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Research Paper

Quality of Life and Caregiving Burden among Primary Caregivers of Patients Undergoing Haemodialysis in Two Teaching Hospitals, Osun State

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Abstract: *Primary caregivers of patients undergoing haemodialysis may assume diverse responsibilities during the patient's trajectory and the consequence can be highly burdensome with negative impact on the quality of life. This study aimed at assessing the quality of life and care giving burden among primary caregivers of patients undergoing haemodialysis in two teaching hospitals in Osun State. A descriptive cross-sectional survey was employed. A self-administered structured questionnaire was used to collect data using total enumeration sampling method. The sample size was one hundred and twenty-six (126); 49 from UNIOSUNTH and 77 from OAUTHC. Data collected were analysed using descriptive statistics and Chi square analysis was used to test the hypotheses at a significant level of 0.05 alpha using Statistical Package for the Social Sciences (SPSS) version 23. Findings from this study revealed that 77% of respondents were female, 48.4% were between the age of 31-60 years, 42.1% were married while 31.8% respondents earn above N1,000,000 per annum. Eighty-one (64.3%) caregivers had high level of care burden score, 70% caregivers had low level of quality-of-life score. The study revealed a correlation between caregiving burden and quality of life among primary caregivers of haemodialysis patients (x^2 = 77.903, p = .000). There is significant relationship between caregivers' socio-demographic characteristics (x^2 = 30.765, p = .001); age (x^2 = 21.008, p = .000); educational status (x^2 = 54.411, p = .000) and income per annum is (x^2 = 39.432, p = .000) and quality of life among primary caregivers. A significant negative relationship also existed between caregivers' socio-demographic characteristics - gender is (x^2 = 30.765, p = .001); age (x^2 = 21.008, p = .000); educational status (x^2 = 54.411, p = .000) and income per annum is (x^2 = 39.432, p = .000) and caregiving burden among primary caregivers studied. In conclusion, primary caregivers of haemodialysis patients experienced a significant level of care burden that negatively impacted their quality of life and patient's health. Health care workers and policy makers should pay more attention to the needs of primary caregivers.*

Key words: *Caregiving Burden, Haemodialysis, Care recipient, Primary Caregivers, Quality of life.*

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I. INTRODUCTION

Primary caregivers of patients undergoing haemodialysis may assume diverse responsibilities during the patient's trajectory and the consequence can be highly burdensome with negative impact on the quality of life. Haemodialysis is the most widely used mode of renal replacement therapy in acute or chronic kidney failures and a lifelong treatment in end stage renal disease, yet it is physically and psychologically demanding as it imposes many restrictions on patients with physical, psychological, social, and economic consequences [1][2]. The global dialysis population is growing rapidly, especially in low-income and middle-income countries. There has been an increased recognition of the importance of significant roles that primary caregivers play in the support of patients undergoing haemodialysis for coping and care effectiveness. Many dialysis patients rely on the primary caregivers for their daily activities and medical care, since many of the patients have some activity intolerance and cognitive impairment and are therefore unable to look after themselves [3].

Primary caregivers are essential for the health, safety, support and independence of many patients and incur financial and other personal cost such as managing medications, liaising with health carers, helping to bathe or dress, meal preparation [2]. As a result of this, they suffer increased burden and lower quality of life compared to the general population [4]. According to [5] chronic diseases are lifelong, continuing situations that require continuous treatment, periodic monitoring, support and maintenance to maximize the functionality of the individual. This brings different responsibilities and burdens to the people who carry on the caregiving at home or in the hospital environment [6]. In other words, the patients on haemodialysis suffer some degree of self - care and other deficiencies which necessitate the need for significant others to fill the gap of care deficiency that patients suffer. Usually, the patient on haemodialysis needs more support and help during the initial time of starting dialysis because it is a new situation that needs to be coped with considering the high cost of haemodialysis therapy [5].

