Caregiving Burden among Informal Caregivers of Cancer Patients in Lagos, Nigeria

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Abstract

Purpose: The coping mechanisms adopted by cancer caregivers especially in developing countries of the world is given little attention. The aim of this study was to assess the caregiving burden and coping mechanisms among caregivers of cancer patients attending a tertiary hospital in Lagos, Nigeria.

Methods: This was a cross-sectional descriptive study. An interviewer-administered questionnaire, Zarit Burden Interview (ZBI) tool, Katz index instrument of activity, Lawton Brody tool and Brief-Coping Orientations to Problems Experienced (COPE) scale were used to collect data from 385 informal caregiver-patient dyads. The data was analyzed using the Epi Info version 7.

Results: Of the 385 caregivers in the study, 162 (42.1%) were males and 223 (57.9%) were females. Almost half (47.3%) of the caregivers had severe burden and the mean ZBI score was 39.1 ± 12.5 . Adult children caregivers (56.3%) of cancer patients reported the highest proportion of severe burden among the patients' relatives. All the respondents who had been caregivers for over a period of 12 months and those who spend at least 12 hours on caregiving role daily experienced severe burden. Almost half (46.3%) of caregivers who received no support from other people in caring for the patient reported severe burden.

Conclusion: Older caregivers experienced higher caregiving burden than their younger counterparts. Duration of caregiving was associated with level of caregiving burden experienced. Social support groups and health professional need to assist caregivers reduce the burden of caregiving to chronically ill patients in sub-Saharan Africa.

Introduction

Cancer is a leading cause of death globally, and it serves as a significant barrier to increase in life expectancy in every country of the world.¹ Worldwide an estimated 19.3 million new cases and 10 million deaths occurred in 2020.² Cancer as a chronic disease is associated with considerable, continuous, and fluctuating problems and special needs of patients.³ Nigeria has limited specialized human resources and facilities for cancer care for patients present at the late advanced stages of the disease,⁴ so the burden of caregiving rests on the family members.

Informal caregivers such as family members and friends need preparation to face the demands of their new roles and responsibilities such as helping in drugs administration, counselling, dressing, and other treatment plans all through the different phases of managing the condition.⁵ Most of the caregivers assume caregiving role without adequate training and are expected to meet up with caregiving demands without much help, and this results in negative experience of psychological worries, increasing rate of physiological illness, and social problems.⁶ Caregivers may also suffer social and economic deficits such as lifestyle disruption, less socializing, greater out-of-pocket and lost productivity.⁷ Additionally, families

of patients at end-of-life stage of the disease, caregivers face the dual obligations of providing care and beginning to process anticipatory grief.^{8,9}

Studies in the developed countries had established that informal caregivers of patients with cancer are vulnerable to all kinds of psychological (e.g., anxiety, stress, depression) and physical (e.g., burn-out, increased mortality, loss of weight, poor immune functioning, and insomnia) burden.^{10,11} However, there is little information about challenges facing the informal caregivers of patients with cancer in sub-Saharan region of Africa, Nigeria inclusive.

Caregiver burden encompasses the difficulties of the caregiver role and the associated alterations in caregivers emotional and physical health that can occur when care demands exceeds resources.¹² An area of emphasis that is underdeveloped in both descriptive research and clinical intervention delivery is coping measures adopted by family cancer caregivers. Coping has been conceptualized as changes in cognition and behavior to deal with stressful events.¹³ Coping attitudes are unique to each individual and differ on the basis of multiple factors such as gender, age, culture and disease. Caregivers of cancer patients use different coping strategies to cope with the difficulties they experience.¹⁴

A significant amount of literature on caregiving burden among caregivers of cancer patients worldwide, focused more on the nature of burden of care for professional caregivers. Very few research exists about the caregiving burden of family relatives of oncology patients.¹⁵ Also, few research has examined the effects of cancer caregivers coping strategies on key dimensions of stress, negative mental health or physical outcome. This study aimed at determining the levels and pattern of burden, as well as identified the psychosocial factors that protect cancer caregivers from a range of negative outcomes.

