

Managing Caregiver Burden among Families of Patients with End-Stage Renal Disease

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Abstract

Family caregivers of patients with end-stage renal disease (ESRD) play a significant role in providing substantial care for a prolonged period for their sick relatives, often with very limited resources, making it a difficult environment. Government support for family caregivers of patients with ESRD is lacking in Nigeria, increasing their vulnerability to caregiver burden and its consequences. An action research study using a complimentary mixed-method approach was used to develop the intervention model for managing caregiver burden. Quantitative data were collected to measure the extent of caregiver burden using a Zarit Burden Interview questionnaire for 96 family caregivers, while individual in-depth interviews with 15 participants provided the qualitative data. Integrating the quantitative and qualitative data led to the identification of four moderators to manage the caregiver burden in this study. The model for managing caregiver burden was developed from the findings, using stressors and associated moderators of caregiving, and the role played by culture and finance in this context. An implementation checklist was developed, which was used by registered nurses to implement the concepts in the model with the family caregivers during the model implementation phase. Family caregivers of patients with ESRD need to be supported by nurses during the caregiving process. Nurses can increase caregivers' identity and knowledge of the disease as a way of preventing the family caregivers from being overwhelmed by their caregiving role.

Keywords: action research; caregiver burden; family caregivers; intervention model; Nigeria

Introduction

Caregiving, as an ever-changing experience, with a peculiar history and an unpredictable future, evokes numerous emotions, often inflicting deleterious consequences on family caregivers (Aneshensel et al. 1995; Bastawrous 2013). Caregiving refers to the care provided to a sick, diseased or disabled person, the intensity and duration of which depend on the needs of the patient (Longacre, Ross, and Fang 2014). According to Nakken et al. (2015), family caregiving is providing care by family or friends, without the person receiving any remuneration or formal training for doing so. Caregiver burden is the physical, spiritual and emotional impact of taking responsibility for a seriously ill loved one, and this can have a considerable effect on one's social, mental and economic health (Mathias 2019). End-stage renal disease (ESRD) is a condition of the kidneys that is characterised by irreversible loss of renal function to a degree sufficient to render the patient permanently dependent on dialysis, renal replacement therapy, and family caregivers for providing care (Odubanjo, Oluwasola, and Kadiri 2011).

Caregiving to patients with ESRD is resource intensive, time-consuming, and goes on for a long time, requiring an indefinite commitment by a family caregiver to care for a loved one from diagnosis until death (Noble, Kelly, and Hudson 2013). The demand for caregiving increases as the patient's health deteriorates, placing a heavier burden on the family caregiver (Noble, Kelly, and Hudson 2013). Peculiar to most low-income countries, government support for family caregivers of patients with ESRD is often very limited or non-existent, increasing their vulnerability to physical, social, and emotional burdens (Brinda et al. 2014; Dondorp, Iyer, and Schultz 2016; Hannon et al. 2016; Thrush and Hyder 2014).

Caregiving occurring in a resource-limited environment is restrictive and challenging, compelling family caregivers to provide substantial care for their loved ones (Dondorp, Iyer, and Schultz 2016). The current authors are of the opinion that family caregivers provide care because of the lack of sufficient healthcare personnel in hospitals, however, family and cultural expectations also appear to be factors that motivate family caregivers to undertake such a role. In Nigeria, family caregivers are often required to settle medical bills directly due to limited health insurance; the cost of which can be substantial (Olakunde 2012). Whereas the governments of high income countries such as the United States of America, Australia, and the United Kingdom provide support in terms of covering costs for dialysis and renal replacement for patients with ESRD, the same cannot be said of patients in low- and middle-income countries; often family caregivers bear these costs (Arogundade 2013; Cruz 2016; Family Caregiver Alliance 2011). The need to provide extensive caregiving can have considerable consequences on all aspects of family caregivers' lives, making them experience caregiver burden (Garlo et al. 2010). This study undertaken in Nigeria found that family caregivers' who provided care to sick relatives with ESRD developed moderate to severe forms of caregiver burden in all domains of care.

