Caring for the seniors with chronic illness: The lived experience of caregivers of older adults

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ABSTRACT

Background: Caregivers of the elderly with chronic illnesses are exposed to the burden associated with their caregiving activities. This study described the lived experience of caregivers of older adults in Nigeria.

Methods: A qualitative design guided by interpretive phenomenology informed the design of the research, whereby 15 in-depth interviews were conducted with caregivers of older adults with chronic illnesses. The interview sessions were audiotaped and transcribed verbatim and analysed using constant comparison analysis method.

Results: Fifteen caregivers, from different parts of Osun State, Nigeria, took part in the in-depth interviews. The caregivers were aged between 19 and 70 years, ten were women, five of them had secondary education, seven were self-employed and six were in a spousal relationship. The study uncovered four interrelated themes with explanatory subthemes—commitment to preservation of life (managing challenges associated with daily routine, problem with mobility, bathing and grooming, feeding, and problem with hygiene) (ii) denial (refusal to accept that burden exists), other things suffer (disruption of family process, suffering from poor health and social isolation), (iv) reciprocity of care (pride in caregiving, caregiving as a necessity and not by choice, and law of karma).

Conclusion: This study provides insight into the burden of care of older adults with chronic illness. Caregivers' commitment to preserving life makes them provide assistance whose performance even run contrary to their own wellbeing. Intervention programme should be designed to support the caregivers thereby improving their wellbeing.

What is already known about the topic?

- Chronically ill older adults are dependent upon their informal caregivers in the performance of activities of daily living.
- Caregivers of older adults are exposed to a various degree of burden ranging from physical, psychological and financial burden.
- There is a growing body of knowledge on caregivers' burden in developed counties and few studies exist in the developing nations.

What this paper adds

- This study is the first of its kind that qualitatively explores caregivers' burden of the older adults in Nigeria.
- This study also demonstrated that family members are keys to providing care to their sick older adults in a resource constraint setting like Nigeria.
- This study established various caregiving activities performed by caregivers and demonstrated the existence of caregivers' burden among the population.

1. Introduction

Caregivers of the elderly with chronic illnesses are exposed to the burden associated with their caregiving activities (Reinhard, Given, Petlick, & Bemis, 2008). A caregiver is a family member or any significant person who assists with most, if not all, of the patient's daily care needs (Agrawal, 2013). Caregivers are exposed to a lot of stressors in the course of carrying out their caregiving activities. When these stressors exceed their coping threshold, they result in stress among caregivers (Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers' burden has been described as a “state, impact or persistent difficulty resulting from the action of taking care of a dependent, elderly person, relative with a disability or some type of deterioration which threatens the physical and mental health of the caregiver, other family relations, the...
job, and the financial status of the caregiver” (Gaugler et al., 2000 and Pearlin et al., 1990 and Zarit, Reever, & Bach-Peterson, 1980) Studies have shown that caregiver’s burden is associated with negative impact on physical, social and psychological health (Morimoto, Schreiner, & Asano, 2003 and Zarit et al., 1980)

The global ageing population has been projected to reach two billion people by the year 2050 (United Nation, 2002) This increase, with the associated chronic illness and debility, the need for caregiving will also be on the increase (Gao, Raven, & Tang, 2007). Currently, there is a high prevalence of chronic illness and disability among Nigerian older adults (Faronbi & Fajemilehin, 2012). Many of whom are living with osteoarthritis and other chronic conditions and these limit their performance of activities of daily living and ability to move from place to place (Faronbi & Fajemilehin, 2012). Literature shows that quite a large number of them need to be assisted in activities of daily living such as bathing, feeding, tidying the house, running errand and others activities (Keefe & Fancey, 2000). All these often result in demand for caregivers' assistance. Caregiving among elderly with chronic illness is a long-term activity since patients often need to cope with significant challenges inherent in the aftermath of diagnosis and treatment of chronic illness (Woo, Maytal, & Stern, 2006).

