The Synergy between Burden and Anticipatory Grief among Caregivers of People Living with HIV/AIDS in Calabar Municipality, Nigeria

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ABSTRACT

Contents: Caregiving remains the crux of management in terminal diseases, but little attention is given to the effects of terminal illnesses on the caregivers and the associated anticipatory grief that aggravates caregivers' burden.
Aim: This study assesses the correlations between burden and anticipatory grief experienced among caregivers of people living with HIV/AIDS (PLWHA) in Calabar Municipality, Cross River State, Nigeria.
Methods: Correlations and descriptive cross-sessional design were utilized to assess and purposefully recruit 231 eligible caregivers of PLWHA, respectively. Validated revised Zarit Burden Interview scale (ZBI) and Anticipatory Grief Scale were the primary data collection instruments. Data were analyzed using SPSS version 21.0.
Results: Study findings revealed that the highest percentage, 36.4% (84) participants experienced a moderate burden, while 22.1% (51) experienced a severe burden. Similarly, the highest percentage, 33.3% (77) of the participants experienced moderate anticipatory grief at the range of 57-76, while 30.7% (71) participants experienced severe anticipatory grief within 77- 135. Positive and significant correlations ($r = 0.61$, $P < 0.05$; $r = 0.53$, $P < 0.05$; $r = 0.66$, $P < 0.05$) were obtained for the relationship between no anticipatory grief/burden; mild anticipatory grief/ burden and severe anticipatory grief/ burden respectively) during the study. These positive correlations revealed a strong synergy between the two variables, caregiver's burden and anticipatory grief.
Conclusion: As sub-Saharan African disproportionately bears the burden of HIV, more persons will have to take up family caregivers' roles despite the high level of burden and associated anticipatory grief. The need for educational intervention backed by the policy cannot be over-emphasized and should be implemented to enhance and acquaint caregivers on the nature of anticipatory grief and its connection with a terminal disease like HIV/AIDS.

Keywords: Caregivers burden, anticipatory grief, HIV, PLWHA, Nigeria

1. Introduction

Sub-Saharan African remain the epicenter for HIV, with more than 25.6 million individuals living with HIV/AIDs. It accounts for two-thirds of the global HIV burden, and above 70% of deaths related to HIV, but only home to 10% of the global population *(Amuche et al., 2017; Deeks et al., 2015).* Nigeria is the most populous country in Africa and home to 1.9 million people living with HIV, with 130,000 new infections accounting for the highest HIV infection rate and the second-largest HIV epidemic globally *(Avert, 2019).*

The country adopted 'test and treat' according to WHO policy in 2015, yet retroviral uptake remained low, with only 33% coverage among PLWHA *(UNAIDS, 2019).* Lack of adherence to treatment and inadequate coverage accounted for about 150,000 AIDS-related death in 2017 *(Avert, 2019; Rosen et al., 2016; UNAIDS, 2019; World Health Organization, 2015).* The high prevalence of HIV coupled with intermittent periods of exacerbation and remission, migrating finally into AIDs related death divulge that many will function as caregivers to the affected family members and significant others *(Asuquo et al., 2013; Asuquo et al., 2017).* Apart from death associated with caregiving, retroviral use, shorter hospitalization, and inadequate discharge planning have increased caregiving responsibilities to families who adopted caregiving roles for extended periods *(Akpan-Idiok & Anarado, 2014; Family Caregiver Alliance, (FCA)2006b).*

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Caregiving remains the crux of management in terminal cases, but little attention is paid to terminal illness's effect on the caregivers. Caregivers of people living with HIV/AIDS (PLWHA) have been reported to experience a high level of the burden while assuming caregiving role *(Asuquo et al. 2013; (Asuquo et al., 2017; FCA* 2006a; *Schnall et al., 2018; Zarit, 2006).* Unlike diseases like dementia, where deterioration may major on physical and cognitive impairment, HIV/AIDS, on the other hand, is compounded with multiple co-morbidities, which is eminent in AIDS or the terminal phase of HIV *(Schnall et al., 2018*). Multi-morbidities further reduce their cognitive and functional abilities, which compounds the caregivers *(Asuquo et al., 2013; Werner et al., 2012).*

