Burdens of Care as Correlates of Quality Of Life among Informal Caregivers of Cancer Patients in Teaching Hospitals in Osun State

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Abstract

Background: Research has shown that providing care to a loved one with chronic illness such as cancer can cause a great deal of emotional and physical distress for family members who are the caregivers; this often makes caregivers neglect their own needs on behalf of the patient. It is in the light of this that this researcher was carried out to ascertain the correlation between burdens of care and quality of life among informal caregivers of cancer patients in Teaching Hospitals in Osun State.

Method: This study employed a descriptive correlational design. The population was informal caregivers of cancer patients in the two selected hospitals. Thus, the number of participants at OAUTHC was 55 and 40 at LAUTECH, Osogbo to make up the population of 95 participants in the study. A structured questionnaire with 54 items under 3 sections was used for data collection. Face and content validity ensured and the questionnaire reliability established through Cronbach alpha with the coefficient value of 0.79 for caregivers' burden and 0.89 for Quality of Life. A total of 100 questionnaires were administered out of which 95 questionnaires were adequately completed and found useful for the study making a 95% response rate. The data retrieved from the participant were coded and analyzed using percentage distribution, mean and standard deviation as well as correlation and student t-test analysis with the aid of Statistical Package for Social Sciences (SPSS) version 25.

Results: Findings from the study revealed an overall low level of perceived burden among informal caregivers of cancer patients with an average mean of 1.54; As well as a moderate level of quality of life of informal caregivers with an average mean of 3.17 on the scale of 5 points; it indicated a significant negative relationship between perceived burden and quality of life of informal caregivers (r = -0.412, P < .05); the study revealed a significant difference in the average level of care burdens among family caregivers of cancer patients between OAUTHC and LAUTECH hospitals (t = -3.051, P < .05). There was a significant mean difference of -10.514 based on gender. Lastly, the study revealed a significant difference in levels of quality of life among family caregivers of cancer patients between OAUTHC, Ile-Ife, and LAUTECH hospital, Osogbo (t = 2.399, P < .05).

Conclusion: The study concluded that the level of burden of caregivers of a cancer patient is low while the quality of their life is moderate. Hence, it was recommended that family members and friends of the sick person should be ready and willing to carry the burdens of care and quality of life of informal caregivers in all hospital settings so that this will not only affect a single member of the family but all family members.

Keywords; Burdens of Care, Quality Of Life, Informal Caregivers, Cancer Patients

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I. Introduction

The burden of care has been an issue of great concern among informal caregivers of patients with cancer because of its negative effects on the optimum physiological, psychological and social functioning of the informal caregivers as well as their productivity. Cancer is a challenging ailment adversely affecting the physical and emotional wellness of not only the patients but also their families. Statistics have shown that the disease killed over 23,681 and 23,775 persons in Turkey in 2000 and 2003 as well as 635,000 and 556,400 persons in India in 2008 and 2010 respectively. In the United States of America (USA) and Africa, 559,650, 542,000 persons died of cancer in 2007. The recent new cases of cancer diagnosed were 1.5 million in America in 2009; 715,000 cases in Africa in 2008; and 500,000 cases in Nigeria in 2010 (Jemal, et al., 2012). The World Health Organization (WHO) reports that without immediate action, the global number of deaths from cancer will increase by about 80% by 2030, with most occurring in low- and middle-income countries (Jemal, et al., 2012; Omolara, 2014).

The rising figure may become a major challenge for caregiving with its related burden on the caregiver. There is a sudden need for diagnostic and treatment decisions, as well as active involvement by the

patient and family members after cancer diagnosis (Given, Given, & Sherwood, 2012). A cancer diagnosis is often sudden, this makes family members usually unprepared to take on the role of caregiver and have little time for preplanning. Caregivers take on their role immediately and continue throughout the treatment and survivorship stages of the disease (Given et al., 2012). Caregivers themselves also go through certain physical, mental, social, and financial troubles during the time they provide care to their patients (Jackson, McCrone, & Turner-Stokes, 2015; Terakye, 2014). A study on caregivers of cancer patients' experience reported intense emotional and physiological stress during the caregiving process; hence they themselves become vulnerable to physiological and psychological health problems (Yakar & Pinar, 2013).

