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Renal Data from Asia–Africa

The Burden of Caring for Renal Patients: The Nurses Perspective

Oluwafunmilola Mary Mobolaji-Olajide[1], Oluwatoyin Christiana Amira[2], Iyabo Yewande Ademuyiwa[1], Fatiu Abiola Arogundade[3], Emon Duke[4]

[1]Department of Nursing Science, Faculty of Clinical Sciences, College of Medicine, University of Lagos, Lagos, Nigeria, [2]Department of Medicine, Faculty of Clinical Sciences, College of Medicine, University of Lagos, Lagos, Nigeria, [3]Department of Medicine, College of Health Sciences, Obafemi Awolowo University, Ile-Ife, Osun State, Nigeria, [4]Department of Nursing, University of Calabar, Calabar, Nigeria

ABSTRACT. Prevalence of chronic kidney disease (CKD) in Nigeria is on the increase and it is associated with increasing caregiving burden for both the professionals and informal caregivers. This study evaluated the burden experienced by nurses caring for CKD patients, identified the procedures causing the caregiving burden and factors associated with burden in two hospitals in Ondo State, Nigeria. Two hundred and forty nurses caring for renal patients were selected from two health institutions in Ondo State. Information on sociodemographic data was obtained using a self-administered questionnaire. The burden of care was evaluated using the Zarith Burden of Life Instrument (ZBI), with aggregate score ranged from 0–88. A score of 21–40 indicates mild-to-moderate burden while a score >40 indicates high burden. The mean age of the respondents was 33.7 ± 7.5 years (age range: 20–67 years). Forty percent experienced no burden, 48.3% experienced mild-to-moderate burden, 10.4% experienced severe burden while only 1.3% experienced very severe burden. Dialysis procedure (65.5%) was identified as posing the greatest caregiving burden. Factors identified as responsible for caregiving burden were shortage of staff (68%), followed by lack of funds on the part of the patients (67.1%). Caregiving burden was not associated with age, gender, or years of experience. Prevalence of caregiving burden was very high among the respondents and dialysis was identified as causing greatest burden. Government should fund and improve staffing of dialysis units to reduce caregiving burden.

Correspondence to:

Dr. Oluwafunmilola Mary Mobolaji-Olajide,
Department of Nursing Science,
Faculty of Clinical Sciences,
College of Medicine, University of Lagos,
P.M.B. 12003, Idi- Araba, Lagos, Nigeria.
E-mail: funmilolabolaji2010@gmail.com

Introduction

The incidence and prevalence of chronic kidney disease (CKD) is on the increase worldwide and it has become a major public health concern. In Nigeria, CKD occurs either as a complication of primary disorders of the kidney or systemic diseases, thus increasing

the population of patients with the disorders. The rising prevalence of CKD has assumed epidemic proportions worldwide with the developing countries carrying a huge burden of the disease.[1,2] Most of these patients were not diagnosed early and often present late when the disease is advanced and often do not have funds for renal replacement therapy, thus resulting in high morbidity and mortality.[3] Furthermore, the disease affects young adults in their economically productive years resulting in devastating social and economic consequences on the patients, their families and the nation at large.[3] This is unlike what is seen in the Western world where renal replacement facilities are readily available and health insurance is accessible to the patient. In addition to late presentation, there is a paucity of well-trained personnel as well as dialysis facilities for the care of these patients.[4]

Studies have shown that patients with certain chronic diseases e.g., dementia, schizophrenia, cancer, stroke, and their caregivers experience a lot of stress (burden),[5,6] but little or no study has been done on CKD patients, which is another chronic disease. Furthermore, the nurses caring for these patients may also experience some caregiving burden because of poor work environment, overstretching of the facilities and little resources available. The number of renal nurses available in Nigeria to care for these patients is grossly inadequate compared to what is obtainable in developed countries, even with the increasing number of dialysis centers in urban areas (e.g., Lagos) of Nigeria, actual utilization of such facilities remains very low because of the prohibitive cost,[7] thereby posing a burden on the very few that are available. Data on the burden of caring for renal patients in Nigeria are sparse.[8] The effect of the caregiving burden among nurses must therefore be understood to be able to evolve ways of enhancing quality of nursing care. Therefore, the objective of this multicenter study was to evaluate the caregiving burden experienced by nurses involved in the care of renal patients, and to identify factors associated with caregiving burden.