In the developing countries such as Nigeria, where the ratio of the sick to professional health care providers is very disproportionate, the informal caregivers have increasingly assumed more responsibilities in the care of their loved ones and they face a greater risk of deteriorating health status. These caregivers often manifest caregivers' burden ranging from physical, social, mental and emotional problems (Buhs, 2008) and financial strain (Togonu-Bickersteth, 1989). Caring for the elderly with chronic illness is generally associated with a higher level of stress (Jorgensen, Parsons, Jacobs, & Arksey, 2010).

In developed countries, many studies have been conducted among the older adults and their caregivers to examine prevalence and health effects of caregivers' burden as well as coping and support strategies (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009; Schulz & Martire, 2004). Previous studies in the sub-Saharan (Dotchin et al., 2014 and Mugisha et al., 2013) as well Nigerian studies on caregiving have focused on specific illness conditions especially mental illness (Adesosun, 2013 and Jack-Idie, Utts, & Middleton, 2013) and (Yusuf, Nuhi, & Akinbiiyi, 2009) older adults with hip fracture (Diaemta et al., 2018), cancer (Akpan-Idiok & Anarado, 2014), and patients with End-Stage Renal Disease (Oyegbile & Bysiewicz, 2017). Similarly, Faronbi (2018) and Faronbi and Olaogun (2017) quantitatively examined the burden of caregiving for older adults chronic illness. Despite all these arrays of studies, little information exists that qualitatively examines caregivers’ burden among caregivers of older adults with chronic illness from most low-income countries. Therefore, this study explored the day-to-day experience of caregivers of older adults with chronic illness in Osun State, Nigeria. Conducting this study will identify measures that could assist in developing an intervention programme which could mitigate caregivers’ burden, enhance the quality of life of caregivers, and may be used as an educational tool for nurses and other health care providers. This will have a resultant effect of reducing the burden of disease and caregiving in our society.

2. Methodology

We conducted a phenomenological qualitative method to explore the day-to-day experience of caregivers of older adults with chronic illness in Osun State, Nigeria, from October 2014 to March 2015. We interviewed the study participants in the homes of the elderly and their caregivers located within Osun State. We purposively sampled 15 caregivers of older adults aged 60 years and above with chronic illness who have rich experiences of the burden of care and possess the ability and willingness to express them formed the participants for the study with maximum variation.

We selected the first participant out of the pool of caregivers who met the criteria and interview sessions continued until the fifteenth participants when the saturation point was reached. Data saturation occurred when no more codes or themes could emerge in the last two interviews We included individuals who assisted a chronically ill older with most activities of daily living (ADL) and Instrumental Activities of Daily Living (IADL) (caregiving tasks); 18 years or older; domiciled within Osun State. These ensured samples with maximum variation were selected out of caregivers with diverse socio-demographic characteristics who have been caring for the elderly for a minimum of one year.

The average duration of the interviews was 50 min. We took field notes during the interview, detailed observations of some of the events taking place at the home of the elderly, activities performed by the caregiver as well as some of the verbal and non-verbal expression of burden and challenges associated with caregiving were taken. The transcript was read and re-read and all words and phrases that captured the daily caregiving experience of caregivers were identified as codes. These also include codes related to caregivers’ burden. The report was compiled and read several times and organized into key themes and subtheme. Similar themes were grouped together and emerged as major themes. Identification of themes was guided by Van Manen’s method (van Manen, 2014). The transcript text was imported into NVivo (QSR N10), qualitative data analysis and management software package to assist in the analysis of data.

2.1. Validity and reliability of the data

To ensure validity (or ‘trustworthiness’) of the findings of the qualitative data, the researcher’s prolonged engagement, triangulation and member checking were employed. We read the transcripts multiple times, compared the coding system results which led to the emergence of themes and subthemes as a measure of ensuring trustworthiness of the data. Researcher’s prolonged engagements ensure constant interaction with the data until data saturation was reached. In the course of writing the manuscript, the emergent themes were compared with the transcript individually and as a whole. Findings from the observation were used to validate that of the in-depth interview. Similarly, member checking was also done by visiting two of the participants to confirm if they are in agreement with the preliminary findings of the study. In addition, the study got approval from appropriate institutions.

