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Research Article

Caregivers' Perceptions of Burden and Health- Promoting Behaviours among Informal Caregivers of Cancer and Stroke Patients Attending Tertiary Care Facilities in South- South Nigeria

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ABSTRACT

Family caregivers' role in cancer and stroke care is overly burdensome. Studies have considered burden and predictors of burden but the influence of caregiving burden on health - promoting behaviours among cancer and stroke family caregivers in Nigeria is scarce. The purpose of this study was to determine the influence of caregivers' perceptions of burden and health-promoting behaviours on informal caregivers of cancer/ stroke patients attending tertiary care facilities in South- South Nigeria. A descriptive cross-sectional survey was employed among 410 purposively selected cancer/ stroke patients' family caregivers in tertiary care facilities, South- South Nigeria. A standardized Zarit burden interview scale and structured questionnaire were used to measure burden and determine health-promoting behaviours respectively. Descriptive (means, standard deviation and percentages) and inferential (ANOVA) statistics with a Fisher's protected t- test at 0.05 level of significance were used for data analysis. The respondents experienced severe ($F= 14.02$; $P= 0.810$) burden in caregiving to cancer/ stroke patients. The influence of health- promoting behaviours (primary, secondary and tertiary preventions) among caregivers of cancer/ stroke is significantly high in the tertiary care facilities, South-South, Nigeria. Caregivers of cancer and stroke patients experienced severe levels of burden and health-promoting-behaviours in terms of prevention at the primary, secondary and tertiary activities were significantly high among respondents. This calls for knowledge mobilization and dissemination in Nigeria and beyond.

Keywords: *Burden, Health - promoting behaviours, Cancer/stroke caregivers, Nigeria.*

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INTRODUCTION

Cancer and cardiovascular accident (stroke) remain the second leading cause of mortality and third major source of disability worldwide (Adogu, Ubajaka, Emelumadu & Alutu, 2015; Johnson, Onuma, Owolabi, & Sachdev, 2016). However, low- and middle-income countries including Nigeria disproportionately bear the burden of cancer/stroke accounting for 70% strokes mortality and 87% infirmity – attuned life expectancy years. Stroke alone has a universal annual dead toll of 5.5 million people with a rising predominant projections in unindustrialized nations due to demographic changes among populace (Vincent-Onabajo, Gayus, Masta, Ali, Gujba, Modu, & Hassan, 2018 & Owolabi et al., 2015). Other complications of stroke are peripheral neuropathy and permanent disability among 50% stroke survivors climaxing to financial and societal concerns (Adogu, et al., 2015; Donkor, 2018). The high prevalence of cancer and stroke in low- and middle-income countries

coupled with complications of disability accrue huge burden on the family members providing informal care to their love ones with cancer and stroke. (Levine, Halper, Peist & Gould, 2010; Adogu et al., 2015; Vincent-Onabajo, Gayus, Masta, Ali, Gujba, Modu, & Hassan, 2018). The chronic nature of these conditions with persistence need for ongoing assistance at the terminal phase of cancer with limited functional abilities in stroke/ cancer patients predicts higher levels of burden experienced by caregivers (Bhattacharjee, Vairale, Gawali, & Dalal, 2012, Kozier, Erb, Berman & Burker, 2005; Akpan-Idiok & Ehiemere, 2018; Holzapfel, Bosch, Lee, Pohl, Szeto, Heyer, & Ringenbach, 2019). This is pertinent given their socioeconomic background, late reporting with metastasis, shortage of manpower and inadequate health facilities. Its current treatment modalities encourage outpatient treatment which accrue more burden on family caregivers (Rha, Park, Song, Lee, & Lee, (2015). Studies reveal a significant relationship exists between functional ability and caregivers' burden as well as burden and quality of life of care recipient

(Jeong, Myong and Koo 2015; Akpan-Idiok & Ehiemere, 2018; Asuquo, Adejumo, Akpan & Akpan-Idiok, 2020; Abbasi, Mirhosseini & Ebrahim, 2020), Moreover studies reveal that caregivers characteristic and receiver dependency couple with financial status as it is obvious in low and middle income countries also affect quality of life of the caregiver (Haley, Roth, Hovater, Clay 2015; Tsai, Lou, Feng, et al., 2018).