There are models of care for family caregivers of patients with ESRD in high resource countries (Australian Government 2010), however, these are resource-driven, making them unsuitable for Nigeria which is a multicultural, resource-limited country (Obansa and Orimisan 2013; WHO 2014; World Bank 2018). As the main component of the healthcare workforce, nurses are ideally positioned to assist family caregivers to manage their caregiver burden.

Aim

The aim of this study was to develop and implement an intervention model for nurses in the management of caregiver burden experienced by the family caregivers of patients with ESRD in Nigeria. The conceptual framework underpinning this study was the stress process model by Aneshensel et al. (1995), which consists of factors, stressors, moderators and outcomes. Background and contextual factors are social, economic, cultural, and political factors within which the stress process unfolds, and availability of these resources can determine the extent to which care-related stress might be experienced or contained (Aneshensel et al. 1995; Del-Pino-Casado et al. 2012; Gysels et al. 2012). Stressors are difficulties experienced in the course of providing care to sick relatives that could be directly related to caregiving (primary stressors) or indirectly related to caregiving (secondary stressors) (Pearlin et al. 1990). Moderators are personal and social resources available to family caregivers that help to modify the causal relationship between the stressors and the outcomes (Pearlin 2010). Moderators function by reducing the magnitude of the relationship between the stressors and the outcomes or by breaking the link altogether (Pearlin 2010). This model describes the relationship between the background and contextual factors, stressors and the moderators, and how this leads to the required outcome; the potential reduction of the caregiver burden.

Model Assumptions

For the model to be useful in this context certain assumptions were accepted:

- There will always be some degree of difficulty for family caregivers providing care for ESRD patients.
- Caregiving is resource intensive, often inflicting serious consequences on all aspects of the family caregivers' lives.
- Part of the cultural aspects in this context dictates that caregiving is obligatory.

Research Methodology

Mutual collaborative action research (AR) guided this study and actively engaged a six-member research team comprising two family caregivers, two nurses, one medical

doctor and the researcher. This approach was chosen to ensure that the model developed was appropriate and relevant and to promote sustainability of the initiated change in practice (Holloway and Wheeler 2010; McNiff and Whitehead 2010). Family caregivers were included in the study if they were 18 years or older and had been providing care to ESRD patients for at least six months. Registered nurses were included if they had provided care to ESRD patients in the last six months and at the time of study.

The sample size was calculated with the help of a statistician using the formula, $n = Z^2_{(1-\alpha/2)}pq/d^2$ (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)). This yielded a final required sample size of 96 for the quantitative component. For the qualitative component, 15 family caregivers were interviewed until data redundancy.

The model for managing caregiver burden (MMCB) was developed from data obtained from the questionnaires, interviews, a workshop and research meetings. The intention was to develop a model with stressors, moderators and outcomes, with a checklist of actions to enable nurses to use the model for the management of caregiver burden.

The study consisted of four cycles. Cycle One established the need for the study, measured the caregiver burden and highlighted the discrepancies between low-income and high-income countries. The quantitative data identified stressors from the caregivers using the Zarit Burden Interview (ZBI) questionnaire (Zarit, Reever, and Bach-Peterson 1980). In Cycle Two, in-depth individual interviews obtained qualitative data from 15 family caregivers and revealed that family caregiving was informed by cultural and financial expectations. Five categories emerged describing the family caregiver's experiences, namely disconnection with self and others, never-ending burden, "a fool being tossed around", obligation to care, and promoting closer relationships.

In Cycle Three, the intervention model was developed through the collaborative effort of the research team members, guided by Chinn and Kramer (2011), and was presented for discussion to practicing nurses at a workshop in a renal care hospital. In Cycle Four, members of the research team participated in developing the model's implementation checklist to operationalise the model. The model was then piloted in one research setting for six weeks.

Ethical Considerations

Ethics approval was provided by the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BREC 226/14) and from the participating private sector institution in Nigeria. Privacy and confidentiality of the information were maintained to ensure that no data could be traced back to the participants or institutions. The participants gave written consent to participate in the study.