Caregiving's negative consequences are well documented, especially when the caregivers are not prepared for the role coupled with little or no support *(Family Caregiver Alliance, 2006a; Metzelthin et al.,2017). Schulz and Tompkins (2010)* asserted that most caregivers are "silent patients" when the caregiving burden becomes chronic. Providing care negatively affects caregivers' psychological wellbeing, which may manifest as a high level of anxiety, stress, and depression *(FCA 2006a; Schulz et al., 1997; Zarit 2006).* Other health-related negative consequences of caregiving identified by studies include anxiety and depression *(Schulz et al., 1997; Zarit, 2006);* frustration with lower self-esteem, loose of self- identity, and feeling of uncertainty *(FCA, 2006b; Pinquart & Sorensen, 2003)* and physical ailment such as cancer, heart attack, arthritis and diabetes *(Ho et al., 2005).*

However, caregiving in Africa is a normative role, and many derive joy in fulfilling's this role with the expectation of receiving a similar type of care when they become old or sick *(Asuquo et al. 2017; American Psychological Association, 2020).* Moreover, it is believed that depending on fate, and the roles may be swap from caregiver to the recipient as people advance in age. Similarly, the *National Opinion Research Center (2014)* affirmed positive experiences among caregivers who derive satisfaction with caregiving and leave a caregiving legacy to the future generation. Embedded in the positive consequences of caregiving is the development of a bond between the caregiver and recipient, and the bond promotes positive health behavior, which enhanced the wellbeing of the care recipient *(Litwin et al., 2014).*

Mosack and Petroll (2009) asserted that caregivers and receivers develop a strong emotional relationship with honest communication, which helps the receiver cope with stigma, especially in HIV/AIDs, and improve care quality. According to *Litwin et al.,(2014)*, this relationship imbibes closeness and affectionate feelings, increasing with time. *Whitlach et al. (2001)* revealed that caregivers get emotionally involved in caregiving, which benefits the recipient more. *Litwin et al. (2014)* discussed closeness and affectionate feelings in the course of the caregiver-recipient relationship with mutual benefit to the caregiver and recipient while *Blieszner and de Vries (2001)* affirmed cognitive and physical intimacy. *Rattinger et al. (2016)* divulged the cost-effective benefit of a positive relationship with the care recipient. However, as closeness ensue, it leads to an increase in anticipatory grief.

Anticipatory grief (AG) has been used in the study of terminal diseases like Alzheimer's disease. However, the unique nature of HIV, which connotes 'death' to many, makes it a significant issue. Therefore, experiencing bereavement phases before the actual loss of a care recipient is eminent *(Garand et al., 2012).* The diagnosis of the terminal phase of disease and hospital transferring management to home is likely to trigger anxiety, sorrow, fear, and uncertainty in the family members and the afflicted individual *(Holley & Mast, 2009).* The reactions which are secondary to anticipatory grief culminated in the burden experienced by the family caregiver.

Similarly, *Marwit and Meuser (2005)* reported a significant correlation between AG and caregivers' burden. In a cross-sectional study assessing anticipatory grief on the burden of caregivers in people with dementia in Hong Kong, China, the result revealed the highest level of AG and subjective caregiving burden among caregivers of those in later stages of dementia than those in earlier stages of dementia *(Cheung et al., 2018)*. Anticipatory grief may be perceived as "the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one (death) and in recognition of losses in the past, present, and future" *(Rando, 1986).* According to *Parkes (2010)*, there is nothing wrong with grieving, and grief should not be assumed as pathological, but the individual reaction to grief and the consequences can be pathological.