Long-term caregiving is a whole process impinging upon health, socio-financial state, a psychological state which is all together indicators of life-quality (Atagun, Balaban, & Atagun, 2017). According to the World Health Organization (WHO) 2016, QOL is defined as "a perception of life, perceived values, and interests in the scaffold of culture." In western countries, QOL evaluation has become more and more important as health care providers seek to understand the role health care interventions play in patients' lives rather than their physical outcomes (Rahmawati & Bajorek, 2017). Quality of life is a multidimensional, subjective construct that involves the health, socioeconomic status, and psychological, emotional, spiritual, and familial well-being of the informal caregiver (Chronister, Chan, Sasson- Gelman, & Yi-Chiu, 2013).

Objective of the Study

- 1. assess the level of care burdens among informal caregivers of cancer patients.
- 2. ascertain the quality of life of informal caregivers of cancer patients
- 3. determine the correlation between burdens of care and quality of life of family caregivers of cancer patients the factors associated with informal caregivers' burden for cancer patients.

Research Questions

The following research questions were answered

- 1. What is the level of care burdens among informal caregivers of cancer patients?
- 2. What is the quality of life among informal caregivers of a cancer patient?
- 3. What is the correlation between burdens of care and quality of life among family caregivers of cancer patients the factors associated with informal caregivers' burden for cancer patients?

II. Material and Methods

Research Design: This study used descriptive correlational design to assess burdens of care as correlates of quality of life among family caregivers of cancer patients in teaching hospitals in Osun State because it shows the correlations that may exist between burdens of care and quality of life among informal caregivers of cancer patients.

Study location: The study was carried out in two teaching hospitals in Osun state namely; Ladoke Akintola University Teaching Hospital, Osogbo, Osun State, and Obafemi Awolowo University Teaching Hospital, Ile Ife, Osun State.

Sample size: 95 patients.

Study duration: January to June 2019

Study calculation: The numbers of participant in OAUTHC was 55 while only 40 caregivers of cancer patient participated in the study in LAUTECH, Osogbo to make up the total number of 95 participants arrived at using Slovin's formula.

Inclusion Criteria:

- 1. Family caregivers providing assistance and supportive care to diagnosed cancer patients in the selected tertiary healthcare institutions in Osun-State.
- 2. Family caregivers must have spent at least 1 week or more with diagnosed cancer patients admitted on the wards in the selected tertiary healthcare facilities

Exclusion Criteria:

- 1. The caregivers whose age is less than 18 years of age.
- 2. Family caregivers who only provide financial support but do not participate in supportive care.
- 3. Family caregivers who do not give consent to participate in the study.

Data Collection Procedure

Permission was secured from the appropriate authority and the study supervisor to administer questionnaires to the study participants, questionnaires were self-administered by the researcher to informal caregivers of all cancer patients at OAUTHC, Ile-Ife and LAUTECH hospital, Osogbo. The copies of the questionnaire filled were collected and checked for completeness at the point of collection.

At each study location, efforts were made to acquaint the target audience with the overall objectives of the study. Assurance of the confidentiality of all information supplied was guaranteed. In most cases, the administered instruments were retrieved on the spot, and in other instances the complete questionnaire was collected later as agreed by both parties. Field editing was also carried out immediately to maximize the response rate.

Data Analysis

Data analysis was done using statistical package for social science version 23. Tables were made and data were presented on it. Two research questions were answered using descriptive statistics of frequency, percentages, mean and standard deviation while three hypotheses were tested using Pearson's product-moment correlation at 0.05 level of significance.