Methods

This was a descriptive cross-sectional study designed to assess caregiver burden and the various coping mechanism adopted by informal caregivers of cancer patient attending a tertiary institution in Lagos State. Lagos State is located in the South-western geopolitical zone of Nigeria. It was established on the 27th of May, 1967. It is located on latitude 6° 35' N and longitude 3° 45' E. The National Population Commission (NPC) of Nigeria in 2016 put the population at over 21 Million.¹⁶ This survey was carried out in one of the four tertiary health institutions in Lagos State. The facility is equipped with an appropriate range of cutting-edge treatment solutions covering chemotherapy, brachytherapy and radiotherapy. The hospital provides care for at least 5000 patients annually across various classes of cancer and different categories of adult and children.

The oncology centre operates five clinics weekly with an average of 25 patients attending per clinic day. About 5–10 new patients are registered every clinic day, and between 1200–1500 estimated cases are presented yearly at the centre. The study population comprised of unpaid adults of at least 18 years of age identified by the cancer patient as the individual who provides the most care for him/her. Caregivers

with severe functional or cognitive impairments, and caregivers of cancer patients who were also caring for other patients with chronic illnesses were excluded from the study.

A minimum sample size was calculated using the Cochran formula for proportions; $n = z^2pq/d^2$. With a 95% confidence interval and using a prevalence of 0.363 from a previous study¹⁵ and a 0.05 level of precision, a sample size of 382 was calculated and was approximated to 395. On each clinic day, caregivers who met the inclusion criteria and had given consent were recruited consecutively for the study till the sample size was reached.

The study was conducted using an interviewer-administered questionnaire. The questionnaire was made up of seven sections namely: Socio-demographic and socio-economic characteristics of the caregivers and the patients; description of caregiving role, determination of caregiver burden using Zarit Burden Interview 22 (ZBI 22), determination of functional ability of patients using Katz Activities of Daily Living (ADL) and Lawton-Brody Instrumental Activities of Daily Living (IADL) and determination of coping mechanisms using Brief- Coping Orientations to Problems Experienced (COPE). The pre-tested and corrected questionnaires were administered to the respondents by the researcher and her trained assistants at an appropriate time during the clinic days. The data was collected from 385 caregivers and analyzed using EPI Info. Version 7.

Measures

Caregivers' burden was assessed by Zarit Burden Interview 22 tool (ZBI). ZBI is a 22 item instrument measured on a 5-point Scale option as 0 = never, 1 = rarely, 2 = sometimes, 3 = frequently and 4 = nearly always. The scores were categorized as follows: Scores 0–20 indicate 'no to mild burden', scores 21–40 indicate 'moderate burden', and scores Scores ≥ 41 indicate 'severe burden'.¹⁷

Functional status was assessed using the katz ADL and Lawton Brody LADL tool. The Katz index of independence in Activities of Daily living comprises of 6 basic activities items (bathing, dressing, toileting, transferring, continence and feeding) on two scales of no supervision. Independence = 1 point and dependence with supervision = 0 point. The sum of a total score of 6 = high (patient independent), 0 = low (patient dependent).¹⁸

The Lawton-Brody instrumental activity of daily living scale made up of 8 items. The item description that most closely resembles the patient's functional level (either 0 or 1) is circled. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women and 0 through 5 for men to avoid potential gender bias.¹⁹

The Brief-COPE was used to compute the coping mechanisms, and it comprised of 28 items, grouped into 14 scales of coping strategies. Respondents rated the degree of how much or how frequently to which they use each coping strategy to deal with a particular stressful event on a 4-point scale that ranges from "1 = I haven't been doing this at all to 4 = I have been doing this a lot." Total scores on each scale are

calculated by summing the appropriate items for each scale. There is no overall total score, only total scores for each of the scales.²⁰

The results of the analysis were presented in frequency tables and Chi-square test was used to test the association at 5% (0.05) significance.