Progression of disease with subsequent deterioration in functional and cognitive abilities attracts grief. Caregivers may experience grief in response to changes in their various roles, interferences with the recipient's functional abilities, uncertainty about the future, and loss of personal freedom *(Holley & Mast, 2009). Sanders et al. (2008)* reported on grief sources among caregivers to include loss of intimacy, uncertainty about the relationship, and loss of role and control. Research evidence, however, reveals that caregivers who experience prolonged and intense grief are at risk of both physical and mental health consequences *(Prigerson, & Maciejewski, 2006; Prigerson et al., 1997),* which in turn reduces the quality of care rendered to the care recipient.

The high prevalence of HIV/AIDS in Nigeria and advances in therapeutic capabilities depicts a long interval between diagnosis of terminal disease and death time. This prospect informs the need for more family caregivers who bear caregiving's brunt and initiate anticipatory grief that looms before care recipients' death *(Kang & Yoo, 2007). Holley and Mast (2009*) affirmed a significant impact of anticipatory grief on the burden experienced by dementia patient caregivers. The authors revealed that AG accounted for an extra 14-22% burden apart from background characteristics, the care recipient's functional problem, and depressive symptoms in assessing known predictors of burden.

A recent study revealed that a high AG level is concomitant with low preparedness coupled with high

depression experience after loss and increases caregivers' burden *(Holm et al., 2019).* Although much is known about the care receiver's characteristic compounding the burden of care in Nigeria *(Asuquo, 2013),* little is known about the effect of anticipatory grief on Nigeria's level of burden. Therefore, this study seeks to know the relationship between caregivers' burden and anticipatory grief among caregivers of PLWHA in Calabar Municipality, Cross River State, Nigeria.

2. Significance of the Study

The extent and impact of anticipatory grief on caregivers of PLWHA are not fully known primarily in Africa, Asia, and the Caribbean. This study reveals the strong interaction and relationship between caregivers' burden and anticipatory grief, which has not been documented previously. This study will be of great significance to health care workers who discharge the patient without preparing family givers for their new role. Hospital administrators may utilize these findings in promulgating relevant policies that will enhance continuity of care and ameliorate the impact of caregiving. Additional findings may be utilized to develop educational intervention measures to reduce the impact of anticipatory grief, which is inevitable at the terminal phase of HIV/AIDS.

3. Aim of the study

This study assesses the correlations between burden and anticipatory grief experienced among caregivers of people living with HIV/AIDS (PLWHA) in Calabar Municipality, Cross River State, Nigeria.

4.Subjects & Methods

4.1. Research design

The descriptive cross-sessional design was utilized to recruit a subset of caregivers and enhance the description of both caregiver's burden and anticipatory grief experienced by study participants. This study is part of the larger study which assessed the psychosocial factor affecting the caregiver's burden.

4.2. Research setting

The study was conducted in Calabar Municipality, Cross River State, Nigeria. Calabar city is the capital of Cross River State. It situates in the Southern Senatorial District of the state between latitude 5.008834 N and longitude 8.357783 E. It has a landmass of about 142 km² and a population of 461,796 as of the 2016 *(Mindat.org and The Hudson Institute of Mineralogy, 2020).* It is bounded by Odukpani Local Government Area in the North, Great Kwa River in the North-East, Calabar South Local Government Area, and Calabar River form the southern borders. It has ten political wards *(Kabir, 2019).*

It has three primary health Centres, two secondary and one tertiary health care facilities. However, the University of Calabar Teaching Hospital (UCTH), a tertiary institution, was used to recruit study participants for the study. It serves as a referral center for both primary and secondary health care facilities. It collaborates with a non-governmental organization such as the Positive Development Foundation in the treatment of PLWHA from rural/urban areas and neighboring country, Cameroon. Cross River State ranked fifth (7.1%) with HIV prevalence in Nigeria, although a disproportionate HIV burden exists between urban (7.7%) and rural areas (4.2%) *(Ifop, 2018),* which informed the choice of the setting.

