

## Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients

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### SUMMARY

**BACKGROUND:** Caregivers of chronic kidney disease (CKD) patients play an important role in the management of the patients. Their psychological needs are often overlooked and unmet by the managing team. This study assessed the psychosocial well-being and quality of life (QoL) of caregivers of CKD patients in two hospitals in Southern Nigeria.

**METHODS:** Burden of caregiving, QoL, depression, and anxiety were assessed using standardized instruments; modified Zarit questionnaire, modified SF-12 questionnaire and Hospital Anxiety and Depression Scale (HADS) respectively among caregivers of CKD patients on maintenance haemodialysis and controls.

**RESULTS:** Fifty-seven caregivers of CKD patients and aged and sex-matched controls participated in the study. Anxiety was significantly higher in caregivers compared to control (31.6% vs 5.3%,  $p = 0.004$ ). Also, depression was significantly higher in caregivers (31.6% vs 3.5%,  $p < 0.001$ ). Twenty-eight (49.1%) of the caregivers had mild to moderate burden and 19 (33.3%) had a high burden. The mean Zarit burden score was higher in female caregivers compared to male caregivers ( $18.30 \pm 8.11$  vs  $14.83 \pm 6.70$ ,  $p = 0.09$ ). The mean depression score was higher in female caregivers compared to male caregivers ( $8.58 \pm 3.83$  vs  $6.75 \pm 3.80$ ,  $p = 0.08$ ). There was significant positive correlation between Zarit burden and hospital anxiety score ( $r = 0.539$ ,  $p < 0.001$ ) and depression score ( $r = 0.472$ ,  $p = 0.005$ ).

**CONCLUSION:** Depression, anxiety and burden were common among caregivers of CKD patients especially females compared to controls. Supportive interventions for these caregivers should be included in treatment guidelines in order to improve overall patients' outcome.

**Keywords:** caregiver, chronic kidney disease, burden, anxiety, depression

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### INTRODUCTION

Chronic kidney disease (CKD) is ranked among the 20 causes of death according to the Global Burden of Disease and is fast becoming a disease of public health importance.<sup>1</sup> It is associated with a huge socio-economic, physical and psychological burden on its sufferers and their caregivers.<sup>2-8</sup>

Most patients with advanced CKD, especially those requiring renal replacement therapy (RRT) such as haemodialysis (HD) and peritoneal dialysis often require assistance from other people for their activities of daily living. Caregivers are people who are majorly involved in caring and assisting patients during the period of disease.<sup>9</sup>

Previous studies have reported that caregivers have increased psychological problems, impaired quality of life and increased mortality.<sup>10-13</sup>

Caregivers of CKD patients play a pivotal role in their management such as medication administration, preparation of special diet, transportation to the hospital to keep up with clinic attendance, dialysis treatments and personal care.<sup>10</sup> Majority of these caregivers are family members or close friends who are not paid for their services and are hence designated informal caregivers. These caregivers have an increased risk of stress, depression, anxiety and poor quality of life in the course of providing care and support for their loved ones.<sup>14-17</sup> Deterioration in family relationships, stress and social isolation are frequently encountered by CKD caregivers.<sup>18-20</sup>

The psychological needs of these caregivers are often overlooked and unmet by the health workers attending to these CKD patients because most renal teams do not fully include these caregivers in their management plan. These situations may subsequently impact negatively on the overall outcome of the CKD patients.

There is still a paucity of information on the burden and psychosocial well-being of caregivers of CKD patients in Africa because most of the existing studies focused on the burden of CKD on its sufferers with only a few on their caregivers. This study, therefore, focused on caregivers of CKD patients in two hospitals in Southern Nigeria to assess their psychosocial well-being and quality of life.

The findings from this study, if significant will create awareness among physicians on the psychosocial needs of caregivers of these renal patients. This will also provide evidence on the need to include evaluation of caregivers in the treatment guidelines of CKD patients.

## METHODS

### Study location

This study was conducted in Kidney Care Centre, Ondo and the Renal unit of the Department of Internal Medicine, University of Benin Teaching Hospital, Benin City, Edo State, Nigeria.