Results

The eligible participants (caregiver-patient dyad) recruited into the survey were 395, but only 385 completed the survey. About two-thirds (69.4%) of the caregivers were aged between 19 and 40 years with the median age of 35 ± 10.3 years. The predominant gender was female (57.9%), more than half were married (56.6%) and 68.8% were christians. Majority of the caregivers (87.3%) had at least secondary education, with 34.5% as self-employed and 40% unemployed. (Table 1)

The median age of patients was 48 ± 15.84 years with the youngest at 6 and the oldest being 80 years of age. More than half (59.0%) were females, and married (55.8%). Three-quarter of the patients (75.6%) had a minimum of secondary school education and were currently unemployed (35.6%). (Table 1)

Table 2 revealed that a third (34.6%) of the caregivers were parents to the patient, 15.8% were spouses, 24.2% siblings, 8.3% were children, while 17.1% were other relatives including friends, colleagues, neighbors or share the same religious faith with the patient. Almost two-third (64.4%) of the caregivers shared the same home with the patients and 13.9% had been caregivers for over 12 months spending an average of 6 ± 5.80 hours on caregiving daily. More than half (64.2%) of the caregivers were adequately informed about the patient's care requirement and 40.3% reported that they had received training to meet the care requirements of the patients. Half of caregivers (50.7%) always provided the patient with constant help, while 77.4% had other people support them in caring for the patient. Some (27.0%) caregivers providing care for the cancer patient were suffering a chronic disease.

The distribution of mean and standard deviation of caregiver's responses to the Zarit Burden interview were depicted in Table 3. The subscales of the ZBI were as follows: Relationship burden (10.97 ± 3.86), Emotional burden (11.56 ± 5.39), social (6.22 ± 3.13), loss of control of one's life, (7.78 ± 2.62), and financial burden (2.30 ± 1.08). Among caregivers, the overall burden of taking care of a sick relative was 2.01. The burden score of feeling angry when around the patient was the least mean ZBI score of 1.18 ± 1.15 , next to it is the feeling of being embarrassed about the relative's behavior (1.29 ± 1.18), followed by caregiving role currently affecting relationship with other family members or friends in a negative way (1.43 ± 1.11). The highest mean ZBI scores was feeling of wanting to do more for your relative (2.33 ± 1.10). This is followed by feeling to provide higher quality care for the patient. Financial burden (Not having enough money to take care of relative in addition to other expenses) was the highest form of burden with a mean score of 2.30. This is followed by the fear of what the future holds (2.26). This table also revealed that stress about caring for the patient and trying to fulfill other responsibilities for family or work, lack of privacy and loss of one's control over life since patient's was diagnosed have the same

mean scores of 1.70 with SD of 1.06, 1.12 and 1.11 respectively. The uncomfortable feeling of having friends around was the least burden (1.43) in the social domain. According to the Zarit burden category, the grading of caregiver burden was in three levels. It was observed that almost half (47.3%) of caregivers experienced severe burden, 42.3% show moderate burden while only 10.4% of caregivers reported no or mild burden. With total scores ranging from 6–78, the mean ZBI score was 39.1 ± 12.5 .

In Table 4, all (100%) caregivers aged 20 years and below reported no or mild burden, moderate burden was reported among caregivers between the ages of 21 and 40 years, while severe burden was experienced by all (100%) caregivers above 41 years of age. Almost half (48%) of females reported severe burden, while moderate burden was observed in 44.4% of males compared to their female counterparts. Higher proportions (49.7%, 44.3%, 60%) of severe, moderate and mild burden respectively was observed among those without spousal partners. The uneducated (51%) and semi-literate (49.4%) caregivers reported severe burden, while about half (50.7%) of educated ones experienced moderate burden. In addition, 51.0% of the unemployed caregivers experienced severe burden, followed by the caregivers in employment (47.0%). A higher proportion of caregivers who are self-employed (46.1%) reported moderate burden.

There was a statistically significant difference between caregiving duration, number of hours spent on caregiving per day and caregiver burden. Caregivers who are sons and daughters (56.3%) of cancer patients reported the highest proportion of severe burden, followed by those who are spouses (52.5%) of patients. Relatively, moderate burden was experienced by 48.1% of caregivers who are parents of cancer patients. Caregivers who share the same home with the patient reported almost equal proportions of moderate (44.4%) and severe (45.2%) burden. In addition, severe burden was experienced by all (100%) respondents who have been caregivers for over a period of 12 months and those who spend not less than 12 hours on caregiving role daily. About half (46.3%) of caregivers who had no support from other people in taking care of the patient reported severe burden.