4.3. Subjects

Purposive sampling technique guided the recruitment of 238 participants who were the primary caregivers to people living with HIV/AIDS with functional abilities. Therefore, participants who accepted to be part of the larger study and gave consent to measure anticipatory grief were recruited. However, 231 completely filled the AG questionnaire in addition to the burden scale. The inclusive criterion was being a primary caregiver for more than one month to PLWHA, 18 years and above, and full awareness of the care recipient HIV status. 18 years connotes the age in which an individual is considered an adult with the ability to appreciate terminal diagnosis and signs of deterioration in care recipient.

As previously described in *Asuquo et al. (2013),* primary caregivers' eligibility entailed providing physical assistance with daily living activities, food preparation, shopping, managing medical appointments, overseeing medication administration, emotional and financial support without any form of financial remuneration. During this study, almost all the PLWHA received care at home with intermittent visits to the hospital. However, the home environments were not modified to accommodate the care recipient's disability.

Study participants were recruited from the University of Calabar Teaching Hospital (UCTH) and the HIV clinic and visitation list of Positive Development Foundation, a non-governmental Organization Calabar in Cross River State, Nigeria. A letter of invitation with contact information was posted at UCTH, and the main office of Positive Development Foundation, Calabar, where interested study participants contacted the first author.

4.4. Tools of the study

Structured interview questionnaires in conjunction with the adapted Anticipatory Scale by *Theut et al. (1991)* and the Zarit Burden Interview Scale (ZBI) *Zarit (1980*) were the instruments used for data collection.

4.4.1. Structured Interview Questionnaires

The questionnaire comprised 5-item demographic variables, including information on gender, age, marital status, highest educational qualification, and relationship to care receiver.

4.4.2. Anticipatory Grief Scale (AGS)

The adapted AGS scale by *Theut et al. (1991)* was used for the study. The AGS scale is a multi-dimensional tool that measures grief reactions before the loss of a loved one. The AGS scale was initially designed to assess grief in dementia caregivers but was adapted to assess grief in caregivers of

PLWHA. Dementia mentioned in the instrument was replaced with HIV/AIDS. The scale has 27 items on a 5-point Likert scale ranging from strongly disagree (rated 1), disagree (rated 2), somewhat agree (rated 3), agree (rated 4), and strongly agree (rated 5) with a score range of 27 to 135. The higher the score, the higher the anticipatory grief experienced. The score range of 27-36 represents no anticipatory grief, 37-56 represents mild anticipatory grief, 57-76 represents moderate anticipatory grief, while 77-135 represents severe anticipatory grief. The instrument was translated into Efik language and re-translated into English to ensure that no meaning was lost. The internal consistency of this current sample was good (alpha = 0.82).

4.4.3. Zarit Burden Interview Scale (ZBI)

The revised ZBI was used for this study *(Zaritet al., 1980).* It is a popular self-reporting scale which measures the perception of caregivers about caregiving demands. The measures encompassed and illuminate the degree of the emotional, physical, and social impact of providing care for PLWHA *(Zarit, 2004).* The 22-item scale is rated on a 5-point Likert scale with response option ranging from 0 (never) to 4 (nearly always). The individual scores ranged between 0–88, with higher scores correlating with a higher level of perceived burden. Zero to twenty (0-20) represented little or no burden, 21-40, mild to moderate burden; 41-60, moderate to severe, and 61-88, a severe burden. The instrument was translated into Efik language and re-translated into English again to ensure the meaning after interpretation for participants who do not understand English. The reliability coefficient was 0.85 after making these instruments culturally sensitive by test-retest and pilot study methods. *Hérbert et al. (2000)* asserted that ZBI has an excellent internal consistency of 0.92.