### Study design

This was a cross-sectional study that spanned from February 2017 to August 2018. It involved 57 consecutive caregivers of CKD patients who were on maintenance HD and 57 age and sex-matched controls. The sample size was derived using the Fleiss formula<sup>21</sup> with the following information: confidence interval = 95%, power of study = 80%, the ratio of cases to control of 1:1. The percentage of control and caregivers with depression were 3.3 and 32 respectively from previous studies.<sup>22, 23</sup> This formula gave a minimum sample size of 27 CKD caregivers and 27 controls.

### Study participants

The study participants were caregivers of CKD patients on maintenance HD for at least 1 month who gave informed consent. The controls were hospital workers who were not caregivers of relatives with any chronic illness. Control participants with known anxiety disorder or depression were excluded.

### Data collection

This was done through the use of a researcher-administered questionnaire which sought information from both CKD patients and their caregivers on socio-demographic, monthly income, duration of illness and duration on

maintenance HD. Standardized instruments were used to assess the psychological well-being and quality of life of caregivers.

Quality of life, Psychological well-being (Depression and Anxiety) were assessed using the Modified SF-12 questionnaire and Hospital Anxiety and Depression Scale (HADS) respectively among caregivers and control participants.<sup>24-26</sup>

These instruments have been previously validated in maintenance HD population.<sup>24-26</sup> Modified Zarit questionnaire which has been previously validated in Nigerians was used to assess the burden of caregivers of CKD patients.<sup>27</sup>

### Standardized questionnaires

**Hospital Anxiety and Depression Scale:** This is based on a 14-item scale with 4 possible responses to each item. Each item is scored from 3 to 0 ('yes definitely' to 'not at all') with reversal of the scoring system for items 7 and 10. Anxiety score is based on items 2, 4, 6, 8, 11, 12, and 14 while depression score is based on items 1, 3, 5, 7, 9, 10, and 13. The total score range for both anxiety and depression is 0 to 21. Interpretation of total score; 0 - 7 = Non-case, 8 - 10 = Borderline case,  $\geq 11$  = Case.

**Zarit Burden questionnaire:** It consists of 12 items in 2 domains, personal strain and role strain. Each item is scored in five-point likert scale from 0 to 4 ('never' to 'almost always'). The total score range is 0 to 48 with a high score representing a higher feel of burden. Guidelines for interpretation of total score; 0-10= no to mild burden; 10-20= mild to moderate burden;  $>20$ = high burden.

The SF-12 is a multipurpose short form survey with 12 questions that assesses the mental and physical functioning and overall health-related quality of life (QoL). Questions 2 and 3 are scored from 1 to 3, questions 1, 8 and 12 are scored from 1 to 5, questions 9, 10, 11 are scored from 1 to 6, questions 4,5,6,7 are scored from 1 to 2. Total score ranges from 12-47.

### Ethical consideration

Ethical approval with Protocol Number ADM/E22/A/VOL.VII/14711 was obtained from Ethics and Research Committee of University of Benin Teaching Hospital for this study. Informed consent was obtained from all participants in the study. The study did not involve any therapeutic trials.

### Data analysis

Data generated were analyzed using the statistical package for social sciences (SPSS) version 17.0. Results were

presented in tabular form. Univariate analysis was used in the description of the characteristics of the study population. Discrete variables were presented as frequency and percentages.

Continuous variables were presented as means and standard deviation for data that were not skewed while the median and interquartile range were used to present continuous data that were skewed. Student t-test was used to compare mean values of data that were not skewed while Mann Whitney U was used to compare skewed data.

Chi-square test was used to determine the significance of observed differences for categorical variables. Pearson's correlation was used to determine the association between continuous variables that were not skewed while Spearman's correlation was used to determine the association between skewed continuous variables. P values < 0.05 were considered significant.

