Burden of Care and Perceived Psycho-Social Outcomes among Family Caregivers of Patients Living with Cancer

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ABSTRACT

Objective: Caring for patients living with cancer requires the support of family caregivers. Literature reports experiences of diverse burdens and health effects among caregivers. This study examined the burden, physical, psycho-social, and financial outcomes of caregiving among caregivers of patients living with cancer. Methods: This cross-sectional descriptive study was conducted in the University College Hospital, Ibadan, Nigeria, between January and March 2019. A convenient sample of 201 caregivers who were direct family relatives were selected to complete a validated Zarit Burden Interview (ZBI) Questionnaire (r = 0.994) and perceived outcomes of caregiving questionnaire. The burden scale score ranged from o to 20 (no burden) to 61–88 (severe burden). Other outcomes of caregiving were measured on a Likert scale 0–4 (where 2.00 is the threshold score of effect of caregiving experienced), to determine the strength of the effect of caregiving on each variable of interest. The factors that contributed to the health outcomes were also identified. The Statistical Package for the Social Sciences version 22.0 was used for data analysis. Results: The mean age was 37.68 ± 14.29 years and

majority (60.4%) were female. The mean duration of caregiving was 2.34 ± 1.14. Caregivers (44.5%) reported a mild level of the burden while 4.4% reported severe burden. The mean burden score was 28.30 ± 15.78. Findings also indicate that caregiving affected the physical health (mean = $2.58 \ge 2.00$) and social well-being (mean = $2.42 \ge 2.00$) of the caregivers. The impact on psychological health was less than the threshold value (mean = $1.88 \le 2.00$), suggesting less impact. Some factors associated with physical effects include poor eating (mean = 2.80) and lack of sleep (mean = 2.92). However, the psychological outcomes were associated with loss of hope (mean = 1.53) and feelings of frustration (mean = 1.65). Conclusions: Reported burden of care was mild; although negative health outcomes were noted. Health-care professionals can ameliorate such effects through a regular systemic assessment with standardized instruments, for early identification and intervention.

Key words: Burden of care, cancer, family caregivers, psycho-social outcomes

Introduction

Cancer is one of the leading causes of morbidity (terminal illness), with its incidence increasing worldwide. In 2018,

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there were 18.1 million new cases $^{[1]}$ and an estimated death rate of 9.6 million globally. $^{[2]}$

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People living with cancer have many options for disease management after diagnosis, of which caregiving is one of the measures incorporated in cancer management. The caregiving roles are more often rendered by family members or people who have a significant relationship with the person living with cancer.^[3,4] These individuals who may be primary or secondary caregivers live with or separately from the person receiving care.^[3] Family caregivers are critical in the overall management of cancers and they help persons living with cancer to also be active and remain connected to their communities.^[5]

The number of caregivers is increasing with the rising incidence of new cancer cases as well as other chronic illnesses,^[6,7] as they provide varying types and levels of support to their loved ones. Moreover, their levels of involvement depend on the complexity of the disease, treatments required, stage of the disease, or closeness to death.^[8] Findings from one study suggested that caregivers provide 70%–80% of care required by patients living with cancer and other chronic conditions.^[9] They render physical, emotional and often financial support or care to their loved ones, who are incapacitated due to ill health.^[3,10] The physical support includes providing assistance with activities of daily living like bathing, cooking, as well as taking patients to and from medical appointments.^[11,12] Literature documents that the time in hours spent for caregiving ranges from 20 to 30 h/week,^[3,13,14] which is a significant part of the caregivers' lives, affecting their quality of life.

A wide range of effects of caregiving has been documented. The level of burden experienced by caregivers is dependent on the stage of illness, goals of care, duration of care, and potential for survival.^[15,16] In general, the effects on health range from physical, psychological, economic to social health problems. In Nigeria, studies have shown a high level of burden among caregivers of people living with cancer.^[16,17]

Several interventions, like nonpharmacological therapies, have proven to be helpful and cost-effective in relieving the burden of care among caregivers.^[18] Some of the interventions documented in the literature include education on coping strategies, counseling, support, use of technology (telephone calls and programs), parental social-cognitive intervention program, coping strategies, and social support.^[19-26] Furthermore, the literature suggests that interventions that are individualized are highly effective in reducing the burden experienced by caregivers.^[27]

Despite the overwhelming impact of caregiving on the health of caregivers, few studies in Nigeria have examined the health effects experienced by family caregivers of patients living with cancer and interventions to relieve those challenges. In addition, the researcher has observed that less emphasis or attention is paid to caregivers' health or welfare by clinicians during the care of people living with cancer in hospitals within the research setting. Most care delivery models focus primarily on individual patients and this can affect the proper assessment of the needs and burdens of caregivers, proper engagement in the care of their loved one, education, and support to family caregivers or other informal care providers.^[28] When less attention is paid to caregivers' health, the caregivers develop burden. Furthermore, the health-care systems do not have proper documentation of the burdens of caregivers.