3. Results

The age distribution revealed that 33.3% were between 41–50 years of age, 66.7% were female, 33.3% of the caregivers had secondary education and 46.7% were self-employed. The relationship showed that 40% of the caregivers were daughter and 40% were spouse (Table 1).

3.1. Caregiving experience

The following major themes related to caregiving experience emerged from the responses of the participants. These themes include (a) Commitment to preserving life (b) Denial (c) Other things suffer and (d) Reciprocity of care.

(a) Commitment to the preservation of life

As a result of old age or chronic illness, some of the elderly have regressed to an earlier stage of development and thereby unable to meet their daily need of performance of activities of daily living. Performance of such activities is required for sustenance and promotion of health. In Yoruba land, no matter how old an individual is, family members and relatives will be willing to do everything possible to sustain his/her life. Even in the midst of age-related debility or chronic illness, it is their belief that supports and assistance are necessary to keep him/her alive. The caregivers believed that the performance of
activities of daily living promotes and preserves life. The caregivers expressed that when these activities are not performed, it may lead to progression of illness, deterioration of the condition and early death. Thus in the situation when there is a deficiency on the part of the older adult to perform these roles, the caregivers consider it necessary so that life could still be sustained.

Caregivers assist with the following activities such as managing challenges associated with daily routine, changing of position, assisting with mobility, bathing and grooming and feeding. In addition, caregivers also assist in keeping a medical appointment.

3.1. Managing challenges associated with the daily routine

Some of the caregivers reported that they have to wash cloth soiled with urine and faeces, do everything for the elderly and support the elderly at all times.

I have to wash clothes soiled with urine and faeces all the time like nursing new babies. This is one is even worse compared to nursing a baby. (59 yr Spouse Food vendor).

I do everything for her, she cannot do anything on her own (65-year-old – daughter, retiree).

You have to teach and supervise her so that she does not add anything to her food (27-year-old - Daughter-in-law, businesswoman)

3.1.1. Changing of position. Another task performed by the caregivers is regular changing of position. Appropriate positioning is required not only for proper circulation and body functioning but also for prevention of contracture and other complications such as bed sore and disuse syndrome. When an individual is healthy, he/she performs this unhindered, but as a result of debilitation, he/she would need an assistant to meet this daily task.

He has become totally dependent. You have to feed him, clean him up and change his position from time to time. … when you are trying to help to change position, he always complains of pain … (59-year Spouse).

I have to carry her from bed to chair, when I want to clean her or when I want to feed her (65-year Daughter, retiree)

3.2. Problem with mobility

Mobility is another problem expressed by the caregiver in caring for the frail and debilitated elderly. As a result of old age or illness condition, some of these elderly were unable to move from one place to another on their own. Some of the elderly required assisted mobility by carrying them from the bed to chair or assisted to a sitting position on the bed whenever they need to be fed or defecate. This often poses a great challenge to the caregivers especially those elderly who are obese. The description by caregivers further buttressed challenges they encounter moving the elderly from place to place because of immobility.

We cannot carry her down when we want to go to the hospital, as you can see; she has no leg to walk (47-year house-wife).

There is a problem with mobility, who will help us to carry him from the house to the hospital and when we get to the hospital, you have to carry him by yourself (42-year businesswoman).

3.3. Bathing and grooming

This includes daily bed bath and assisted bathroom bath for those who could be assisted to the bathroom. Depending on the degree of dependency, some of the caregivers bath the elderly daily or alternate days which range from an assisted bathroom bath to complete bed bath. On occasions when the caregivers were very busy combining these with their schedule may be burdensome. Participants expressed frustration especially on instances when an elderly person soils himself after they have been cleaned which forces the caregiver to repeat the exercise for the elderly.