The patterns of coping strategies utilized by caregivers in dealing with stress and burden of caregivers are shown in Table 5. The most frequently utilized coping strategy was religion (mean = 6.15), followed by planning and instrumental support with mean scores of 5.94 and 5.79 respectively. Venting (2.67) and use of substance (3.79) were less utilized as coping mechanisms among caregivers.

Discussion

The mean Zarit Burden Interview (ZBI) score of caregiver burden in this population was $39.1 (\pm 12.5)$ with a range of 10.4 to 47.3. This finding supports a local study conducted among informal caregivers of breast cancer patients in northern Nigeria (37.1).²¹ In contrast, a study in Turkey reported lower score (28.4) of caregiver burden among patients with hematological cancer.²² The high prevalence caregiver burden observed in the Nigerian settings could be due to low socioeconomic levels and inadequate medical resources compared with developed countries. The level of caregiver burden was also found to vary depending on the progression of the disease. Informal caregivers of patients with advanced cancer

also experienced lower caregiver burden in South England, (18.5) and in studies in Malaysia, (23.3, 26.0) compared to this study.²³⁻²⁵ The patients recruited in these three studies were terminally ill, and as such, caregivers may have reached acceptance of the inevitable end-of-life. This is supported by another study in Ontario where caregiver burden to terminally ill breast cancer patients were significantly lower compared to the initial phase of palliative intervention. (19.4 and 26.2).²⁶

Almost half of the caregivers (47.3%) in this study were found to have severe burden, suggestive of the low functionality of the patients. This result is consistent with previous studies conducted in other parts of Nigeria (Ibadan, Zaria and Calabar) which reported severe burden among informal caregivers.^{15,27,28} The study in Calabar revealed that their respondents provided care for advanced cancer (stage iii and iv) patients, who had low functionality level and thus the high prevalence of severe burden observed.²⁸

The age of caregiver was found to be significantly associated with caregiver burden. All caregivers who were above 40 years and about half of those between 31 and 40 years experienced severe burden contrary to those 30 years and below. Older caregivers may be less energetic and have frequently co-morbid conditions, resulting in frailty and decreased physical aptitude.²⁹ A study done in Ibadan similarly showed that caregivers older than 60 years of age reported feelings of impaired health and higher burden.¹⁵ Other studies have also confirmed age as one of the determinants of burden among caregivers.^{30,31} Healthcare providers need to evaluate the burden of care for older caregivers and provide necessary assistance to help reduce burden associated with care.

In this study, both genders experienced almost equal level of severe burden. Typically, studies revealed that women experience severe burden more than men, hypothesizing that women encounter consequences of caregiving due to their characteristic engagements in more personal care than men in the caregiving role.^{15,32,33} Women have also reportedly felt more obligated towards caregiving compared to men when given the task whereas men more often than not receive assistance from others.³⁴

Although caregiver's relationship to cancer patient was well established as an influencing factor of caregiver burden,^{29,35,36} but there was no statistically significant association between this relationship in this study. Spouses are typically the primary caregiver to a sick adult partner. Adult children usually function as the secondary caregivers and only step into the main caregiving roles when spouses are indisposed.³⁷ The children of cancer patients and spousal caregivers had higher level of burden compared to other relatives of the patient. The result obtained from this study is in keeping with a similar study done in Ibadan which showed that spousal caregivers had a higher burden.¹⁵ Most studies reported that spousal caregivers have a greater burden than adult children caregivers. However, this study found the contrary in keeping a study where adult children caregivers were found to have high levels of depressive symptoms and feeling of abandonment when caring for terminal cancer patients.^{6,21,28} Adult children have greater burden than spouses possibly because of additional obligations.

