
**Original Article**

## The Socioeconomic Burden of Family Caregivers of Patients with End-Stage Renal Disease in A Tertiary Hospital in North West, Nigeria: A Mixed Methods Study

**Emmanuel Ejembi Anyebe<sup>1\*</sup>, Hadiza Lawal<sup>2</sup>, Abubakar Isa<sup>3</sup>, Salamatu Hassan<sup>2</sup>, and Ruth Elejo Bello<sup>4</sup>**

<sup>1</sup>Department of Nursing Sciences, College of Health Sciences, University of Ilorin, Kwara State, 240001, Nigeria

<sup>2</sup>Paediatric Unit, School of Post Basic Nursing Programmes, Ahmadu Bello University Teaching Hospital, Zaria, 810107, Nigeria

<sup>3</sup>Department of Nursing Sciences, Ahmadu Bello University, Zaria, 810107, Nigeria

<sup>4</sup>School of Post-Basic Nephrology Nursing, University of Ilorin Teaching Hospital, Kwara State, 240001, Nigeria

**ARTICLE INFO**
**Article History**

Received 01 August, 2023

Accepted 22 November, 2023

Available online 5 December, 2023

**Keywords**

Family caregiver  
Burden of care  
End-stage kidney disease  
Socioeconomic burden  
Social life

**Corresponding Author**

*Emmanuel Ejembi Anyebe*, PhD,  
RN

*Department of Nursing Sciences,  
College of Health Sciences,  
University of Ilorin, Kwara State,  
Nigeria.*

*Phone Number: +2348036422771*

*Email: anyebe.ee@unilorin.edu.ng*

*Zip code: 240001*

**ABSTRACT**

Kidney diseases constitute one of the non-communicable diseases with significant global burden. Each year, about 1.7 million people die of kidney-related diseases. Chronic kidney diseases present a significant socio-economic and psychological burden for family members, especially the family caregivers. This study examined the social and economic burdens of family caregivers of patients with end-stage renal diseases, to bring to limelight the burden experienced by caregivers for possible interventions and the needed support. A mixed research method was adopted for the study. Data was collected using the modified Zarit Burden Interview (ZBI) and in-depth interviews from all 21 consecutive family caregivers. Data was analysed using IBM SPSS 23.0 for the quantitative data and thematic analysis for the IDIs. Results show that respondents suffer a huge socio-economic burden ranging from loss of social life (85.7%) to financial hardship (85.7%). Overall, respondents rate their burden as between moderate to severe range in caring for their sick ones. It is concluded that that caregivers of patients with end-stage renal disease experience a variety of socio-economic burdens in their caring roles, that require support (socially and economically). It is recommended that caregivers be better prepared psychosocially to enable them to cope effectively with the caring role. Health insurance coverage should be made available to cover more cost of managing people with end-stage renal disease to relieve the burden on the caregivers.

Please cite this article as: Anyebe, E.E., Lawal, H., Isa, A., Hassan, S. and Bello, R.E. (2023). The Socioeconomic Burden of Family Caregivers of Patients with End-Stage Renal Disease in A Tertiary Hospital in North West, Nigeria: A Mixed Methods Study. *Al-Hikmah Journal of Health Sciences*, 3(1), 1-9.

**Introduction**

Kidney disease is attributed to a laudable economic burden. It was presumed that high-income countries spend more than 2-3% of their annual healthcare

budget on the treatment of end-stage renal disease. Despite this money spent, less than 0.03% of the population receives the treatment (Liyanage, *et al.*, 2015). However, it was stipulated that if risk factors

