



Burden of Care and Quality of Life among Caregivers of Stroke Survivors: Influence of Clinical and Demographic Variables

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Authors' contributions

This work was carried out in collaboration between all authors. Authors HB and AN designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Author AIB managed the analyses of the study. Author JNAQ managed the literature searches. All authors read and approved the final manuscript.

Article Information

DOI: 10.9734/BJMMR/2017/31903

Editor(s):

(1) E. Umit Bagriacik, Department of Immunology, Gazi University, Turkey.

Reviewers:

(1) Olufemi O. Oyewole, Olabisi Onabanjo University Teaching Hospital, Sagamu, Nigeria.

(2) P. G. Raman, Devi Ahilya University, Indore, India.

(3) Surona Visagie, University of Stellenbosch, South Africa.

Complete Peer review History: <http://www.sciencedomain.org/review-history/18243>

Original Research Article

Received 29th January 2017

Accepted 10th March 2017

Published 17th March 2017

ABSTRACT

Aim: To determine the factors that significantly impact on the caregivers' burden and their quality of life (QoL) in the process of caring for stroke survivors.

Study Design: A cross sectional study design was used.

Place and Duration of Study: The study was conducted at the Physiotherapy Department of the Komfo Anokye Teaching Hospital, Kumasi-Ghana, between August 2016 and January 2017.

Methodology: Data capturing form, Caregiver strain index and Short Form 36 Health Survey (RAND SF-36) were used to retrieve information concerning demographics, burden of care and QoL respectively from the caregivers while Barthel index was used to assess the stroke survivors'

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functional limitation. Statistical analyses were performed on the interrelationships among the study variables.

Results: Sixty (60) caregivers participated in this study out of which, 39(65.0%) were females. Forty-one (68.3%) of the caregivers were employed, of which 25(61.0%) were involved in blue collar jobs. Children of the stroke survivors constituted majority 23(38.3%) of the caregivers. Most of the caregivers 31(51.7%) have been giving care for up to 4 months prior to this study. The average score on the Caregiver Strain Index (CSI) was 9 ± 3 which implies severe strain. Role limitation due to physical functioning and emotional problems were the worst affected QoL domains. There was a positive significant association between the strain experienced by the caregivers and the functional limitation of the stroke survivors ($p=0.028$). Sex, employment status, relationship to patient, and marital status of the caregivers were significantly associated ($p<0.05$) with their QoL.

Conclusion: The level of functional limitations presented by the sampled stroke survivors in this study was the single major determinant of burden among the caregivers whilst sex, employment status, relationship to patient, and marital status of the caregivers also have appreciable impact on their QoL.

Keywords: Stroke survivors; caregivers; care burden; quality of life.

1. INTRODUCTION

Stroke is the third cause of mortality and the leading cause of adult disability in Ghana [1,2]. Because of the increasing number of stroke survivors and the limited rehabilitation centres in Ghana, the involvement of caregivers in the long term stroke recovery is paramount [3]. As the population ages and the cost of health care rises, relatives and friends are compelled to provide complimentary care in their homes [4]. The family caregivers do not only provide financial, emotional and social support but also continue with rehabilitation in their homes [5,6]. Previous studies have reported that increased therapy time by family caregivers is positively associated with post stroke recovery and functional outcome [7,8]. These findings attest to the significant impact of caregiving by relatives and significant others.

In recent years, studies with family caregivers have demonstrated substantial burden and stress due to the debilitating and chronic nature of stroke [9,10]. It was indicated that caregiver's stress may negatively affect their quality of life which may potentially have implications for rehabilitation outcome [10,11]. According to Choi-kwon et al. [10], the perception of caregiver's burden is based on the society and culture in which the caregiver lives. In Ghana, men are supposedly the breadwinners of the family whilst women are usually home bound to perform every house hold chore [12]. Therefore, caring for family member with a stroke may place appreciable burden and affect the QoL of female caregivers [13]. Unlike in the developed countries where there is availability of nursing homes and

institutions that care for people with chronic illness including stroke, developing countries such as Ghana lack these facilities which could increase the risk of burden among the informal family caregivers and may implicate their QoL [10,14].

Although age, sex, duration of caregiving, social status of the caregiver, and the functional limitation of the stroke survivor have been found to affect caregiver's burden and QoL, the influence of cultural differences cannot be over explored. Indeed, the socio-economic profile of individuals in the developed countries may not be necessarily at par with the profile of the similar population in the developing countries. Further effort in this regard is therefore necessary as the environment-based findings can be employed to inform health reform policy. In this study, we determined the factors affecting caregivers' burden of care and their QoL at a tertiary health institution in Ghana.

