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# The Exceptional Role of Women as Primary Caregivers for People Living with HIV/AIDS in Nigeria, West Africa

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## Abstract

In Africa, women play an indispensable role in family life. The normative roles of women extend from reproductive role to the raising of children and caring for sick family members. These roles are very unique and are dictated by culture, religion and beliefs. Despite these, their contributions in caregiving remain unrecognized except by the beneficiaries. Caregivers of people living with HIV/AIDS (PLWHA) experience high level of burden due to the expanded role and inadequate preparation for the caregiver's duty. A descriptive cross-sectional research design was utilized to elicit data from 260 participants in Calabar municipality, Nigeria. Caring for PLWHA is an exceptional service due to exacerbation of symptoms and co-morbidities peculiar to terminal phase of HIV. The study revealed gender inequalities in burden levels. Significant relationships ( $p < 0.05$ ) also existed between burden of care, availability of support and duration of care during this study. Despite the perceived consequences, the family care givers were still determined to continue caregiving role. This informs the need for governmental support to ameliorate the negative consequences of caregiving by female caregivers.

**Keywords:** women caregivers, burden, PLWHA, Nigeria

## 1. Introduction

Africa is a patriarchal society with women role detected by ethno-religious ideologies, economic as well as socio-cultural factors. These factors inform assignment of resources and responsibilities which is often laden with inequities between men and women [1, 2]. However, women have proven to be the central crux that holds family together while serving as primary caregiver to children and elderly globally as well as facilitating or hindering change in family life [3]. Additionally, with the scourge of HIV in the African society, the responsibility rest on them, a situation describing AIDS as having “a woman's face” in Africa [4]. While HIV prevalence continues to soar in Africa, it is eroding the health of women directly as well as indirectly diminishing their skills and productivity which adversely affects family life [4, 5].

An average of 75.7 million (55.9 million–100 million) people have been infected with HIV with about 32.7 million (24.8 million–42.2 million) AIDS-related death recorded since the onset of HIV epidemic in 1981 [6]. Presently, UNAIDS fact

sheet [6] reveal about 31.6 million–44.5 million (38.0 million) people living with HIV, with about 1.7 new infection in 2019. African disproportionately bear the burden of HIV with about 25.7 million people living with HIV and 470,000 AIDS related death in 2018. Although global effort has been directed to combat HIV impact in Africa, the continent still contributes about two thirds of global new HIV infections with about 1.1 million people infected in 2018 [7]. Nigeria remains Africa's most populous country, with about 1.9 million people living with HIV, 130000 new infection, and 53,000 AIDS-related death in 2018 [6]. The high prevalence of HIV will invariably invoke strain on family life especially when affected member returns home for succor.

The African nuclear family is a potent therapeutic force, and highly sensitive to the needs of its member, by providing physical, financial, emotional and spiritual support. Studies reveal that family remains the primary entity in caring for individuals, through which socialization, trust, loyalty and inter-family cooperation develops, and many counts on these attributes in adverse health condition [8, 9]. These attributes attracts afflicted members and act as a succor especially during terminal stage of HIV with co-morbidities [9, 10]. Caregiving although a normative role, is assumed most often by people without preparation or questioning even though it may disrupt work, family and social life of the caregivers. As the number of people living with HIV/AIDS increases, the demand for family members who assume caregiving role increases [11]. Moreover without appropriate restructuring of existing role to accommodate new caregiving roles, the increase in responsibility may constitute burden, which is detrimental to the caregiver's health as well as quality of care rendered to the care recipient [10–12].

## **2. Women and HIV**

Women disproportionately bear the burden of HIV and this is often secondary to gender inequalities which are obvious in economic status, cultural and societal norms. Women and girls constitute more than half the population of PLWHA, accounting for 18.8 million prsons. Studies reveal that in every 4 minutes, three young women are infected with HIV with approximately 870,000 new HIV every year among women and girls [13]. Additionally among female age 15–49, AIDS-related illnesses remains the leading cause of death [14]. Although, no HIV gender disparity existed in children, gender disparities became obvious during adolescence, with girls accounting for 75 per cent (130,000) of new HIV infections among adolescents, globally in comparison to about 44,000 adolescent boys [14]. In sub-Saharan Africa, young women are two times more likely to be infected with HIV than male and they account for 59% of all new HIV infections [6]. Women also disproportionately bear the burden of HIV in Nigeria, among 1,800,000 adults with HIV, and the majority, 1,000,000 (55.56%) were women. New HIV infection among those aged 15–24 years were more (26000) among female compared to 15,000 among their male counterparts [6]. New HIV infections among young women aged 15–24 years were almost double those among young men: 26000 new infections among young women, compared to 15,000 among young men. The high prevalence among female is fueled by biological vulnerability, gender inequalities which encouraged early and forced marriage, lack of information on sexuality, lack of negotiating power as well as economic autonomy [15]. The need to bridge the gap by improving the quality of life of females by encouraging social justice with equal access to employment, education, health services and freedom from discrimination and violence had been advocated as a panacea for ending HIV epidemic by 2030 [4]. In spite of high HIV burden among women, they also bear the brunt of caring for those affected, a double jeopardy.