3.4. Problem with hygiene

In addition to grooming activities, caregivers also assist in maintaining hygiene whenever the elderly obey the call of nature. Most of the frail and chronically ill elderly are immobile and dependent. Caregivers assist them with cleaning after every bowel movement. Most of the elderly in this study required substantial levels of assistance from their caregivers. The caregivers reported that they assisted in daily cleaning and on every occasion as nature demands.

The only problem is that she couldn’t lift her body again; you have to do everything for her on the bed (65-year Daughter, retiree).

If he wants to defecate, I assist him, if he wants to urinate, I assist him. I carry him to the toilet and I also bathe him (30-year-old son self-employed)

3.5. Feeding

Caregivers provide assistance ranging from assisting the elderly to a sitting or leaning position, positioning the food appropriately and directly feeding the elderly. One of the challenges encountered while feeding includes when food splashes on the body during feeding or experience of fear of suffocation.

- Denial

Our data suggest that while the burden of giving care to the elderly is immense, caregivers in this study do not often immediately acknowledge or realise it. For instance, when asked to describe how caregiving activities inflict on different areas of their lives, many respondents first started by denying that taking care of their elderly mothers, fathers, in-laws etc. was a burden to them. For example, one woman narrated that there is no associated problem taking care of her husband. She later reported that combining the care of her husband with her food vendor job is burdensome and it is affecting her health, finance and social life. Another respondent, John a 30-year-old man
who initially denied he was experiencing any difficulty caring for his aged father, later recounted that he has to abandon his wedding plan because of his aged father’s illness and this has torn has proposed marital relationship into pieces. Failure to immediately acknowledge the burden of caregiving for older adults could be related to sociocultural beliefs associated with caregiving among the Yorubas as well as relationships of the caregivers to the older adults in many Nigerian societies.

However, upon further questioning, these caregivers began to recall and express how their engagements in caregiving have been interfering with every area of life. For instance, a 32-year-old male who takes care of his 82-year-old father says he wakes up every day at 5.00 a.m., he estimated that each day he spent about 9h in direct care for his father. These activities stress the caregivers beyond the limit and they often get to the breaking point whereby it manifests as the burden which affects various aspects of their life.

There is no burden at all ...any time I want to take her to the hospital; I have to abandon my own schedule (30-year-old male self-employed)

There is no problem, he is my husband, and there is nothing that I can do but just to continue to support him (56-year-old Food vendor)

There is no problem or any challenge at all, she is my mother, I have to take care of her (64-year-old daughter)

I cannot say that I have any problem taking care of him, he is my husband ... in the course of care for him, all my capital have disappeared because I cannot take oversee my business (47-year-old spouse businesswoman)

There is no problem or any challenge, even though, when I go out for social activities, I have to return on time because I cannot leave him alone for a long period (27-year-old businesswoman)

- Other things suffer

Even though there is a denial of burden which was only expressed after further and deep probing, caregivers expressed burden associated with their caregiving activities and these were captured in the followed subthemes (i) disruption of the family process (ii) suffering from poor health and (iii) social isolation

3.6. Disruption of the family process

Participants stated that they experience a disruption in the family process due to the inability to effectively combine the caregiving activities with their family and personal daily demand. The daily routine of care of the elderly impeded on caregivers’ attendance to their own daily business, family matters and other personal obligations. Respondents mentioned that as a result of the sickness of their loved one, they have to either abandoned or neglect their family, work or devote less time to it. Those that were self-employed claimed that they have not been giving enough attention to their business and this has made them lose many of their customers. Some claimed that when the customer comes around repeatedly and did not find them they look for another one.

