

# Prevalence and Severity of Depression among Caregivers of HIV-infected Children in Enugu, South-East Nigeria

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## Abstract

**Background:** HIV infection significantly increases depression risk in the caregivers of HIV-infected children. Our study is aimed at determining the depression prevalence and severity in caregivers of children who are infected with HIV. **Materials and Methods:** This was a hospital-based, cross-sectional, and comparative study. Study participants who met the inclusion criteria were enrolled consecutively to achieve the calculated sample size. Their sociodemographic variables were obtained, and the Zung Self-rating Depression Scale was used to assess the prevalence and severity of depression in the caregivers. **Results:** There were 352 study participants which comprised 176 caregivers of children infected with HIV, who served as cases and 176 caregivers of HIV-negative children, who served as controls. One hundred and fifty-five (88.1%) of the cases were the biologic caregivers, whereas the biologic caregivers comprised of 133 (75.6%) for the controls. Furthermore, 43 (24.4%) and 133 (75.6%) of the cases were males and females, respectively, whereas 47 (26.7%) and 129 (73.3%) of the controls were, respectively, males and females. The prevalence of depression among the cases and controls was 43.2% and 6.8%, respectively ( $P < 0.001$ ; odds ratio [OR]: 10.39). Among the cases with depression, 73 (47.1%) were the biological caregivers, whereas 3 (14.3%) were the nonbiological caregivers. This was statistically significant ( $P = 0.009$ ; OR = 5.341). The severity of depression among the cases was mild depression (52.6%), moderate depression (30.3%), and severe depression (17.1%). **Conclusions:** There is a high prevalence of depression among the caregivers of children infected with HIV and the biologic caregivers of these children tend to have a higher depression burden than their nonbiologic counterparts.

**Keywords:** Caregivers, children, depression, HIV, Nigeria

## INTRODUCTION

HIV/AIDS is a global health challenge that is ravaging developing countries.<sup>[1]</sup> Sub-Saharan Africa is the most affected region,<sup>[1-3]</sup> and Nigeria is among the countries with the heaviest burden of the disease in the world.<sup>[4-7]</sup> Nigeria also has the highest burden of pediatric HIV worldwide,<sup>[5,7]</sup> and the South-east geopolitical zone of Nigeria has the third highest concentration of people living with HIV.<sup>[3]</sup> Due to the early diagnosis and availability of highly active anti-retroviral therapy drugs, children tend to survive much longer without necessarily achieving complete remission.<sup>[1,8-11]</sup> Thus, HIV/AIDS is regarded as a chronic disease. Chronic diseases can have negative effects on the person's physical state as well as his/her emotional and mental well-being.<sup>[12-14]</sup> Geist *et al.*<sup>[15]</sup> observed an increased risk of psychosocial disorders in children with chronic disorders who survived into adulthood. These psychosocial

disorders include depression, anxiety, and social dysfunction. Depression is the single largest contributor of disability, and it impacts negatively on the population.<sup>[16]</sup> It is the most commonly reported psychosocial disorder in the caregivers of children with chronic diseases.<sup>[17]</sup> For instance, Ijezie *et al.*<sup>[18]</sup> noted that the most common psychosocial disorder in parents whose children had cerebral palsy was depression. This high prevalence of depression in the caregivers of children with chronic disorders was also noted by a study on the caregivers of children with cancer in the

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Netherlands.<sup>[19]</sup> Altinda *et al.*<sup>[20]</sup> observed an increase in the incidence of depression in mothers whose children had cerebral palsy. This psychosocial disorder may result from the heavy financial burden associated with chronic diseases, chronic medication, stigmatization and discrimination, frequent hospital visits and hospitalization, and from the disease itself.<sup>[21]</sup> Risk factors that precipitate psychosocial disorders in chronic illnesses are also evident in HIV infection.<sup>[16,21,22]</sup> There has been documented evidence of a high prevalence of depression among people infected or affected by HIV.<sup>[23,24]</sup> For instance, Gonzalez *et al.*<sup>[25]</sup> noted that 36% of HIV-infected individuals are likely to have depression. Bhatia and Munjal<sup>[17]</sup> documented a high prevalence of depression of 58.8% among HIV-infected individuals. Similarly, Petrushkin *et al.*<sup>[26]</sup> documented a prevalence of 54.3% in HIV-infected individuals, whereas Lwidiko *et al.*<sup>[24]</sup> noted a prevalence of depression of 32.8% in HIV-infected children and adolescents. Caregivers who provide care and support for HIV-infected children can also have depression.<sup>[27]</sup> However, there is a paucity of literature regarding depression in these caregivers. These include the study by Santiesteban *et al.*<sup>[28]</sup> in Cuba, who noted that 39% of caregivers of HIV-infected children had depression. A similar study done by Wainaina<sup>[23]</sup> in Kenya documented a high prevalence of 64.5% with depression. Similarly, Abasiubong *et al.*<sup>[29]</sup> in a study of caregivers of HIV-infected adults and children in Nigeria documented that depression was present in 65.2% of these caregivers. Except for the study by Santiesteban *et al.*<sup>[28]</sup> that noted mild and moderate depression severity rate of 60% and 40% of the caregivers, respectively, the earlier cited studies did not document the pattern of depression. Despite the high depression prevalence noticed in earlier studies, none has been done in our area of practice with a high burden of HIV/AIDS. With the knowledge of this high depression prevalence seen in the caregivers of HIV-infected children from documented studies done abroad<sup>[23,28]</sup> and considering the burden of HIV/AIDS in Enugu,<sup>[5]</sup> there is a need to determine the local burden of depression in the caregiver of HIV-infected children. We, therefore, hypothesize that caregivers of HIV-infected children in Enugu will have higher depression prevalence than the caregivers of HIV-negative children.