can be averted, with early identification, chronic kidney disease can be prevented with inexpensive interventions (Luyckx, *et al.*, 2018). Where this is not achieved then there is a need for renal replacement therapy (dialysis) to sustain life. To address the burden of dialysis around the world, a round table discussion on dialysis economics was held at the first International Congress of Chinese Nephrologists in 2015 where it was agreed that the potential solution to cope with the heavy burden of dialysis includes prevention and retardation of the progression of Chronic Kidney Disease, wider use of home-based dialysis therapy especially peritoneal dialysis, promotion of kidney transplant and use of renal palliative care services (Li, *et al.*, 2017). Ogunde (2018) buttressed the global public health problem of CKD with a scale not fully appreciated in developing countries. It was estimated that about 70% of patients with end-stage renal disease will be living in developing countries like Sub-Saharan Africa (Starnifer, *et al.*, 2014). In Sub-Saharan Africa, more than 80% of the population is estimated to consume herbal medicines which are thought to have been associated with 35% of all new cases of acute kidney injury. Renal Replacement Therapy (RRT) as a treatment of choice is expensive and contributes a heavy burden on the health care system. Hemodialysis (HD) is more common in Africa than peritoneal Dialysis (PD) due to the cost of importing fluids and only seven countries in Sub-Saharan Africa offer renal transplants to their patients and this is mostly from a living donor (Naicker, 2013). Africa is said to have a high disparity between demand and supply of RRT (Okpechi, 2017) and in Nigeria it was reported that less than 1% of patients can afford treatment for more than three months due to financial constraints. The cost of dialysis ranges from \$110 -120 USD in Nigeria (Bamgboye, 2016) while the cost of renal transplant in Sub-Saharan Africa ranges between \$3,000-20,000 USD and in addition to financial constraints, there is a shortage of health personnel to provide such services. To dialyze per week an individual requires about 100,000NGN with out-of-pocket expenses and the National Health Insurance Scheme offers little or no support to the affected. The impact of chronic kidney disease is multi-dimensional. Thus, the challenges of families of patient with chronic kidney disease requires more search. Hence, the need for the study.

### Methods and Materials

**Research Design:** the study adopted a mixed method (quantitative and qualitative) design. This involved a descriptive cross-section design in combination with concurrent mixed research method, used to collect

both quantitative and qualitative data from the study participants.

**Research Setting:** The study was carried out in the Dialysis Unit of a 500-bedded Federal Government owned tertiary referral health facility in North West Nigeria. The hospital runs special clinics like Neurology, Paediatrics, and Oncology Clinics including a Renal Clinic, amongst others. It has a variety of health personnel who are specialists in various fields. Among the specialists are Nephrology Doctors and Nurses who offer healthcare services to patients with renal failure. The Renal Clinic offers Renal Replacement Therapy (RRT) or dialysis services for adults and children with chronic renal failure. This makes a suitable setting for this study.

**Target Population:** The target population consisted of all care givers of patients diagnosed with End Stage Renal Disease, undergoing dialysis in the Teaching Hospital at the time of data collection. The total population was drawn from the records in the dialysis unit of the hospital. A total of twenty-five patients were currently undergoing dialysis, consisting of both male and female patients of different age categories, religious and ethnic affiliations and social backgrounds. The targeted population included patients' significant others including spouses, sons and daughters, parents (fathers and mothers), siblings, and other family members such as uncles, aunts and cousins that are accessible and available to care for the patients.

**Sampling and Sampling Technique:** All family caregivers, including those for in- and out-patients, who are responsible for caring for the patient's undergoing dialysis in the hospital were selected through availability and convenience methods. A total of 21 family caregivers participated in the study.

**Instrument:** The Zarit Burden Interview (ZBI) tool was adapted for data collection. The ZBI was designed to determine the burden of caregiving by family caregivers and has been used by different researchers to conduct studies on chronic diseases. The ZBI is a 22-item questionnaire, covering 4 themes namely; psychological, physical and social and economic aspects of burden. The instrument has a scale of 5 gradings basically: never, rarely, sometimes, frequently and nearly always respectively.

Also, a semi-structured interview In-depth Interview Guide for 4 purposively selected informants (two males and two females) was used to explore the caregivers' experiences.

**Data Collection:** Two of the authors distributed the questionnaire to the family caregivers of patients

diagnosed with End Stage Renal Disease. For respondents who could not read or write, the instrument was interpreted and used as an interview schedule for them. The data was collected over a period of three weeks.

The In-depth Interview (IDI) was conducted by the first author and notes were taken by another colleague. The IDI was also audio-recorded. Some of the interviews were conducted in Hausa language while the rest were in English

**Data Analysis:** The data collected was edited, coded and entered into Statistical Package for Social Sciences (SPSS) version 17.0. The grading of the tool was used to determine the overall burden of caregivers. The grades group respondents as having mild, moderate or severe levels of burden. Results were presented in simple frequency tables, percentages and charts. On the other hand, the IDI was translated, transcribed and then thematically analyzed to meet the research objectives. Three thematic areas: social life, economic burden and health insurance concerns were identified and analysed.

