

Quality of Life Among Caregivers of Stroke Survivors in Accra, Ghana

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Abstract

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Background: The impact of stroke on the quality of life of stroke caregivers is often given lower priority in its management, regardless of the consequences of caregiving and its economic benefits to the patient and community at large. Currently there is paucity of research data on quality of life among caregivers of stroke survivors in Ghana. Objective: To investigate the quality of life (QoL) among caregivers of stroke survivors.

Methods: Fifty stroke survivors and their caregivers attending physiotherapy at Korle-Bu Teaching Hospital, Accra and fifty non-caregivers were purposively recruited for this cross-sectional study. World Health Organization Quality of Life Scale (WHOQoL)-Bref was used to obtain information regarding the QoL of the caregivers and non-caregivers. The level of functional independence of the stroke survivors was assessed with Barthel Index. Independent t-test and unpaired t-test were used to analyse the data obtained.

Results: The mean age of the caregivers, stroke survivors and the non-caregivers were 41.6±14.2, 59.5±10.9, and 41.5±14.8 respectively. Out of the 50 caregivers, 31(62%) were females. The overall QoL of the caregivers and non-caregivers were 54.5±10.3 and 59.3±9.8 respectively. There was significant difference in the physical health between caregivers and non-caregivers.

Conclusion: Caregivers of stroke survivors in Accra have reduced QoL. The level of functional independence of the stroke survivor, age and educational status of the caregiver can influence caregivers' QoL.

Keywords: Stroke, caregivers, stroke survivors, quality of life, non-caregiver

Introduction

There is a reported increase in the incidence of stroke with high burden especially in developing countries [1,2]. In recent years, because of improved health care systems, which have reduced stroke mortality, there has been significant increase in the prevalence of stroke survivors [3]. Due to the chronic and debilitating nature of stroke, survivors will have to undergo rehabilitation for a long time depending on the severity of the condition [4]. Some of these survivors will have permanent disability and might be functionally dependent [4]. They will therefore require the assistance of caregivers to perform most if not all of their basic daily activities.

In developed countries, most of these stroke survivors are sent to rehabilitation homes to be catered for by professionals [5]. However, in developing countries like Ghana where there is scarcity of such facilities, family members assume the role of primary caregivers [6]. These caregivers provide physical, financial, social and emotional support and are also required to continue the rehabilitation process at home as there has been sufficient evidence that such gestures increase post stroke recovery and function [6,7]. This sudden additional duty of giving care, coupled with the fact that these caregivers are inexperienced and have no technical training in caregiving can be stressful [8]. This may increase their daily tasks and body demands thereby causing wear and tear of the body leading to body pains, tiredness and illness, which might affect caregivers' QoL.

Quality of life, according to the World Health Organisation [9] is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment [10, 11].

Recent studies have repeatedly reported negative impact of stroke on caregivers' health, including feelings of burden and depression, particularly for caregivers of

patients with significant impairments [6,7, 12]. Quality of life among caregivers has adversely been found to be influenced by several factors including physical and emotional burdens related to patients' functional status, changes in social relationships, satisfaction with service provision as well as caregivers' age, gender, economic status and their appraisal to cope [6,7,8 12].

The impact of stroke on the QoL of caregivers is often given low priority in the management of stroke, regardless of the physical, psychological and social consequences of caregiving and its economic benefit to the society [13]. Despite the sparsely documented data on caregivers' QoL in the western world and some parts of Africa, most of the studies did not compare the QoL with apparently healthy non-caregivers with similar socio-demographic characteristics to ascertain the true state of caregivers QoL.

This study, therefore, sought to investigate the QoL among caregivers of stroke survivors in Ghana and compare with non-caregivers.

Materials and Methods

This cross-sectional study included 50 stroke survivors and their caregivers who attend physiotherapy treatment at Korle-Bu Teaching Hospital, and 50 non-caregivers within the Accra Metropolis. Korle-Bu Teaching Hospital has a bed capacity of 1600, is the largest hospital in Ghana located in Accra, the capital city of Ghana. Caregivers who have provided care for a minimum of one month, first episode stroke survivors and apparently healthy non-caregivers with similar socio demographic characteristics of the caregivers were purposively recruited for this study. The study excluded stroke survivors with recurrent attacks, caregivers and non-caregivers who had a history of chronic diseases, cognitive or communication impairments.