### **3. Women and caregiving**

It is imperative that as humans navigate through life with changing demographics that some will have to function as caregivers. Caregiving is a role expected of family members however, the irrefutable strength of informal caregiving lies on female family caregivers, whose role are often designated by ideologies and endorsed by culture. It has been asserted that caregiving is feminized and women are socialized into nurturing roles [16]. Studies affirmed that round the world women make-up about 57 to 81% of informal care givers for family members with chronic disabilities [17–21]. Females commenced their caregiving activities at a very young age and maintain this role as they aged [22]. Most often their roles are not recognized by other family members and health care system except by the care recipient [23].

A Canadian study revealed that in every five persons there was a female family caregiver who provided 70 percent or more of required caregiving needs [24]. In the United States, about 41 million family caregivers served 34 billion hours of care to recipient with functional disabilities accounting for an estimated \$470 billion of unpaid caregivers [23]. The female form (65%) majority of family caregivers and about 80% provide care to elderly relative or friend [25]. Another study revealed that 82.8% of family caregivers were females in a study with 583 family caregivers [26]. A similar report was obtained from an Australian research where 2.65 million family caregivers in 2015, were females (12.3%) and only 9.3% were males [27]. Studies in Nigeria also revealed gender difference when it comes to caregiving, where majority were female, (67.3%) and experience a higher level of burden than men [12, 28]. In France majority of caregivers were women and whenever one caregiver was needed to provide care it was most often female [29]. Additionally, daughters form three-quarters of those caring for their elderly parent, and 70% of those caring for their spouses were wives while men tend to seek professional assistance with care duties [29]. Similarly among couples, women most often shoulder caregiving role than their spouses [30]. When it comes to physical care or personal care, such as bathing or getting dressed, women are more likely (19% vs. 8%) than men to provide such care to care recipients [31]. It has been affirmed that caregiving is a traditionally driven activity earmarked for women [32].

### **4. Duration of care**

Unlike formal caregivers, informal caregivers may not have stipulated time period for caring and are often required to perform multiple task both planned and unplanned for the day with progressive increase in activities over time which induces burden [10, 11]. A study affirmed the disparity between men and women caregiving involvement with changing demographics and suggested the need for more male involvement in order to reduce caregiving burden on women [30, 33]. The period spent providing care to a sick family member differs between men and women. The variation however exists between the types of care provided as well as duration, thereby exacerbating women perceived burden. Studies have revealed disparity in hours between men and women providing care, that women provides full time care with an average of 9 hours 45 minutes, that is, with an additional 2 hours more than men, who provide 7 hours 20 minutes of care [30, 34]. With regards to gender specific differences in providing care, women approach to caregiving is more comprehensive (more hands-on care) supporting care recipient with activities of daily living. Furthermore, women provide care for longer duration than men, with caregivers spending more than 11 hours per week [32, 35, 36]. The feminization of



female role in caregiving and home centered care give a greater sense of family obligation with longer duration spent in caregiving than men [37–39]. Another report stated that duration of care increased among cultures and societies who designate caregiving as a woman's primary role [39]. Additionally, females' care giving role commenced at a younger age and persists as they grow older with an average age for female primary caregivers ranging between 30 and 55 years [22].

## **5. Gender and caregivers burden**

African traditional gender norms feminize caregiving and exclude men and boys from caregiving. The normative women roles extend from reproductive role to nurturing infant and sick family members and remain progressive all through their lifetime [40]. However, these roles remain unrecognized except by the beneficiaries. Therefore, personal sacrifice comes with fulfillment of this role, while some female may have to leave school to provide care [41]. The added responsibility may overshadow the individual coping ability and it manifest as stress or burden. Caregiver's burden is defined as an individual response to physical, emotional, psychological, financial as well as social stressors in Ref. to caregiving experience [42]. Burden maybe objective or subjective. Objective burden refers to disruption in household routines, social relations, leisure, time, finances, work as well as physical health which is often observable [43–45]. Subjective burden refers to how the caregiver appraises the caregiving task [44]. However it has been reported that objective burden depends on subjective appraisal of the caregiving task [44]. Report reveals that caregivers of PLWHA experienced high level of burden [34]. With common sessional symptoms and exacerbation in terminal phase of HIV, many are overwhelmed with caregiving demands resulting in burden [46]. Moreover burden may be compounded with lack of support and financial constraint. Studies revealed higher level of both subjective and objective burden among females compared to males [17, 38, 47, 48] and higher level of physical and social burden [49]. But women experienced more objective burden which is often associated with physical task of caregiving [40]. Similarly, another report stated that women are directly involved in providing personal care which is more demanding and significantly contributes to burden [11, 33]. Studies in Nigeria also affirmed a significant relationship between caregiver's burden and gender with 67.5% female accounting for those with high level of caregivers' burden [10, 28]. Similarly, another study in Lagos, Nigeria also affirmed higher level of burden among female and more stressor emanating from financial, physical as well as emotional domain of burden scale.