Materials and Methods

This was a descriptive hospital-based study carried out among nurses involved in the care of renal patients. Ethical approval was given by the research and ethics committee of each of the selected hospitals. The population for this study was drawn from Federal Medical Centre, Owo (FMC), being the only center with facilities and staffing for dialysis at the time of this study. The State Specialist Hospital, Akure (SSH) was also selected because majority of the patients were referred from there and sent back there to continue management. FMC, Owo is a 401-bedded facility which offers specialist care to the residents of Ondo state. The SSH, Akure is a 320-bedded secondary level hospital providing secondary care to the patients that were referred from other hospitals in the state. Two hundred and forty nurses, who were on duty at the time of conducting the study in the two selected hospitals, were selected by purposive sampling technique.

Using a self-administered questionnaire, information on age, duration in the profession, caregiving burden and the burdensome procedures in renal care were obtained from the respondents. The Zarith Burden of Life (ZBI) instrument[9] was used to evaluate the burden of care experienced by the nurses. The Zarith burden of life instrument is a 22-item questionnaire which has been widely used and validated in different populations with a Test–retest reliability coefficient of 0.823. The score ranged from 0–88 based on a summation score of all 22-item scores (range: 0–4). A score of 0–20 indicates no to mild burden, 21–40 mild-to-moderate burden, >40 high burden. A cut-off score ranging from 24–26 has significant predictive validity for identifying caregivers at risk for depression.[4] The participants were categorized into two groups based on their rank into junior category consisting of nursing officers (NOs) and senior NOs and senior category [principal NOs , assistant chief NOs , chief NOs, assistant director of nursing (ADNS) and deputy director of nursing (DDNS)]. All participants gave written informed consent.

Statistical Analysis

Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 19.0 for Windows (SPSS Inc., Chicago, IL, USA). Frequency and percentages were used to describe the sociodemographic variables whereas Chi-square and correlation coefficient were also used to test for factors associated with caregiving burden. P <0.05 was considered statistically significant.

Results

Overall, 243 questionnaires were distributed among the respondents but only 240 were completed, giving 98.8% response rate. There were 78 males (32.5%), and 162 female (67.5%) respondents. The mean age overall was 33.7 ± 7.5 (range: 20–64 years). A total of 92.5% were Christians and the remaining 7.5% were Muslims. Majority of the respondents were from Yoruba tribe. 95% held registered nurse/registered midwife certificate, while only 1.3% were hospital-based certificated nephrology nurses. About 34.1% were working in the medical unit, 18.7% in surgical unit, 14.5% in the renal/hemodialysis (HD) unit, and the others were distributed in other wards as shown in Table 1. Majority (65%) were NOs, while only 0.4% were ADNS. The years of experience of the respondents ranged from 1 to 35 years, with a mean of 7.6 ± 6.9 years; 75.4% of respondents had <10 working years.

More than half of the respondents (60%) expressed that there was burden with the care of patients with renal diseases while the remaining 40% did not see care of renal patients as a burden (Figure 1). A few of the nurses (1.3%) considered renal care as posing severe burden and, dialysis as the main procedure causing heavy burden. The level of burden as experienced by nurses is shown in Table 2. In terms of study location, 37.04% and 43.80% of the nurses in FMC and SSH, respectively expressed that there was no or little care-giving burden, while a higher number of respondents (14.8%) in FMC experienced severe burden compared with only 4.8% in SSH. Only three nurses (2.2%) in FMC declared that there was severe burden in caring for renal patients. The level of burden was higher among junior nurses (NOs and SNOs), in both hospitals. 25 NOs and 20 SNOs declared experiencing mild-to-moderate burden in the state, while 59 NOs declared mild-to-moderate burden in the federal hospital. Table 2 shows the level of burden experienced by the nurses in the two hospitals.

In terms of the procedures causing care-giving burden, dialysis procedures, [157: (65.4%)] and intake and output record keeping [39: (16.3%)] were indicated as the major causes of care-giving burden. Other procedures causing burden are shown in Table 3.