Similarly, those who were employed in the formal sector claimed that they even received a query as a result of their absenteeism and poor attention to their daily duties. Some of the caregivers related their state of divided attention and internal struggle that they experience in the process of providing care to their sick old folks. This is expressed as follow:

When my children needed my assistance to babysit, now that I retired, I couldn’t go... The only challenge is that I couldn’t visit them, even when my grandchildren call and said they wanted to come, they couldn’t come (65-year Daughter, retiree)

I cannot travel, my journey can only be one day. All my activities are scheduled around the house. If I go out, I must return as soon as possible (56-year Spouse machine operator).

Some caregivers also expressed neglect and abandonment of their business because of the caregiving process. The caregiving role made it difficult for them to concentrate on their daily business engagement. This is then expressed as follows:

If I have somewhere to go and I cannot go, I have to send somebody there. That person may not represent me very well. Yoruba people say “Oju mewa kole jo oju eni” meaning no one can defend you appropriately in your absence (28-year-old business woman).

3.7. Suffering from poor health

Caregiving demand also has its toll on the health of the caregiver. Caregivers experience various ailments in the process of assisting their sick older adults such as frequent upper respiratory tract infection, headache, malaria, frequent stooling, weight loss and weight gain. Some of these conditions are communicable and might have been acquired from the sick older people or vice versa. Weight loss has been associated with poor attention to health, poor eating pattern and frequent illness. It may also be associated with fatigue and exertion and inability to observe adequate rest. All these were reported by the caregivers. Overeating is one of poor coping response.

Physical exhaustion is also a common experience of the caregivers. This may be associated with activities required to meet the daily need of the older adult and may be worse during the period of admission when caregivers have to traverse the length and breadth of the hospital to perform a task. This is further presented in the expression of some of the caregivers.

It is not easy, by the time I move up and down cleaning the house, preparing the food and taking care of him, I am tired and worn out. (64-year-old daughter)

(47-year-old house-wife)

Despite these health challenges, some of the caregivers reported that they were unable to attend to their health need, thereby resulting in further deterioration. Similarly, some of the caregivers expressed a sense of abandonment and isolation. They felt that other family members who should have been there for them to support physically, financially or emotionally have abandoned them and they were left alone isolated. This could be seen in the expression of some of them as follow:

They have all left me. I am the only one taking care of him (65 Daughter Retiree)

None of his relatives or family members is coming around; I am the only one here (59-year Spouse Food vendor)

There is no one to talk to except God. Only one of her relatives comes around once in a while. That is not even regular. (65-year Daughter, retiree)

- Reciprocity of care

In pursuit of the caregiving role, certain factors serve as driving forces for the caregiver to be enlisted or continuing in the caregiving process. The factors are associated with the cultural practices and expectations to enter into the caregiving role or continue in caregiving activities. Even in the midst of challenges associated with caregiving, they still keep their commitment intact. These factors include (i) Pride in caregiving (ii) Caregiving as a necessity and not by choice, (iii) Law of Karma

3.7.1. Pride in caregiving (social and cultural norm)

Some of the caregivers perceived caregiving as a pride. The act of caring for an elderly towards the end of life is seen as something
worthwhile. This becomes important when mutual love exists between the elderly and the children, siblings or relatives. Respondents claimed that they felt happy and had a sense of belonging that the elderly were cared for and died in their arms. Such an individual is considered as the beloved of the elderly. It is believed that the elderly would have revealed some personal secrets to the person on whose hands he or she rested. In addition, the elderly would be seen as someone who passed on with dignity and it is in contrast to an individual who dies without the presence of any relative.

She is my mother. My mother is a mother, if there is any other thing to use in describing her, she is more than that. I am the only child. (65-year Daughter Retiree)

“owo omo lo ku le” meaning he died in the hand of children (62-year Daughter House-wife)

3.8. Law of Karma

Some of the caregivers gave their reasons and motivation for involving themselves in caregiving role based on the law of Karma that is, whatever you sow is what you will reap.