III. Results Table 1: Caregivers' Burden of Cancer Patients								
S/N	Caregivers' Burden of Cancer Patients	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Mean	SD
1	You feel you should be doing more for your relative	7(7.4)	14(14.7)	34(35.8)	23(24.2)	17(17.9)	2.31	1.15
2	You feel you could do a better job in caring for your relative	9(9.5)	21(22.1)	25(26.3)	25(26.3)	15(15.8)	2.17	1.22
3	You feel stressed between caring for your relative and trying to meet other responsibilities for your family or work	17(19.7)	10(10.5)	30(31.6)	30(31.6)	8(8.4)	2.02	1.22
4	You feel that because of the time you spend with your relative that you don't have enough time for yourself	13(13.7)	16(16.8)	36(37.9)	25(26.3)	5(5.3)	1.93	1.09
5	Your relative (client) ask for more help than he/she needs	21(22.1)	14(14.7)	33(34.7)	23(24.2)	4(4.2)	1.74	1.18
6	You feel your relative is depended on you	27(28.4)	11(11.6)	28(29.5)	20(21.1)	9(9.5)	1.72	1.33
7	You feel that you don't have enough money to take care of your relative in addition to the rest of your expenses	22(23.2)	17(17.9)	29(30.5)	21(22.1)	6(6.3)	1.71	1.23
8	You feel that you don't have as much privacy as you would like because of your relative	22(23.2)	21(22.1)	31(32.6)	16(16.8)	5(5.3)	1.59	1.17
9	You feel that your relative seems to expect you to take care of him/her as if you are the only one, he/she could depend on	25(26.3)	14(14.7)	36(37.9)	15(15.8)	5(5.3)	1.59	1.19
10	You feel embarrassed over your relative	27(28.4)	15(15.8)	33(34.7)	16(16.8)	4(4.2)	1.53	1.19
11	You feel your health has suffered because of your involvement with your relative	26(27.4)	20(21.1)	32(33.7)	11(11.6)	6(6.3)	1.48	1.19
12	You are afraid what the future holds for your relative	34(35.8)	15(15.8)	23(24.2)	13(13.7)	10(10.5)	1.47	1.38
13	You feel strained when you are around your relative	28(29.5)	19(20.0)	28(29.5)	17(17.9)	3(3.2)	1.45	1.18
14	You feel uncertain about what to do about your relatives	32(33.7)	17(17.9)	26(27.4)	16(16.8)	4(4.2)	1.40	1.23
15	You feel uncomfortable about having friends over because of your relative	39(41.1)	14(14.7)	18(18.9)	18(18.9)	6(6.3)	1.35	1.35
16	You feel that your social life has suffered because you are caring for your relative	37(38.9)	15(15.8)	25(26.3)	13(13.7)	5(5.3)	1.31	1.26
17	You feel that you was unable to take care of your relative much longer	40(42.1)	14(14.7)	20(21.1)	17(17.9)	4(4.2)	1.27	1.29
18	You feel burdened in caring for your relative	35(36.8)	20(21.1)	22(23.2)	15(15.8)	3(3.2)	1.27	1.21
19	You feel you have lost control of your life since your relative's illness	35(36.8)	18(18.9)	28(29.5)	11(11.6)	3(3.2)	1.25	1.17
20	You feel that your relative currently affects our relationships with other family members or friends in a negative way	38(40.0)	17(17.9)	25(26.3)	13(13.7)	2(2.1)	1.20	1.17
21	You wish you could leave the care of your relative to someone else	41(43.2)	15(15.8)	27(28.4)	9(9.5)	3(3.2)	1.14	1.17
22	You feel angry when you are around your relative	48(50.5)	13(13.7)	27(28.4)	4(4.2)	3(3.2)	0.96	1.12
	Average Mean = 1.54							

Table 1 revealed an overall low level of perceived burden among informal caregivers of cancer patients with an average mean of 1.54 on the scale of 5 points. Also, the construct with the highest mean score was feeling of doing more for relative (mean = 2.31). This was closely followed by doing a better job in caring for

the relative (mean = 2.17). on the other hand, ranked the third most important burden was feeling of stressed between caring for relative and trying to meet other responsibilities for family and work (mean = 2.02). Overall, there was a low level of perceived burden among informal caregivers of cancer patients in the study area with an overall mean of 1.54 on the scale of 5 points.