About one-third of caregivers in this study did not have other people support them in patient care and therefore, experienced severe burden. A similar finding was obtained from a study done in Zaria among poor caregivers in an African urban setting where the majority of the caregivers did not receive any form of assistance outside the family.²⁷ Currently, due to shortage of medical resources in Nigeria, family members are the major support for caregivers, specifically emotional support. Receiving support from other people with patient care will positively reduce overall caregiver burden, and give caregiver more time for self-care. Social support is considered an important factor for the quality of life of caregivers, influencing their emotional and physical health. Social support had an inverse relationship with caregiver burden.³⁸

All caregivers in this study reported severe burden after a period of 12 months duration. Similar to what was obtained in Calabar where more than half of the caregivers at 11 months or above suffered severe burden.²⁸ Caregivers sometimes take away time that could be spent in their paid employment to care for their patient, and represents a “second shift” situation. This reduces caregiver’s rest time, and implies that the more the years/months/hours a person spends on caregiving, the more the burden of care increases.

Coping mechanisms motivates caregivers to provide care to cancer patients despite the challenges they often encounter. The family caregivers mainly preferred religious coping strategies. This is expected considering the fact that Africans especially Nigerians are highly religious. Also, this study was done in the Southwestern region Nigeria, where religious beliefs are among the very important cultural and religious feature of the region of study. A positive relationship and “full reliance on God” gave caregivers hope that He was in control. The results suggest that belief in God helped carers to accept the reality of the situation and cope with the stress. Similar studies proved that caregivers using a religious coping strategy had a higher life satisfaction,³⁹ experienced lower psychosocial distress and had a higher cancer adaptation.^{40,41}

The mean planning score was high for caregivers. This type of strategy enables caregivers to be more active, establish action plans, use problem-solving skills and accept the problem to find new solutions. This finding may be linked to the age-group and educational status of majority of caregivers in this study. Studies proved that caregivers displaying constructive problem-solving skills experienced less stress and that there was a reduction in the negative stress response.^{39,42} Similar studies also showed active planning as an effective coping strategy in reducing burden experienced by caregivers of chronically ill cancer patients.^{41,43} Substance use and venting were the least strategies used by caregivers to cope with the burden associated with care. This could be attributed to the fact that the caregivers were predominantly females who are less likely to use alcohol, drugs and substances.⁴⁴ Though substance use was adopted in other studies, the result was an increase in psychosocial issues and care burden for caregivers causing bad adaptation periods and decreasing their quality of life.^{39,45}

Limitation of study

This study was among a heterogenous population of cancer patients and did not collect data on the type of cancer or stage of cancer of the patients receiving care by the caregivers. Hence the interpretation of the care burden score must be viewed in this regard. Also, a qualitative aspect to this study may have explored other factors such as how financial status of the dyads may affect the burden experienced by caregivers.

Conclusion

Almost half of the caregivers of cancer patients attending the cancer center in this study experienced severe burden. There was a statistically significant association between caregiver burden and caregiver age as high level of burden was found among older carers. In addition, duration of caregiving and number of hours spent on caregiving role per day were found to be statistically significantly associated to caregiver burden. Religion was the most predominant coping strategy used by caregivers to deal with stressful situation while substance use was rarely adopted as a coping strategy by caregivers. Linkages of social support groups with health care providers giving information through seminars to informal caregivers on the intricacies of caregiving in chronically ill patients would enhance positive caregiving outcomes.

Abbreviations

ADL	Activities of Daily Living
COPE	Coping Orientations to Problems Experienced
HREC	Health Research Ethics Committee
IADL	Instrumental Activities of Daily Living
LUTH	Lagos University Teaching Hospital
NPC	National Population Commission
ONS	Oncology Nursing Society
ZBI	Zarit Burden Interview

Declarations

Not applicable

Ethics approval and consent to participate

Ethical approval was obtained from Health Research Ethics Committee (HREC) of the Lagos University Teaching Hospital, (LUTH), Lagos with approval number ADM/DCST/HREC/APP/3014. The respondents

signed the consent form after adequate explanation and the participation of respondents was completely voluntary. The researcher assured respondents of their privacy and confidentiality.

Consent to publish

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interest

The authors declare that they have no competing interest.

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None

Authors' contributions

AO, AU and AA conceptualized and designed the study; AU analyzed the data while all authors interpreted the results and provided critically important inputs; EO wrote the first draft of the manuscript; All authors contributed to the revision of the manuscript, read and approved the final manuscript.

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Tables

Table 1: Socio- demographic and Socio-economic characteristics of caregivers and their patients.