**Ethical Consideration:** The researchers obtained ethical approval from the Research Ethics Committee of the hospital to undertake the study. Also, individual informed consent was obtained from each respondent. All information was treated as confidential and are strictly for academic purpose.

## Results

### Sociodemographic characteristics of the study population

The socio-demographic characteristics of the family caregivers (Table 1) show that many (42.9%) of them are within the age bracket of 31 to 40 years old. They are predominantly males (76.2%), Muslims (85.7%), and Hausa (81.0%). This speaks to the study setting (Zaria), a predominantly Hausa Muslim-dominated area.

Less than half (47.6%) of them had tertiary level of education with some (19.0%) without any formal education. The occupational affiliation indicates that a few (23.8%) of the family caregivers are civil servants, and petty traders, respectively.

**Table1: Socio-Demographic Characteristics of the Family Caregivers**

| Variables    | Frequency (N-21) | Percentage |
|--------------|------------------|------------|
| <b>Age</b>   |                  |            |
| <20          | 3                | 14.3       |
| 21 – 30      | 7                | 33.3       |
| 31 -40       | 9                | 42.9       |
| 41 – 50      | 1                | 4.8        |
| 51 and above | 1                | 4.8        |

|                                   |    |      |
|-----------------------------------|----|------|
| <b>Sex</b>                        |    |      |
| Male                              | 16 | 76.2 |
| Female                            | 5  | 23.8 |
| <b>Religion</b>                   |    |      |
| Islam                             | 18 | 85.7 |
| Christianity                      | 3  | 14.3 |
| <b>Tribe</b>                      |    |      |
| Hausa                             | 17 | 81.0 |
| Igbo                              | 1  | 4.8  |
| Others                            | 3  | 14.3 |
| <b>Educational status</b>         |    |      |
| Non-literate                      | 1  | 4.8  |
| Primary                           | 6  | 28.6 |
| Secondary                         | 10 | 47.6 |
| Tertiary                          |    |      |
| <b>Occupation</b>                 |    |      |
| H/wife                            | 1  | 4.8  |
| Business                          | 5  | 23.8 |
| P/trading                         | 5  | 23.8 |
| C/servant                         | 8  | 38.1 |
| Others                            |    |      |
| <b>Relationship with patients</b> |    |      |
|                                   | 6  | 28.6 |
| Father                            | 2  | 9.5  |
| Husband                           | 3  | 14.3 |
| Sibling                           | 2  | 9.5  |
| Son                               | 5  | 23.8 |
| Mother                            | 2  | 9.5  |
| Uncle                             | 1  | 4.8  |
| Cousin                            |    |      |

Table 1 also presents the caregivers' relationships with the patients with chronic kidney diseases; some of the caregivers are children of the sick (28.6% and 23.8% of the respondents are caring for their parents' father and mother, respectively); others are caring for their spouses, children, siblings, or uncles.

### Sociodemographic characteristics of the patients with chronic kidney diseases

In Table 2, the socio-demographic characteristics of patients are presented. It shows that more male patients aged 51 to 60 years (23.8%) with no formal education (33.3%) were more affected (71.4%). The duration of illness shows that the majority (47.6%) of patients were recently diagnosed (less than six months), with many (33.3%) being sick for six to twelve months. Associated illnesses suffered by the patients were hypertension (33.3%) and other diseases (14.3%).

**Table 2: Socio-Demographic Characteristics of the Patients with Kidney Disorders**

| Variable                 | Frequency | Percentage |
|--------------------------|-----------|------------|
|                          | (N-21)    | (100%)     |
| Age of Patient           |           |            |
| <20Yrs                   | 5         | 23.8       |
| 21 - 30yrs               | 2         | 9.5        |
| 41-50                    | 4         | 19.0       |
| 51-60                    | 5         | 23.8       |
| 61- above                | 5         | 23.8       |
| Patient Gender           |           |            |
| Male                     | 15        | 71.4       |
| Female                   | 6         | 28.6       |
| Other illness            |           |            |
| Hypertension             | 7         | 33.3       |
| SCD                      | 1         | 4.8        |
| Hypertension and DM      | 1         | 4.8        |
| Others                   | 3         | 14.3       |
| None                     | 9         | 42.9       |
| Patient Education status |           |            |
| None literate            | 7         | 33.3       |
| Primary                  | 2         | 9.5        |
| Secondary                | 5         | 23.8       |
| Tertiary                 | 7         | 33.3       |
| Duration of illness      |           |            |
| <6months                 | 10        | 47.6       |
| 6-12months               | 7         | 33.3       |
| 13-24months              | 2         | 9.5        |
| Above 24months           | 2         | 9.5        |