You know there is a law that says you should treat others the way you want to be treated. When I grow old, I want my daughter-in-law to treat me well also. My son will marry too and whatever I do, my daughter-in-law will do it to me also. Whether you like it or not, it still bothers on that. That is the way I see it (27-year-old Daughter in law, Business Woman)

3.9. Caregiving as a necessity and not by choice

Some caregivers felt that they have to do it as a matter of necessity or compulsion. This may be for fear of rebuke and condemnation for abandoning the older adults by the relative.

I cannot leave him if I leave me and go anywhere, and any of the relatives come around, they will think that I abandoned him (56-year Spouse Machine operator)

What can I do, if I have him as my own father, I have to take care of him (55-year Spouse Food vendor)

I have been living with my grandmother from my childhood. I have always seen her as my own mother. The love and affection has grown so much that now that she is sick I cannot leave her alone (19-year-old Grandson)

Findings from this study revealed that participants were responsible for the care of their elderly parents either by way of providing physical care or by ensuring that daughters and daughters-in-law are always there to attend to the need of the older adults. In some few situations, when the extended family system is effective, the care of a sick older adult is collectively provided by the entire family members. However, as a result of the collapse of the traditional family system, immediate family members are living in isolation and the responsibility of providing care for the older adults also rest on immediate family members. And this often imposes some forms of a burden on the caregivers. Nearly all of our participants expressed various degrees of the burden associated with their caregiving roles. They stated that caring for an older person with chronic illness has placed an all-around burden on their health, job, economic, and social life.

4. Discussion

One of the main findings of this study is that family members were the major caregivers of their sick older adults. This was also reported by the National Alliance for Caregiving and American Association of Retired Persons (2009) which states that family members are core in assisting their sick older people in meeting their daily activities demand. Kwok, Bel Wong, Chui, Young, and Ho (2013) further submitted that family members provide an array of support for their loved ones ranging from assistance with the performance of activities of daily living, financial, psychological and spiritual assistance. Wimo et al. (2013) identified that in most low-and-middle-income countries family members are saddled with the responsibilities of providing care to their loved ones with chronic illness. Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, and Pimporm (2013) observed that the Asian family is expected to be responsible particularly in the area of taking care of parents when they are getting older. The situation is similar among the Yorubas.

Findings from this study further revealed that a good number of the respondents were spouse caring for their partners. This is similar to previous studies by Pickard et al. (2009) and Yin et al. (2014) who observed in their study that spouses/partners comprise a large percentage of caregivers. Similarly, Zhang, Yao, Yang, and Zhou (2014) and Muangpaisan et al. (2010) documented that majority of caregivers were either women who were spouse, daughter or daughter-in-law. Holroyd (2001) reported that daughters were more likely to take on a caregiving role when they lived with their parent and believed that women were most capable to provide personal care. This may be attributed to the fact that traditionally women are expected to stay more at home and provide direct care for the family. They enter into this role either as a wife, daughter or daughter in law. On the other hand, men are usually seen as the breadwinners and are committed to working outside the home. In Yoruba culture, women are the main caregivers at the household level, while men are engaged in decision-making at both the household and community level. Women are also more involved in domestic care while men engage in activities to fetch for the livelihood of the family. Also, women are believed to stay more with their sick loved one because of their compassionate nature. Findings from this study also show that women are predominantly involved in caregiving.

Caregivers in this study spend substantial numbers of hours in providing care daily for their sick elderly. They assist in activities of daily living such as feeding, grooming, changing of position, medication and running errands. Almost one-third of the respondents in this study claimed that they spend almost the entire day caring for the sick elderly. This is congruent with the findings from the study by Schulz and Martire (2004) which shows that half of the caregivers spend at least 46 h per week assisting patients with activities of daily living and instrumental activities of daily living.

Although family members are keys in providing care, it burdened them as was reported by all the respondents in this study. It is expected that a typical African person may see it as part of his responsibilities and may not want to acknowledge the presence of burden. However, when the caregivers were stressed beyond the limit and the protective measures are no longer effective, it may manifest as a burden which is multi-dimensional. The multiple tasks and roles that they engage in the cause of providing care for their loved ones may explain the associated burden.