### **5.1 Caregiving and support**

The high prevalence of HIV in Africa and Nigeria, coupled with improvements in treatment modalities and life expectancy predict the inevitable loss of autonomy as disease trajectory progressed into AIDS. It has been noted that in spite of prophylaxis for opportunist infection and antiretroviral therapy in preventing AIDS associated illness, PLWHA will still be sick and have disability in functional ability, hence require care [50]. This terminal stage invariable signals the need for either formal or informal caregivers. Studies also revealed that HIV infected individuals return to their homes for physical and psychological support and adequate discharge preparation which incorporate health care team; and family care givers become imperative [50]. However, health care system especially in developing countries do not have the capacity to provide long-term services, they rarely involved family caregivers in the discharge planning, neither are they educated

about their roles. Patients are discharged home without contact with family caregivers and most health systems lack structured and effective discharge plans [51, 52]. But effective discharge planning plays a role in continuity of care [53]. Although there are benefits associated with caregiving such as fulfilling normative role and reciprocity when the chips are down [10, 54]. Reducing the cost of institutionalization and receiving care in an environment one is familiar with as well as being in the company of loved ones improved the quality of life of the care recipient. Moreover, during caregiving bonding relationship develops between the caregiver and recipient, but the type of relationship depends on the age of caregiver and recipient [55]. It is however pertinent to note that in spite of family resiliency with care, their experience of physical and emotional strain should never be ignored [56]. Most caregivers are “hidden” patients which health care professional fail to recognize [57]. Besides, while discharging the patient they fail to think about continuity of care to full recovery, based on the implicit assumption that family members would care for them, without educational preparation on how to manage discharged patient. The assumption of caregiving role without preparation might affect the individual coping mechanism resulting in the experiencing of stress or burden. Caregiving has both positive and negative consequences although the two may exist concurrently [57]. Excessive life stressor on the other hand results in negative consequences and without adequate intervention may affect role performance [58]. This informs the need for family caregivers support. Support is conceptualized as what others do to help the individual cope [58]. This conceptualization of involving significant others in the caregivers’ capability constitute the principal theme that is exemplified in this study.

The forms of support have been categorized into three namely: (a) instrumental aid (actions or resources provided to aid caregiving responsibilities), (b) socio-emotional aid (infer demonstrations of love, caring, esteem, sympathy and group belonging) and (c) informational aid (communications of information that makes life challenges easier) [59]. These forms of social support buffer the negative consequences of caregiving. Although men have jobs more than female [30], the female combine caregiving most often with productive and reproductive activities, therefore they need support for adaptation as responsibilities changes or increases, in order to ensure quality care and life of the care recipient. This study therefore seeks to assess the level of burden experienced by all caregivers of PLWHA, identify and compare the gender differences in the degree of perceived burden, ascertain the duration of care, assess the availability of support as well as the willingness of caregivers to continue caregiving in the future.

## **6. Materials and method**

### **6.1 Location of the study**

The study was conducted in Calabar Municipality, a local government in Cross River State (CRS) of Nigeria between June to December 2009. Cross River State is one of the 36 States of the Federal republic of Nigeria situated in the South South zone of Nigeria. Calabar Municipality has an area of 142 km<sup>2</sup> and a population of 179,392 by the 2006 census. Calabar Municipality otherwise called ‘Efik eburutu’ has a rich cultural heritage and very hospitable. Compared with other communities in Nigeria, they operate the patriarchal system with male preference and dominance. Moreover the families take responsibilities for their sick member. CRS operate the three tier health care system which includes primary, secondary and tertiary, however the health facility is skewed to the urban area. The University of Calabar

Teaching Hospital (UCTH) is a tertiary institution and a referral center to other health care facilities. The facility offers both inpatient and outpatient services and collaborates with nongovernmental organizations (NGOs) in the treatment of PLWHA from rural/urban areas and neighboring country, Cameroun. The state is one the 12 + 1 states which contribute about 70% of HIV burden in Nigeria. UCTH is one of the centers for the management of PLWHA. The high HIV prevalence (10.4%) at the study site inform the choice of study setting [10, 60].