Description of the Model

The MMCB (see Figure 1) illustrates the three components, namely stressors, moderators, and outcomes for family caregivers. This intervention model was based on the stress process model that underpinned the study, which illustrates the interaction between these crucial concepts to manage caregiver burden. Stressors are problems experienced by family caregivers in the process of providing care and were identified by the family caregivers in Cycles One and Two of the study as those elements that could produce serious outcomes for family caregivers.

An increasing number of moderators, as indicated by the unidirectional arrow in Figure 1, were potentially perceived by the participants to alter the process of the stressors that lead to caregiver burden. These moderators were perceived to reduce the caregiver burden experienced. The bidirectional arrow situated between the moderators and the outcome illustrates the influence they have on each other. Culture and finance are threads running throughout, indicating that they have a profound influence on all components. Nurses and family caregivers must therefore take measures to identify their influences and deal with them appropriately.

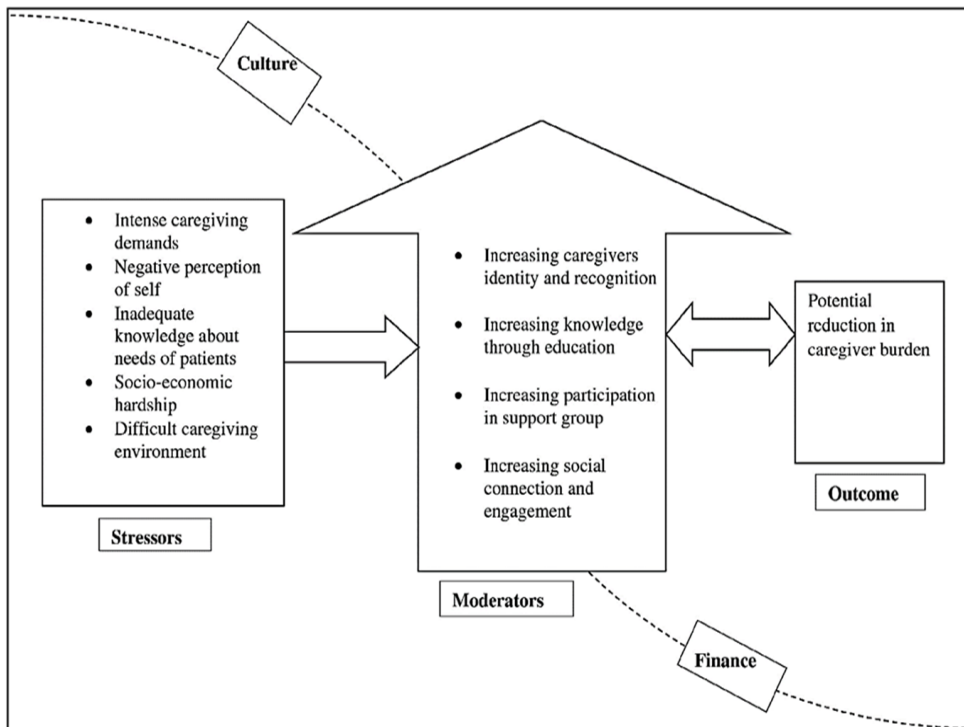


Figure 1: Model for managing caregiver burden (Authors)

Moderators

The synthesis of quantitative and qualitative data informed the identification of the moderators to manage caregiver burden, which could occur at any time, individually or collectively. The literature was reviewed to identify similarities and differences in the concepts before a decision was made about what was included. Four moderators were identified that could assist in dealing with their stressors.

Increasing Social Connection and Engagement

The data from the interviews revealed that family caregivers perceived themselves as perpetually providing care, with no time to attend to personal needs. This separated them from those activities that made their lives meaningful and worth living. Although they felt obliged to provide care, this created conflict between the achievement of life aspirations and the restrictions placed on their lives as a result of prolonged duration and the time spent in caregiving.