This study hopes to determine the prevalence of depression and severity among caregivers of children that are infected with HIV. This will help in the formation of a template for future studies. It will also make data available for the development of future studies on this topic. This will, in general, help to educate health-care workers on the importance of the mental health of caregivers and other family members of children who are infected with HIV.

## MATERIALS AND METHODS

### Study design

This hospital-based study was cross-sectional and comparative in design.

### Study site

This research was conducted at the Pediatric HIV clinic of UNTH, Enugu, South-Eastern Nigeria. This clinic provides treatment, care, and support for both HIV-infected and HIV-exposed children.

### Study population

The study participants comprised of primary caregivers whose children aged between 2 and 15 years were infected with HIV and who were enrolled and receiving treatment in the pediatric HIV clinic of UNTH. This group of people served as cases. The controls for this study comprised of HIV-negative caregivers of children with HIV-negative status and who were attending the children outpatient clinic of UNTH for acute illnesses or medical examinations for a medical certificate of fitness. A primary caregiver as defined in this study is the person with the utmost responsibility of providing care and support to the HIV-infected child.<sup>[23,30]</sup> These caregivers were further subdivided into biologic and nonbiologic caregivers, and a biologic caregiver in this context referred to a first-degree relative (a parent).

### Sample size determination

The sample size was obtained using the statistical formula for prevalence studies, as documented by Araoye.<sup>[31]</sup>

### Inclusion criteria

Primary caregivers who gave their consent and whose children were confirmed to be HIV-infected were included in the study.

### Exclusion criteria

Primary caregivers whose children's HIV status are not known and who have children with other chronic disorders (such as epilepsy, cerebral palsy, or sickle cell anemia) under their care were excluded from this study.

### Sampling method

A consecutive sampling method was used to enroll study participants who met the inclusion criteria.

### Recruitment of study participants

The HIV-infected children were matched for age and gender with the HIV-negative children before the recruitment of their caregivers. The cases and controls underwent HIV counselling and testing using the HIV testing national algorithm.

The caregivers' sociodemographic variable was collected by the researchers by means of a structured questionnaire designed for this purpose and their social classes were derived from Oyedeji's social classification.<sup>[32]</sup> In this classification, the educational level and the occupation of each of the caregivers were scored and the average of the scores, to the nearest whole number was documented. The scores were graded from 1 to 5. The higher the grading, the lower the social class. In this study, higher social class was represented by classes 1 and 2, the middle social class was represented by class 3, and the lower social class by classes 4 and 5. This stratification of social classes from Oyedeji's classification has also been done by other authors.<sup>[14,33-35]</sup>

The depression prevalence and severity in the caregivers were assessed using the Zung Self-rating Depression Scale (ZDS).<sup>[36,37]</sup> It has been validated and used in a number of studies in Nigeria.<sup>[38-40]</sup> ZDS is a 20-item self-administered questionnaire with a score of 1 to 4 for each item. The minimum raw score on the ZDS is 20, while the maximum is 80. Based on the ZDS scoring method,<sup>[36]</sup> all the scores on the 20 items were added, and their cumulative scores were converted to indices. This was done by dividing the caregivers' raw scores by 80 (the maximum raw score) and subsequently multiplying the outcome by 100. A ZDS index of 50 and above signified the presence of depression among these caregivers. In addition, a ZDS index of 50–59 indicated mild depression; 60–69 indicated moderate depression; while a ZDS index of 70 and above indicated severe depression.

### Pilot study

A pilot study was carried out on 15 cases and 15 controls. This was to test the questionnaires for any ambiguity. At the end of the exercise, all the participants in the pilot answered the questions correctly. The caregivers who participated in this pilot were excluded from the main study.

### Ethical approval and consent

Ethical approval by the health research and ethics committee of UNTH, Enugu, was obtained before the commencement of this research. The study participants were provided with enough details concerning the study. They were allowed to voluntarily opt-in or out, without any form of inducement or gratification. At the end of this exercise, only those that consented were enrolled for the study. An informed consent form was filled and signed (or thumb-printed) by the consenting caregivers.