Hence, this study assessed the burden of care, and physical, psycho-social and financial effects among family caregivers of patients living with cancer in University College Hospital, Ibadan.

Methods

A cross-sectional descriptive study design was used. The research was conducted in the University College Hospital, Ibadan, Nigeria, from January 2019 to March 2019. It is a tertiary institution with an oncology department for managing patients living with cancer. Purposive sampling technique was used to select the wards and radiotherapy clinic. Respondents were selected using convenience sampling technique and a calculated sample size of 201 based on Fisher's (1998), $n = Zpq/d^2$ formula. Respondents also met the inclusion criteria, which included: (1) being a direct caregiver on the admission of the patient or from diagnosis of patient's condition; (2) attending radiotherapy clinic; (3) willingness to participate.

Data were collected using two validated instruments: A structured questionnaire developed from literature review to measure the perceived outcomes of caregiving, and a standardized 22- item Zarit Burden Interview (ZBI) Questionnaire (1980)^[13] to measure levels of burden of caregivers. Other outcomes (physical, psychological, social and financial) of caregiving were measured on a Likert scale of 0-4, never = 0, rarely = 1, sometimes = 2, quite frequently = 3, and nearly always = 4, to determine the strength of the effect of caregiving on each variable of interest (where 2.00 is the threshold score of effect of caregiving experienced). The weighted mean (WM) score for each variable greater than or equal to the threshold value (2.00) suggests an increasing effect of caregiving on that aspect of the caregivers' life. Furthermore, the mean of each item or variable making up physical, psychological, social, and financial outcomes was obtained and compared with the WM for each domain of health outcome and used to determine the factors that contributed to the health outcome. A mean (variable) greater than or equal to the WM of each health outcome indicates that the variable is a factor associated with the health outcome. The level of burden was measured on a scale of 0–4, with the options: never = 0, rarely = 1, sometimes = 2, quite frequently = 3, and nearly always = 4. The burden scale was measured thus: 0–20 (no burden), 21–40 (mild burden), 41–60 (moderate burden), and 61–88 (severe burden). The mean score was also determined. Mean was used to determine the burden of care. A test re-test reliability showed a reliability coefficient 0.994.^[16]

Out of a sample size of 201 recruited for the study, only 182 respondents returned appropriately completed questionnaire that were adequate for the analysis. Data were analyzed using descriptive statistics of frequencies, percentages, and mean; using the IBM Corp. released 2013. IBM SPSS statistics for windows, version 22.0. Armonk, NY: IBM Corp.

Ethical approval was obtained from the institutional review board (Approval No. UI/EC/18/0669). Ethical principles were observed.

Results

Table 1 shows the distribution of the sociodemographic characteristics of the respondents. The mean age was 37.68 ± 14.29 years. Majority, were female [110 (60.4%)], had tertiary education [111 (61.0%)], and 119 (65.4%) were parents.

Table 2 shows the level of burden of caregivers. The level of burden of caregivers is mild, with a mean score of 28.30.

Table 3 shows the summary of perceived physical effects of caregiving experienced by caregivers. The WM score is 2.58, which is greater than the threshold 2.00. This shows that the respondents quite frequently have physical effect. Furthermore, three variables contributed to the development of this frequent physical effect and in their order of seriousness are poor eating pattern (mean = 2.80 > 2.58), lack of sleep (mean = 2.92 > 2.58), and change in activities of daily living (mean = 3.12 > 2.58).

Table 4 shows the summary of the perceived psychological effects of caregiving experienced by caregivers. The WM score is 1.88, which is less than the threshold 2.00. This shows that the respondents sometimes experience psychological effect. Furthermore, four variables contributed to the development of the perceived psychological effect and they are in their order of seriousness are loss of hope (mean = 1.53 < 1.88), feeling of frustration (mean = 1.65 < 1.88).