The concept of caregiver refer to an adult who assume unpaid caregiving role to family member who is sick with chronic disease like cancer/stroke with limited abilities in performing activities of daily living both at hospital, home environment or community (Family caregivers Alliance (FCA) 2016; Akpan-Idiok & Ehiemere, 2018). Caregivers' role integrates OncoLink Team (2018) managing spiritual, emotional, physical as well as practical needs of care receiver in conjunction to managing their own needs, life and in many cases career. Care receiver needs may become enormous, tasking caregivers' resources thereby affecting physical, emotional and social wellbeing of the caregivers leading to isolation and caregivers' burden (Akpan – Idiok & Anarado, 2014; Asuquo, et al., 2013; FCA 2016). Burden is therefore the extent to which a cancer / stroke family care provider perceives physical, emotional, psychological health, social life and economic consequences that impairs one's ability to provide care. Burden of caregivers to cancer/stroke patients is assessed using the Zarit Standardized Scale (Zarit, 2006). The sudden onset of cancer/stroke invite sudden role assumption without preparation, however the protracted nature of two ailment subjects both the cancer/stroke primary caregivers to physical & physiological torture, anxiety, fatigue and many cases uncertainties about life (Akosile, Banjo, Okoye, Ibikunle & Odole, 2018; Vincent-Onabajo et al., 2018). Studies reveal disproportionate level of burden between developed and developing countries, with a skew toward family caregivers in developing countries bearing higher level of burden in cancer give giving (Akpan-Idiok et al., 2014 ; Chellappan & Rajamanikam 2016), while Litzelman et al., (2018) accentuate the same tilt among stroke caregivers. The higher levels of burden could be annex to the poor financial status of patient and poor economic condition with little or no facility equipment, linked with inadequate institutional support. Care-giving in this perspective becomes disappointing, rigorous and excessively burdensome (Gaston-Johnson, Lachica, Fall-Dickson & Kennedy, 2012; Akosile et al., 2018. Akosile, Okoye, Nwankwo, Akosile and Mbada, (2011) enumerated common caregiving challenges to include fatigue, stress poor time management and limited resources.

Caregivers as used in this study refer to an adult family member, from 20years and above, providing an unpaid – help to family member with confirmed diagnosis of cancer/stroke (within the study settings) for two months interval and above. Family, informal and primary caregivers to cancer and stroke or cancer/stroke patients are interchangeably used in current study. The need to promote health in the absence of disease becomes imperative among family caregivers who are laden with high level of stress. Health-promoting behaviours in this study refers to caregivers' primary (exercises, healthy diets, no smoking & adequate intake of alcohol), secondary (cancer & stroke screening tests) and tertiary (managing chronic

diseases) preventive behaviours during cancer and stroke caregiving trajectory. So primary prevention in current context connotes avoidance of disease; secondary prevention curbs the spread by nipping the disease on the bud. While tertiary prevention involves restoration process to reduce the disease complications during cancer/stroke family caregiving roles. The use of various health- promotion therapies in terms exercise like hiking with bicycle, feeding adequately, leisure/recreation, adequate rest and sleep are better predictors of family caregivers' health and well-being (Obiako et al., 2011; Watila et al., 2012; Holzapfel et al., 2019; Abbasi et al., 2020). Studies reveal that cancer and stroke caregiving burden could be minimized by effective utilization of the three tier-health-promotion behaviours which enhance sustainable approach to living as well as self-actualization (Aston 2002; Akosile et al., 2011;). This pioneer study was guided by two null hypotheses; and seeks to determine the influence of caregiving burden perceptions and health-promoting behaviours by adult cancer/stroke patients' family members at tertiary health facilities in the Niger-Delta region of Nigeria.