**Socio economic challenges of the care givers**

From Table 3, it is shown that majority (85.7%) of the family care givers reported lack of time to attend to personal issues as a result of the caring role they assumed for their sick ones. Regarding their relationships, respondents felt the current state of health of their sick relatives affects their relationships

negatively; (61.9%) and (47.6%) of them respectively reported severe impact on their private and social life. A good number of them (47.6%) felt uncomfortable having friends around due to the state of health of their sick relatives. Majority (85.7%) reported financial burden as they lacked enough money to even cater for their relatives. Also, many (71.4%) feel they could do a better job caring for their relatives.

**Table 3: Socioeconomic Burden Experienced by Caregivers**

| Socioeconomic burden                                  | Frequency |           | Percentage |
|---|-----------|-----------|------------|
|   | Yes (%)   | No (%)    |            |
| 1. Feel no enough time for self                       | 18 (85.7) | 3 (14.3)  | 21 (100.0) |
| 2. Affect relationship negatively                     | 9 (42.9)  | 12 (57.1) | 21 (100.0) |
| 3. Lack privacy                                       | 13 (61.9) | 8 (38.1)  | 21 (100.0) |
| 4. Social life has been affected seriously (suffered) | 13 (61.9) | 8 (38.1)  | 21 (100.0) |
| 5. Uncomfortable having friends around                | 10 (47.6) | 11 (52.4) | 21 (100.0) |
| 6. No enough money                                    | 18 (85.7) | 3 (14.3)  | 21 (100.0) |
| 7. Lost control on self-care activities               | 10 (47.6) | 11 (52.4) | 21 (100.0) |
| 8. Could not carry our job as good as before          | 15 (71.4) | 6 (28.6)  | 21 (100.0) |

As shown in Table 4, most respondents reported spending 41,000 – 50,000 Naira (Nigeria currency) on weekly basis. This precluded the cost of transportation

and laboratory investigations and other sundry charges. In addition, the cost of investigations ranges from 5,000 – 15,000 Naira per week while many of the

patient had at least one hospital admission per month (38.1%) and a few (9.5%) either had twice or four times.

This financial burden is increased by frequency of visit hospital which is at least twice a week as reported by 38.1% of the respondents. Majorly (85.7%) reported spending within 5,000 Naira for transportation and

cost of dialysis per week spent ranged between 41,000 – 50,000 Naira per week and between 51,000-60,000 Naira.

Other activities within the treatment in the Teaching Hospital (71.4%) and outside the location (28.6%) also increase the financial burden (Table 4).