Ethics approval was sought and obtained from the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences, College of Health Sciences, University of Ghana. Appropriate permissions and consent were also sought and obtained before the commencement of the study. The questionnaires were administered to the

stroke survivors and their caregivers during their treatment appointment days prior to treatment.

A data capturing form designed by the researchers was used to obtain information on participants' socio-demographic variables (age, sex, marital status, employment and educational status). The Barthels' index scale (which examines a variety of activities of daily living (ADLs) and household mobility activities to assess a patient's self-care ability) was used to measure the level of functional independence of stroke survivors. The Barthels' index consists of 10 items (feeding, moving from wheelchair to bed and return, grooming, transferring to and from toilet). The maximum score is 100, indicating that the patient is independent with mobility and self-care activities. A score of 75 to 90 indicates a mild disability and 50 to 70 indicates moderate disability. Twenty-five (25) to 45 indicates severe disability, and a score of less than 20 indicates very severe disability [14]. To assess the subjective QoL of caregivers and non-caregivers, the World Health Organization Quality of Life Scale (WHOQoL) – Bref was used. This is a 26-item self-administered generic questionnaire, a short version of the WHOQoL –100 scales. It took approximately 20 minutes to complete the questionnaires.

Data obtained from the participants were entered into the Statistical Package for Social Sciences (SPSS) version 20 software. The data was summarized using descriptive statistics of mean, standard deviation and percentage. Comparison of the QoL domain scores and the total QoL scores of caregivers and non-caregivers were tested for differences using independent t-test. Unpaired t-test was used for the effect of gender, employment and educational status separately on the overall QoL of the stroke caregivers. Pearson's correlation test was used for the association between the overall QoL score and patients and caregivers' social demographic data, duration of stroke, duration of caregiving and the Barthels' index scores measured. P value <0.05 was considered as statistically significant.

Results

A total of 150 participants made up of 50 stroke survivors' caregivers, 50 stroke survivors and 50 non-caregivers with similar socio-demographic characteristics living in the

Accra metropolis participated in this study. The demographic characteristics of the participants are presented in Table 1.

Variables	Caregivers (n=50)	Stroke survivors (n=50)	Control group (n=50)
Age			
Range	19-69	36-85	18-71
Mean± SD	41.62±14.23	59.46±10.92	41.52±14.81
Variables	Number (%)	Number (%)	Number (%)
Gender			
Male	19(38)	26(52)	22(44)
Female	31(62)	24(48)	28(56)
Marital status			
Single	13(26)	1(2)	19(38)
Married	34(68)	38(76)	25(50)
Divorced	2(4)	5(10)	4(8)
Widowed	1(2)	6(12)	2(4)
Educational level			
None at all	1(2)	2(4)	2(4)
Primary school	1(2)	3(6)	4(8)
Junior high sch.	13(26)	17(34)	11(22)
Senior high sch.	16(32)	7(14)	12(24)
College/university	18(36)	19(38)	20(40)
Post-graduate	1(2)	2(2)	1(2)
Employment status			
Unemployed	13(26)	10(20)	17(34)
Self-employed	18(36)	15(30)	15(30)
Employed	14(28)	12(24)	16(32)
Pensioner	3(6)	9(18)	1(2)
House wife	2(4)	4(8)	1(2)

The means of the duration of stroke and caregiving were 9.83±10.26 and 8.33±9.26 months respectively with the same range (from one to 48 months). The level of functional independence yielded a mean of 70.20±14 from a range of 40-95 on the Barthel's index scale. Table 2 shows comparison of the overall QoL and its domains scores of the caregivers and non-caregivers. The mean of the overall QoL was 54.51±10.21 for the caregivers and 59.30±9.76 for the non-caregivers. The non-caregivers exhibited higher QoL in all the four main domains. There was significant difference (p = 0.001) in physical health between the caregivers and non-caregivers. There was significant association (p value=0.018) of QoL between caregivers and non-caregivers.