MATERIALS AND METHODS

Study Area/study population: Cross-sectional descriptive survey design was carried out among eligible 410 cancer and stroke caregivers attending University of Calabar Teaching Hospital in Calabar, Cross River State and University of Uyo Teaching Hospital in Uyo, Akwa Ibom State all in South-south Nigeria. Calabar is located at the extreme of Southern Senatorial District of Cross River State. The geographical location of Calabar urban is latitude 4°58' North and 8°17 East. It has a common boundary with the republic of Equatorial Guinea to the South, in the West, Oron Local Government Area of Akwa Ibom State, in the East, Akpabuyo Local Government Area in Cross River State and bounded by Odukpani Local Government Area in the North. This hospital serves as referral centre to other hospitals, health centres and other health institutions where cancer patients are admitted. Apart from being a referral centre, it is an embodiment of all cultural groups within and outside Nigeria. The population includes all advanced (stages iii and iv) cancer and stroke patients in the study area. The participants for the study would cut across all ethnic groups and diversified culture from within and outside the State. On the other hand, Uyo is the state capital of Akwa Ibom State. It is located in the coastal southern part of the country, lying between latitudes 4°32'N and 5°33'N, and longitudes 7°25'E and 8°25'E. The state is located in the South-South geopolitical zone, and is bordered on the east by Cross River State, on the west by Rivers State and Abia State, and on the south by the Atlantic Ocean and the southernmost tip of Cross River State. Though the state is blessed with both primary and secondary healthcare facilities, University of Uyo Teaching Hospital represents the tertiary health care facility significant in handling referral cases of infectious and chronic diseases.

Ethical perspective: The guiding principles and guidelines for international bioethical standard were strictly adhered to throughout the study. Permission to undertake this research was obtained from the Heads of the Ethical Committee of the

hospitals and informed consent gained from each informal cancer and stroke caregivers. The purpose of the research was explained to the caregivers and was assured of their right to withdraw from the study at any stage. All adult unpaid family caregivers aged 18 years and above within the study area who was willing to participate in the study took part in the study.

Sample, sampling and instrument: Using “a priori computer power analysis software (G Power 3.1.5) calculator”, 410 respondents were purposively sampled for the study. This sampling method allowed for wider coverage of the study respondents. A validated questionnaire divided into four sections namely: socio-economic characteristics, duration of care, functional levels of care receiver and health promoting behaviours were developed by the researcher. Also adopted was 22- item standardized zarit burden interview (ZBI) 5 - point Likert scale (never = 0, rarely = 1, sometimes = 2, quite frequently = 3 and nearly always = 4) for measuring caregivers' burden. The results of the perceived levels of burden of caregivers to advanced cancer/ stroke, and health promoting behaviours among caregivers of cancer/ stroke is determined by F-ratio and P- value respectively. The higher the F- ratio, the severe the influence level of burden and health promoting behaviours amongst caregivers of cancer/ stroke. On the other hand, the higher the P- value the less severe the severe the influence level of burden and health promoting behaviours amongst caregivers of cancer/ stroke. The Standardized Zarit Burden Interview (ZBI) instrument was also designed, validated and subjected to reliability test using Cronbach alpha reliability estimate. The reliability coefficient of the instrument was 0.95. This is an indication that the instrument is reliable enough to test what it was purported. The Zarit interview scale score range from 0-88. Where 0 to 20 represent trivial or no burden, 21- 40 mild burden, 41- 60 moderate burden while 61- 88 is severe burden (Zarit, 2004). The higher the score, the higher the experience of burden among cancer/ stroke caregivers and vice versa. The instrument was made culturally sensitive by translating into Efik and retranslated into English to ensure that no meaning was lost.

Method of data analysis

Analysis of data was carried out using computer software Statistical Package for the Social Sciences (SPSS) version 21.0. Descriptive statistics (means, standard deviation and percentages) and one way analysis of variance (ANOVA) were used for data analysis.