Other issues raised include feeling that because of the time one spend with relative, an individual don't have enough time self (Mean = 1.93); relative (client) ask for more help than they need (Mean = 1.74); feeling relative is depended on an individual patient (Mean = 1.72); feeling that one don't have enough money to take care of relative in addition to personal expenses (Mean = 1.71); feeling that one don't have as much privacy as one would like because of relativeandfeel that one's relative seems to expect him/her to take care for him/her as if an individual is the only one, he/she could depend on(Mean = 1.59);

Others concerns include feeling embarrassed over one's relative (Mean = 1.53); feeling an individual's health has suffered because of involvement with relative (Mean = 1.48); fear of what the future holds for ones' relative (Mean = 1.47); feeling strained when around the relative (Mean = 1.45); feeling uncertain about what to do about relatives (Mean = 1.40); as well as feeling uncomfortable about having friends because of relative (Mean = 1.35); feeling that ones' social life has suffered because of caring for your relative (Mean = 1.31); feeling that one was unable to take care of your relative much longer and feeling burdened in caring for relative(Mean = 1.27); there was also feeling of lost control over ones' life because of relative's illness (Mean = 1.25); feeling that relative currently affects personal relationships with other family members (Mean = 1.20) wishing one could leave the care of relative to someone else (Mean = 1.14) and feeling of angry when around the relative (Mean = 0.96).

Table 2: Quality of Life of Caregivers' of Cancer Patients								
S/N	Quality of Life of informal caregivers	Very	Poor	Neither	Good	Very	Mean	SD
		poor		poor nor		Good		
				good				
1	How would you rate your quality of life?	3(3.2)	5(5.3)	29(30.5)	36(37.9)	22(23.2)	3.80	0.86
2	How satisfied are you with your health?	5(5.3)	14(14.7)	20(21.1)	39(41.1)	17(17.9)	3.52	1.11
6	To what extent do you feel your life to be meaningful?	5(5.3)	9(9.5)	28(29.5)	42(44.2)	11(11.6)	3.47	1.00
11	Are you able to accept your bodily appearance?	6(6.3)	13(13.7)	30(31.6)	22(23.2)	24(25.3)	3.47	1.19
9	How healthy is your physical environment?	3(3.2)	13(13.7)	38(40.0)	28(29.5)	13(13.7)	3.43	0.90
23	How satisfied are you with the conditions of your living place?	4(4.2)	17(17.9)	28(29.5)	29(30.5)	17(17.9)	3.40	1.11
19	How satisfied are you with yourself?	4(4.2)	25(26.3)	16(16.8)	32(33.7)	18(18.9)	3.37	1.19
8	How safe do you feel in your daily life?	3(3.2)	18(18.9)	30(31.6)	39(41.1)	5(5.3)	3.36	0.85
16	How satisfied are you with your sleep?	5(5.3)	22(23.2)	20(21.1)	31(32.6)	17(17.9)	3.35	1.17
7	How well are you able to concentrate?	3(3.2)	18(18.9)	31(32.6)	31(32.6)	12(12.6)	3.33	1.03
18	How satisfied are you with your capacity for work?	5(5.3)	18(18.9)	25(26.3)	35(36.8)	12(12.6)	3.33	1.09
20	How satisfied are you with your personal relationships?	2(2.1)	27(28.4)	17(17.9)	37(38.9)	12(12.6)	3.32	1.08
21	How satisfied are you with your sex life?	5(5.3)	17(17.9)	27(28.4)	35(36.8)	11(11.6)	3.32	1.07
17	How satisfied are you with your ability to perform your daily living activities?	5(5.3)	24(25.3)	18(18.9)	34(35.8)	14(14.7)	3.29	1.16
22	How satisfied are you with the support you get from your friends?	3(3.2)	20(21.1)	28(29.5)	35(36.8)	9(9.5)	3.28	1.01
24	How satisfied are you with your access to health services?	4(4.2)	24(25.3)	16(16.8)	43(45.3)	8(8.4)	3.28	1.07
10	Do you have enough energy for everyday life?	4(4.2)	14(14.7)	36(37.9)	34(35.8)	7(7.4)	3.27	0.95
15	How well are you able to get around?	7(7.4)	15(15.8)	29(30.5)	39(41.1)	5(5.3)	3.21	1.02
5	How much do you enjoy life?	4(4.2)	19(20.0)	36(37.9)	35(36.8)	1(1.1)	3.11	0.88
13	How available to you is the information that you need in your day-to-day life?	4(4.2)	16(16.8)	48(50.5)	26(27.4)	1(1.1)	3.04	0.81
25	How satisfied are you with your mode of transportation?	5(5.3)	35(36.8)	21(22.1)	31(32.6)	3(3.2)	2.92	1.02
4	How much do you need any medical treatment to function in your life?	14(14.7)	27(28.4)	39(41.1)	14(14.7)	1(1.1)	2.59	0.95
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	14(14.7)	34(35.8)	27(28.4)	18(18.9)	2(2.1)	2.58	1.03
12	Have you enough money to meet your needs	17(17.9)	22(23.2)	37(38.9)	16(16.8)	3(3.2)	2.58	0.97
12	To what extent do you have the opportunity	14(14.7)	35(36.8)	31(32.6)	12(12.6)	3(3.2) 3(3.2)		
	for leisure activities?						2.53	1.00
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	12(12.6)	49(51.6)	22(23.2)	9(9.5)	3(3.2)	2.39	0.94