2. MATERIALS AND METHODS

2.1 Participants

This cross sectional study was conducted at the Komfo Anokye Teaching Hospital (KATH) which is a Tertiary Health Facility in Ghana between August 2016 and January 2017. Sixty (60) stroke survivors and their caregivers receiving physiotherapy at KATH physiotherapy department were approached to participate in the study as they reported for physiotherapy with their patients. Those who met the set criteria were included through consecutive sampling

technique. The study included caregivers who have lived with the stroke survivors for a minimum of one month prior to the study and provided assistance in most, if not all of patient's activity of daily living. Caregivers with previous history of chronic diseases or disorders, cognitive or communication impairment were excluded in the study during the pre-recruitment interview.

2.2 Study Instruments

2.2.1 Data capturing form

This was designed by the researchers and used to obtain caregiver's socio-demographic variables as follows: age (21– 30, 31 – 40, 41 – 50, 51 – 60, 61+), duration of caregiving (1-4 months, 4 -9 months, 9-12 months, more than 12months), relationship with the patient (spouse, children, parents, grandchildren, siblings, other relatives), education (none, basic, senior high, tertiary), employment status (employed, unemployed) and marital status (single, married, divorced).

2.2.2 The Caregiver Strain Index (CSI)

This standardized questionnaire was designed to measure the impact of caregiving among caregivers of stroke patients [15]. It consists of 13 items that measure burden related to care provision and there is at least one item for the following major domains; employment, financial, physical, social and time. The score ranges from 0 to 13. Although the tool was not validated for local Ghanaian setting, it can be both self and researcher administered which confers an added advantage as assistance can be given to those who cannot express themselves in English language. A positive response to seven or more items on the index indicates severe strain and a positive response to six or less items indicate less strain. This instrument was adjudged to be very valid and reliable (Cronbach's α was 0.81) [16].

2.2.3 RAND-SF36 items Health Survey (version 1.0)

It is a standardized questionnaire meant to assess Health-Related Quality of Life (HRQoL) of the caregivers. The questionnaire comprises eight dimensions namely Physical functioning, Role limitation due to physical health, Role limitation due to emotional problems, Energy/Fatigue, Emotional wellbeing, Social functioning, Pain and General Health. It is a

researcher administered questionnaire which has been widely used in divergent socio-cultural settings. Items in the various domains were summed up and calculated in percentage. All questions are scored on a scale of 0 to 100, with 100 representing the highest level of functioning possible. Aggregate scores are compiled as a percentage of the total points possible, using the RAND scoring table. The norm for normal response on the 8 domains of the questionnaire is as follows: Physical functioning 84.2%, Role limitation due to physical health 81.0%, Role limitation due to emotional problems 81.3%, Energy/Fatigue 60.9%, Emotional wellbeing 74.7%, Social functioning 83.3%, Pain 75.2% and General Health 72.0% [17]. This instrument is widely used and has indicated sufficient validity and reliability as reported by Kelly et al. [18].

2.2.4 Barthel Index scale

The Barthel index scale was developed to measure patient's performance in activities of daily living [19]. This tool determines the level of functional/activity limitation in patients. It consists of 10 items describing activity of daily living and mobility. These include feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility and stairs. Scores of 0-20 indicate 'total' dependency, 21-60 'severe' dependency, 61-90 'moderate' dependency and 91-99 indicates 'slight' dependency [20]. The Ability Scale of this tool has satisfactory test-retest reliability and sufficient responsiveness for patients with stroke [21]. It was used in this study to assess the level of independence of the stroke survivors.

2.3 Procedure

The study was approved by The Committee on Human Research Publication and Ethics (CHRPE/RC/140/16) of the School of Medical Sciences, Kwame Nkrumah University of Science and Technology Kumasi and the KATH, Kumasi. Permission was sought and obtained from the Head of the Physiotherapy Department. Accompanied by a consent form and information sheet explaining the rationale of the study, the questionnaires were administered by a trained research assistant to participants who consented to voluntarily participate. The questionnaires were administered to all the 60 recruited participants during a normal treatment appointment day before they commenced treatment for the day. It took approximately 30

minutes for the stroke survivors and their caregivers to complete copies of the questionnaires.