Caring role, in acute and chronic diseases such as having patients undergoing haemodialysis put some pressure on the primary caregivers with negative effect on their health. Difficulty in caregiving is a multidimensional response with physical, psychological, emotional, social and economic consequences associated with caregiving. Due to their caring responsibilities, caregivers have problems such as not having enough time for themselves, chronic fatigue, sleeping disorder, nutritional deficiency, muscle aches, concentration difficulty, anxiety, depression, substance abuse, fatigue, social isolation, deterioration of family relations and financial problems [7]. Patients on dialysis continue to bear a high burden of disease, shortened life expectancy, and report a high symptom burden and a low health-related quality of life that puts higher care burden and negatively affects primary caregivers' quality of life [2]. Caregivers' burden describe the physical, financial, and emotional cost of care which reflects the permanent difficulty, stress, and negative experiences derived from the provision of care to the patient [8]. Haemodialysis is an incredibly stressful procedure, which must be faced jointly by the patients and their families. The primary caregivers' responsibility to haemodialysis care recipients is tasking and many caregivers experience emotional challenges, for instance anxiety, fear of something bad happening to the patient, depression, and the burden of caregiving to the patient [6].

Several factors have been associated with different experiences of primary caregiver burden such as living with the patient, age, gender, education, socioeconomic status, relationship to the patient and comorbidity. The burden on caregivers of chronically ill patients has received less attention and commonly focuses on psychiatric illness such as dementia, breast cancer and with limited research interest considering caregiver burden in CKD and haemodialysis [6]. Having someone living on haemodialysis affects family members, spouse, friends, colleagues, etc. Fear of the disease and its treatment impacts feelings of helplessness, ambiguity about the future, anxiety, sadness, anger, grieving reactions, economic worries, psychological stress in interpersonal relationships, and fear of death are among the major psychosocial burden [9][10].

However, the complexity and many complications of haemodialysis treatment on patients undertaking haemodialysis, cause the caregivers and their family members to experience a high level of care burden, in a way that, their overall health is influenced to various degrees. [11][12]. Studies have established that primary caregivers of haemodialysis patients are under physical, emotional, and financial pressure from caring for patient that negatively affects their health and quality of life. Higher caregiving burden has been found to result in lower quality of life of primary caregivers [13]. According to [8], caregiving negatively affects quality of life of the primary caregiver, impairs family and work organization, decreases participation in social activities, and causes emotional stress. Mashayekhi, et al [8] reported that the primary caregivers do neglect their own needs devote most of their time to making appointments for physician visits, transport to dialysis center, and accompanying patient during dialysis, and preparing renal diet while providing care to the dialysis patient due to the routine caregiving tasks. In view of this, the researcher seeks to assess the quality of life and caregiving burden among primary caregivers of patients undergoing haemodialysis in two teaching hospitals, Osun State, Nigeria. This study was guided by the following questions;

i. What is the level of care giving burden among primary caregivers of patients undergoing haemodialysis?
ii. What is the quality-of-life status among primary caregivers of patients undergoing haemodialysis?

II. MATERIALS AND METHODS

Design: The study employed the descriptive survey research design to assess the quality of life and caregiving burden among primary caregivers of patients undergoing haemodialysis. The study population comprised Primary caregivers of haemodialysis patients in the two teaching hospitals in Osun state. The sample consisted of One hundred and twenty-six (126) primary caregivers of patients undergoing haemodialysis in the two teaching hospitals forty-nine (49) in UNIOSUNTH and seventy-seven (77) in OAUTHC) using purposive sampling and consecutive sampling methods.

Settings: The study was conducted at Osun State University Teaching Hospital Osogbo (OSUNTH) and Obafemi Awolowo University Teaching Hospital Complex (OAUTHC), Ile- Ife both in Osun State.

Instrument: The instrument used for this study were adapted questinnaire- Caregiver Burden Inventory by Novak & Guest, 1989 (CBI) and World Health Organization Quality of Life Questionnaires (WHOQOL-BREF). The data gathering tool consisted of a three-part questionnaire including socio-demographic characteristics consisting of 5 items such as age, sex, the amount of income, education level and caregiver's marital status; the Caregivers Burden Inventory (CBI) questionnaire for caregiving burden consisiting of 24 items and five sub-scales of time-dependence, developmental, physical, social, and emotional care burdens. Scores for each item were evaluated using a 5-point Likert scale ranging from 0 – 4. [Not at all (score 0), a little (score 1), Moderately (score 2), Much (score 3) and very much (score 4). The scores of the questionnaire ranged from 24 to 120, with scores of 24 - 47 indicating low Burden, 48 - 71 moderate Burden, 72 - 95 high Burden and 96 -120 very high Burden; and WHOQOL- BREF for quality-of-life questionnaire consisting of 12 items covering four areas of physical, psychological, social relationship and environ-mental health to assess caregivers' quality of life. The questionnaire is based on the 5-point Likert's scale, using response - Not at all (1), A little (2), Moderately (3), Very Much (4) and Extremely (5).Qol was rated as high, moderate and low.

