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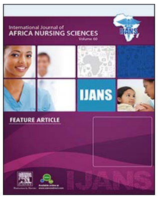

Exploring caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease in Nigeria

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ABSTRACT

Background: Family caregivers in many African countries bear the burden of caregiving alone, with the paucity of research, especially for caregivers of End-Stage Renal Disease patients, having concealed their needs.
Aim: To explore the caregiver burden of family caregivers of End-Stage Renal Disease (ESRD) patients in South-West Nigeria.
Design: Following a complementary mixed method data collection strategy, the quantitative data was collected using the Zarit Burden Interview questionnaire to measure the burden of caregiving. Qualitative data was thereafter obtained through in-depth, individual interviews and was analysed using content analysis.
Settings: The three research settings consisted of two state hospitals and one private hospital that provide renal care in South-West Nigeria.
Result: The mean burden of caregiving for the sample was 50.18 thus indicating that family caregivers experienced moderate to severe burden, which is high compared to the other studies. The participants' experiences of caregiving revealed the following categories: total dependence, acceptance of caregiving role, competing responsibilities, financial sacrifice and "not making mistakes".
Conclusion: Understanding the extent of caregiver burden, what constitutes burden to family caregivers in low/middle-income countries, and the difficulties associated with caregiving for care-recipients with ESRD, allows appropriate strategies and interventions to be developed.

1. Background

Caregiving is defined as help, which may be in the form of aid and assistance provided to persons in need (Brown & Brown, 2014). Extensive activities of care provided by family members exerts a considerable burden on them, especially in terms of demands and duration of care-provision (Northouse, Katapodi, Schafenacker, & Weiss, 2012). Family caregivers are those individuals who provide the majority of the patient's physical, emotional, financial, and social care needs throughout the continuum of care, from being hospitalised to providing care at home, without receiving any remuneration (Collins & Swartz, 2011).

Caregiver burden is "the physical, financial, and psycho-social hardships of caring for a loved one, usually a family member, struggling with a medical condition" (Garlo, O'Leary, van Ness, & Fried, 2010, p. 2315). Family caregivers may develop caregiver burden, when the stress of care exceeds the resources available to cope with the demands of care (Northouse et al., 2012). As caring demands increase, family caregivers are usually isolated from social activities (Bauer & Sousa-Poza, 2015; Crespo et al., 2013), which can make family caregivers vulnerable to varied health problems, both physical and psychological (Tong, Lowe, Sainsbury, & Craig, 2010).

End Stage Renal Disease (ESRD) is a severe stage of chronic kidney disease that occurs when the glomerular filtration rate of the kidney is less than 15 ml/min, thus requiring dialysis and or renal transplantation (Levey & Coresh, 2012). ESRD prevalence is high among young people, usually between 20 and 50 years, in sub-Saharan African countries, and being diagnosed with a terminal illness at such an age carries a considerable demand for prolonged and substantial caregiving on the part of the family caregivers (Arogundade, 2013).

The substantial amount of caregiving required by patients with ESRD may increase family caregiver's vulnerability to emotional, physical and psychological consequences, which are typically high in resource limited countries (Ajuwon & Brown, 2012; Ekelund & Andersson, 2010). This vulnerability is due to the shortage of health care professionals, and in some instances institutions, making it necessary for the family caregiver to provide formal and informal care for patients with ESRD, at home and in the hospitals (Khosravan, Mazlom,

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Abdollahzade, Jamali, & Mansoorian, 2014).

The caregiving environment in resource-limited countries presents with unique limitations and burdens (Dondorp, Iyer, & Schultz, 2016). Tertiary care required by patients with ESRD is usually located in urban areas in low-resource countries, meaning that for many family caregivers and their sick relatives they are forced to relocate to a completely new environment, thereby disrupting the dynamics of the entire households, as well as its social and financial relationships (Tong et al., 2010; Walker et al., 2016). Re-adjustments regarding family responsibilities and other aspects of life become essential to cope with the changed circumstances. In Nigeria, as in other low-income countries, the unavailability of basic resources, and the limited healthcare infrastructure and personnel often delays treatment and increases the burden for the caregivers (Okafor & Kankam, 2012).

Although Nigeria is the largest economy in Africa (National Bureau of Statistics, 2014), it has challenges in terms of providing basic health services to its inhabitants, with a population of over 177.5 million people (The World Bank, 2014). Approximately, 63% of the population lives below the poverty line of US$1.00 per day (African Development Bank Group., 2013), making access to private health care and external assistance difficult. The country's inability to utilize its vast resources for health development programmes may be responsible for the lack of support for family caregivers, resulting in them having to bear the considerable burden of care alone (Okafor & Kankam, 2012). A health insurance scheme, still in its infancy, covers only the formal sector, while most Nigerians in the informal sector settle medical bills through the out-of-pocket payment system (Adeosun, 2013). Similar to the experiences of ESRD patients in other low-income countries, dialysis and ESRD treatments are not covered by the scheme (Nugent, Fathima, Feigl, & Chyung, 2011).