2.4 Data Analysis

All the data were analyzed using Statistical Package for Social Science (SPSS) version 20.0 and Microsoft excel (2010). Descriptive data were presented with mean, standard deviation and frequencies. Chi square test and Multiple Logistics Regression analysis were used to test the associations between the variables at 0.05 alpha level of significance.

3. RESULTS AND DISCUSSION

3.1 Results

3.1.1 Socio-Demographic Characteristics of the Caregivers

A total of sixty (60) stroke survivors and their caregivers who met the inclusion criteria were recruited for the study out of which 39 (65.0%) were females. Majority of the caregivers were in the age group 31-40 years. Twenty three (38.3%) of the caregivers had up to basic education level as shown in Fig. 1. The results indicated that 36 (60.0%) of the caregivers were married, 22 (36.7%) were single and only 2 (3.3%) were divorced. Regarding their employment status, the results showed that 41 (68.3%) were employed out of which 25 (61.5%) were involved in blue collar jobs and 16 (39.0%) in white collar jobs. With regards to the relation to the patients, 16 (26.7%) were wives whilst 13 (21.7%) were daughters of the patients. The results indicated

that as many as 31 (51.7%) have been giving care within four months as shown in Fig. 2.

3.1.2 Caregivers' Strain

Considering the burden of the caregivers, findings from our study indicated that stroke caregivers experience high burden in the process of caring for stroke survivors with a mean score of 9 ± 3 on the caregiver's strain index. Majority of the caregivers 54 (90%) indicated that caregiving is confining and there has been other demands on their time. Thirty three (55.0%) responded negatively to the question my sleep is disturbed as shown in Table 1. Majority of the caregivers 46 (76.7%) indicated that they experienced severe strain whilst a small proportion 14 (23.3%) indicated that they were under less strain.

3.1.3 Health-related quality of life

The results showed that an overwhelming number 56 (93.3%), of the caregivers had role limitation due to physical health. A significant number 55(91.7%), of the caregivers indicated that they had role limitations due to emotional problems. The general health of majority of the caregivers 44 (73.3%), was normal as shown in Table 2.

3.1.4 Functional limitation among the stroke survivors

The results indicated that as many as 25(41.7%) had severe functional limitations and 9 (15.0%) had total functional limitations as shown in above Fig. 3.