To ensure the content and face validity of the instrument, adapted questionnaire was given to the Supervisor and Methodologist for review, correction, and appraisal. The corrected instrument was administered to primary caregivers of patients undertaking haemodialysis in LAUTECH Teaching Hospital, Ogbomoso. To reduce response error a pilot study was conducted among 10 primary care giver in another setting with similar characteristics with the research setting.

Internal Reliability of the questionnaire was determined using Cronbach Alpha coefficient and value obtained was 0.94 for care giver burden instrument and 0.89 for quality of life instrument at 0.05 level of significane.

Statistical Analysis: Data collected were coded and analysed using statistical package for social sciences (IBM SPSS) version 23.0; variables were analyzed using descriptive statistics of table, frequency, percentages mean score, standard deviation while hypothesis were tested using chi-square.

Ethical Consideration: Ethical approval for the study was collected from Babcock University Health Research Ethics Committee (BUHREC) with reference number 278/21. Also, the researcher had obligation to the subjects by getting their informed consent consistent with the principle of individual autonomy. Their voluntary participation, anonymity, privacy and confidentiality when collecting the data were also guaranteed. The respondents' right to decline participation or withdraw their participation anytime they wish to was reiterated.

III. RESULTS

Table 4.1 Socio-demographic profile of respondents

SN	Variable		N = 126			
			OSUTH (N = 49)		OAUTHC (N =77)	
			Freq.	%	Freq.	%
1	Gender	Female	32	65.3	65	84.4
		Male	17	34.7	12	15.6
2	Age	Less than 30 years	23	46.9	24	31.2
		31-60 years	21	42.9	40	51.9
		60 years above	5	10.2	13	16.9
3	Marital Status	Single	13	26.5	17	22.1
		Married	23	46.9	30	39.0
		Divorced/separated	10	20.4	25	32.5
		Widow/widower	3	6.1	5	6.5
4	Occupation	Unemployed	10	20.4	14	18.2
		Artisan	5	10.2	3	3.9
		Trader	15	30.6	20	26.0
		Civil servant	9	18.4	29	37.7
		Dependant	10	20.4	11	14.3
5	Income per annum	Below ₦100,000	7	14.3	7	9.1
		₦101,000 – ₦500,000	19	38.8	23	29.9
		₦501,000 – ₦1,000,000	14	28.6	16	20.8
		above ₦1,000,000	9	20.4	31	40.3

Sixty-one point one of the respondents were from OAUTHC while 49(38.9%) were from OSUNTH. The findings revealed that 32 (65.3%) and 65 (71.4%) of the respondents were female in the two centers OSUNTH and OAUTHC respectively. Majority were between the ages of 31 to 60 years in OSUNTH (42.9%) and OAUTH (51.9%). The marital status of the participants shows that 23 (46.9%) in OSUNTH and 30 (39%) in OAUTH were married. Their occupation shows that most of them in OSUNTH (30.6%) were traders and in OAUTH (37.7%) were civil servants. Their yearly income shows that 20.4% of the participants in OSUNTH earned above ₦1,000,000 and 40.3% in OAUTH earned above ₦1,000,000.

Table 2: Level of caregiving burden among respondents

Caregiving burden	Frequency	Percentage
Little	18	14.3
Moderate	27	21.4
Much	81	64.3
Total	**126**	**100**

Sixty-four point three percent of the respondents had much (high) level of care burden, 27 (21.4%) had moderate care burden scores and 18 (14.3%) had low score as presented in Table 2.

Table 3: Quality of Life among Caregivers of respondents (N = 126)

Quality of life	Frequency	Percentage
Low	88	70
Moderate	25	20
High	13	10
Total	**126**	**100**

Eighty-eight (70%) of caregivers had low level of quality of life score, 25 (20%) had moderate level of quality of life score and 13 (10%) had high level of quality of life score. Quality of life of caregiver is presented in Table 3.