Findings also revealed that caregivers experienced financial difficulties as a result of their caregiving experience which could be likely explained by the financial drain that chronic illness exerts on families. Similarly, Thrall (2005) argued that the medical care costs of people with chronic illnesses represent 75 per cent of the U.S. annual health care spending.

As reported in other studies, Koenig, Steiner, and Pierce (2011) and Marimbe-Dube (2013) and Wancata, Alexandrowicz, Marquart, Weiss, and Friedrich (2006), family caregivers are at an increased risk for poor physical health, depression, and anxiety, lower levels of subjective well-being, and deteriorating physical health. Findings from this study also corroborate this assertion, caregivers experienced health challenges such as a headache, body pain, gastrointestinal disturbance and joint pain.

Sherwood, Given, Given, and Von Eye (2005) further expressed that negative stress responses have been well documented over the past
decade for both caregivers of persons with cancer and for caregivers of persons with a neurologic disorder. Pearl et al. (1990) also documented that caregiving is potentially fertile ground for persistent stress. Similarly, Yang, Hao, George, and Wang (2012) argued that caring for older people not only affects caregivers’ daily lives but also poses dramatic and considerable psychological and physical challenges.

Nigeria is one of the African countries where there is no working policy or provision for older adults. Earlier, two states out of thirty-six states in the Federation offered social security for the elderly. One of the states was paying only N5000 ($16) per month and the other was paying 10,000 ($32) per month. In the face of rising inflation, what will an older adult person make out of this? This condition may even be worse when such an older adult is faced with multi and co-morbidity.

There are even worse situations when the older adults have unemployed children and all the family members have to live on the meagre stipends. The sad news is that as at the time of writing this report, these two envious states have even stopped payment of stipend to the older adults. What is then, the lot of the older adults, those whom the society supposed to care for and cherished in order to keep our custom and traditions? This situation often put much pressure on the family caregivers.

5. Limitations and strength

This study was conducted among family caregivers of older adults attending care in the hospital. This was done to ensure that only caregivers of older adults with diagnosed illnesses were included in the study. There are possibilities that the very poor who never visited the hospital might have been excluded from the study. This might have implication on the generalisation of the finding. However, this study was meaningful as it provided significant insights into the caregiving activities of older adults and its associated burden in Nigeria and other countries with similar settings.

6. Conclusion

This study has revealed the presence of obvious, denied and poorly communicated burden associated with the care of the older adults. This study showed that despite the presence of this burden associated with caregiving, the commitment to preserve life makes the caregivers persist in the caring process. Their beliefs that caring for an older adult is an investment serve as a motivation to continue despite all odds. The authors hope that the findings will be useful for policymakers to formulate strategies to help caregivers of older adults to mitigate their problem. These may include providing prevention programme to reduce chronic illness, designing a programme to improve the quality of older adults and providing relevant informational, emotional and social supports to caregivers of older adults. The study further recommends that provision of effective structured educational programs for caregivers will be beneficial to them. In addition, establishing a support group will play an important role in assisting caregivers to overcome their daily challenges.

Conflict of interest

None.

Ethical approval

Ethical approval for the study was obtained from the Human Research Ethics Committee, Institute of Public Health, Obafemi Awolowo University, Ile-Ife (IPHOAU/12/101) and Ethics and Research Committee, Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife (NHREC/27/02/2009a). Permission was also obtained from the authority of the institution, and in addition, informed consent was obtained from the caregivers before the commencement of the study.

We ensured that we respect the sanctity of life of the older adults and give them the right to autonomy. For the older adults who were cognitively intact, the content and purpose of the study were explained to them and we sought their consent to interview their caregivers. We interviewed only caregivers of those elderly who consented that their caregivers should be interviewed. Participants were guaranteed anonymity and confidentiality of the information provided.

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