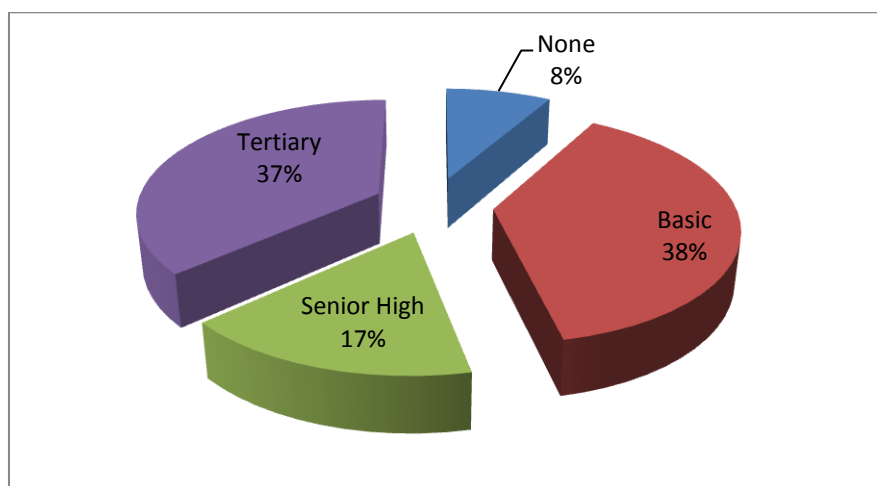


Fig. 1. Frequency of the educational background of the caregivers

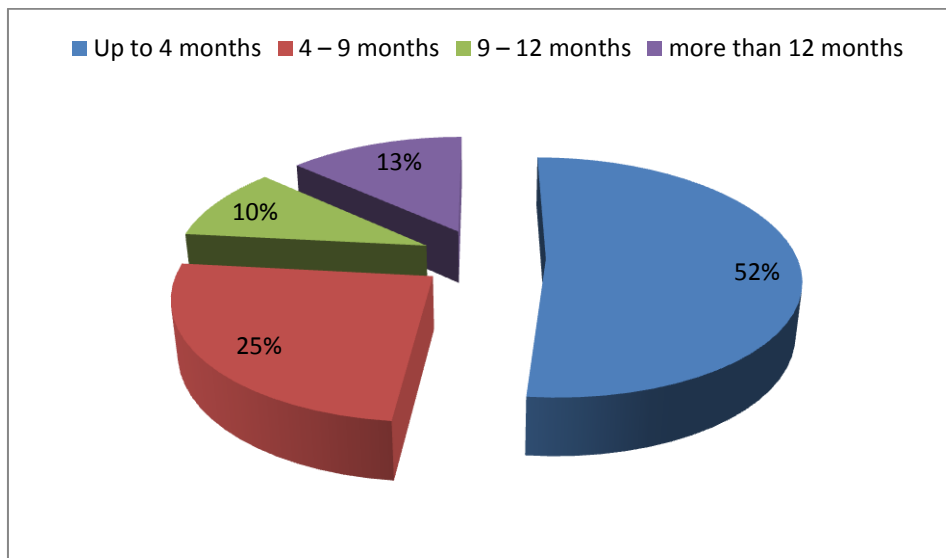


Fig. 2. Frequency of the duration of caregiving

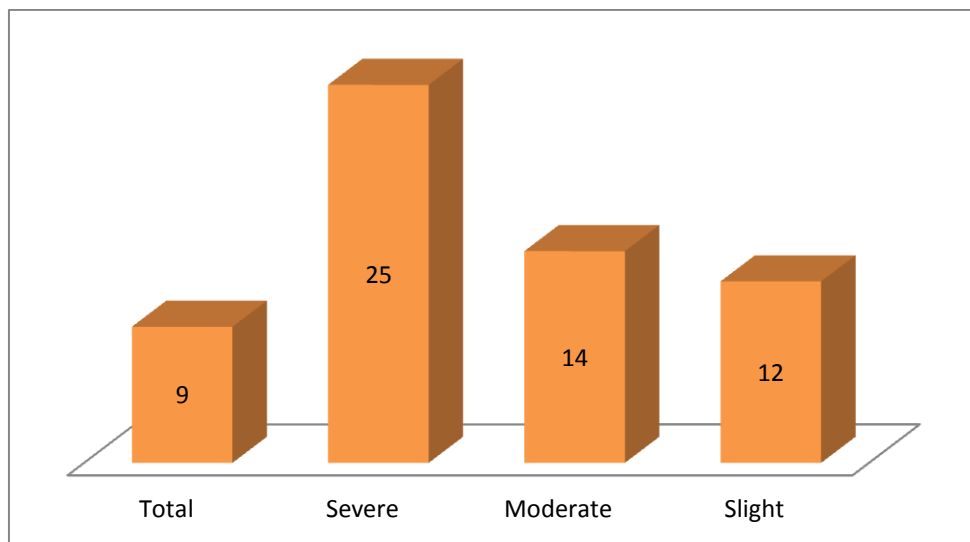


Fig. 3. Level of activity /functional limitations experienced by stroke survivors

3.1.5 Associations of the selected variables with burdens of care and quality of life

Chi square was performed to test the associations among the variables at $p < 0.05$. There was significant association between the strain experienced by the caregivers and the functional limitation of the stroke survivors ($p = 0.028$) as shown in Table 3. Similarly, sex of the participants was significantly associated with their physical functioning ($p = 0.011$), Energy/fatigue ($p = 0.02$) and emotional wellbeing (0.002). There were also significant associations of employment status with physical functioning ($p = 0.046$), and role limitation due to emotional problems ($p = 0.02$). Results are presented in

Table 4. Multiple Logistic Regression analysis was performed to find the association between the caregiver’s burden and the eight domains of the QoL as shown in Table 5.

3.2 Discussion

This is the first attempt to determine the factors that significantly impacts on the caregivers’ burden and their quality of life in the process of caring for stroke survivors in Ghana. A greater number of the caregivers in this study were females 39(65.0%), which agrees with studies by Morimoto et al. [9], Heuvel et al. [22], McCullagh et al. [23], McCusker et al. [24] Hassan et al, [25]. However, studies by Akosile et al, [26] and