## **7. Study design and participants**

The study utilized a cross-sectional descriptive research design with a convenient sampling technique. Two hundred and ninety nine (299) participants were selected for the study; however 260 completely filled their questionnaires and were aware of care recipient HIV status. Family caregivers were recruited through HIV clinic of the UCTH and Positive Development Foundation (NGO) visitation list of voluntary caregiver of PLWHA. Information letter and invitation were posted at UCTH HIV clinic and the Positive Development Foundation office where interested and willing participants were contacted by the researcher. This study is part of the research project previously published [10]. Therefore participants who met the inclusion criteria were individuals: who have been a primary caregiver for more than 1 month, have awareness of the care recipient status or have provided care for PLWHA patient with some functional abilities as a family member. Family caregivers age cuts across all age brackets, and often include children under the age of 16 [61]. The role of primary caregiver as associated with this study involved participants who provided unpaid physical support such as helping in activities of daily living, food preparation, shopping, managing scheduled medication, managing finances, overseeing medical appointment and emotional support to PLWHA. Questionnaires were coded and contact information was not included to ensure confidentiality. Ethical consent for the study was obtained from Health Research Ethics Committee of UCTH Calabar. Consent was also obtained from the Managing Director of Positive Development Foundation who helped to identify PLWHA caregivers. Informed consent was also obtained from study participants after full explanation of the aims and objectives of study. Participants were appreciated for their time.

## **8. Instrument and measures**

Structured questionnaires were the instrument for data collection, two versions of the questionnaire was developed: the English version and the Efik version (local dialect). The Efik version was translated from English into Efik and back-translated into English by experts to prevent loss of meaning. The researcher and trained field assistants helped with data collection through face to face contact, however some questionnaires were deposited with the caregivers who filled and returned within 1 week. The structured questionnaires consisted of 41 items, 7 demographic variables, 22 from Zarit Burden Interview (ZBI) scale and 12 measuring social support. Reliability of the instruments was attained through test-retest method. The questionnaires were administered to 10 caregivers of PLWHA in Calabar South. After 2 weeks the same questionnaire was administered again to the same subjects. Their responses during the two occasions were correlated using Pearson product-moment correlation to obtain a reliability coefficient ranging from 0.85 to 0.96.

## 9. Demographics

Seven items make-up the demographic variables which included: participant's age, marital status, their current occupation, highest educational qualification, household income level, number of people in the household and duration of care. Duration of care was categorized into two namely: hours spent per day and years spent as a caregiver of PLWHA. Duration of care was predefined for the caregivers.

### 9.1 Caregivers burden

The Zarit Burden Interview (ZBI) scale is a caregiver self-report questionnaire consisting of 22 items. Each item reflected the impact that patient disabilities have in the caregiver's life. The caregiver endorsed the degree of physical, emotional and social discomfort experienced on a 5-point Likert scale ranging from never, rarely, sometimes, quite frequently, or nearly always. The 22 items validated ZBI scale had reliability coefficient ranging from 0.88 to 0.92. Scores ranged from 0 to 88 and a high score is associated with higher level of burden.

### 9.2 Support

The support questionnaire contained 12 items which assessed the extent of support received in the form of information, financial help, emotional support as well as physical help with caregiving activities. The instrument was pilot tested with a reliability coefficient of 0.85 to 0.96. Caregivers indicated the extent of support received on a 4-point Likert-type scale, ranging from lots of support, some support, very little support and no support.

### 9.3 Data analysis

Descriptive and inferential data were obtained using Statistical Package for the Social Sciences (SPSS 16.0 software) which generated the frequency and percentages of the values. Chi-square test and T-test was used for inferential statistics. The level of significance was also determined at the  $p$  value of 0.05. The ZBI scale scores ranged from 0 to 88. The scores were categorized into four namely: 0 to 20 represented little or no burden; 21 to 40, mild to moderate burden; 41 to 60, moderate to severe burden; and 61 to 88, severe burden [62]. The support instrument was grouped into two namely: availability of support for "lot of support and some support," and lack of support for "very little support and no support."

## 10. Results

### 10.1 Socio-demographic characteristics

**Table 1** describes the socio-demographic variables of 260 caregivers of PLWHA who participated in the study. The majority of caregivers were females 199 (76.5%). Age ranged from 10 to 80 years, with majority between 31 and 40 years, however the females formed the majority in all age ranges. Marital status revealed majority (93/35.8%) were single females. The majority (77/29.6%) had tertiary education as the highest educational qualification and (89/34.2%) caregivers were employed, while 60 caregivers left school to care for their loved ones with majority 49 (18.8%) among the female caregivers of PLWHA (**Table 1**).