As family caregivers often bear the burden of caregiving alone, their physical, social, emotional, and financial life are negatively impacted, leading to caregiver burden (Given, Given, & Sherwood, 2012). A paucity of research regarding caregiver burden among family caregivers of ESRD patients has meant that there appears to be a lack of support for these family members (Oyegbile & Brysiewicz, Unpublished).

This study therefore aimed to explore the caregiver burden of family caregivers of patients with ESRD patients in South-West Nigeria. This was part of a larger action research study to develop a model to manage caregiver burden among family caregivers of patients living with ESRD in Nigeria.

2. Methods

The use of quantitative measures alone to explore the extent of caregiver burden is insufficient to uncover deeper emotional experiences (Bastawrous, 2013). The Zarit Burden Interview (ZBI) (Zarit, Reever, & Bach-Peterson, 1980) questionnaire was chosen for this study, as it has been widely used to measure the extent of caregiver burden. This predominantly quantitative study included qualitative data to further elaborate the domains of caregiving, with the former providing the foundation and context to integrate the latter results.

2.1. Research setting

The study settings was two tertiary state (public) hospitals and one privately owned hospital in South-West Nigeria. The initial quantitative data was collected from all three settings while only two settings (one public and one private hospital) participated in the qualitative data component. The hospitals were strategically located in the capital cities of their respective states, positioning them for referrals from the surrounding primary and secondary health care centres. The hospitals were purposively selected as they provide renal care and are attended by an average of 15 (current and new) renal patients weekly, with approximately 5–8 of these patients attending with their family caregivers.

2.2. Sample and sampling

Participants were purposively selected from among family caregivers accompanying the ESRD patients to the wards and outpatient clinics of the three facilities. Inclusion criteria for both the quantitative and the qualitative data collection components included the following: (i) adult male or females, 18 years or older (ii) been a family caregiver to a patient with ESRD for at least six months and (iii) not receiving remuneration from the government or family members for providing the care. The sample size was calculated with the help of a statistician using the formula, $n = Z^2_{(1\text{-}\alpha/2)}pq/d^2$ (where $Z_{(1-\alpha/2)} = 1.96$ at 95% confidence; p = proportion of caregivers with moderate-severe burden, $q = 1 - p$; and d = absolute allowable error (precision)). For this study, we assume no prior knowledge with regards to the proportion of who were moderately-severely burdened, we assume maximum possible variability i.e. $p = .5$; $q = 0.5$ and a precision (d) $\pm$ 10%. This yielded a final required sample size of 96 for the quantitative component.

2.3. Research tool

The Zarit Burden Interview (ZBI) (Zarit et al., 1980) was used to explore the extent of caregiver burden. It contains 22 items investigating the five domains of caregiver burden namely: burden in the relationship, emotional wellbeing, social and family life, finances, and loss of control over life. The questionnaire items were rated using a five-point Likert scale, with 0 (rarely) being the lowest and 4 (nearly always) being the highest. Zarit et al. (1980) recommend that the total score of all responses should be summed up to reveal the level of caregiver burden. A score of 0–20 indicated little or no burden; 21–40 means a mild to moderate burden; 41–60 moderate to severe burden; while 61–88 means a severe burden is present (Zarit et al., 1980).

The qualitative interview question asked; "*How has it been looking after your loved one, can you tell me your experience?*" Follow-up questions were asked to elicit further responses from participants regarding caregiver burden. Permission to use and translate the questionnaire was granted by the copyright owner and the questionnaire, interview guide and informed consent form were translated into Yoruba language, which is the predominant language spoken by people in South-Western Nigeria. A certified Yoruba language teacher checked all documents for correctness and ease of comprehension, and the questionnaire was back translated into English (Chen & Boore, 2010).

2.4. Data collection

Data were collected between February and May 2015, with patients diagnosed with ESRD being identified by registered nurses on the wards and in the outpatient clinics, who then informed the researcher. The patients were individually approached by the researcher who explained the study to them. They were required to identify the person(s) who had been providing care for them during the last six months before their participation was confirmed and informed consent obtained.

The researcher built rapport with family caregivers through the regular sharing of relevant, study-related information, as she was in the settings daily and the participants got to know her. For the convenience of the caregivers, the questionnaires were handed out to them while they were waiting at the patient's bedside (either in the wards or at the outpatient department), and were asked to return the completed document to the researcher once completed, either the same day or the following day.

After collecting the quantitative data, the researcher then returned to two of the research settings two weeks later to collect the qualitative data. Interviews were conducted in Yoruba and English, depending on the preference of participants, in a private space away from the other patients, lasting approximately 35–45 min. Of the 110 who participated