Table 4: Relationship between caregivers' socio-demographic characteristics and care giving burden

	Caregivers' socio-demographic characteristics		Caregiver Burden						
			Not at all	A little	Moderate	Much	Very much	X^2	P
1	Gender	Female	-	20	19	33	23	37.059	.000
		Male	7	-	6	16	-		
2	Age	Less than 30 years	3	12	15	8	9	18.081	.000
		31-60 years	-	-	11	30	20		
		60 years above	-	3	3	12	-		
3	Educational status	No formal education	-	3	1	3	3	29.123	.000
		Primary education	1	3	5	6	9		
		Secondary level	3	6	8	16	13		
		Tertiary level	-	9	8	15	14		
4	Income per annum	Below ₦100,000	-	-	-	9	5	56.888	.000
		₦101,000 – ₦500,000	-	7	8	14	13		
		₦501,000 – ₦1,000,000	-	-	8	12	10		
		above ₦1,000,000	-	5	10	14	11		

As presented in Table 4, the chi-square value obtained for gender is (x^2 = 37.059, p = .000); age (x^2 = 18.081, p = .000); educational status (x^2 = 29.123, p = .000) and income per annum is (x^2 = 56.888, p = .000) at the significant levels of less than 0.05 for the caregivers' socio-demographic characteristics (gender, age, education and financial status). Since these p-values were equal to or less than 0.05 values, it could be said that gender age, education and financial status are correlates of care giving burden among primary caregivers. Therefore, there is a significant relationship between caregivers' socio-demographic characteristics (age, education and financial status) and care giving burden among primary caregivers of patients undergoing haemodialysis.

Table 5: Relationship between caregivers' socio-demographic characteristics and quality of life

Caregivers' socio-demographic characteristics			Quality of Life among Caregivers						
			Not at all	A little	Moderate	Very Much	Extreme	X^2	P
1	Gender	Female	6	16	21	33	21	30.765	.001
		Male	1	6	7	12	3		
2	Age	Less than 30 years	5	10	17	10	5	21.008	.000
		31-60 years	-	8	23	20	10		
		60 years above	2	1	10	3	2		
3	Educational status	No formal education	2	1	1	4	2	54.411	.000
		Primary education	3	1	8	3	9		
		Secondary level	-	9	12	16	9		
		Tertiary level	2	9	10	13	12		
4	Income per annum	Below ₦100,000	-	-	3	7	4	39.432	.000
		₦101,000 – ₦500,000	1	5	10	19	7		
		₦501,000 – ₦1,000,000	-	10	6	9	5		
		above ₦1,000,000	-	6	8	21	5		

As shown in Table 5, the chi-square value obtained for gender is (x^2 = 30.765, p = .001); age (x^2 = 21.008, p = .000); educational status (x^2 = 54.411, p = .000) and income per annum is (x^2 = 39.432, p = .000) at the significant levels of less than 0.05 for the caregivers' socio-demographic characteristics (gender, age, education and financial status). Since these p-values were equal to or less than 0.05 values, it could be said that gender age, education and financial status are correlates of quality of life among primary caregivers. Therefore, there is a significant relationship between caregivers' socio-demographic characteristics (age, education and financial status) and quality of life among primary caregivers of patients undergoing haemodialysis.

Table 4: Relationship between care giving burden and quality of life among respondents

		Quality of Life among Caregivers					**X^2**	**P**
		Not at all	**A little**	**Moderately**	**Very Much**	**Extremely**		
Caregiver Burden	Not at all	32	35	25	20	14	77.903	.000
	A little	31	16	44	15	20		
	Moderate	29	32	30	16	19		
	Much	9	13	17	30	57		
	Very much	10	22	26	37	31		

The chi-square value obtained for the relationship between care giving burden and quality of life among primary caregivers of patients undergoing haemodialysis is (x^2 = 77.903, p = .000). Since the p-value was equal to or less than 0.05 values, it could be said that there is a significant relationship between care giving burden and quality of life among primary caregivers of patients undergoing haemodialysis. Therefore, earlier set null hypothesis was rejected. The relationship was presented in Table 4.

IV. DISCUSSION

The findings from the study showed high level of caregiving burden among primary caregivers of patients undergoing heamodialysis as over two-third of the respondents reported that their care receiver needs their help to perform many daily tasks which made them to have inadequate sleep; get physically tired and ill. This negative experience resulting from the provision of care includes financial, physical and mental costs. This result is in tandem with the findings of [4] that increased distress on caregivers resulted in consequences such as family isolation, lack of hope for social support, disorders in family relations, and inadequate care of the patient, and eventually the patient may give up the treatment. However, according to [13], care burden affects caregivers' quality of life and may result in reduced care provision and deteriorating condition for patients with chronic illness. Moreso, the deterioration of patient's condition can increase care burden and cause a vicious cycle, if timely intervention is not undertaken, it may lead to a gradual exhaustion of the primary caregivers [13]. The findings from the study also revealed that caregiver burden is developed in the relationship when care-recipients depended totally on them for provision of all forms of care. This corroborate the report of [14] that the burden developed in the relationship the caregiving demand increased, especially among patients who lost their functional ability. As care-recipients' illness symptoms worsen, the time spent on providing caregiving increases, invariably encouraging care dependency and higher caregiver burden [12].