G	Age (years) Range n (%)		Marital status Type n (%)		Educational qualification Type n (%)		Occupation Type n (%)		Duration of care (hr/day) Range n (%)		Years of care Range n (%)	
F	10–20	22 (8.5)	Married	79 (30.)	Primary (Basic)	22 (8.5)	Employed	89 (34.2)	3–8	16 (6.2)	<1	67 (25.8)
	21–30	31 (11.9)	Single	93 (35.8)	Secondary (high)	31 (11.9)	Un-employed	31 (11.9)	9–12	145 (55.8)	1–2	90 (34.6)
	31–40	63 (24.2)	Divorced	10 (3.8)	Tertiary	77 (29.6)	Business/ farming	79 (30.4)	13–24	38 (14.6)	2–3	32 (12.3)
	41–50	46 (17.7)	Widowed	8 (3.1)	Never been to school	20 (7.7)	Employed	89 (34.2)	—	—	>3	10 (3.8)
	>51	37 (14.2)	Living together/ domestic partner	9 (3.5)	Left school for caregiving	49 (18.8)	Un-employed	31 (11.9)	—	—	—	—
T	199 (76.5)		199 (76.5)		199 (76.5)		199 (76.5)		199 (76.5)		199 (76.5)	
M	10–20	3 (1.2)	Married	34 (13.1)	Primary (Basic)	4 (1.5)	Employed	11 (4.2)	3–8	36 (13.8)	<1	34 (13.1)
	21–30	8 (3.1)	Single	15 (5.8)	Secondary (high)	16 (6.2)	Un-employed	29 (11.2)	9–12	17 (6.5)	1–2	19 (7.3)
	31–40	22 (8.5)	Divorced	4 (1.5)	Tertiary	28 (10.8)	Business/ farming	21 (8.1)	13–24	8 (3.1)	2–3	6 (2.3)
	41–50	15 (5.8)	Widowed	5 (1.9)	Never been to school	2 (0.8)	Employed	—	—	—	>3	2 (0.8)
	>51	13 (5.0)	Living together/ domestic partner	3 (1.2)	Left school for caregiving	11 (4.2)	Un-employed	—	—	—	—	—
T	61 (23.5)		61 (23.5)		61 (23.5)		61 (23.5)		61 (23.5)		61 (23.5)	

*Note: G, gender; F, female; M, male; T, total.*

**Table 1.**  
The socio-demographic characteristics of caregiver respondents.

10.2 Gender difference in duration of care

Gender difference existed in the duration of care provided for PLWHA. The least duration 3–8 hours was spent by 36 (13.8) male caregivers while only 16 (6.2) female caregivers spent the same. 9–12 hours majority were spent by 145 (55.8) female caregivers. 13–24 hours of care was provided mostly by 38 (14.6) female caregivers. With reference to the years spent in caregiving, the majority 90 (34.6) female caregivers spent between 1 and 2 years, while the least 10 (3.8) female and 2 (0.8) male caregivers provided care to PLWHA for more than three years (**Table 1**).

**Table 2** describes the household income as well the number of people in the household. The majority 130 (50%) family caregivers of PLWHA lived below a household income of US\$6.00/day while only 15 (5.8%) family caregivers spent US\$14.00 and above. The majority 153 (58.9%) lived in a household with about three to six members and only about 19 (7.3%) lived in small households with one to three persons (**Table 2**).

**Table 3** describes gender difference in the level of burden among family caregivers of PLWHA ranging between 14 and 71 on ZBI Scale (**Table 3**); among the 49 (18.8%) caregivers that experienced no burden, the majority were females 39 (15.0) while 10 (3.9%) males. The 46 (17.7) female caregivers experienced mild to moderate while providing care. Ninety-three (35.8) caregivers experienced moderate to severe burden and the majority 69 (26.6) were females. Fifty-one (19.6%) family caregivers experienced severe level of burden in providing care to PLWHA and majority 45 (17.3) caregivers were females.

Household income level US\$/Day		
Variables	Frequency	Percentage (%)
Less than US\$6.00	130	50.0
US\$7.00-US\$8.00	59	22.7
US\$9.00-US\$10.00	25	9.6
US\$11.00-US\$12.00	18	6.9
US\$13.00-US\$14.00	13	5.0
US\$14.00 and above	15	5.8
Number of people in the household		
1–3	19	7.3
4–6	153	58.9
7 and above	88	33.8

**Table 2.**  
*Household income and the number of people in the household.*

Gender				
Level of burden	Female (%)	Male (%)	N = 260 (%)	Range
No burden	39 (15.0)	10 (3.9)	49 (18.9)	0–20
Mild to moderate	46 (17.7)	21 (8.1)	67 (25.8)	21–40
Moderate to severe	69 (26.6)	24 (9.2)	93 (35.8)	41–60
Severe burden	45 (17.3)	6 (2.3)	51 (19.6)	61–88
Total	199 (76.5)	61 (23.5)	260 (100.0)	0–88

**Table 3.**  
*The distribution of burden on Zarit burden interview (ZBI) scale.*

Level of burden	Class interval (range)	Class mark (x)	F1 (female)	F2 (male)
No burden	0–20	10.0	39	10
Mild to moderate burden	21–40	30.5	46	21
Moderate to severe	41–60	50.5	69	24
Severe burden	61–88	74.5	45	6
Total	0–88		199	61

Note: T-test Cal. = 1.27. T-test tab. = 1.62, N = 260,  $p < 0.05$ .