Ogunlana et al. [27] reported otherwise. Culturally, the former findings corroborate the norms in Ghanaian society where men are supposedly the bread winners of the family thereby conceding other domestic affairs to the women including caring for the sick. The caregivers were also comparatively younger than those reported in the previous studies by Morimoto et al. [9], Heuvel et al. [22], McCullagh et al. [23] and Hassan et al, [25]. This is not surprising as the majority of the caregivers 23(38.3%) in this study were children of the stroke survivors contrary to the other studies which indicated spouses as the majority of the caregivers. Regarding caregivers' employment status, 41(68.3%) were gainfully employed. However, majority (56.67%) of the stroke survivors had severe to total functional limitations which raises question as to how they were able to cope with the care of their family members who were stroke survivors. Two major factors might have accounted for this result. On one hand, 25(61.5%) of the caregivers were self-employed, thus they could manage their work with the caregiving. On the other hand, the Ghanaian society permits an extended family system whereby most survivors could live with their extended family members. The present findings have partly attested to the norms of the Ghanaian culture. In this regard, the extended family members provided assistance when the principal caregivers were at work. This corroborates the findings of Ogunlana et al. [27] where an overwhelming number (72.2%) of the caregivers were employed, yet the gesture of care was still in place. On another dimension, a study by Hassan et al, [25] reported that 19% of the caregivers had to resign from employment to be able to provide the necessary care giving required by their family members.

Table 1. Participants' responses on Caregiver Strain Index

CSI Items	Positive response N(%)
Disturbed sleep	27(45.0)
Inconvenient	36(60.0)
Physical strain	49(81.7)
Caregiving is confining	54(90)
Family adjustment	28(46.7)
Changes in personal plans	49(81.7)
Time demands	54(90.0)
Emotional adjustment	35(59.3)
Behaviour is upsetting	33(55.0)
Person has changed	27(45.0)
Work adjustment	47(78.3)
Financial strain	47(78.3)
Completely Overwhelmed	42(70.0)

Table 2. Participants' responses on RAND SF 36

Dimension of RAND SF 36	N(%)
Physical functioning	
Normal	42(70.0%)
Abnormal	18(30.0%)
Role limitation due to physical health	
Normal	4(6.7%)
Abnormal	56(93.3%)
Role limitation due to emotional problems	
Normal	5(8.3%)
Abnormal	55(91.7%)
Energy/Fatigue	
Normal	25(41.7%)
Abnormal	35(58.3%)
Emotional wellbeing	
Normal	24(40.0%)
Abnormal	36(60.0%)
Social functioning	
Normal	11(18.3%)
Abnormal	49(81.7%)
Pain	
Normal	22(36.7%)
Abnormal	38(63.3%)
General Health	
Normal	44(73.3%)
Abnormal	16(26.7%)

Table 3. Chi square analysis of the associations of the participants' socio demographic profile and level of survivors' disability with burden of care

Caregiver's strain variable	chi-square	p-value
Disability level	9.07	0.03
Sex	0.00	0.95
Age	5.89	0.20
Educational level	1.99	0.58
Marital status	3.59	0.17
Employment status	0.50	0.48
Duration of care	1.56	0.67
Relation to patient	7.44	0.11

3.2.1 Associations of the socio demographic profile and level of survivors' disability with burden of care

Age, marital status, education level, and the duration of caring for the survivors were largely not significantly associated with the burden of care experienced by the caregivers. Although few studies have reported meaningful association between burden and some socio-demographic characteristics such as age, sex and employment, there are still conflicting views which might be due to varying cultural impacts and possibly the usage of different research tools

[9,27]. For instance, a study by Morimoto et al. [9] reported that wives experienced higher burden in the process of giving care to stroke survivors than any other group of caregivers. Contrary to this, studies conducted in the Sub Saharan Africa indicated that being a female

caregiver has no significant influence on the burden. This they ascribed to culture, in the sense that African women are brought up to accept caring for relatives and as such considers caregiving as basic and normal role [26,27].

Table 4. Chi square analysis of the associations of the participants' socio demographic profile and level of survivors' functional limitation with their quality of life