No other activity takes place in my life except caregiving. I am always making sure that he is well taken care of. I do all sorts of things just to make sure he is well taken care of. I am like everything to him and [do] everything that will make him feel better. I do not have time for myself ... (Caregiver 1)

Family caregivers who provide prolonged care often ignored their own needs for physical and emotional care; they experienced disconnection with themselves and others as they were engrossed in the caregiving role (Moore and Gillespie 2014). To lessen this, Eslami et al. (2016) suggest that family caregivers create time to participate in social, family, and spiritual activities in order to derive joy, hope and renewed relationships with others in the community. Van der Lee et al. (2014) agree, stating that family caregivers must connect socially in society and engage with resources in the community to ensure adequate self-care.

For these reasons, significant others and nurses need to collaborate with family caregivers to create space for them to increase their social connection and engagement, which ultimately might lead to improved self-care, emotional well-being and participation in community life activities (Deek et al. 2016). Such connection could provide respite and a renewal of energy to continue caregiving unabated.

Increasing Participation in Support Groups

The participants revealed that a lack of support increased the experiences of caregiver burden for family caregivers.

Providing care for her is a challenge for me. I am all by myself, feel the pain alone and cry alone, I provide care in the hospital and run around sourcing for money to settle medical bills ... Um ... My father left us and relocated to another town when my mother's sickness failed to go. He has not called or visited us since [he left] two years ago. I feel

sad because I have nobody to run to for assistance. I feel abandoned, isolated, and lonely all the time. (Caregiver 2)

Prolonged caregiving can deplete family caregivers' resources, impacting negatively on all aspects of their lives. Kelly (2010) explained the relevance of support groups as a place where family caregivers can feel supported. A support group can facilitate relationships in which they discuss the issues of caregiving openly, express their fears and concerns, and listen to other caregivers' experiences (Northouse et al. 2010). Support groups accomplish this by providing information on available resources, individual counselling, and educational services (Northouse et al. 2012). These resources can be useful ways for family caregivers to develop therapeutic relationships and open communication among members. Although participation in support groups can be beneficial, some family caregivers experienced a loss of privacy in the process, while others said it was ineffective and discouraging (Wittenberg-Lyles et al. 2014; Wong et al. 2014).

Increasing Knowledge through Education

Family caregivers perceived themselves as “fools being tossed around” as they were not knowledgeable in terms of the disease process, the needs of their relatives, or the prognosis. Most participants stated that healthcare professionals did not provide information regarding their relative's disease status. The only time they interacted with them was when they needed to settle medical bills or when their sick relatives needed medical supplies that had to be purchased from a pharmacy shop outside the hospital.

Nurses only call me to go buy one thing or another. I have no idea of what her needs are ... when doctors come ... they speak medical jargons and go ... I wonder if what they say could help my mother ... I think someone should talk to me. (Caregiver 14)

Another participant said:

Although nurses are trying their best ... but they need to do more in terms of providing information ... since most of us are novices. I really need to be educated on how long this illness will take? What other type of care can I provide to give her some peace? I desire to know ... (Caregiver 4)

Another participant said:

We have spent our fortune on these diseases ... and they are not resolving at all. His retirement benefits was used to pay up his medical bills ... I am spending my business capital to pay for medical bills ... it's painful! [sobs] (Caregiver 12)

Family caregivers need to be provided with information on the disease process, symptom management, referral services and available resources that support caregiving (Gladsam, Timm, and Vittrup 2010). Family members are often anxious, apprehensive and may experience depression due to a lack of information about the disease process,

the needs of the patients at different stages of the disease, referrals, and other services that may be beneficial to the patients' recovery (Gaeni et al. 2015).

Knowing about the financial implications related to providing care for ESRD patients might prepare family caregivers and their sick relatives adequately and thereby reduce the experiences of burden. For this reason, nurses should inform family caregivers about the changing needs of the patients and show them how they can provide assistance that supports positive outcomes for their sick relatives. Research has shown that educational interventions empowered family caregivers with the required knowledge, engendered their emotional stability and the adoption of suitable coping skills (Epiphaniou et al. 2012; Northouse et al. 2012). Gaeni et al. (2015) added that this is beneficial because well-informed family caregivers might develop more positive responses to caregiving, make future plans and be better prepared for patient outcomes.