**Table 4.**  
The relationship between gender and caregivers burden.

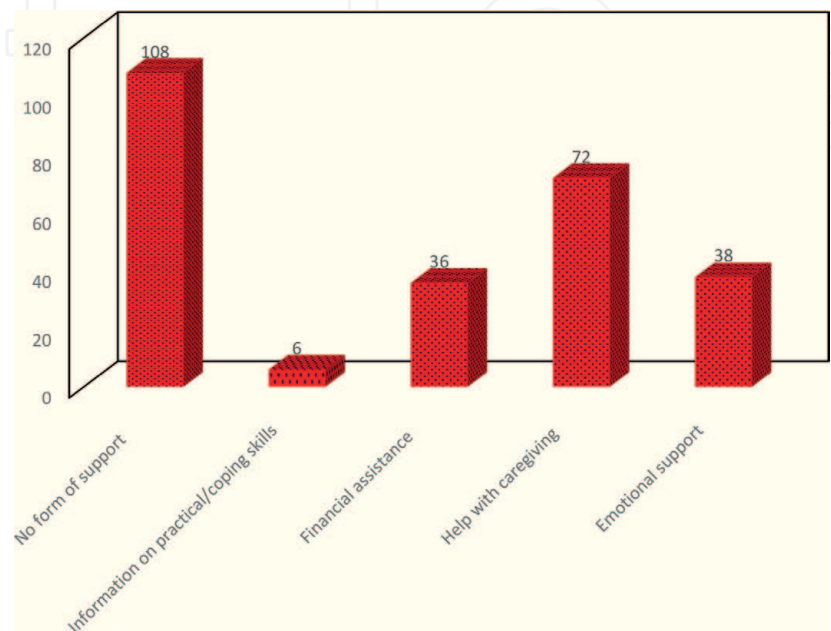
Significant statistical relationship existed between gender and caregivers burden assessed with the students  $t$  test. Calculated  $t$  test value of 1.27 at  $p < 0.05$ , indicated a significant relationship between the levels of burden experienced by gender (**Table 4**).

### 11. Availability of support to caregivers

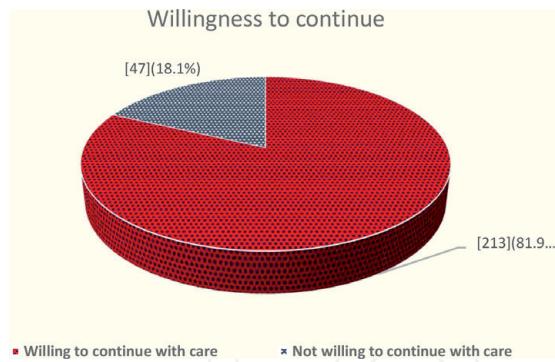
One hundred and eight (108, 41.5%) family caregivers received no form of support, while 152 (58.5%) received some form of support. The forms of support received included information on practical and coping skills 6 (0.2%), financial assistance 36 (13.9%), help with care giving 72 (27.7%), while 38 (14.6%) caregivers received emotional support. There was no difference in the types of support by gender (**Figure 1**).

In spite of burden experienced by the majority of family caregivers, 213 (81.9%) representing 171 females and 42 males, were willing to continue with caregiving, while 47 (18.1%) caregivers (28 females and 14 males) did not feel like continuing with caregiving role (**Figure 2**).

**Table 5** presents the relationship between availability of support and caregivers burden. One hundred and eight (108) caregivers received no support, 12 caregivers experienced no burden, 23 caregivers experienced mild to moderate burden, 37 caregivers experienced moderate to severe burden while 36 caregivers experienced severe burden. A chi-square value of 25.1 at  $p < 0.05$ , reveal a significant relationship between availability of support and caregivers burden.



**Figure 1.**  
Assessing the extent of support to caregivers of PLWHA in Nigeria.



**Figure 2.**  
The caregiver’s willingness to continue in caregiving role.

Availability of support	No burden	Mild to moderate burden	Moderate to severe burden	Severe burden	Total
Received any form of support	37 (28.7)	44 (39.2)	56 (54.4)	15 (29.8)	152
Received no support	12 (20.4)	23 (27.8)	37 (38.6)	36 (21.2)	108
Total	49	67	93	51	260

Note: Figures in parentheses are expected frequencies.  $\chi^2$  Cal. = 25.1.  $\chi^2$  Tab. = 7.81,  $df = 3$ ,  $N = 260$ ,  $p < 0.05$  where “ $\chi^2$  Cal.” and “ $\chi^2$  Tab.” Represents Chi square calculated and Chi square tabulated, respectively.