4.5. Procedures

Ethical consent was obtained from the Human Research Ethics Committee of the University of Calabar Teaching Hospital No. UCTH/HREC/33/098, while individual verbal consent was obtained from participants before the administration of questionnaires. This consent forms part of the study that examined the psychosocial factors that influenced caregivers' burden of PLWHA in Nigeria. Appointments were scheduled after contact with the first author, and questionnaires were administered on a face-to-face basis. The questionnaires' content was carefully explained to study participants to enlighten them and provide information for easy understanding and response. Moreover, the principles of confidentiality, voluntary participation, and anonymity of the data collected were ensured.

4.6. Limitations

Cross River State is one of the states with high HIV prevalence in Nigeria, characterized by a disproportionate HIV burden between urban and rural areas. The study is only limited to Calabar Municipality, an urban setting, and did not extend to the rural areas.

4.7. Data analysis

Data analyses were achieved using Statistical Package for the Social Sciences (SPSS 21.0) software, which aids the generation of frequency and percentage values. Pearson Product Moment Correlation Coefficient (PPMCC) and Multiple Correlation Analysis (MCA) were used to establish the statistical relationship between caregivers' burden and anticipatory grief at the p-value of 0.05. While the Zarit interview scale had 22-items, Anticipatory grief had eight items (2, 5, 8, 11, 19, 22, 26, 27) with a positive bearing. Therefore, the scores were reversed before the total score was calculated.

5. Results

Two hundred and thirty-eight participants were eligible for the anticipatory grief study; however, only 231 responded, representing a 97.1% retrieval rate of persons who filled the questionnaire. Socio-demographic variables of study participants (Table 1) reveals that the majority of 173 (77.1%) of the study participants were females, while 53 (22.9%) were males. The highest percentage, 49.8% (115), was within the age group of 38-47years, and 25.1% (58) was 58 years and above. The highest number of participants, 78 (33.8%) were married, 75 (32.5) single, 38 (16.5%) divorced, 20 (8.7%) widowed while 20 (8.7%) represented persons living together. Data on educational qualification revealed 26 (11.3%) with primary, 72 (31.2%) had secondary education, the majority 95(41.1%) were tertiary while 38(16.5%) had never been gone to school. In assessing relationship to care receiver, the highest number 55 (23.8%) were wives, 36 (15.6%) were husbands, 42 (18.2%) were daughters, 16 (6.9%) were sons, 24 (10.4%) were siblings, 40 (17.3%) were mothers while 18 (7.8%) were fathers.

Table 2 demonstrates that among the 231 participants used for the study, 41 (17.7%) experienced no burden, while 55 (23.8%) experienced mild burden. The highest percentage, 84 (36.4%), experienced a moderate burden, whereas 51 (22.1%), experienced a severe burden.

Table 3 indicates that the highest percentage, 33.3% (77 participants) experienced moderate anticipatory grief at the range of 57-76, 30.7% (71 participants) experienced severe anticipatory grief within the range of 77- 135, 16.5% (38 participants) experienced mild anticipatory grief while 19.5% (45 participants) experienced no anticipatory grief within the range of 27-36.

Figure 1 illustrates a strong positive relationship between caregiver's burden and anticipatory grief. This figure signifies a linear relationship between the two variables showing that as anticipatory grief increases, Caregivers burden also increases, and vice versa ($p<0.05$).

Table 4 shows that for no anticipatory grief and caregivers burden, $r = 0.61$ at $P<0.05$, for mild anticipatory and caregivers burden, $r=0.53$ at $P<0.05$, for moderate anticipatory grief and caregivers burden, 0.01 at $P>0.05$ and severe anticipatory grief and caregivers burden, $r=0.66$ at $P<0.05$. Since P (0.00) <P (0.05) for no anticipatory, mild and severe anticipatory grief and caregivers' burden, there is a significant relationship between these three variables,

while there is no significant relationship existing between moderate anticipatory grief and caregiver's burden. Moreover, on a composite note, the result showed (r=0.645, P < 0.05) a combined effect of anticipatory grief on caregivers' burden.