The comparison of the socio-demographic variables of caregivers and strokes survivors and their effect on the quality of life of the caregivers are shown in Table 3. Each variable was subdivided into two making it possible to compare their means using independent t-test. There was a significant difference between older and younger caregivers QoL scores (p = 0.004) but no significant difference in the QoL between male and female caregivers (p = 0.106).

The result shows a strong association between caregivers' overall quality of life and

the level of functional independence of the stroke survivors (p value =0.001). Caregivers' age was also found to be statistically related with the overall quality of life ($p=0.016$) as shown in Table 4.

Table 2: Comparison of QoL scores between the Study and Control groups

OVERALL QOL / DOMAINS SCORES	STUDY (n = 50)	CONTROL(n=50)	t-test	p-value
	MEAN±SD	MEAN±SD		
Physical Health	49.79±10.95	57.29±10.90	3.427	0.001*
Psychological Health	58.92±11.00	62.81±12.28	1.671	0.098
Social Relationship	56.27±17.10	61.66±16.49	1.604	0.122
Environment	52.75±14.60	55.43±12.76	0.976	0.331
Overall QOL	54.51±10.21	59.30±9.76	2.398	0.018*

Table 3: The effect of socio-demographic variables on the overall quality of life scores of caregivers of stroke survivors

VARIABLES	GROUPS		Df
AGE	Youth (n=23)	Adult (n=27)	
Mean± SD (years)	58.59±8.01	49.16±13.42	43
GENDER	Male (n=19)	Female (n=31)	
Mean± SD	57.22±7.29	52.85±11.43	47
EDUCATIONAL STATUS	Pre university(n=31)	University (n=19)	
Mean± SD	51.24±9.79	59.84±8.69	41
EMPLOYMENT STATUS	Unemployed (n=23)	Employed (n=31)	
Mean± SD	54.10±10.00	54.82±10.45	39
LEVEL OF FI (BI)	Low =BI<70 (n=29)	High=BI> 7(n=21)	
Mean± SD	51.10 ±9.91	59.22±8.81	48
MARITAL STATUS	Single (n=16)	Married (n=34)	
Mean± SD	56.78±8.36	53.44±10.90	37

Table 4: Correlation between age, duration, functional independence and QoL (n=50)

OVERALL OQOL/ VARIABLES		Care givers' age	Stroke survivors' age	Duration of stroke	Duration of care giving	Functional independence (BI Scores)
OQOL	r	0.338	0.085	0.008	0.135	0.473
	p	0.016	0.557	0.557	0.350	0.001*

Discussion

Results obtained in this study indicate that stroke survivors' mean age, is below the approved retirement age of 60 in Ghana. This means majority of the stroke survivors in this study, are within the working age bracket, which in turn affects national productivity and invariably development of the country, because these people live with various forms of disability. This outcome is similar to outcomes of Donkor *et al*, [15] who reported a mean age of 58 years for Ghana. Additionally, Nketia-Kyere *et al* [16] reported that majority of the stroke survivors in Ghana were between the ages 50-59 years. On the contrary McCullagh *et al* [8] and Lima *et al* [17] reported a mean age of 74 and 62 years respectively for studies done in Brazil.

Globally, gender is considered a risk factor of stroke. However, there appears to be inconsistency indicating which gender is at a higher risk across countries. This study showed that more males were at higher risk of suffering from stroke than females. Previous studies done in Ghana [15, 16], United Kingdom [8] and Brazil [17] corroborates this finding. However, other studies [18, 19] reported that females were at a higher risk than male. On the other hand, studies by Emdin *et al* [20], Van Staa *et al* [21], and Friberg *et al* [22] reported equal risk for male and female. Considering the fact that in Ghana women are considered the managers of the home including taking care of the sick and elderly, it was not surprising that majority of the caregivers in this study were females. Previous studies by Boakye *et al* [6], McCullagh *et al* [8], Hassan *et al* [23], McCusker *et al* [24] also reported similar findings. However, Ogunlana *et al* [12] and Akosile [25], reported that the male caregivers were more than their female counterparts. This disparity could be due to

cultural differences in the perceived roles of males and females.