Table 5 shows the summary of perceived social effects of caregiving experienced by caregivers. The WM score = 2.42 which is greater than the threshold 2.00. This shows that the respondents sometimes

Variables	Frequency (%)
Age (years)	
10-30	65 (35.7)
31-50	82 (45.1)
≥51	35 (19.2)
Mean±SD	37.68 ± 14.29
Gender	57.00±14.25
Male	72 (39.6)
Female	110 (60.4)
Occupation/employment status	110 (00.4)
Business man	48 (26.4)
Civil servant	48 (20.4) 28 (15.4)
Self-employed	68 (37.4)
Unemployed	38 (20.9)
Highest level of education	50 (20.9)
No formal education	4 (2.2)
Primary	4 (2.2) 18 (9.9)
Secondary	49 (26.9)
Tertiary	111 (61.0)
Marital status	(01.0)
Single	63 (34.6)
Married	113 (62.1)
Divorced	2 (1.1)
Widow	3 (1.6)
Widower	1 (0.5)
Relationship with care receiver	1 (0.5)
Brother	12 (6.6)
Sister	20 (11.0)
Parents	119 (65.4)
Husband	17 (9.3)
Wife	14 (7.7)
Duration of caregiving	(/.//)
<1 month	52 (28.6)
1 month to 6 months	63 (34.6)
>6 months to 1 year	21 (11.5)
>1 year	46 (25.3)
Mean±SD	2.34 ± 1.14
SD: Standard deviation	2.5121.11

Table 2: Level of burden of caregivers						
Burden level	Frequency (%)					
No burden	65 (35.7)					
Mild burden	81 (44.5)					
Moderate burden	28 (15.4)					
Severe burden	8 (4.4)					
Mean±SD	28.30 ± 15.78					
0-20: No burden; 21-40: Mild burden; 41-60: Modera	te burden; 61-88: Severe burden.[13]					

have social effect. Furthermore, three variables contributed to the development of this social health effect and they are in their order of seriousness are lack of social activities (mean = 2.45 > 2.42), poor leisure time (mean = 2.65 > 2.42) and poor family support (mean = 3.75 > 2.42).

Table 3: Summary of perceived physical effects of caregiving experienced by caregivers								
Items	F (%) of N	F (%) of R	F (%) of S	F (%) of QF	F (%) of NA	Total of N/%	Mean±SD	
Do you feel tired as a result of caring for your loved one?	66 (36.3)	28 (15.4)	49 (26.9)	22 (12.1)	17 (9.3)	182 (100.0)	2.43 ± 1.33	
Have you had adequate sleep since you started caring for your loved one?	43 (23.6)	35 (19.2)	36 (19.8)	30 (16.5)	38 (20.9)	182 (100.0)	2.92 ± 1.46	
Has your eating pattern changed since you started caring for your loved one?	51 (28.0)	30 (16.5)	39 (21.4)	29 (15.9)	33 (18.1)	182 (100.0)	2.8 ± 1.46	
Does caring for your loved one make you feel restless?	85 (46.7)	33 (18.1)	34 (18.7)	17 (9.3)	13 (7.1)	182 (100.0)	2.12 ± 1.28	
Do you feel exhausted as a result of caring for your loved?	75 (41.2)	28 (15.4)	38 (20.9)	19 (10.4)	22 (12.1)	182 (100.0)	2.37 ± 1.41	
Has your activity of daily living been affected since you started caring for your loved one?	37 (20.3)	30 (16.5)	41 (22.5)	22 (12.1)	52 (28.6)	182 (100.0)	3.12 ± 1.50	
Have you had headache since you started caring for your loved one?	72 (39.6)	32 (17.6)	42 (23.1)	22 (12.1)	14 (7.7)	182 (100.0)	2.31±1.31 WM=2.58	

SD: Standard deviation; WM: Weighted mean; N: Never; R: Rarely; S: Sometimes; QF: Quiet frequently; NA: Nearly alwa

Table 4: Summary of perceived psychological effects of caregiving experienced by caregivers									
ltems	F (%) of N F (%) of R	F (%) OF S	F (%) of QF	F (%) of NA	Total of N/%	Mean±SD			
Does caring for your loved one make you feel depressed?	96 (50.0) 31 (17.0)	34 (18.7)	12 (6.6)	14 (7.7)	182 (100.0)	2.02 ± 1.30			
Do you feel anxious since you started caring for your loved?	82 (45.1) 34 (18.7)	34 (18.7)	21 (11.5)	11 (6.0)	182 (100.0)	2.15 ± 1.28			
Does your loved one's condition or caring for your loved one make you lose hope in life?	133 (73.1) 25 (13.7)	7 (3.8)	11 (6.0)	6 (3.3)	182 (100.0)	1.53 ± 1.04			
Do you feel nervous as a result of caring for your loved one?	94 (51.6) 38 (20.9)	32 (17.6)	10 (5.5)	8 (4.4)	182 (100.0)	1.90 ± 1.14			
Do you feel sad as a result of caring for your loved one?	102 (56.0) 28 (15.4)	21 (11.5)	16 (8.8)	15 (8.2)	182 (100.0)	1.98 ± 1.33			
Do you feel frustrated as a result of caring for your loved one?	121 (66.5) 26 (14.3)	20 (11.0)	7 (3.8)	8 (4.4)	182 (100.0)	1.65 ± 1.10 WM=1.88			