VARIABLE	CAREGIVERS n=385 (%)	PATIENT n=385 (%)
Age(Years)		
≤ 18	6 (1.6)	15 (3.9)
19-30	139 (36.1)	50 (13.0)
31-40	130 (33.3)	80 (20.8)
41-50	72 (18.7)	75 (19.5)
51-60	38 (9.9)	86 (22.3)
≥ 61	0 (0.0)	79 (20.5)
	Median: 35 ± 10.3	Median: 48 ± 15.8
Gender		
Female	223 (57.9)	227(59.0)
Male	162 (42.1)	158(41.0)
Marital Status		
Married	218 (56.6)	218(56.6)
Single/Widowed/Divorced	167 (43.4)	167(43.4)
Religion		
Christianity	265 (68.8)	271(70.4)
Islam	105 (27.3)	102(34.7)
Others	15 (3.1)	12(3.1)
Educational Status		
Uneducated	49 (12.7)	94 (24.4)
Semi-literate	160 (41.6)	137 (35.6)
Educated	176 (45.7)	154 (40.0)
Employment Status		
Unemployed	154 (40.0)	137 (35.6)
Self-employed	133 (34.5)	151 (39.2)

Employed	98 (25.5)	97 (25.2)
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Table 2: Characteristics of caregiving role among caregivers

VARIABLE	FREQUENCY (n=385)	PERCENTAGE(%)
Relationship to Patient		
Parent	133	34.6
Sibling	93	24.2
Spouse	61	15.8
Child	32	8.3
Others	66	17.1
Reside in the same house		
Yes	248	64.4
No	137	35.6
Duration of Caregiving (months)		
≤ 6	125	43.4
7 – 12	123	42.7
≥ 13	40	13.9
Median = 12 (±12.6)		
Time spent on caregiving role per day (hours)		
1 – 5		
6 – 11	204	53.0
≥ 12	132	34.3
Median =6 (±5.8)	49	12.7
Has adequate information about care requirement of patient		
Yes		
No	247	64.2
	138	35.8
Received training to meet patient's care		

Yes	155	40.3
No	230	59.7
Help the patient		
Always	195	50.7
Mostly	190	49.4
Has other people support in patient care		
Yes	298	77.4
No	87	22.6
Has a chronic disease		
Yes	104	27.0
No	281	73.0

Table 3: Distribution of relationship, emotional, social and financial forms of burden

Burden	Total Score	Mean	SD
Relationship Burden			
That relative ask for more help than needed	598	1.55	1.12
Relative is dependent on you	766	1.99	1.15
Wish to leave care of relative to someone else	606	1.57	1.11
Relative expect you to take care of them as the only one	708	1.84	1.09
Should be doing more for relative	895	2.32	1.09
Do not have as much privacy as would like	654	1.70	1.12
Emotional Burden			
Not having enough time for self	625	1.62	1.04
Embarrassed about relative behavior	495	1.29	1.18
Angry when around relative	454	1.18	1.15
Strained when around the relative	579	1.50	1.10
Health has suffered because of involvement with relative	633	1.64	1.11
Overall feeling of burden	772	2.01	1.18
Could provide higher quality of care to relative	892	2.32	1.09

Social/Family Burden			
Social life has suffered because of caring for relative	639	1.66	1.50
Stressed about caring for relative and trying to fulfill other responsibilities	653	1.70	1.06
Caring for relative currently affect other family members	549	1.43	1.11
Uncomfortable about having friends around	582	1.43	1.11
Loss of Control of Oneself			
Afraid of what the future holds for your relative	871	2.26	1.17
Unable to take care of relatives for much longer	757	1.97	1.08
Loss control of one’s life since relative’s illness began	654	1.70	1.11
Uncertainty about what to do for relative	709	1.85	1.10
Financial Burden			
Not having enough money to care for relative in addition to other expenses	885	2.30	1.16
Level of burden	Frequency	Percentage(%)	
No or mild (0-20)	40	10.4	
Moderate (21-40)	163	42.3	
Severe (41-88)	182	47.3	
Mean	39.1(SD±12.5)		