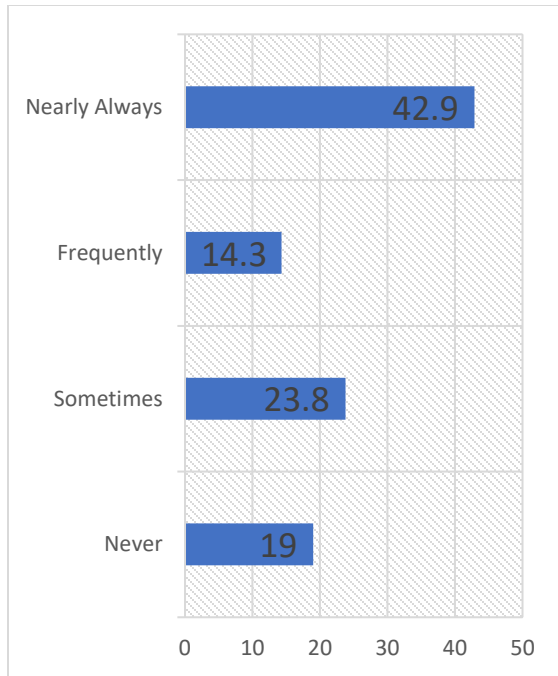
**Table 4: Other Economic Activities**

| Other financial implications |                     | Frequency | Percent |
|------------------------------|---------------------|-----------|---------|
| Visit to hospital per week   | Appointment         | 2         | 9.5     |
|                              | Once                | 5         | 23.8    |
|                              | Twice               | 8         | 38.1    |
|                              | Thrice              | 6         | 28.6    |
| Distance to the hospital     | Within the setting  | 15        | 71.4    |
|                              | Outside the setting | 6         | 28.6    |
| Cost of transport            | <5,000              | 18        | 85.7    |
|                              | 5,000 above         | 3         | 14.3    |
| Cost of dialysis per week    | <40,000             | 3         | 14.3    |
|                              | 41,000-50,000       | 12        | 57.1    |
|                              | 51,000-60,000       | 3         | 14.3    |
|                              | 61,000-70,000       | 1         | 4.8     |
|                              | 71,000-80,000       | 2         | 9.5     |
| Cost of Investigation        | <5,000              | 3         | 14.3    |
|                              | 5,000-15,000        | 9         | 42.9    |
|                              | 16,000-25,000       | 5         | 23.8    |
|                              | Above 25,000        | 4         | 19.0    |
| No of admissions per month   | Once                | 8         | 38.1    |
|                              | Twice               | 2         | 9.5     |
|                              | Thrice              | 1         | 4.8     |
|                              | Four times          | 2         | 9.5     |
|                              | Never Admitted      | 8         | 38.1    |

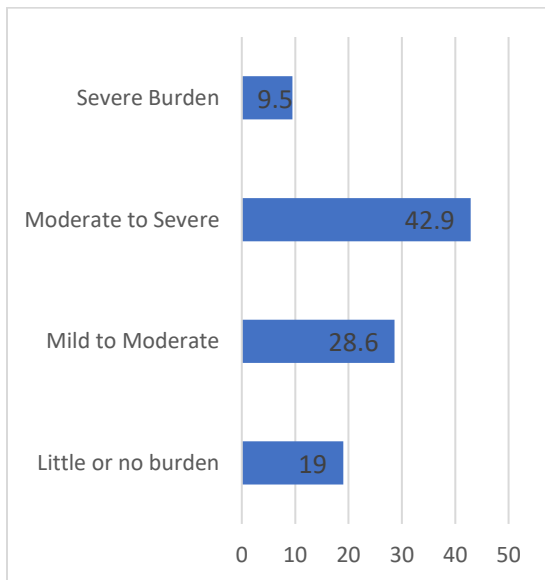
#### The overall burden of care

Figure 1a shows the respondents' perceived overall burden of caring for their relatives. 42.9% perceived nearly always being overburdened, 23.8% sometimes feel over burden while 19% never felt overburdened.

This indicates that majority (42.9%) of family care givers experience moderate to severe burden, 28.6% mild to moderate burden while 9.5% experience severe form of burden (see Figure 1b).



**Fig.1a: Perceived overall burden by respondents**



**Fig.1b: Range of Burden**

**Qualitative Results: Effect on Social and Private Life of Caregivers**

The quantitative findings were supported extensively by respondents interviewed using the IDI guide. Their responses on how the care burden affect the life are placed under the following themes:

**Social life**

Family caregivers were interviewed to explore their experiences while caring for their loved ones experiencing dialysis. Almost all of them lamented the amount of time being expended in their care role, emphasizing not being able to do anything for their social and economic lives. They claimed to have lost their social life. This cut across both male and female informants. For example, in some of the interviews, family caregivers stated:

I can't even remember when last I went for an activity. I basically stay with him. I even had to stop schooling to take care of him (a wife)

I had to transfer my work closer to home and most times I am not at work. Thank God for my colleagues who have been helping me with my work (a husband).

Similar assertions were made in the narratives where some respondents lamented forgetting everything about themselves and focusing on caring on their relatives.

.... I don't have time to hang out with my friends any more, even when she tells me to go, I find it difficult to (husband).

Another female respondent said:

I don't go for any female functions any more. I don't attend naming ceremonies, no funerals or weddings. Am always with hi, here (wife).