Increasing Caregivers' Identity and Recognition

The interviews revealed that family caregivers seemed to change the way they perceived themselves, namely as someone perpetually providing care. Family caregivers also complained that their sick relatives and other family members did not appreciate their caregiving efforts.

I have been doing this for some time now, it's like there is no end to it. My life revolves around him and the four medical conditionshypertension, diabetes, kidney disease and leg ulcers... [sobs] (Caregiver 11)

Another participant said:

I feel very angry and frustrated when my father doesn't say 'thank you' for the care I give him. He never appreciates the fact that I gave up many things to take care of him. He is a complainant per excellence! He complains about almost everything I do in the process of giving care. It is either the food is not warm enough or that he prefers someone over the other to feed him. (Caregiver 10)

Strained relationships between family caregivers and their sick relatives, and also between them and their significant others could be discouraging for family caregivers and result in their experiencing caregiver burden (Ngangana et al. 2016). Studies have highlighted that significant others and healthcare professionals are better positioned to acknowledge and recognise the family caregivers' enormous role and responsibilities (Aoun et al. 2015). Family caregivers could change their perception of themselves from someone perpetually performing caregiving responsibilities to someone that is recognised for playing a significant role in the life of their loved ones (Moore and Gillespie 2014; Skovdal and Andreouli 2011). Healthcare professionals can encourage family caregivers to take time off temporarily from caregiving so as to regain their self-identity, focus on their personal needs and request assistance or support when needed (Aoun et al. 2015, Northouse et al. 2012). By increasing caregivers' identity and

recognition, they can improve their self-esteem, find meaning and satisfaction in the caregiving experience (Mystakidou et al. 2013; Skovdal and Andreouli 2011), and maintain an adequate sense of self.

Culture

In this study, culture was one of the threads connecting the family caregivers' experiences of caregiving and caregiver burden. Cultural expectations and a preference for family care over institutionalised care placed a heavy burden of care on family caregivers, specifically the women (McCleary and Blain 2013, Okoye and Asa 2011). Data from Cycle Three revealed that family caregivers who were compelled by their culture to provide care for their sick relatives experienced caregiver burden, and a fear of contravention of cultural taboos increased their experience of caregiver burdens (Årestedt, Persson, and Benzein 2014). Although family caregiving promotes the continuity of cultural practices and the sustenance of values and traditions, support could be provided to manage the caregiver burden.

Finance

The availability of financial resources plays an important role in providing adequate care to patients with ESRD, especially in low- and middle-income countries. Caregiving for ESRD patients is resource intensive, and family caregivers experienced economic burden in the process, this being identified in Cycles Two and Three as one of the stressors or challenges of providing care to their sick relatives. In Nigeria, family caregivers have to settle medical bills, buy surgical supplies and medication before their loved ones are treated. This often places the burden of responsibility for the cost of care directly on family caregivers, and if patients die, it becomes the family caregivers' fault.

Dondorp, Iyer, and Schultz (2016), and Karopadi et al. (2013) substantiated this, stating that the economic burden of ESRD in low-income countries was substantial and prohibitive, impoverishing family caregivers and increasing their vulnerabilities to financial burden. Whereas basic renal care might be affordable and accessible in high-income countries, the same cannot be said of low- or middle-income countries where the cost is prohibitive and access to care is limited (Dondorp, Iyer, and Schultz 2016). Inadequate numbers of healthcare personnel also limit patients' access to expert care. Brinda et al. (2014), and Hoffman et al. (2012) assert that this lack also compels family caregivers to provide all forms of care, including professional levels of care. Although nurses do not have the capacity to meet the financial obligations of the family caregivers, they can assist them by helping them to feel supported and encouraged through participation in support groups.