Fable 2: Quality of Life of Careg	givers' of Cancer	Patients
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Average Mean = 3.17

Tale 2 revealed a moderate level of quality of life of informal caregivers with an average mean of 3.17 on the scale of 5 points. An analysis of the individual responses on quality of life of informal caregivers revealed that the respondents agreed with the fact that there was a good quality of life of informal caregivers in OAUTHC. The 5 most notable responses include satisfied with ones' health (mean = 3.52), satisfaction with extent of meaningful life (mean = 3.47), accepting ones' bodily appearance (mean = 3.47) including an individual's physical environment (mean = 3.43); satisfaction with the conditions of living place (mean = 3.40) and satisfied with oneself (mean = 3.37) among others.

Table 3. Correlation between	nerceived burdens of care and	quality of life of informal caregivers
Table 5: Correlation between	perceived burdens of care and o	quality of me of informal caregivers

Parameters	Ν	Mean	Std. Deviation	r	P value	Remarks
Caregivers' Burden of Cancer patients	95	33.84	17.347	412**		
Quality of Life of caregivers' of cancer patients	95	82.36	16.518	412	0.001	sig

Table 3 revealed the mean distribution of both caregivers' burden of cancer patients (mean = 33.84) and quality of life of caregivers' of cancer patients (mean = 82.36). The difference in the mean scores is based on the fact that the two parameters did not have equal number of measuring items. Hence, this is understandable for comparison sake. The table also shows that there was a significant negative relationship between perceived burden and quality of life of informal caregivers (r = -0.412, P<.05). This implies that too much Caregivers' Burden of Cancer patients can have a significant negative Quality of Life of caregivers' of cancer patients in OAUTHC.

IV. Discussion of findings

The findings from the current study revealed a rich outcomes. For example, majority of the respondents from both LAUTCH and OAUTHC were in their active working groups below 50 years. Implying that the respondents (care givers) were people with high level of energy and vigour needed to care for the sick and the injured. Findings from the current study revealed that the three most important burdens were: feeling of doing more for relative (mean = 2.31); doing a better job in caring for the relative (mean = 2.17) and feeling of stressed between caring for relative and trying to meet other responsibilities for family and work (mean = 2.02). Scholars have indicated that informal caregivers are a critical resource to their care recipients and an essential component of the health care system, yet their role and importance to society as a whole have only recently been appreciated. An informal caregiver, often a family member, provides care, typically unpaid, to someone with whom they have a personal relationship (Akgul & Ozdemir, 2014). Indeed it has been reported in the literature that caregivers are people who, during illness and treatment, are the most involved in the care of patients and help them to adapt and manage their chronic disease (Abbasi, et al., 2017). Caregivers are usually family members or friends of the patient who take care of the patients daily and support them physically, mentally and socially, but do not receive any reimbursement for the care they provide (Suri, et al., 2014; Umaru, Omoyemi, & Ade, 2017; van Pletzen & MacGregor, 2013).

