may explain why the informal caregivers do not feel that they may be unable to care much longer for their relatives who were recovering from stroke, but rather that they should be doing more for them to improve their chances of recovery.

The result that there was no significant correlation between age of the caregivers and their perceived burden of caregiving shows that the perceived burden of caregiving is independent of the age of the caregiver. This corroborates that of McCullagh et al. [15] who had earlier concluded that no significant relationship existed between the age of the caregivers of stroke survivors and their perceived burden of caregiving. However, this finding disagrees with that of Bhattacharjee et al. [10] who reported that younger age (less than 45 years) was a factor leading to increase in caregiver's burden. In another study in south-eastern Nigeria, Akosile et al. [21] stated that caregiver’s burden has positive correlation with caregiver’s age.

The finding that there was no significant relationship between gender of the caregiver and their perceived burden of caregiving could be attributed to the African culture where significant others of individuals in ill-health are assumed to have primary responsibility towards the well-being of their ill-relatives irrespective of their gender. In this study, more of the caregivers were males (51.6%) which is in contrast with the gender spread in other previous studies [15,21,22] on caregivers’ burden. This male gender preponderance in this study could be attributed to the fact that the participants were recruited from the hospital setting when they accompanied their relative for physiotherapy treatment. Most of the time, the offshore works and works that require physical exertions are often seeded to the male gender that have been known to have physical make-up for it. Females are more involved in domestic activities of caregiving. However, the results of this study did not show any relationship between gender and caregivers’ burden. This finding disagrees with that of Bhattacharjee et al. [10] who opined that female gender was a factor relating to high caregiving stress.

The results that most of the caregivers were either child (47.8%) or spouses (28.7%) show that stroke survivors in Lagos State enjoy support from their close relatives. This finding corroborates those of Akinpelu and Gbiri [18] that stroke survivors in south-western Nigeria enjoyed the same level of intimacy with their relatives comparable with their apparently healthy individuals. This shows that stroke survivors in Lagos State do not suffer neglect from relatives. The fact that there were more children caring for their stroke survivors shows that children assume great responsibility for their parents. In the study of Akosile et al. [21], the children and grandchildren constituted a greater percentage of the caregivers thereby supporting the findings of this study. However the negative correlation between the type of relationship with the patient and the burden of caregiving indicates that the closer relationship with patient increases the burden on a caregiver. This finding corroborates that of Low et al. [23] and Akosile et al. [21]. However, in contrast McCullagh et al. [15] reported no significant relationship between caregiving burden and relationship with the caregiver.

The fact that the more the caregivers the less the burden of caregiving can be explained by the principle of sharing of responsibilities among the caregivers. It is obvious that when there are more caregivers who are responsible to a stroke survivor, there is likely to be less hour of care and less responsibility carried by a single caregiver. This may have affected the perceived burden

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**Table 4**
The burden of informal caregiving expressed by respondents.

<table>
<thead>
<tr>
<th>Burden</th>
<th>Frequency, n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Mild</td>
<td>47</td>
<td>29.8</td>
</tr>
<tr>
<td>Moderate</td>
<td>96</td>
<td>60.8</td>
</tr>
<tr>
<td>Severe</td>
<td>14</td>
<td>9.0</td>
</tr>
<tr>
<td>Subjective</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Mild</td>
<td>125</td>
<td>79.2</td>
</tr>
<tr>
<td>Moderate</td>
<td>29</td>
<td>18.4</td>
</tr>
<tr>
<td>Severe</td>
<td>2</td>
<td>1.2</td>
</tr>
</tbody>
</table>

**Table 5**
Relationship between socio-demographic characteristics, caregiving roles and perceived burden of the participants.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Spearman’s rho</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.151</td>
<td>0.059</td>
</tr>
<tr>
<td>Gender</td>
<td>0.145</td>
<td>0.070</td>
</tr>
<tr>
<td>Type of relationship</td>
<td>-0.203</td>
<td>0.011</td>
</tr>
<tr>
<td>Number of caregivers</td>
<td>-0.241</td>
<td>0.002</td>
</tr>
<tr>
<td>Hour of caregiving</td>
<td>0.330</td>
<td>0.000</td>
</tr>
<tr>
<td>Duration of stroke</td>
<td>-0.239</td>
<td>0.003</td>
</tr>
</tbody>
</table>