RESULTS

Socio-economic characteristics of informal caregivers of cancer/stroke patients: Table 1 shows that the informal caregivers were more of female 264 (64.39%) and male 146 (35.61%). In the age category, youths between the age of 36-40 were 162 (39.51%) that are within the active economic bracket with mean age of 42.3 ± 19.3, 30-35 years were 135 (32.93%), 41-45 years 83 (20.24%) and 46/ above were 30 equivalent to 7.32%. On religion Christians were 296 (72.20%), Muslims 104 (25.37%) and other religion 10 (2.44%). Data for marital status showed that married

caregivers were 284 (69.27%), single 103 (25.12), divorced 20 (4.88%) and others 3 (0.73%). Educational qualification showed that caregivers with primary education were 152 (37.07%), followed by tertiary 145 (35.37%), secondary education were 106 (25.85%) and no formal education were 7 (1.71%). Caregivers' occupation showed that civil/ public servant dominated with 132 (32.20%), followed by farmers 90 (21.95), not employed were 82 (20.00%), self- employed 59 (14.39%), student/ apprentice 40 (9.76%) and retiree 7 (1.71%). Data on relationship to care receiver was dominated by sibling 196 (47.80%), followed by parent 100 (24.39%), spouse / partner were 86 (20.98) while friend and member of same religion were 14 each which is equivalent to 3.41 each

Table 1:
Socio-demographic characteristics of informal care givers

Characteristics	Frequency	Percentage	
Gender	Male	146	35.61
	Female	264	64.39
Age	30-35 years	135	32.93
	36-40 years	162	39.51
	41-45 years	83	20.24
	46/above	30	7.32
	Mean	42.3 (SD ± 19.3)	
Religion	Christianity	296	72.20
	Muslim	104	25.37
	Others	10	2.44
Marital Status	Married	284	69.27
	Single	103	25.12
	Divorced	20	4.88
Educational qualification	Others	3	0.73
	No Formal education	7	1.71
	Primary	152	37.07
	Secondary	106	25.85
Occupation/ Work Status	Tertiary	145	35.37
	Self- employed	59	14.39
	Not employed	82	20.00
	Farmer	90	21.95
	Civil/ public servant	132	32.20
	Retiree	7	1.71
	Student/ apprentice	40	9.76
Relationships to care receiver	Sibling	196	47.80
	Friend	14	3.41
	Spouse/partner	86	20.98
	Parent	100	24.39
Member of religion	14	3.41	

Perceived levels of burden of caregivers to advanced cancer/ stroke patients: The result of analysis presented in Table 2 shows that the perceived level of burden of caregivers to advanced cancer/ stroke patients is severe (F= 14.02; P= 0.810). Since the F- ratio (F= 14.02) is greater than the P-

value (P=0.810) at the 0.05 level of significance, it implies that the burden of caregivers to advanced cancer/ stroke patients is very severe in the tertiary care facilities in South- South Nigeria.

Table 2: Perceived influence on levels of burden of caregivers to advanced cancer/ stroke (n= 410)

Perceived influence on levels of burden	N	\bar{x}	SD		
Trivial or no burden	182	18.03	3.72		
Moderate burden	96	16.92	4.37		
Severe burden	132	18.43	5.56		
Source of variance	SS	df	MS	F-ratio	P-value
Between groups	82.025	3	18.892	14.02*	.810
Within groups	16627.517	406	52.062		
Total	16709.542	409			

Significance at the 0.05 level of significance
 F- ratio- Calculated result; P-value- Table value
 Therefore, the F-ratio and P-value are predictors of the outcome. The higher the F-ratio, the severe the influence level of burden on the predictor's variable and vice versa.

Since the result of analysis of variance of the perceived influence level of burden of caregivers of advanced cancer/ stroke patients is significant, a Fisher's protected t- test analysis was used to determine where the significance difference is highest among the various levels of burden compared. The result is presented in Table 2b From the result presented in Table 2b above, the mean difference is highest at the severe burden (.2436) while the least mean difference is at the moderate burden (-1.4892) respectively.