Table 4 shows the causes of care-giving burden. Majority of the respondents (68.3%) indicated that shortage of staff was a major factor responsible for care-giving burden. A good number (67.1%) also claim that lack of funds on part of the patients pose much burden to the nurses. Other factors are difficulty in getting donor, erratic power supply, poor family support, insufficient equipment, to mention a few.

Discussion

This study evaluated the care-giving burden experienced by nurses that are involved in the care of patients with CKD. The study population comprised mainly of young adult female nurses with <10 years working experience. Majority (67.5%) of our respondents were females in keeping with reports from other studies.[10,11] This is not surprising since nursing is a female dominated profession, more so going back to the history of the profession, nursing started at home with females taking care of the sick individuals. Most of the respondents had the registered nurse/midwife certificate with very few (1.3%) having post basic specialist training in nephrology nursing. In spite of this, they were still saddled with the responsibility of caring for renal patients.

Majority of the respondents were young adults (20–40 years) in keeping with the findings of Oyelana et al.[12] Most of the respondents [228 (95%)] had their main area of

Table 1. Socio demographic characteristics of the respondents by location of practice.

Variables	FMC Owo	SSH Akure	All subjects
	n (%)	*n* (%)	*n* (%)
Gender			
Male	40 (16.7)	38 (15.8)	78 (32.5)
Female	95 (39.6)	67 (27.9)	162 (67.5)
Age-group (years)			
20–30	55 (22.9)	48 (20.0)	103 (42.9)
31–40	66 (27.5)	37 (15.4)	103 (42.9)
41–50	9 (3.8)	15 (6.3)	24 (10)
51–60	4 (1.7)	5 (2.1)	9 (3.8)
61–65	1 (0.4)	0 (0)	1 (0.4)
Religion			
Christianity	129 (53.8)	93 (38.8)	222 (92.5)
Islam	6 (2.5)	12 (5.0)	18 (7.5)
Ethnic group			
Yoruba	112 (46.7)	87 (36.3)	199 (82.9)
Igbo	15 (6.3)	13 (5.4)	28 (11.7)
Hausa and others	8 (3.3)	5 (2.1)	13 (5.5)
Professional qualification			
Registered nurse	131 (54.58)	97 (40.42)	228 (95)
Nephrology nurse	2 (0.8)	1 (0.4)	3 (1.3)
Registered peri-operative nurse	1 (0.4)	5 (2.08)	4 (1.7)
Registered public health nurse	0 (0.0)	2 (0.8)	2 (0.8)
MSc. nursing (postgraduate)	1 (0.04)	0 (0)	1 (0.4)
Ward/Unit			
Medical	37 (15.4)	45 (18.8)	82 (34.1)
Renal/hemodialysis	31 (12.9)	4 (1.7)	35 (14.5)
Surgical	27 (11.3)	18 (7.6)	45 (18.7)
Obstetrics and gynecology	15 (6.3)	18 (10.6)	33 (13.7)
Pediatrics	11 (4.6)	0 (0.0)	11 (4.5)
Theater and intensive care unit	9 (3.7)	13 (5.5)	22 (9.1)
Community health	3.3 (1.3)	0 (0.0)	3 (1.3)
Accident and emergency/trauma	2 (0.8)	8 (3.3)	10 (4.2)
Designation			
Nursing officer	105 (43.8)	51 (21.3)	156 (65)
Senior nursing officer	5 (2.1)	23 (9.6)	28 (11.7)
Principal nursing officer	11 (4.6)	12 (5.0)	23 (9.6)
Assistant chief nursing officer	6 (2.5)	5 (2.1)	11 (4.6)
Chief nursing officer	7 (2.9)	14 (5.8)	21 (8.8)
Assistant director of nursing	1 (0.4)	0 (0.0)	1 (0.4)
Years of experience (Years)			
1–10	108 (45)	73 (30.4)	181 (75.4)
11–20	26 (10.8)	19 (7.9)	45 (18.8)
21–30	1 (0.4)	6 (2.5)	7 (2.9)
31 and above	0 (0)	7 (2.9)	7 (2.9)

FMC: Federal Medical Centre, SSH: State Specialist Hospital.