Table (1): Frequency and percentage distribution of demographic variables of study participants (N=231).

Demographic variables	Frequency	Percentage (%)
Gender		
Male	53	22.9
Female	173	77.1
Age in years		
18 -27	17	7.4
28 -37	23	10.0
38- 47	115	49.8
48-57	18	7.8
58 years and above	58	25.1
Marital status		
Married	78	33.8
Single	75	32.5
Divorced	38	16.5
Widow	20	8.7
Living together/ Domestic Partner	20	8.7
Educational qualification		
Primary	26	11.3
Secondary	72	31.2
Tertiary	95	41.1
Never been went to school	38	16.5
Relationship to care receiver		
Wife	55	23.8
Husband	36	15.6
Daughter	42	18.2
Son	16	6.9
Sibling	24	10.4
Mother	40	17.3
Father	18	7.8

Table 2: Frequency and percentage distribution of caregiver's burden among the respondents.

Level of burden	n = 231	%	Range
No burden	41	17.7	0 - 21
Mild burden	55	23.8	21 - 40
Moderate burden	84	36.4	41 - 60
Severe burden	51	22.1	61 - 88
Total	**231**	**100**	**0 - 88**

Table 3: Frequency and percentage distribution of Anticipatory Grief among the participants.

Level of Anticipatory Grief	n = 231	%	Range
No anticipatory grief	45	19.5	27 - 36
Mild anticipatory grief	38	16.5	37- 56
Moderate anticipatory grief	77	33.3	57 - 76
Severe anticipatory grief	71	30.7	77- 135
Total	**231**	**100**	**27-135**

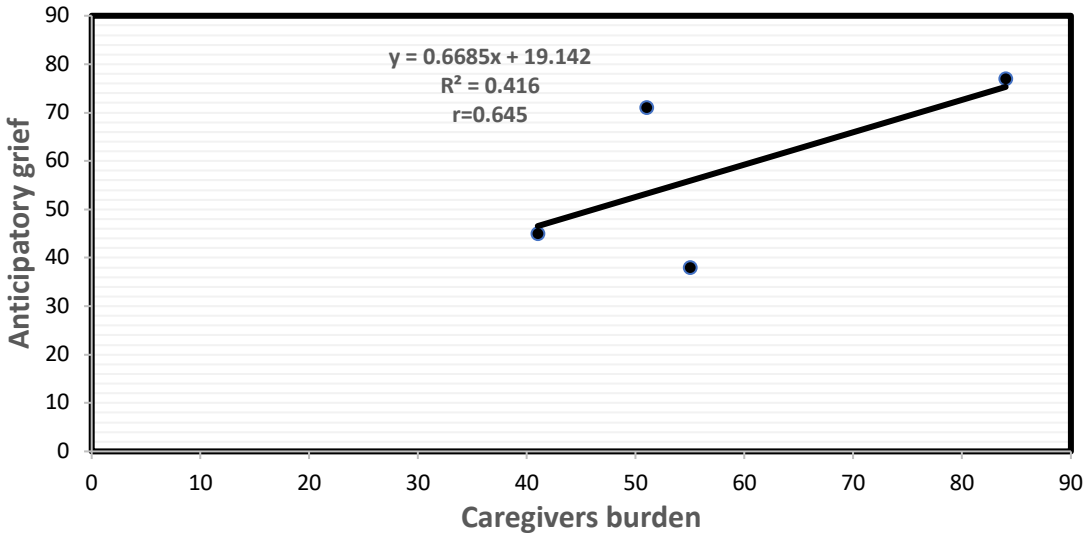

Figure (1): Relationship between Caregivers Burden and Anticipatory grief (n= 231).

Table 4: Multiple correlation analysis of the relationship between anticipatory grief and caregiver's burden.