**RESULTS**

The study participants consisted of fifty-seven caregivers of CKD patients and fifty-seven age and sex-matched healthy adults who were not caregivers as controls. Each group was made up of 33 (57.9%) females and 24 (42.1%) males. A higher proportion of the study participants were young Christians, educated and employed. (Table 1)

The monthly income /earnings of participants were significantly higher in the control group (p = < 0.001). The controls were more educated than caregivers (p = < 0.001). Twenty-four (42.1%) of CKD caregivers were spouses to CKD patients, 19 (33.3%) were children while 13 (22.8%) were siblings and parents. All the caregivers except one were not paid for their services. (Table 1)

The median (IQR) duration of CKD and maintenance HD for the patients were 9 (5-36) months and 4 (2-7) months respectively. The median (IQR) HD session was 10 (5-22). (Table 2)

**Table 1:** Socio-demographic characteristics of study participants (N=114)

	Caregiver Group (n=57) n (%)	Control Group (n=57) n (%)	P value
<i>Gender</i>			
Male	24(42.1)	24(42.1)	1.000
Female	33(57.9)	33(57.9)	
<i>Age group</i>			
<40 years	30(52.6)	30(52.6)	1.000
≥40 years	27(47.4)	27(47.4)	
<i>Religion</i>			
Christianity	54(94.7)	55(96.5)	1.000
Islam	3(5.3)	2(3.5)	
<i>Level of Education</i>			
Primary	5(8.8)	0(0)	
Secondary	16(28.1)	1(1.8)	<0.001
Tertiary	36(63.1)	56(98.2)	
<i>Monthly Income (Naira)</i>			
< 20,000	16(28.1)	2(3.5)	<0.001
20,000-100,000	32(56.1)	5(8.8)	
> 100,000	9(15.8)	50(87.7)	
<i>Employment Status</i>			
Employed	49(86.0)	57(100)	0.014
Not employed	6(10.5)	0(0)	
Retiree	2(3.5)	0(0)	
<i>Relationship to patient</i>			
Spouse	24(42.1)		
Child	19(33.3)		
Sibling	8(14.0)		
Parent	5(8.8)		
Cousin	1(1.8)		
<i>Paid Caregiver</i>			
Yes	57(98.2)		
No	1(1.8)		

Anxiety was present in 31.6% of caregivers which was higher than 5.3% in controls (p = < 0.001).

**Table 2:** Characteristics of chronic kidney disease patients (N=57)

Parameters	n(%) / Median(IQR)
<i>Median Haemodialysis Sessions*</i>	10(5-22)
<i>Number of HD sessions</i>	
≤ 20	41(71.9)
21-40	11(19.3)
>40	5(8.8)
<i>Median Duration of CKD*</i>	9(5-36)
<i>Duration of CKD</i>	
< 12 months	31(54.4)
≥ 12 months	26(45.6)
<i>Median duration of MHD (months)</i>	4(2-7)
<i>Duration of MHD</i>	
≤ 6 months	43(75.4)
>6 months	14(24.6)

MHD (Maintenance Haemodialysis), CKD (chronic kidney disease), \*Expressed as Median(IQR)

Depression was higher in caregivers \*31.6%) than in controls (3.5%) (p = < 0.001). (Table 3)

**Table 3:** Prevalence of anxiety and depression in study participants (N=114)

	Caregiver Group (n=57) n (%)	Control Group (n=57) n (%)	P value
<i>Anxiety</i>			
Non Case	30(52.6)	51(89.5)	
Borderline Case	9(15.8)	3(5.3)	< 0.001
Case	18(31.6)	3(5.3)	
<i>Depression</i>			
Non Case	27(47.4)	51(89.5)	
Borderline Case	12(21.0)	4(7.0)	< 0.001
Case	18(31.6)	2(3.5)	

The median (IQR) anxiety score was significantly higher in caregivers compared with controls; 6(4-11) vs 3(1-5.5);  $p = < 0.001$ . Also, the median (IQR) depression score was significantly higher in caregivers compared to controls; 8(4-11.5) vs 3(1-5)  $p = < 0.001$ . There was no significant difference between mean QoL scores of caregivers and controls (30.23±2.20 vs. 30.65±2.83;  $p = 0.377$ ). (Table 4)