**Table 5.**  
The relationship between availability of support and caregivers’ burden.

12. The duration of care for caregivers

Fifty-two family caregivers provided 3–8 hours of care per day, however a majority of 28 caregivers experienced no burden, 10 caregivers experienced mild burden, eight caregivers experienced moderate to severe burden while six caregivers experienced severe burden. Among 162 caregivers that delivered care for 9–12 hours per day, the majority 73 caregivers experienced moderate to severe burden while 23 respondents experienced severe burden. Forty-six family caregivers provided care for 13–24 hours per day, five caregivers experienced no burden, seven caregivers perceived mild to moderate burden, while the majority 22 caregivers experienced severe burden (Table 6).

A chi-square value of 80.0 at  $p < 0.05$  revealed a significant relationship between duration of care and caregivers burden (Table 6).

Duration, hours/day	No burden	Mild to moderate burden	Moderate to severe burden	Severe burden	Total
3–8	28 (9.8)	10 (13.4)	8 (18.5)	6 (10.2)	52
9–12	16 (30.5)	50 (41.8)	73 (58.0)	23 (31.8)	162
13–24	5 (8.7)	7 (11.9)	12 (16.5)	22 (9.0)	46
Total	49	67	93	51,260	260

Note: Figures in parentheses are expected frequencies.  $\chi^2$  Cal. = 80.0,  $\chi$ Tab. = 10.65,  $df = 6$ ,  $N = 260$ ,  $p < 0.05$ .

**Table 6.**  
The relationship between duration of care and caregivers’ burden.



### 13. Discussion

The high disease burdens in low and middle countries outweigh the available capacity and resources of the health care system, which prevent institutionalization for full recovery. Early discharge depicts the need for family caregivers, most often female who assumes caregiving role without adequate preparation as it is obvious in this study. This finding corroborates with previous report that about four to five million people serve as caregivers with the majority being women and they provide more than 80% of the care needed by HIV individuals [63]. Even though the proportion of male involved with care giving is on the increase, specific gender differences still exist as caregiving remains the traditional role of women [32].

Caregiving though a rewarding role with intrinsic benefit is laden with burden especially while caring for PLWHA at the terminal phase. This finding is consistent with other studies which affirmed that caregiving adversely affect the physical, social and psychological wellbeing of the caregiver [10, 11, 46]. The demanding role of caregiving, which requires patience, empathy and show of affection irrespective of the physical disabilities of the care recipient, is an attribute which most women acquire from birth [64]. This commensurate the finding of this study that the burden of care in HIV/AIDS affected household rest more on women and girls than men. Similarly, previous reports identify women as the primary caregivers in most households and societies [19, 22, 65]. It is however pertinent to note that female dominance in caregiving is in consonance with the Nigerian patriarchal system which culturally relegate caregiving and domestic chores to women and girls except where there are no eligible females. This is also similar to studies which report caregiving as being culturally feminized and women are socialized into nurturing roles [16, 65]. It is obvious that the traditional gender norms emancipate men from caregiving thereby exacerbating burden of care on primary caregivers who are predominantly females.

In spite of female dominance in caregiving this study revealed that majority of primary caregivers experienced high burden level (**Table 3**). This stipulates the degree to which caregiving to PLWHA impacts on physical health, emotional, financial and social life of the caregiver. It is obvious that the physical labor of accomplishing activities of daily living especially in the presence of functional disabilities of the care recipient invoke burden. This finding is similar to studies that asserted that caregivers experienced a high level of burden which produces detrimental effects on the carer's own health [10, 54, 66]. This study revealed that burden may also be exacerbated with the lack of resources to spend on medication and other basic household needs especially where household spend less than \$6 dollars/day (**Table 1**). This is apparent because HIV disproportionately affects low and middle income countries especially in Africa, which contributes two thirds of global new HIV infections [7]. Encouraging care provision in homes is regarded as a cost-effective strategy for governments and the private sector, but little consideration is given to the physical, emotional and economic costs to households and the caregivers who take on the additional burdens, many of whom are often poor and living below US\$ 1.00 to US\$1.25 per day [10, 67, 68]. In sub-Saharan Africa, not only does correlation exist between poverty and HIV infection but HIV remained the exact outcome of poverty in the region with sexual trade, migration, polygamy, and teenage marriages as its predictors [69].