A man who accompanied his relative for an outpatient dialysis session complained: "I sometimes don't go to work because if we have to come for dialysis, the whole day is gone."

Some respondents felt uncomfortable having friends, well-wishers, and visitors come over to visit their sick relatives. For instance, one of the respondents said as captured in this narrative:

.... When the situation becomes serious, I don't like anyone visiting at that time. I prefer just us in the house around (sic). Sometimes he becomes so aggressive. In fact, initially I use to get angry but now I just simply laugh.

From the foregoing, many caregivers suffer deficits in their social lives as a result of caring for relatives with chronic kidney problems undergoing treatment in hospitals. There are situations that they prefer not being visited by even social associates depending on the severity of symptoms being experienced by their sick relatives. The social burden appears mixed and incapacitating!

#### **Financial burden and associated emotions**

Financial challenges were extensively presented the major burden faced by the care givers. They lamented how much they had to spend each time they visited the hospital, while not being able to engage in meaningful economic activities to generate the money. This is captured by one of the respondents who said:

we spend a lot. In fact, at times it feels we may not cope for long. Because of the money, we don't get to dialyze him three times per week, we just do twice and sometimes once. Even though, we see him do better when he gets full dialysis. But because of the money, we can't.

One of the respondents whose father is the affected one also said:

.... the money we use is from me, my brother and mother. No help from anyone else and everything about this condition is money.

There were several emotional episodes associated with these socioeconomic challenges experienced by the caregivers, especially when sole breadwinners of households become patients. For instance, a woman whose husband is on dialysis said, sobbing:

...he is our breadwinner. We have no one else but him to care for us. Our eldest son is just twenty years old. We have been using the money (the husband's money) he uses for his business. Even the extended family depends on him. So, no help from anywhere....

Lest I forget, the Chairman of our Local Government once gave us five hundred thousand (N500,000.00) naira, but it didn't even last us a month. Just last week, we lost someone in our village to this same problem because they had no money for dialysis.

These financial burdens get worse when a kidney transplant becomes the last resort. As captured in one of the narratives where one of the respondents said:

if only we could get money for her to have a transplant since that is the only way out, but we were told it cost between 7 to 10 million and its better outside Nigeria.

Thus, the financial burden is significantly increased by costs of transportation, investigations and hospitalization. Narratives from the respondents reiterated these facts, as one of them said, bitterly:

We have to do urea and electrolyte investigation, Packed Cell Volume every week. We also have to work on his blood level either by transfusion or use of a special drug called.... something poitin... (*meaning erythropoietin injection*). We spend more on transport because one person cannot do the up and down alone. For me (a caregiver), I have to wheel him (my father) from and to the car.... we are always in and out of the hospital".

These narratives corroborate the quantitative results of increasing financial burden associated with cost of treatment, transport and other financial costs incurred due to the treatment regimens.

#### **Lack of health insurance coverage**

Respondents narrated the lack of or limited insurance coverage for the treatment of end-stage kidney diseases at the centre. Lamenting the insurance coverage situation for patients on dialysis, a respondent said: "*We do not enjoy any coverage because we are not under NHIS (National Health Insurance Scheme)*". While another said, *NHIS only covers for three sessions of dialysis and some of the investigation.*

#### **Discussion**

The socio-demographic characteristics show that most respondents are young males and Hausa, with some good level of formal education. The respondents being mainly civil servants or petty traders are themselves economically active. The respondents are within the reproductive age group (31-40 years) and share a close relationship with the people they are caring for. 28.6% were caregivers for their fathers, and mothers (23.8%) and a few (14.3%) serve as caregivers for their husbands. This finding predicts the nature of the study

area being in a predominantly Hausa-Muslim setting with verse accessibility to educational institutions and buying and selling grounds. Also, in this study, the major caregivers are males. These findings are in line with that of Saeed *et al.* (2010) but negate those by Pinquent and Sorensen (2003) where it was reported that the major caregivers were females. This may be due to the fact that the males have the energy to assist with mobility as captured in one of the narratives during the In-depth interview where a respondent said “I have to wheel him (his father) from and to the car”. This may probably be due to the fact majority of the sick ones were males and the study environment being a culturally gender-sensitive one.