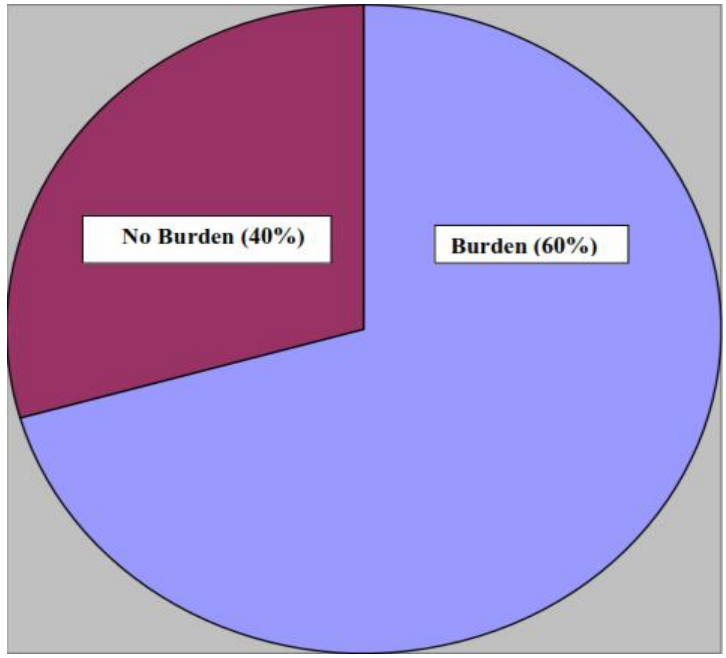

Figure 1. Nurses perception of caregiving burden in renal care.

Table 2. Level of caregiving burden by location.

Level of burden	All subjects	SSH	FMC
	N (%)	N (%)	N (%)
No – Mild burden (0–20)	96 (40)	46 (43.8)	50 (37.0)
Mild – Moderate burden (21–40)	116 (48.3)	54 (51.4)	62 (45.9)
Severe burden (41–60)	25 (10.4)	5 (4.8)	20 (14.8)
Very severe (61–88)	3 (1.3)	0 (0)	3 (1.3)
Total	240 (100)	105 (100)	135 (100)

SSH: State Specialist Hospital, FMC: Federal Medical Centre.

Table 3. Burdensome procedures in renal care.

Procedures	Frequency (%)
Dialysis	157 (65.4)
Care of vascular access (catheter)	39 (16.3)
Intake and output	30 (12.5)
Renal biopsy	26 (10.8)
Renal scan	19 (7.9)
Post kidney transplant care	19 (7.9)
Psychological care	16 (6.7)
Fistula access care	11 (4.6)
Diet monitoring	9 (3.8)
Treatment of pressure areas	7 (2.9)
Bone marrow biopsy	6 (2.5)
Counseling of patient	5 (2.1)

Table 4. Identified factors responsible for caregiving burden in renal care.

Factors	Frequency (%)
Shortage of staff	164 (68.3)
Lack of funds on the part of patient	161 (67.1)
Difficulty in getting donor for transplant	161 (67.1)
Erratic power supply	155 (64.6)
Poor Family Support	154 (64.2)
Insufficient equipment	152 (63.2)
Inability of patient to sustain treatment	146 (60.8)
Patients' non-compliance to medications/treatment	146 (60.8)
Patients' ignorance	145 (60.4)
Patient`s default	144 (60.0)
Poor government support	144 (60.0)
Shortage of expert	143 (59.6)
Lack of infrastructure	136 (56.7)
Short of water supply	123 (51.3)

experience in general nursing/midwifery practice. In terms of working experience, majority of the respondents had <10 years working experience with only a few (5.8%) having >20 years.

This study reveals that becoming a caregiver to a person with kidney disease with other chronic conditions such as dementia, schizophrenia, can be a stressful change and that it is easy to feel overwhelmed and unable to cope.[6,7] Possible reasons for the high care burden experienced by our respondents may be related to lack of any formal training in nephrology nursing. Bradway and Hirschman proposed that in relating and caring for hospitalized patient with dementia, proper training will be an essential element.[5]

In terms of procedures causing care-giving burden, dialysis was the most frequent followed by care of vascular access. HD and peritoneal dialysis (PD) are highly specialized treatments and could be very intimidating for the untrained. Similarly, care of vascular access, particularly needling of arterio-venous fistulae requires

Table 5. Comparison between those who experienced care burden and those who did not.