Furthermore, the finding from the study revealed low quality of life due to the stress of caring for their loved ones undergoing haemodialysis. According to [15], the disease progression in patients reduced physical well-being of their caregivers and this seriously affected patients' health and quality of life. This finding is also in tandem with the result of [15] that low quality of life in patients with epilepsy was related to low levels of caregivers' quality of life. Sajadi, et al. [9] also reported that primary caregivers were overwhelmed with caregiving as they must watch their care recipients constantly because they are dependent on them to perform many daily tasks. Additionally, caregivers, due to taking care of patients with chronic diseases, experienced psychological, physical, and social pressures and as a result, they experienced burnout, anxiety, and depression. Therefore, [16] stated that high level of caregiving burden is a predictor of low quality of life as all the respondents reported that their health had suffered due to caregiving and would wish they could escape from the role, some have physical illness and felt emotionally drained while others had moderate to very much problems with their marriage.

Findings from the study also showed a significant relationship between socio-demographic of gender, age, educational status and income characteristics, care giving burden and quality of life among primary caregiver of patients undergoing haemodialysis. This finding is consistent with the result of [11][12] that financial strain was the most common burden experienced by family caregivers as government support is non-existent. Contrary to the current study findings, [17][18] documented that family caregivers in developed economies enjoyed various forms of support from government, enabling them to continue caregiving without compromising their finances, health and wellbeing. Therefore, [12] stated that primary caregivers of patients on haemodialysis need to be supported by nurses during the caregiving process and nurses can increase caregivers' identification and knowledge of the disease as a way of preventing the family caregivers from being overwhelmed by their caregiving role.

Findings from the study further revealed a significant relationship between caregiving burden and quality of life among primary caregiver. The implication of this is that the more the burden the more negative effect it has on the caregivers' quality of life. This finding showed that ccaregivers of haemodialysis patients experience significant level of care burden, which may affect their quality of life. If there is an increase in care burden, there will be a decline in the quality of life of the caregiver. This finding is in tandem with the findings of [19] who reported a significant relationship between increased care burden and reduced care provided by primary caregivers because care burden have a very devastating impact on individuals.

In line with the result from the study, [8] reported a negative correlation between care burden and quality of life of caregivers of hemodialysis patients. It is believed that, due to the chronic nature of hemodialysis and the high caring need of hemodialysis patients, their caregivers tolerate a high level of care burden, which may lead to a decrease in the caregivers' quality of life. Jafari et al.[19] further reported that factors influencing care burden included variables such as level of patient's caring capability, the amount of task to be performed for care recipients, the level of support received with care giving, and the age of the caregiver, etc. These factors increase the level of caregiving burden on the caregivers with resultant reduction in their quality of life hence it is important that more attention be paid to the needs of caregivers and the provision of adequate social, economic, physical and psychological support for them is germane too [19].

V. CONCLUSION

Caregivers of patients undergoing haemodialysis may assume diverse responsibilities during the patient's trajectory, providing physical assistance, emotional and financial support. This can be highly demanding, emotionally stressful and financially draining and can impact on the caregivers' quality of life (QOL). The findings from the study revealed that there is high level of burden among primary caregivers of patients undergoing Hemodialysis which significantly affect their quality of life leading to low quality of life observed among the participants. Moreso, there is a significant relationship between socio-demographic characteristics, caregiving burden and quality of life of primary caregiver of patient undergoing Hemodialysis. Therefore, understanding the experiences of family members would help the nurses to provide better family-centered healthcare, which is one of the main goals of holistic health care because the nurses who are aware of the difficulties experienced by family caregivers are able to define the caring roles and upgrade the families' skills to adapt to changing situations and this improves the patients and their families' quality of life.

Limitation of the study: The study focused on primary care givers in the hospital, not including those that are financial constraint to present at the hospital.

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