Variables	Burden			r=cal	p-value
	N	Mean±SD	df		
Burden	231	42.17±6.88	229		
No anticipatory grief	231	16.19±3.42	229	0.61	0.00
Mild anticipatory grief	231	15.08±2.47	229	0.53	0.00
Moderate anticipatory grief	231	16.43±2.14	229	0.01	0.67
Severe anticipatory grief	231	16.17±2.41	229	0.66	0.00

**R =0.64*

6. Discussion

Family caregiving remains a normative role in Africa, and Nigeria remains the home to about 1.9 million people living with HIV/AIDS. However, little attention is given to family caregivers who bear the brunt of care and remain themselves 'silent patients' hidden from the care receivers' view, government, and even the health care workers, without any form of support or educational preparation of the family members *(Asuquo et al., 2013)*. This study seeks to assess the relationship between caregivers' burden and anticipatory grief experienced among caregivers of PLWHA in Calabar Municipality, Cross River State Nigeria.

The study reveals high levels of burden ranging from moderate to severe levels. This finding is true because, in the terminal phases of HIV/AIDS, many functional abilities are impaired, coupled with periods of exacerbation and remission, which leave the patient completely debilitating. This finding is similar to many, which affirmed that caregivers experience high levels of burden in caregiving *(Asuquo et al., 2013; Asuquo et al. 2017; Family Caregiver Alliance, 2006a; Gasten-Johnson et al., 2012).*

The high level of burden experienced is secondary to physical, social, and psychological affectation, reducing the caregivers' quality of life. This study also reveals a high level of anticipatory grief, which is evident in a terminal disease like AIDS since HIV connotes death to many, even at the testing level. The exacerbation of symptoms coupled with health system transfer of the burden of care to family members illuminate the inevitable (death) and heighten the experience of anticipatory grief.

These findings are similar to *Holley and Mast (2009),* who affirmed a significant effect of anticipatory grief on the caregiver's burden. This study additionally established a significant composite correlation ($r = 0.645$, $p < 0.05$) between AG and caregivers' burden. This correlation is obvious in HIV/AIDs because the disease itself presages death at the end, especially in low and middle-income countries where compliance and retroviral uptake remain low. This finding is similar to *Marwit and Meuser (2005),* who reported a significant correlation between AG and caregivers' burden.

Additionally, in China *Cheung, et al. (2018)* asserted that the higher the anticipatory grief, the higher the burden of care experienced. Therefore, health care workers must be aware of the negative consequences of discharging hospitalized patients' homes without adequate educational preparation and support to family caregivers. This call for nurse's leadership in the health system to promulgate appropriate policy to enhance capacity building in this context *(Asuquo, 2019).* Additionally, educational intervention on the nature of anticipatory grief would help ameliorate AG's impact and the caregiver's burden.

7. Conclusion

As Nigeria bears the second largest HIV burden globally, more family members must function as caregivers. Health care providers, especially nurses, play an essential role in the discharge of all patients to ensure optimum health and reduce readmission chances. However, in practice, the family members' adequate preparation for assuming their care role and self-care are often ignored. Health care workers focus mainly on their patients and disregard the continuity of care at home. This study revealed a strong relationship between caregiver's burden and anticipatory grief, which suggests the need to ameliorate the caring impact on caregivers of PLWHA. Therefore a focus educational intervention on improving anticipatory grief becomes imperative.

8. Recommendations

It is recommended that nurses and healthcare providers develop effective discharge packages that will adequately prepare family caregivers. The need for educational intervention backed by the policy is inevitable to enhance and acquaint caregivers on the nature of anticipatory grief eminent in terminal diseases like HIV/AIDS.

9. Author Contribution

Ekaete Francis Asuquo (EFA) conceived the idea and designed this study. Regina Ella and Paulina Ackley Akpan-Idiok organized for data collection of the study and edited the manuscript. EFA and Osuchukwu, Easter were involved in the data analysis. All the authors revised and proofread the final manuscript before submission for publication.

10. Conflict of Interest

We now declare that there is no conflict of interest in this paper.

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