**Table 6**
Relationship between burden of caregiving and each of; finances, emotional status, health and social life of the participants.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Spearman’s rho</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving gives financial strain</td>
<td>-0.532</td>
<td>0.000</td>
</tr>
<tr>
<td>Feeling of not having enough money for care in addition to the rest of expenses</td>
<td>0.403</td>
<td>0.000</td>
</tr>
<tr>
<td>Feeling embarrassed about relatives behaviour</td>
<td>0.377</td>
<td>0.000</td>
</tr>
<tr>
<td>Feeling angry when around relative</td>
<td>0.395</td>
<td>0.000</td>
</tr>
<tr>
<td>Caregiving imposes emotional adjustment</td>
<td>-0.503</td>
<td>0.000</td>
</tr>
<tr>
<td>Relatives behaviour is upsetting</td>
<td>-0.434</td>
<td>0.000</td>
</tr>
<tr>
<td>Upsetting for relative to have changed from former self</td>
<td>-0.538</td>
<td>0.000</td>
</tr>
<tr>
<td>Feeling that health has suffered due to caring</td>
<td>0.518</td>
<td>0.000</td>
</tr>
<tr>
<td>Feeling social life has suffered due to caring</td>
<td>0.556</td>
<td>0.000</td>
</tr>
</tbody>
</table>
of the respondents as their burdens are been shared. This is evident in the fact that majority (92.2%) of the stroke survivors had at least more than one caregiver and each caregiver probably carrying less burden. This finding is in contrast with that of Bhattacharjee et al. [10] who stated that the presence of an additional caregiver did not affect the perceived burden of the caregivers.

The positive significant relationship between the hour of caregiving and the perceived burden of care shows that the burden of care is positively related to the length of caregiving rendered on a daily basis. However, the burden is more on those who reported to be with the stroke survivor all the time, attending to their needs thereby performing a dual responsibility of looking after a dependent stroke survivor as well as meeting their personal needs. This finding corroborates those of Tootoh et al. [17] and Bhattacharjee et al. [10] who had earlier reported long caregiving hours to be a major factor contributing to caregivers’ burden. The result that those who cared for stroke survivors with shorter post-stroke duration experienced more burdens could be attributed to the sudden change in family roles of the caregivers and the sudden effect of cumulative burden experienced which was not planned for. This finding agrees with those of previous authors that the duration of caregiving negatively correlates with perceive burden [15,21]. However, the moderate level of burden expressed could have been influence by the fact that majority (65.5%) of the stroke survivors had suffered stroke for less than one year and with (43.9%) having less than six months post-stroke duration. This shows that the burden perceived by caregivers at early stage of stroke is much, which may gradually decrease with post-stroke duration as functional performance improves which may result in less dependency.

The results that caregiving of the stroke survivors had a significant influence on the finaces of their caregivers is not unexpected as more (59.8%) of the caregivers were either on a monthly income of between less than 230 Euro or they have unstable income. This may have been much burden as most (71.8%) of them reported to be spending at least 230 Euro monthly or more specifically on caring. This shows that their expenditure is sometimes more than their incomes, which may mean they might have been borrowing to meet up with the expenses. The negative correlation indicates that the less financially buoyant the caregivers are, the more the influence of caregiving on their finances. This finding agrees with that of Bhattacharjee et al. [10] who also found a significant relationship between caregiving of the stroke survivor and financial well-being of their caregivers.

A previous study on predictors of emotional distress, general health and caregiving outcomes in family caregivers of stroke survivors showed that high task difficulty and low self-esteem increased emotional distress in caregivers [24] while in a later study Bakas et al. [25] found that the tasks perceived as most time consuming, difficult and predictive of mood and other negative caregiver outcomes were managing finances, managing behaviour and providing emotional support. In the same trend, the finding of this study shows that caregiving had negative impact on the emotional, health and social status of the informal caregivers of stroke survivors in Lagos, Nigeria. This corroborates the opinion of McCullagh et al. [15] that caregiver burden in the immediate aftermath of stroke was determined predominantly by survivor and caregiver anxiety rather than by other factors. The emotional disturbance may have been due to the sudden impact of stroke on both the survivor and their caregivers, which leaves little or no time for them to adjust to the sudden changes in their lives. This agrees with the fact that caring for stroke survivors often takes an enormous toll on their caregivers resulting in a decline physical and emotional health, increased depressive symptoms and a decreased sense of well-being [26].

It has been said that caregiving training had an independent effect on reducing caregiver burden regardless of the survivors’ or caregivers characteristics [15]. Training caregivers in the management of disabled survivors reduced caregiver burden and improved their quality of life [15]. Therefore, “hands on training” in the day-to-day management of stroke survivors can lower anxiety and burden of care levels [27]. This suggests that a shift in rehabilitation philosophy from a patient centered approach to a patient-caregiver centered approach, which empowers caregivers, may have better long-term outcomes. Therefore, caregiver education would facilitate and maintain adaptive changes in family function and counseling can help to maintain the benefits of education in several areas of family function and patient adjustment [28].

5. 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.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

References