**Table 4:** Comparison of scores between caregiver and control group (N=114)

	Caregiver Group (n=57) Mean±SD/ Median(IQR)	Control Group(n=57) Mean±SD/ Median(IQR)	P value
Hospital Anxiety Score*	6(4-11)	3(1-5.5)	< 0.001
Hospital Depression Score*	8(4-11.5)	3(1-5)	< 0.001
Quality of Life Score	30.23±2.20	30.65±2.83	0.377

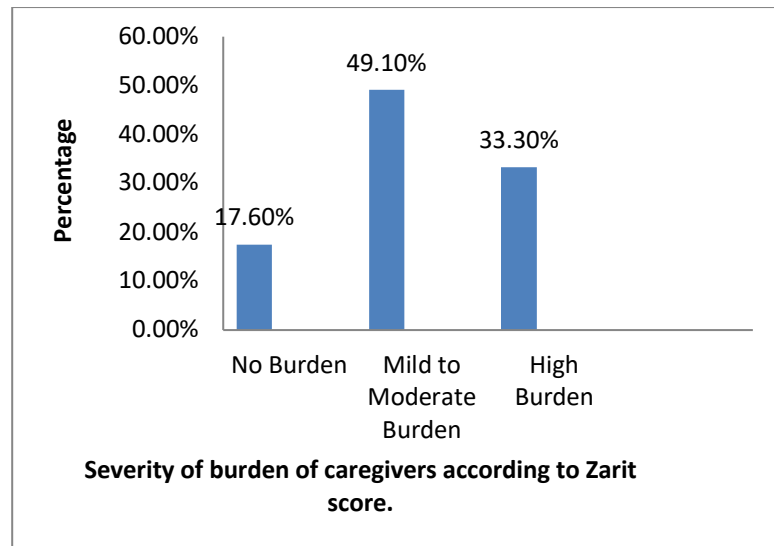
\*Expressed as Median (IQR)

The mean Zarit burden score was higher in female caregivers compared to male caregivers (18.30±8.11 vs 14.83±6.70,  $p = 0.09$ ). The mean depression score was higher in female caregivers compared to male caregivers (8.58±3.83 vs. 6.75±3.80,  $p = 0.08$ ). (Table

**Table 5:** Comparison between male and female caregivers (N=57)

Parameter	Male Caregivers (n=24)	Female Caregivers (n=33)	P value
Zarit Burden Score	14.83±6.70	18.30±8.11	0.092
Hospital Anxiety Score	6.5±4.40	7.94±3.87	0.196
Hospital Depression Score	6.75±3.80	8.58±3.83	0.080
Quality of Life Score	30.33±2.53	30.15±1.96	0.761

According to Zarit burden scores, 28 (49.1%) caregivers had mild to moderate burden and 19 (33.3%) had a high burden. (Figure 1)



**Figure 1:** Severity of burden of caregivers (N=57)

There was significant positive correlation between Zarit burden score and hospital anxiety score ( $r = 0.539$ ,  $p = < 0.001$ ), and Zarit burden score and depression score ( $r = 0.472$ ,  $p = < 0.001$ ). There was no significant correlation with QoL score ( $r = -0.175$ ,  $p = 0.194$ ). (Table 6)

**Table 6:** Correlation between Zarit burden score, hospital anxiety score, hospital depression score and quality of life score among caregivers

Parameter	r	P value
Hospital Anxiety Score	0.539	<0.001
Hospital Depression Score	0.472	<0.001
Quality of Life Score	-0.175	0.194

## DISCUSSION

This study showed that caregivers of CKD patients have increased burden and impaired psychosocial well-being compared to controls. These psychological needs may have a negative impact on the health of CKD patients and their caregivers. There were more female caregivers in this study which is similar to reports from some previous studies.<sup>15, 28, 29</sup> This finding also agrees with reports from other studies that involved caregivers of patients suffering from other chronic diseases such as stroke.<sup>27, 30</sup> The higher proportion of female caregivers may be due to the fact that females are more likely to be empathetic towards sick relatives compared to males. Also, it may also be a reflection of societal and cultural demands on females, especially in Africa.

The majority (91.2%) of caregivers were educated to at least the secondary level. Majority (86%) of the caregivers in our study were employed unlike in the study by Hawamdehet al<sup>17</sup> where 58% were unemployed. This suggests that the additional responsibility of caregiving to their CKD relatives may likely cause additional burden and stress for them.