Furthermore, findings from this study have revealed that family caregivers are usually relatives, partners, or close friends who have a significant personal relationship with the patient and provide a broad range of assistance for the person with a chronic or disabling condition (Blum & Sherman, 2014; Hirdes, Freeman, Smith, & Stolee, 2012).

It was found that there was a good level of quality of life of informal caregivers in Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC) with an overall mean of 3.17 on the scale of 5 points. An analysis of the individual responses on quality of life of informal caregivers revealed that the respondents agreed with the fact that there was a good quality of life of informal caregivers in OAUTHC. The 5 most notable responses include satisfied with ones' health (mean = 3.52), satisfaction with extent of meaningful life (mean = 3.47), accepting ones' bodily appearance (mean = 3.47) including an individual's physical environment (mean = 3.43); satisfaction with the conditions of living place (mean = 3.40) and satisfied with oneself (mean = 3.37) among others.

Besides, investigators have endeavoured to identify who informal caregivers are, what roles they play in providing care, what needs they have, and what strategies might best support their efforts. Individual autonomy, truth, and open communication are the core of the dominant bioethical framework in the western world. However, the perception of autonomy and openness as empowering and providing a sense of control tends to be blind to the fact that the decision-making process of the individual is involved in a complex relationship with the social surroundings. In Islam, families prefer caregivers to live with uncertainty about the fate of one of its members rather than to confront a poor prognosis or "death threat" (Surbone & Baider, 2013). The findings shows that there was a significant negative relationship between perceived burden and quality of life of informal caregivers (r = -0.412, P<.05). This implies that too much Caregivers' Burden of Cancer patients can have a significant negative Quality of Life of caregivers' of cancer patients in OAUTHC. Besides, there was a significant mean difference of -10.514 based on gender. This implies that the average level of care burdens among family caregivers of cancer patients between OAUTHC and LAUTECH hospitals based on gender is different greatly. Literature have shown that decrease in the caregiver's quality of life influences the quality of care and thus the Quality of Life (QOL) of the patient. Research on family caregivers has consistently demonstrated that increased caregiver burden is related to reduce mental and physical health (Morimoto, Schreiner, & Asano, 2016). Caregiving can significantly influence the QOL of these caregivers because of the fear of losing their loved one, the substantial impact of caring on the financial well-being of caregivers, and restrictions regarding their social life (Chen, Chu, & Chen, 2014; Edwards & Ung, 2016;Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2015).

Lastly, the outcome of this study revealed a significant differences in levels of quality of life among family caregivers of cancer patients between OAUTHC, Ile-Ife and LAUTECH hospital, Osogbo based on gender. Studies have shown that quality of life may decrease, resulting in psychological problems that may lead to neglect both of caregiver health and that of the patient (Ferhano glu, Bolaman, & Soysal, 2013).

V. Conclusion

Based on the findings of this research, it was concluded that informal caregivers are a critical resource to their care recipients and an essential component of the health care system, yet their role and importance to society as a whole have only recently been appreciated. This study revealed that the level of burden of caregivers of cancer patient is low while the quality of their live is on the moderate, but it could be seen that caregivers' burden of cancer patients have a significant negative impact on quality of life of caregivers' of cancer patients

VI. Recommendations

The following recommendations are suggested for policy:

- 1. Family members and friends of the sick person should be ready and willing to carry the burdens of care and quality of life of informal caregivers in all hospital settings so that this will not only affect a single member of the family but all family members.
- 2. Policy makers at the different health facilities should make available support medical and social services at the disposal of the informal caregivers in all hospital settings in Nigeria
- 3. Government at all levels should provide more funds for the care of the sick and the injured

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