Model Implementation

The MMCB was implemented in a hospital in South West Nigeria, as this hospital showed an interest in the study. The intention was to develop a checklist for nurses when using the model. On days chosen for the model implementation, a nurse volunteer approached a family caregiver, sought consent, and, using the implementation checklist, implemented the model. Selecting the participants for the model implementation was based on the family caregivers' interest and willingness to participate. Seven family caregivers and three registered nurses participated in the model implementation phase of the study. The volunteer nurse and willing family caregiver decided on a convenient time to implement the model, which took place in the patients' private rooms in the ward. The researcher was there to witness the process and participated in the model implementation when volunteer nurses were unavailable.

Verbal feedback provided by the nurses and family caregivers indicated that they were delighted to have a model to manage the caregiver burden. In particular, family caregivers were excited that the model provided an opportunity for them to talk to the nurses, this being the first time it ever happened, with some requesting more time as they had many things to talk about. A number of family caregivers stated that many of their fears, needs, and anxieties could have been dealt with if the intervention model had been implemented earlier in their caregiving experience. While the insufficient number of nursing staff was a challenge at the hospital, the implementation cycle progressed as scheduled. The nurses reported that the implementation checklist made it possible for them to implement the intervention model to manage caregiver burden. They found the implementation checklist useful in starting and continuing a conversation with family caregivers. The nurses also reported that the checklist guided them to deal with issues affecting family caregivers individually. (See Table 1.)

Table 1: Implementation checklist

Activities required for the implementation of the model				
Instruction: Please check (X) the box when you complete the activity.				
S/N	Activities		Yes	No
1	Welcome and create rapport	Address family caregiver by name or surname and title (if applicable)		
		Create rapport by explaining the purpose of meeting		
		Show concern towards her/his well-being		
2	Increase caregivers' identity and recognition	Recognise active role being played by family caregiver		
		Appreciate him/her in the presence of patient		
		Encourage patient to also acknowledge and appreciate family caregiver		
		Attribute positive meaning to the caregiving role and responsibilities		

Activities required for the implementation of the model				
Instruction: Please check (X) the box when you complete the activity.				
S/N	Activities		Yes	No
		Encourage family caregiver to ask for help when needed		
3	Knowledge about disease process and symptoms management	Assess level of family caregiver's knowledge on ESRD management		
		Provide simple, basic information on specific care requirement for patients with ESRD		
		Provide or reinforce information regarding dialysis, renal replacement therapy, etc		
		Provide contact details of hospital staff to call in an emergency		
		Discuss the prognosis (outcome) of ESRD with the family caregivers in a manner consistent with their values and preferences		
		Permit family caregiver to ask questions		
4	Support group or availability of resources	Describe what support group is and highlight its significance		
		Inform him/her about services and benefits of support group		
		Encourage him/her to sign up for membership when the hospital starts one		
5	Increase social connection and engagement	Ask if family caregivers have enough time to rest		
		Encourage him/her to ask for help when needed		
		Set aside time to meet your own needs		
		Refer family caregivers to medical social worker that can provide support for future care needs and options		
		Engage in healthy lifestyle activities like sleep, exercise, adequate diet		
		Take time off caregiving activities		
		Ask or respond to questions		

Reflections

At the start of the study, family caregivers perceived nurses as “unapproachable individuals”, this having limited their interaction with them. By the end of the study, some had initiated discussions with nurses regarding their concerns, fears and challenges. The AR method was invaluable; it ensured that the model and the implementation guide were relevant and appropriate to the nurses who would be using

them. The participation and collaboration of research team members and relevant stakeholders contributed to a change in practice. Feedback after implementation revealed that the family caregivers were excited to have a model to manage the caregiver burden experienced. The nurses were also excited about its potential as a resource to improve patient care, having not previously realised the extent to which the family caregivers were affected by their responsibilities.

Limitations and Areas for further Research

The model was developed and implemented in one research setting and the findings cannot be generalised. The impact of the model on reducing caregiver burden was not evaluated. This warrants further research in other settings to determine how effective it is to assist in managing caregiver burden.

Conclusion

This study has revealed that family caregivers who provide care to their sick relatives in resource-limited settings need support from nurses during the process of caregiving. They are often not receiving sufficient advice and assistance to ensure that their family members receive the best possible care and that they are supported in the work they do.

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