The majority (98.2%) of the caregivers in this study were not being paid for their services which is similar to the report of a study by Imarhiagbe et al<sup>27</sup> that involved caregivers of stroke survivors in Edo State, Nigeria. This may be due to strong family ties embedded in the African tradition and culture where people take it as their responsibility to cater for their sick relatives without receiving a monetary reward.

The highest proportion (42.1%) of caregivers in our study were spouses of the CKD patients similar to findings in some previous studies.<sup>15,29-31</sup> This finding is however different from the study by Oyegbile et al<sup>16</sup> who reported that the majority of caregivers in their study were children of the CKD patients.

The mean hospital anxiety score of caregivers was significantly higher than that of the controls. Also, the prevalence of anxiety was significantly higher in caregivers compared to the controls (31.6% vs. 5.3%). This prevalence of anxiety in caregivers in our study was lower than the 38.1% reported by Pereira et al.<sup>32</sup> In the same vein, mean hospital depression score was significantly higher in the caregivers compared to the controls.

About thirty-two percent of caregivers had depression while 3.5% of the controls had depression. The prevalence of depression among caregivers in this study is similar to the 32% and 33% reported by Belasco et al<sup>23</sup> and Pereira et al<sup>32</sup> respectively but lower than the 58% reported by Hawamdeh et al<sup>17</sup>. The higher prevalence of depression in the study by Hawamdeh et al<sup>17</sup> compared to our study may be due to the fact that a significant proportion of caregivers in their study were unemployed unlike other studies where almost all the caregivers were gainfully employed. Dooley et al<sup>33</sup> and Yoo et al<sup>34</sup> have reported a significant association between employment and depression.

There was no significant difference in the QoL scores of caregivers and controls. This is at variance to reports from other studies where QoL scores were lower in caregivers compared to controls.<sup>15,35-37</sup> However, the possible explanation for this could be because the CKD patients in our study have not been on maintenance haemodialysis for long duration of time unlike patients in these other studies.

The mean Zarit score for caregivers in this study was 18 which is comparable with 14 reported by Shimomoya et al<sup>38</sup>, but at variance with the mean score of 52.1 and 50.2 reported by Mollaoglu et al<sup>39</sup> and Oyegbile et al<sup>28</sup> respectively. This may be due to the fact that the modified Zarit questionnaire which has 12 questions was used in our study while the other studies used the unmodified Zarit questionnaire which has more questions and hence higher mean scores. Majority of the caregivers in this study had moderate to high burden which is similar to reports by Subhashina et al<sup>40</sup> and Mashayekhi et al.<sup>41</sup>

The mean Zarit burden score was higher in female caregivers than their male counterparts, although this was not statistically significant ( $p=0.092$ ). Oyegbile et al<sup>28</sup> did not find any significant difference in the mean Zarit burden scores between male and female caregivers in their study contrary to other studies who reported significantly higher burden scores in female caregivers.<sup>15,39-41</sup>

There was a significant association between Zarit burden score, hospital depression and anxiety score among the caregivers. This may imply that the burden of caring for CKD may affect the psychological well-being of these caregivers. In order to improve the psychological well-being of caregivers of CKD patients, measures must be put in place to reduce the burden experienced in the course of caring for their loved ones with CKD.

Support programs have been reported to help caregivers develop coping strategies that could reduce the burden of caregiving.<sup>42-44</sup> The caregivers of CKD patients must be seen by Clinicians as important stakeholders in the successful management of CKD patients, hence their psychological needs must be met by adopting this supportive approach. The limitation of this study is the relatively small sample size hence the findings of this study may not be generalized. However, this study has brought to the fore the burden and psychological needs of CKD caregivers in our settings and the need for physicians to include them in their management plans.

## CONCLUSION

Depression, anxiety and burden were common among caregivers of CKD patients especially females. Supportive interventions for these caregivers should be included in treatment guidelines in order to improve overall patients' outcome. There is also a need to develop a formal caregiver network that will include social workers and clinical psychologists.

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