TABLE 2b: Fisher's LSD test of the influence of the influence level of burden of caregivers to advanced cancer/ stroke patients in tertiary care facilities

Level of burden (I)	Level of burden (J)	Mean difference (I-J)	Standard error	p-value
Trivial or no burden	Moderate burden	-3.1095	.7211*	.000
	Severe burden	-4.5987	1.0828*	.000
Moderate burden	Trivial or no burden	-4.3551	1.2125*	.000
	Severe burden	-1.4892	1.1537	.198
Severe burden	Trivial or no burden	-12456	1.2762	.330
	Moderate burden	.2436	1.5103	.872

* Significant at 0.05 level of significance

Table 3: Perceived influence of health- promoting behaviours (primary, secondary and tertiary preventions) among caregivers of cancer/ stroke patients (n= 410)

Health-promoting behaviours	N	\bar{x}	SD		
Low	76	15.83	4.76		
Moderate	137	19.73	3.81		
High	196	21.69	5.73		
Source of variance	SS	df	MS	F-ratio	P-value
Between groups	1350.603	3	514.202	16.07*	.000
Within groups	1532.125	406	36.817		

Significance at the 0.05 level of significance
 F- ratio- Calculated result; P-value- Table value
 Therefore, the F-ratio and P-value are predictors of the outcome. The higher the F-ratio, the higher the influence of health-promoting behaviours the predictor's variable and vice versa.

Perceived influence of health- promoting behaviours among caregivers of cancer/ stroke patient: The result of the analysis presented in Table 3 shows that the perceived influence of health- promoting behaviours (primary, secondary and tertiary preventions) among caregivers of cancer /stroke patients is high (F= 16.07; P= 0.000). Since the F- cal of 16.07 is greater than the P- value of 0.000 at the 0.05 level of significance, it implies that the influence of health-promoting behaviours that is (primary, secondary and tertiary disease preventions) among caregivers of cancer/ stroke is significantly high in the tertiary care facilities in South- south, Nigeria.

Since the result of analysis of variance of the perceived influence of health- promoting behaviours among caregivers of cancer/ stroke is significant, a Fisher's protected t-test analysis was adopted to determine where the significance difference is highest among the various health- promoting-behaviours compared. The result is presented in Table 3B

TABLE 3b: Fisher's LSD of health-promoting-behaviours among caregivers of cancer/ stroke patients

Health - promoting behaviours (I)	Health - promoting behaviours (J)	Mean difference (I-J)	Standard error	p-value
Low	Moderate	-.47701	.71819*	.507
	High	-.22701	1.24859*	.856
Moderate	Low	-2.11987	1.80333*	.240
	High	-.30310	1.44022	.833
High	Low	.47701	.71819	.507
	Moderate	.25000	1.26112	.843

* Significant at 0.05 level of significance
 From the result presented in Table 3B above, the mean difference is highest at the high (.47701) while the least difference is at the Low (-.22701) respectively

DISCUSSION

The study showed that informal caregivers were more of female 264 (64.39%) and male 146 (35.61%). In the age category, youths between the age of 36-40 were 162 (39.51%) that are within the active economic bracket with mean age of 42.3 ± 19.3 , 30-35 years were 135 (32.93%), 41-45 years 83 (20.24%) and 46/ above were 30 equivalents to 7.32%. On religion Christians were 296 (72.20%), Muslims 104 (25.37%) and other religion 10 (2.44%). Data for marital status showed that married caregivers were 284 (69.27%), single 103 (25.12), divorced 20 (4.88%) and others 3 (0.73%). Educational qualification showed that caregivers with primary education were 152 (37.07%), followed by tertiary 145 (35.37%), secondary education were 106 (25.85%) and no formal education were 7 (1.71%). Caregivers' occupation showed that civil/ public servant dominated with 132 (32.20%), followed by farmers 90 (21.95), not employed were 82 (20.00%), self- employed 59 (14.39%), student/ apprentice 40 (9.76%) and retiree 7 (1.71%). Data on relationship to care receiver was dominated by sibling 196 (47.80%), followed by parent 100 (24.39%), spouse / partner were 86 (20.98) while friend and member of same religion were 14 each which is equivalent to 3.41. This is not in support of the study of Unnikrishnan et. al (2019) on socio-demographic characteristics of caregivers, cancer details of patients, and psychosocial burden among caregivers was collected using Zarit Burden Interview (ZBI) scale. Descriptive statistics were used to analyze the baseline data. Chi-square test was done to find out the association of burden with various socio-demographic and disease variables. A p -value of <0.05 was taken as statistically significant. The median (inter-quartile range) ZBI was 20 (10, 34). Fifty percent of the caregivers had no or minimal burden and only 2% had severe burden. Age of the caregiver was a significant determinant of their psychosocial burden. However, the result of the present study varies in a number of perspectives with that of Unnikrishnan et al.; (2019).