This study revealed a significant relationship between gender and level of burden, this obvious because women perform more hands on care than men, probably due to their cultural normative perception. This corroborates with previous report [70], which affirmed that women experienced more burden than men due to their propensity to execute more personal care tasks as primary caregivers and are less likely to obtain formal help. It is however pertinent to note that people rarely acknowledged the psychosocial and physical impacts of caregiving on women's well-being. While most

female caregivers ignore their personal health concerns to consummate the challenges of caregiving, some apparently sacrifice work or school to provide care in addition to reproductive and household economic roles [41, 65, 71, 72]. The caregiver has a right to be supported, valued and compensated appropriately to ensure a high quality care [41]. Without appropriate intervention to ameliorate the impact of burden of care, it produces negative consequences which often manifest as symptoms of depression and anxiety and may subsequently induced changes that could lead to physiological ailment like hypertension, heart disease and suppressed immune responses [10, 19, 73–76]. It is therefore appropriate to recognize caregivers as potential patients and give them the necessary support as much as can be achieved when their well-being is jeopardized [72].

This study also reveals that female caregivers spend more hours and years in providing care than male counterparts. This is obvious because men are regarded as heads of family and if young, they are expected to be in school, therefore they spend less hours in caregiving. However, caregiving is regarded as unique women role; therefore, most female caregivers live with care recipients and may spend 24 hour/day providing care without any social activities or regards to personal needs. This corroborates previous reports [41, 77] that men's low contribution in caregiving is sociocultural since they are expected to provide financial support for their families. However, other studies revealed disparity in hours between men and women providing care, with women delivering more encompassing and full time care than men [23, 30, 34, 78]. A significant relationship also existed between duration of care and caregivers burden (**Table 6**). This agrees with the report that irrespective of the duration of care, caregiving depletes the personal resources of the caregivers and induced burden without appropriate coping abilities [79, 80]. Family caregivers in this study had limited support in terms of financial assistance, information on practical and coping skills, emotional support as well as help with caregiving. Most caregivers assume role without educational preparation and may not be familiar with the type and extent of care needed. It is wrong to assume that caregivers have essential knowledge and skills required to care for an ill relative without training or providing some form of support [80]. Similarly, giving caregivers information on practical and coping skills reduces caregiver's burden or their perception of caregiving as burdensome [81]. Studies affirmed the need for adequate information and proper training on practical and coping skills, to fear of HIV contagion which may induce anxiety and reduce quality of care rendered [10, 66].

Although care recipient symptoms play a critical role in accounting for levels of caregiver's depressiveness or willingness to continue in caregiving role [82]. The willingness to continue despite the high burden experienced with caregiving role, depend to a great extent on caregivers internalize coping behavior [83]. Additionally it may also be accredited to adherence to cultural norms and expectation, strong family bond, fraternal love for the sick as well as sheer need. Annotations analogous to role theory [84] asserted that caregivers strive to fulfill a normative expectation to avoid criticism by others. Similarly, role theory, affirmed that a person's behavior is indirectly or directly influenced by the social environment [85]. This normative role in Nigeria, which is backed by persistent influence of traditional norms, values and behavior, is practiced as deified and not routines [64]. However, studies recommend that, the provision of social support and counseling before the assumption of caregiving role, alleviate burden and enhance willingness to continue with role [65, 86].

It was however obvious that majority of caregivers who decline future caregiving role did not received any form of support, while spending over 9 hours per day providing care. This findings substantiate other studies which assert that increased burden with limited support validate burnout as well as physical and psychological incapacitation [12, 87]. Therefore, with the global commitment to achieve universal access to prevention, care, support and treatment for those PLWHA, there is need to reflect on what these goals might mean in terms of burden on women and girls [41].

## 14. Conclusion/recommendation

The high prevalence of HIV in Sub-Saharan Africa, consumer's preferences and the cost of inpatient care depicts the shift from hospital to home care and predict the need for family caregivers, who will be directly involved with the care of PLWHA at home. This shift invoke high level of burden on family caregivers who have little knowledge and skills for HIV management. Strategies for countering caregiver's burden must be identified and addressed through providing adequate support as well as seeking measures to enhance male involvement in family caregiving. This could be accomplished by creating public awareness of negative impact of caregiving as well as encouraging equal distribution of household and caregiving responsibilities. Additionally, ensuring the health care system adherence to discharge policies by providing adequate information on practical and coping skills, as well as community resources for family caregivers of PLWHA is strongly advocated. With the high prevalence of HIV, there is need for periodic counseling sessions where caregivers of PLWHA can meet with medical professionals for advice. Creating caregiver's forum would provide avenue to vent pressure and discussed problems and challenges encountered in the course of caregiving. It is pertinent for health care professionals to recognize family caregivers as potential patient and develop comprehensive assessment format which will incorporate assessment of both PLWHA and their caregivers during hospital visits. Finally there is need for promulgation of policy that recognizes and support female caregivers of PLWHA in Africa.

### 14.1 Limitation

This study was restricted to caregivers of PLWHA in Calabar municipality. The study did not also identify households that were predominantly male or female controlled.

### Conflict of interest

"The authors declare no conflict of interest."

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