Variables	Care burden	No care burden	T stats or χ^2	*P*
	n (%)	*n* (%)		
Gender				
Male	58 (24.2)	20 (8.3)	2.317	0.347
Females	130 (54.2)	32 (13.3)		
Duration at the profession				
1–10 year	160 (66.7)	21 (8.7)		
11–20 years	30 (12.5)	15 (6.25)	-0.019	0.769
21–30	5 (2.1)	2 (0.8)		
31 and above	6 (2.5)	1 (0.42)		
Age				
20–30	80 (33.3)	23 (9.6)		
31–40	70 (29.2)	33 (13.8)		
41–50	18 (7.5)	6 (2.5)	0.88	0.174
51–60	6 (2.5)	3 (1.3)		
61 and above	1 (0.4)	0 (0)		
Location of Practice				
SSH	59 (24.6)	46 (19.2)	22.145	0.023
FMC	85 (35.4)	50 (20.8)		

SSH: State Specialist Hospital, FMC: Federal Medical Centre.

special skills. In addition, the nurse does the exchanges in PD and engages in most of the activities involved in HD, both of which may be burdensome. Other procedures include keeping an intake and output chart as well as kidney biopsy. These two procedures require frequent monitoring of the patients and in the face of shortage of staff, this could be a source of care-giving burden.

Top among factors responsible for care-giving burden are shortage of staff, lack of funds for treatment, erratic power supply, inadequate equipment and lack of infrastructure. Lack of personnel has been identified as major factor causing care burden and reducing the quality of health care provided, especially in developing countries.[12] Staff shortage combined with ever increasing patient load increase care-giving burden. This is similar to the work done by Hogan[13] who reported that factors such as lack of personnel and poor knowledge of disease condition as factors responsible for care-giving burden and patient dissatisfaction with care received.

Our study revealed that there was no association between nurses' age and care-giving burden. This is surprising because one would have thought that being older comes with more experience and greater capacity at coping with care of these patients. This might perhaps be because the older nurses tend to focus more on administrative work rather than the clinical duties. It was also observed that there was no association between their years of service and the burden of care. This is rather surprising as it is expected that the longer the duration at work the more experienced they should be at handling such cases. The location of practice (federal and state) had significant association with care-giving burden. Nurses in the FMC experienced higher care-giving burden compared with their counterparts in the state hospital. This is because those in the federal setting were the only ones with dialysis facilities and dialysis was observed to be the major cause of burden of care in this study. The dialysis nurses were also very few (seven in all) compared to the number of patients in the state in need of HD which was about 60 at the time of study. In this study, gender was not associated with the burden of care. This is because majority of the respondents were females.

Implication for Nursing Practice

The productivity of nursing services should be devoid of extra burden which can reduce their efficiency. This productivity could only be measured by the level of patient's acceptance or perception of quality of care. The government could therefore help to improve the productivity by improving the staffing of the hospitals to reduce care burden, since it was observed from this study that shortage of staff was a major factor contributing to the burden of care. The quality of care provided if adequate will impact on the recovery of the patients and reduce the period of hospitalization. The Nurse/patient ratio[11] should be taken into consideration in order to meet up with the World Health Organization Standards of one nurse to five patients. This will also help to reduce the workload on the nurses, improve the quality of care rendered to these patients, reduce patients' hospital stay and reduce cost of health care. Since there is also a clear variation in the location of practice and the burden of care, the government should also consider establishing more HD units in the state to reduce the burden of care at the federal center.

Conclusion

This study revealed that the care of renal patients was burdensome to the nurses and the most demanding procedure was dialysis. Care-giving burden was not related to age, gender or years of service but rather to practice location. Other factors contributing to care giving burden include lack of personnel, insufficient equipment, and poor infrastructure. The government should therefore improve on staffing, staff training and establishment of more dialysis facilities in the state so as to reduce renal care burden.

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