Data analysis on the perceived level of burden of caregivers to advanced cancer/ stroke patients revealed that the perceived level of burden is severe ($F= 14.02$; $P= 0.810$). The F -cal ($F= 14.02$) is greater than the P - value ($P=0.810$) at the 0.05 level of significance, it implies that the burden of caregivers to advanced cancer/ stroke patients is very severe in the tertiary care facilities in South- south Nigeria. This is supported by the study of Akosile et. al (2011) who maintained that the commonest of the burden experienced by the informal caregivers in both chronic diseases are stress and fatigue, poor management of time, resources and often time provocation and irritation caused by frontline medical officers in the care facilities. Some of the studies on informal caregiving in low resource settings were conducted among caregivers of cancer and stroke survivors undergoing outpatient rehabilitation whose level of burden may be different from those providing acute phase in-patient care in tertiary health institutions in Nigeria. A few comparative study on the levels of burden among cancer and stroke caregivers maintained that, there is no significant differences in the level of burden of cancer caregivers and those of stroke caregivers respectively.

The result from data analysis on the perceived influence of health-promoting behaviours (primary, secondary and tertiary preventions) among caregivers of cancer /stroke patients showed that the perceived influence of health promoting-behaviours is high ($F= 16.07$; $P= 0.000$). The F -cal of 16.07 is greater than the P - value of 0.000 at the 0.05 level of significance; this implies that the influence of health promoting behaviours (primary, secondary and tertiary preventions) among caregivers of cancer and stroke is significantly high in the tertiary care facilities in South- South, Nigeria. This shows that caregiver were educated and at active age with positive attitude to health-promoting behaviours. The result of this study is in agreement with the finding of Watila et.al (2012) who observed that one of the main reasons for the rise in cancer and stroke as a cause of death is patients' lack of knowledge of the risk factors involved. In addition, there is lack of patients' participation in the management of the disease. This participation demands motivation, knowledge and compliance from the patients since it is a complex lifetime regimen that needs to be followed. Patients who do not have knowledge of the risk factors of cancer and stroke are less likely to engage in cancer and stroke prevention practices like controlling their blood pressure, and behavioral pattern change such as smoking cessation and consuming a low-salt diet (Obiako, Oparah and Ogunniyi, 2011). The above findings is also consistent with Rha, et al (2014) who reported that cancer caregivers' burden experiences did not influence their health-promoting behaviours. Considering the shortage of advanced medical technologies for the care of cancer and stroke patients in Nigeria and the economic recession that is increasingly making healthcare services inaccessible to the predominantly poor populations across the country, it is reasonable to focus our attention on cancer and stroke prevention strategies.

This study is limited by its cross-sectional design and the use of self-report from focus group interviews with respondents about health promoting behaviours. The sampling procedure adopted by the researcher has limited the description about caregivers of cancer and stroke patients that were not part of the study. Furthermore, the use of two tertiary care facilities is responsible for the use of heterogeneous group of caregivers which enable the overall description of caregiving burden and health promoting behaviours of caregivers of cancer and stroke patients, with or without significant functional change. These to a large extent have limited the generalization of the study findings to caregivers in the study area.

In conclusion, cancer and stroke prevention practice are sub-optimal despite good knowledge of the disease's risk factors and prevention among the study participants. Being employed and having a formal education were the main predictors of having good knowledge of the risk factors and being compliant with the prevention strategies. This finding suggests the need for all stakeholders to focus on both patients' education and empowerment in halting the rising burden of stroke across the globe. The primary, secondary and tertiary care facilities should be equipped to manage health conditions like cancer and stroke patients. This way, the burden of caregivers of cancer and stroke patients will be reduced drastically.

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