SD: Standard deviation; WM: Weighted mean; N: Never; R: Rarely; S: Sometimes; QF: Quiet frequently; NA: Nearly always

tems	F (%) of N	F (%) of R	F (%) of S	F (%) of QF	F (%) of NA	Total of N/%	Mean±SD
Do you feel that caring for your loved one has made you socially solated?	88 (48.4)	34 (18.7)	23 (12.6)	17 (9.3)	20 (11)	182 (100.0)	2.16±1.40
Do you think people do not want to relate with you because you re caring for your loved one?	144 (79.1)	14 (7.7)	8 (4.4)	10 (5.5)	6 (3.3)	182 (100.0)	1.46 ± 1.03
as caring for your loved one affected your social activities?	75 (41.2)	29 (15.9)	30 (16.5)	18 (9.9)	30 (16.5)	182 (100.0)	2.45 ± 1.51
as caring for your loved one affected your leisure time?	63 (34.6)	27 (14.8)	33 (18.1)	28 (15.4)	31 (17.0)	182 (100.0)	2.65 ± 1.50
o you feel caring for your loved one has affected your elationship with your friends or people around you?	101 (55.5)	22 (12.1)	25 (13.7)	15 (8.2)	19 (10.4)	182 (100.0)	2.06 ± 1.40
o you receive family support since you started caring for your ved one?	26 (14.3)	15 (8.2)	28 (15.4)	22 (12.1)	91 (50.0)	182 (100.0)	3.75±1.49 WM=2.42

Table 6 shows the summary of the perceived financial effects of caregiving experienced by caregivers. The WM score is 2.14, which is greater than the threshold 2.00. This shows that the respondents sometimes have financial effect. Furthermore, three variables contributed to the development of this financial health effect and they are in their order of seriousness are, lack of money (mean = 2.59 > 2.14), effect on job (mean = 2.86 > 2.14), and loss of money (spent a lot of money) (mean = 2.21 > 2.14).

Discussion

Caregiving constitutes a burden to the family of persons living with cancer, affecting all domains of their human functioning. Findings from the study suggest that there are various levels of burden experienced by caregivers, ranging from mild-to-severe levels. However, the study revealed that most caregivers had mild level of burden. The explanation for this is not hard to find as most people tend to shy away from expressing their views on how they feel because of their relationship with the care recipient, even though the burden exists. In line with this, findings of the qualitative study noted where one of the respondents reported fewer burdens because the care recipient was the father.^[29] This finding is, however, in contrast with other studies where the respondents boldly reported a high level of burden.^[16,17] The implication is that if attention is not paid on assessing the burden of care among caregivers and identifying measures or coping strategies to relieve and avoid this

Onyeneho and Ilesanmi: Perceived Psycho-Social Effects of Caregiving

Table 6: Summary of perceived financial effects of caregiving experienced by caregivers							
tems	F (%) of N	F (%) of R	F (%) of S	F (%) of QF	F (%) of NA	Total of N/%	Mean±SD
Has your job been affected since you started caring for your loved one?	63 (34.6)	21 (11.5)	31 (17.0)	12 (6.6)	55 (30.2)	182 (100.0)	2.86±1.66
Do you feel you don't have enough money to take care of your oved one?	69 (37.9)	23 (12.6)	38 (20.9)	18 (9.9)	34 (18.7)	182 (100.0)	2.59 ± 1.53
las caring for your loved one made you lose your job or source of velihood?	133 (73.1)	17 (9.3)	7 (3.8)	10 (5.5)	15 (8.2)	182 (100.0)	1.66±1.28
Oo you feel caring for your loved one has made you lose money?	89 (48.9)	29 (15.9)	26 (14.3)	12 (6.6)	26 (14.3)	182 (100.0)	2.21 ± 1.47
las caring for your loved one made you to over work or take up xtra jobs just to source for more money to care for him or her?	118 (64.8)	19 (10.4)	25 (13.7)	10 (5.5)	10 (5.5)	182 (100.0)	1.76±1.21
lave you been experiencing job frustration since you started aring for your loved one?	123 (67.6)	21 (11.5)	14 (7.7)	13 (7.1)	11 (6.0)	182 (100.0)	1.73±1.23 WM=2.14
SD: Standard deviation; WM: Weighted mean; N: Never, R: Rarely, S: Sometimes, QF: Quiet frequently, NA: Nearly always							