There was no significant difference between the QoL of married caregivers and single caregivers. It could be assumed that due to extra responsibilities in marriage (caring for spouses and children), caregiving may compound the caregivers' burden and hence pre-dispose married caregivers to poor QoL. On the contrary, this study did not support the assumption and could be assumed that, married caregivers developed coping abilities of caregiving due based on experiences acquired from marriage.

This study revealed that non-caregivers had higher QoL as compared to caregivers. Several reasons could be ascribed to this finding but notable among them as noted in this study is the physical demands of caregiving. The sudden additional duties of giving care coupled with the fact that these caregivers are inexperienced or not professional caregivers makes it stressful [6]. Boakye et al [6] reported that the decrease in stroke caregivers' physical health could be due to lack of technical education such as proper lifting techniques, which could be a contributory factor that lead to musculoskeletal pain experienced by the caregivers.

It was also found that non-caregivers experienced better QoL in their environment, social relationship and psychological health as compared to the caregivers. However, the difference between the QoL of the caregivers and that of the non-givers was not statistically significant. The outcomes of the social domain of this study appear inconsistent with some previous studies [26, 27], which reported a reduction in social relations of caregivers. This could be as a result of the long hours they usually spend with the patient thereby preventing them from attending social activities [6].

On the other hand, the results of this study may be a true reflection of the social relation of most caregivers due to the "multi-caregiving system" that exist in Ghana where all family members including the extended family members find it fit to support in the daily caring for relatives who become victims of any chronic disease like stroke [30]. This can influence the impact of caregiving on the primary caregiver specifically the hours, which he or she usually spends with the stroke survivor [6]. As a result, it creates avenue for

stroke survivors to participate fully in normal social activities without much confinement. This phenomenon could also explain why majority of the caregivers were employed or self-employed.

There was a significant association between QoL and age of the caregivers. It was however found that older caregivers had reduced QoL as compared to their relatively younger colleagues. This corroborates previous findings by Akosile et al, [25] Vincent et al [28] and Ogunlana *et al* [12] in similar African environments where older caregivers recorded significantly lower QoL. This could be expected as aging comes along with its own health consequences and increased responsibilities, hence combining the burden of caregiving and the challenges of ageing is expected to invariably reduce the QoL in older caregivers [31].

This study also showed that highly educated caregivers experienced better QoL than the less educated caregivers. Similar outcomes are observed from studies done by Vincent et al [28] and Fatoye *et al* [29]. This may be ascribed to the fact that, some educated caregivers have been found to be psychological prepared by seeking information on chronic conditions and applying it to their lives, thus helping them cope with stress better [32].

The level of functional independence of stroke survivors is the most likely clinical factor that will influence the QoL of caregivers as revealed by the strong associations between functional independence and QoL of the caregivers in this study. This study showed that caregivers of highly dependent stroke survivors had lower QoL as compared to their non-caregiver counter parts. It could therefore be inferred that caring for highly dependent stroke survivors will be associated with comparatively lower QoL among caregivers because much more physical demands (strength), time and patience in caring for this category of stroke survivors is invariably required.

Conclusion

The results of this study revealed that caregivers of stroke survivors in Accra have reduced QoL and caring for stroke survivors with relatively higher functional dependence can contribute to poor QoL in caregivers. Being older and less educated could also influence the QoL of caregivers. Stroke rehabilitation

specialists may therefore include strategies (such as teaching proper transfers, which may help reduce musculoskeletal disorders, which affects the physical health) in their interventions to help improve the QoL of caregivers.

Declarations

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Author contributions

JQ and FL contributed to the study design, collected and analysed data. BH, SK sourced and reviewed relevant literature. JQ, FL, BH and SK wrote and also reviewed the manuscript for important intellectual content. JQ, FL, BH and SK revised the final draft version and approved the final version of the manuscript for submission.

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