The sociodemographic characteristics of the sick ones whom the respondents serve as care givers for were explored and as depicted in Table 2. Most of the patients are with in ages 51-60 years (33.3%), mainly males (71.4%) with other associated illness suffered by them was mainly hypertension. However, many (42.9%) have no co-disease. Their educational status showed some level of literacy. A few (33.3%) attained tertiary form of education but some (35.3%) had no formal education. Similarly, the sick ones have been ill (diagnosed) for a while ranging between six months to two years. Literatures have it that non-communicable diseases are associated with lifestyle or genetics and are commonly among the elderly (Burke, *et al.*, 2011). As age advances, other co-morbidities set in alongside the primary disease. These assertions are in keeping with that of Gayamoli, *et al.*, (2008) who they documented those co-morbidities are associated with chronic kidney disease and usually at age 65 years and most victims suffer five or more co-morbidities.

The socio-economic burden experienced by caregivers of patients with end-stage renal disease is laudable. Caregivers suffer a quantum of social issues including loss of social life and relationships as well as financial constraints due to increased demand to meet the health needs of their loved ones. The major socio-economic burden experienced in this study was respondents feeling they have no enough time for themselves (85.7%) and lack of money (85.7%) respectively. Other socio-economic burdens included lack of privacy, loss of existing relationships amongst others as indicated in Table 3.

Similarly, from the qualitative findings, a female respondent lamented on how she had to stop school to care for her husband while another could not even remember the last time, she attended social function as their lives rally round their sick ones. Even for some of the male caregivers, some had to adjust their work schedule while some had to seek the help of their colleagues at work to cover up for their absenteeism.

Financial challenge is not left out owing to the gulping of funds by the illness (end-stage renal disease). The majority of the respondents spend a huge sum for dialysis per week (41,000 – 50,000 naira) aside cost of transportation and investigations (see Table 4). To increase the financial burden, the hospital activities reported by respondents from the questionnaire shown in Table 4 indicate that many (38.1%) of the respondents visit hospital at least twice a week, from within the treatment in the Teaching Hospital (71.4%) and outside the location (28.6%) who need to travel to access care for their relatives. Majorly (85.7%) reported spending within 5,000 naira for transportation and cost of dialysis per week spent ranged between 41,000 – 50,000 naira per week and between 51,000-60,000 naira.

In addition, the cost of investigations ranges from 5,000 – 15,000 naira per week while many of the patient had at least one hospital admission per month (38.1%) and a few (9.5%) either had twice or four times.

To further buttress the financial burden, respondents benefit from little or no insurance. Those, that have coverage only enjoy three to six sessions of dialysis only, implying that it only covers dialysis for two weeks because each week, the patients are expected to have three sessions. While those who have no insurance coverage foot their bills all alone. Due to these financial implications, respondents hardly meet up with the required three sessions per week thus, end up having either one or two sessions per week as they cannot afford to sustain the normal renal replacement therapy. Overall caregivers suffer a moderate to severe burden caring for their sick ones diagnosed with end-stage renal disease.

These findings are in keeping with that reported by Maddalene *et al.* (2018) who found out that caregiver had to leave their paid job to attend to the ill one alongside household activities with financial hardship as the social milieu of caregivers' life. The increasing financial hardship was said to be associated with long-distance travelling to access care, loss of employment, relocation in and out of the hospital and renovating the house to fit the ill one. It was concluded that the challenges are quite overwhelming, right from the point of diagnosis to bereavement, a considerable hardship is suffered by caregivers. Trisolini (2008) documented that financially, lack of insurance coverage was a big threat while physically, the activities of care included self-care for the ill, medication administration, meal preparations to meet demands in respect to dietary modification, difficulty getting the ill one to adjust to diet and fluid restrictions and modification. Social affectations included lack of time to care for their selves (care givers), social



isolations, decreased social activities and lack of social support groups.

### Conclusion

Caregivers of patients with chronic renal disease are burdened socially and financially. They suffer loss of social life and economic hardship following the financial demands of the disease. Socio-economic and policy support should lessen these burdens on family caregivers. Health care providers especially nurses and doctors who are at the side of the patients (most of the clinical presence) should be advocates for such policy thrusts for inclusion in healthcare financing. Health Insurance coverage remains a veritable means to explore.

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