burden, this could affect the health of caregivers and affect the care they are rendering. Hence, there is a need for an exploratory study to further understand the extent of burden experienced by caregivers. Furthermore, result from our study confirms the burden of care among caregivers based on ZBI burden instrument. It may be suggested that a regular assessment of family caregivers' level of burden during the period of care is necessary in order to mitigate detrimental health challenges.

Respondents in this study also reported the effects of caregiving on social, physical, psychological as well as financial domains of their lives. On the physical domain, the findings of the study have confirmed caregiving impacts on the physical health of the caregivers. Some of the physical effects reported were feelings of tiredness, exhaustion, effect on activities of daily living, sleeplessness, inability to eat or loss of appetite, weight loss. This corroborates other findings which reported physical burden among 43.4% of the study population (n = 210).^[16] Some of the physical effects reported were sleep disturbances, skipping meals, lack of exercise.^[14,30] It is important to note that lack of sleep or sleep disruption may increase physical exhaustion and risk of physical illness, exacerbation of co-morbidities, emotional distress, reduced cognitive performance, and a greater risk of mortality.^[31,32] Family caregivers need to maintain good physical health in order to continue providing care to their loved ones. Contrariwise, a poor state of physical health of the caregiver could complicate the health of the recipient of care and affect the quality of care during a caregiving episode.

The perceived psychological effects reported by the caregivers were depression, anxiety, anger, emotional dumbness, trauma, sadness, and nervousness. This is in line with a similar study, which stated that caregivers experience psychological burden (43.3%).^[16] When a caregiver is not psychologically stable, several health challenges may arise, which can subsequently interfere with the care they render. A study reported that caregiving

causes psychological strain on the caregivers.^[33,34] Some other studies have reported some of those challenges arising as a result of depression and anxiety as insomnia, weakened immunity^[35] poor concentration and memory.^[32] The timing of entry into the caregiving role and duration of the role significantly influence the psychological well-being of the caregiver.

Socially, the effects included lack of social activities, poor leisure time, poor or lack of relationship with friends, lack of family support among others. Similarly, Akpan-Idiok and Anarado^[16] reported negative effects of caregiving on social relationships. Family caregivers should be encouraged to use social media as a platform to connect with friends in situations where they do not have the opportune moment to be physically present, thereby preventing a feeling of social isolation.

Financially, respondents reported a lack of finance, increased medical expenses and job issues. Previous studies indicated that the financial burden was experienced by 41.4% of the study population.^[16,36] Most people living with cancer can receive health care services with the help of their loved ones. If the cost of health care becomes unaffordable, the caregivers may not be able to continue providing financial support to their loved ones and this will affect their loved ones' health. Hence, there is a need for the government to subsidize the cost of health care for cancer treatment in order to lessen the financial burden on caregivers.

Conclusions

The findings of this study correctly support the diverse burden of care experienced by family caregivers; ranging from negative health effects to social and financial burden. We, therefore, recommend regular systemic assessment of effects of caregiving and shared care responsibility among family members to provide a respite for a particular caregiver. This would reduce the level of burden experience by each family caregiver.

Limitations

The study was conducted in only one cancer setting using a small sample size. These factors reduce the generalizability of the findings. Furthermore, the individual factors which possibly contributed to level of burden experienced by family caregivers were not assessed in this study.

Areas for future research

Future studies can consider the effects of mobile technology on caregivers' and the burden of patients living with cancer may also be considered. In addition, factors associated with the level of burden or health effects experienced by caregivers can be examined in the future.

Recommendations

Based on the findings of this study, we therefore recommend a routine assessment of all caregivers of people living with cancer by health-care providers on outpatient and in-patient basis, using a standard instrument. Furthermore, development of mobile applications that are equipped with adequate information on what caregiving entails, how to manage different symptoms or effects associated with caregiving, coping strategies, and how to do a self-assessment of caregivers' challenges can be investigated.

Furthermore, family and social support should be encouraged during the period of caregiving in order to maintain optimal functioning and lower negative health outcomes associated with caregiving. This can be achieved through public awareness, support group, and family meeting to discuss the need to provide support by family members during this period.

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Conflicts of interest

There are no conflicts of interest.

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