Table 4: Factors associated with burden characteristics of caregivers

VARIABLE	CAREGIVER BURDEN			χ^2	p-value
	No or Mild (%)	Moderate (%)	Severe (%)		
Age(Years)					
≤ 20	6(100)	0(0)	0(0)		
21-30	34(24.5)	105(75.5)	0(0)		<0.0001*
31-40	0(00)	58(44.6)	72(55.4)		
41-50	0(0)	0(0)	72(100)		
≥ 51	0(0)	0(0)	38(100)		
Gender					
Male	15(9.3)	72(44.4)	75(46.3)	0.69	0.707
Female	25(11.2)	91(40.8)	107(48.0)		
Marital Status					
Married	30 (13.8)	89(40.8)	99(45.4)	6.14	0.046
Single/Widowed/Divorced	10(60.0)	74(44.3)	49(49.7)		
Educational Status					
Uneducated	3(6.1)	21(42.9)	25(51.0)	4.06	0.398
Semi-literate	13(8.1)	68(42.5)	79(49.4)		
Educated	24(26.7)	74(50.7)	78(43.4)		
Employment Status					
Unemployed	12(7.8)	64(41.6)	78(51.0)	3.68	0.452
Self-employed	14(10.9)	59(46.1)	55(43.0)		
Employed	14(13.6)	40(38.8)	49(47.6)		
Relationship to Patient					
Spouse	7(11.5)	22(36.1)	32(52.5)		0.762*

Child	4(28.6)	10(31.3)	18(56.3)		
Parent	12(9.0)	64(48.1)	57(42.9)		
Sibling	11(11.8)	40(43.0)	42(45.2)		
Others	6(9.1)	27(40.9)	33(50.0)		
Share same home with patient					
Yes	26(10.5)	110(44.4)	112(45.2)	1.33	0.514
No	14(10.2)	53(38.7)	70(51.1)		
Duration of Caregiving (in months)					
≤ 6					<0.001*
7 – 1≥ 13	40(32.0)	85(68.0)	0(0.0)		
	0(0.0)	78(63.4)	45(36.6)		
	0(0.0)	0(0.0)	137(100.0)		
Number of hours spent on caregiving role daily					
1 – 5	40(25.5)	117(74.5)	0(0.0)		<0.001*
6 – 11	0(0.0)	46(31.1)	102(68.9)		
≥ 12	0(0.0)	0(0.0)	80(100.0)		
Has adequate information about patient care requirement					
Yes					
No	27(10.9)	102(41.3)	118(47.8)	0.41	0.816
	13(9.4)	61(44.2)	64(46.4)		
Received training to meet patient's care requirements					
Yes	20(12.9)	62(40.0)	73(47.1)	1.91	0.384
No	20(8.7)	101(43.9)	109(47.4)		
Renders help to the patient					
Always	17(8.7)	87(44.6)	91(46.7)	1.58	0.454
Mostly	23(12.1)	76(40.0)	91(47.9)		

Other people support in patient care					
Yes					
No	27(9.1)	133(44.6)	138(46.3)	4.14	0.126
	13(14.9)	30(34.5)	44(50.6)		
Has a Chronic Disease					
Yes	11(10.6)	45(43.3)	48(46.2)	0.07	0.965
No	29(21.6)	118 (42.0)	134(47.7)		

*Fisher's exact

Table 5: Patterns of coping strategies utilized by caregivers

Coping Strategy	Range	Mean BRIEF-COPE scores
Acceptance	2 – 8	5.15 ± 1.74
Active Coping	2 - 8	5.78 ± 1.68
Behavioral Disengagement	2 - 7	4.41 ± 1.71
Denial	2 - 8	5.47 ± 1.78
Emotional Support	2 - 8	5.65 ± 1.65
Humor	2 - 7	4.01 ± 1.91
Instrumental Support	2 - 8	5.79 ± 1.73
Planning	2 - 8	5.94 ± 1.64
Positive Reframing	2 - 8	5.54 ± 1.59
Religion	2 - 8	6.15 ± 1.73
Self-Blame	2 - 6	4.32 ± 1.79
Self-Disengagement	2 - 8	5.49 ± 1.78
Substance Use	2 - 5	3.79 ± 1.82
Venting	2 – 8	2.67 ± 1.63

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