QoL domains	Functional limitation	Sex	Age	Educational level	Marital status	Employment status	Duration of care	relation to patient
Physical functioning								
Chi square	3.16	6.45	5.46	1.04	2.05	3.99	1.33	6.86
p-value	0.37	0.01*	0.24	0.8	0.36	0.046*	0.72	0.14
Role limitation due to physical health								
Chi square	1.21	0.18	1.75	0.94	0.42	0.66	0.86	2.33
p-value	0.79	0.66	0.78	0.81	0.81	0.42	0.83	0.68
Role limitation due to emotional problem								
Chi square	2.99	1.49	4.81	2.73	4.43	5.89	2.17	16.45
p-value	0.39	0.22	0.31	0.44	0.11	0.02*	0.54	0.002*
Energy/Fatigue								
Chi square	2.81	5.44	1.07	7.69	2.17	0.002	0.24	5.94
p-value	0.42	0.02*	0.9	0.06	0.34	0.96	0.97	0.2
Emotional wellbeing								
Chi square	1.20	9.57	1.17	4.92	0.58	0.82	1.73	1.21
p-value	0.75	0.002*	0.88	0.18	0.78	0.36	0.63	0.88
Social functioning								
Chi square	0.47	1.67	2.31	0.04	4.38	1.13	2.75	9.12
p-value	0.93	0.2	0.68	0.99	0.11	0.29	0.43	0.06
Pain								
Chi square	3.63	0.03	6.47	3.73	8.15	1.37	3.08	5.81
p-value	0.31	0.87	0.17	0.29	0.02*	0.24	0.38	0.21
General Health								
Chi square	4.57	0.60	5.93	1.02	0.61	3.39	2.97	0.40
p-value	0.21	0.81	0.21	0.8	0.74	0.07	0.4	0.98

Table 5. Multiple Logistics Regression analysis of the associations between Burden of care and QoL

	Coefficient	Odds ratio	95% C.I. for OR		p-value
			Lower	Upper	
Physical functioning	-0.63	0.53	0.09	3.17	0.489
Role limitation due to physical health	0.56	1.76	0.11	29.36	0.694
Role limitation due to emotional problems	1.03	2.80	0.28	28.07	0.382
Energy/fatigue	1.54	4.64	0.81	26.58	0.085
Emotional wellbeing	-1.79	0.17	0.02	1.13	0.066
Social functional	0.54	1.71	0.32	9.14	0.528
Pain	1.42	4.13	0.88	19.48	0.073
General health	1.43	4.17	0.35	49.10	0.256
Constant	-1.13	0.32			0.463

Notable in our study is the fact that, there was a significant association between the burden experienced by the caregiver and the functional limitation of the stroke survivor. This implies that the higher the functional limitation of the stroke survivor, the more burden experienced by them occasioned by the increased level of assistance to be rendered. It presupposes that the functional limitation of the stroke survivor is the major determining factor of the burden experienced by the caregiver rather than the caregiver's socio demographics in this study. This is similar to the findings of Choi-Kwon et al. [10], McCullagh et al. [23] and Hung et al. [28].

3.2.2 Association of the participants' socio demographic profile and level of survivors' disability with their quality of life

There was a significant association between sex and energy level and emotional problems components of SF36. Furthermore, female participants depict more significant association than their male counterparts in the domain of physical functioning. This is not unexpected, because in Ghanaian cultural context, the expression of emotions and strength is largely influenced by the sex of the individual. This submission is similar to a study by Ogunlana et al. [27]. Indeed caring for stroke survivors has been established to exert burden on the caregivers. It is therefore expedient to investigate extraneous activities that might influence the QoL.

One of the most interesting findings in our study was the fact that there was a significant association between the relation of the caregiver to the stroke survivor with the QoL of the caregivers. Thus being a spouse, a child, a parent or other distant relation to the stroke survivor could influence the QoL of the caregiver. We also realized that marital status influenced caregivers QoL as there was a significant association between the marital status of the caregiver and QoL particularly with pain.

3.2.3 Association between Burden of care and QoL

All the eight domains of the QoL were not significantly associated with the burden of care. Contrary to this, findings by Akosile et al, [26] and Ogunlana et al. [27] indicated that increased burden has a negative impact on the QoL. The difference in the results could be due to

caregivers in this study being relatively younger and assumed to have relatively better QoL than the older ones reported in the other studies. Moreover, the differences in the statistical tool used could account for this.

4. CONCLUSION

According to this study the functional limitation of a stroke survivor is the single major determining clinical factor of the burden experienced by the caregiver. Also sex, employment status, relationship to patient, and marital status of the caregiver are important factors that influence the QoL of the caregivers.

Findings from this study could support the advocacy regarding interventional therapy to reduce caregiver burden and improve caregiver quality of life. For example, technical input such as proper transfer techniques should be taught thoroughly to reduce musculoskeletal disorders that might have resulted in the fatigue and pain experienced by the caregivers. This calls for the formation of stroke support groups.

ACKNOWLEDGEMENT

This research was partly funded by StrokeAid Foundation. The sponsors were not involved in the study in any way.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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