### Statistics and data analysis

The data obtained were cleansed and analyzed using the Statistical Package for the Social Sciences (SPSS) software version 19 (SPSS Inc. Chicago, IL, USA). The assumption of normality of the data was done to test if the data was normally distributed. This showed normal distribution of the obtained data. Subsequently, descriptive statistics such as means and standard deviations were used to summarize the continuous variables such as the age of the caregivers and the cumulative depression scores of the caregivers, whereas frequencies and percentages were used to summarize the categorical variables such as the gender and socioeconomic classes of the caregivers. The outcome variables for caregivers of HIV-infected children were compared with those of controls and analyzed for statistical significance. Thus, Student's *t*-test was used to test for significance between the continuous variables such as the age and mean ZDS index scores of the caregivers of HIV-infected children and their control group, whereas Chi-square and logistic regression analyses were used to test for the association between the categorical variables such as the prevalence of the depression between the cases and controls.  $P < 0.05$  was regarded as statistically significant, and all reported  $P$  values were two-sided.

## RESULTS

This study lasted for 11 months with 352 caregivers enrolled. They comprised 176 caregivers of HIV-infected children aged between 2 and 15 years, who served as cases and 176 caregivers of HIV-negative, apparently healthy children of the same age bracket, who served as controls. One hundred and fifty-five (88.1%) of the caregivers of children infected with HIV were the biologic caregivers compared to 133 (75.6%) biologic caregivers of the HIV-negative children. The mean age of the caregivers of HIV-infected children was  $38.81 \pm 9.54$  years, whereas the mean age of the controls was  $38.31 \pm 8.38$  years. The mean age, gender distribution, and socioeconomic classes of the caregivers were comparable. Table 1 shows the comparison between the type of caregivers, mean age, gender distribution, and the socioeconomic classes of the caregivers of the HIV-infected children and HIV-negative children.

The mean ZDS index score of the caregivers of HIV-infected children was  $53.09 \pm 9.61$  (range: 39.00–88.00) while that of the control  $44.85 \pm$  (range: 38.00–65.00). There was a significant difference in their mean ZDS index scores ( $t = 10.51$ ,  $P < 0.001$ ). Among the 176 caregivers of HIV-infected children in this study, 76 (43.2%) compared to 12 (6.8%) of the controls had ZDS indices in the depression range (ZDS index score  $\geq 50$ ). This difference was statistically significant ( $P < 0.001$ , odds ratio [OR]: 10.39). The caregivers of HIV-infected children were ten times more likely to have depression than caregivers of HIV negative children. Table 2 shows the prevalence of depression in the caregivers of HIV-infected and HIV-negative children.

The prevalence of depression according to the type of caregivers revealed that biologic caregivers (47.1%) compared to nonbiologic caregivers (14.3%) had ZDS scores in the depression range. This finding was also statistically significant ( $P = 0.009$ ; OR = 5.341). Biologic caregivers of HIV-infected children were five times more likely to have depression than the nonbiologic caregivers of HIV-infected children. Among the caregivers (of these HIV-infected children) who had depression, 32.4% of them compared to 10.8% were also living with HIV. Despite this high prevalence, there was no statistically significant difference between the HIV-positive caregivers and their HIV-negative counterparts ( $\chi^2 = 0.023$ ;  $P = 0.880$ ). Tables 3 and 4 show the prevalence of depression according to the type and HIV status of the caregivers, respectively.

Out of the 76 caregivers of HIV-infected children with depression, 40 (52.6%), 23 (30.3%), and 13 (17.1%) had mild, moderate, and severe depression, respectively. Figure 1 shows the severity of depression, respectively, in the caregivers of HIV-infected children.

## DISCUSSION

The study's results showed that the prevalence rate of depression in the caregivers of children infected with HIV

**Table 1: Comparison of the mean age, gender distribution and socioeconomic classes of the caregivers of HIV-infected and HIV-negative children**

Variables	Caregivers of HIV-infected children				Caregivers of HIV-negative children				<i>t</i>	$\chi^2$	df	<i>P</i>
	<i>n</i>	<i>n</i> (%)	Mean	SD	<i>n</i>	<i>n</i> (%)	Mean	SD				
Type of caregiver	176				176							
Biologic		155 (88.1)	-	-		133 (75.6)	-	-	-	10.356	1	0.001
Nonbiologic		21 (11.9)	-	-		43 (24.4)	-	-	-			
Mean age	176	-	38.81	9.54	176	-	38.31	8.38	0.522	-		0.602
Gender	176				176							
Male		43 (24.4)	-	-		47 (26.7)	-	-	-	0.239	1	0.625
Female		133 (75.6)	-	-		129 (73.3)	-	-	-			
SEC	176				176							
Upper		19 (10.8)	-	-		24 (13.6)	-	-	-	1.618	2	0.445
Middle		77 (43.8)	-	-		83 (47.2)	-	-	-			
Lower		80 (45.5)	-	-		69 (39.2)	-	-	-			

SD: Standard deviation, SEC: Socioeconomic class, df: Degree of freedom

**Table 2: Prevalence of depression in the caregivers of HIV-infected and HIV-negative children**

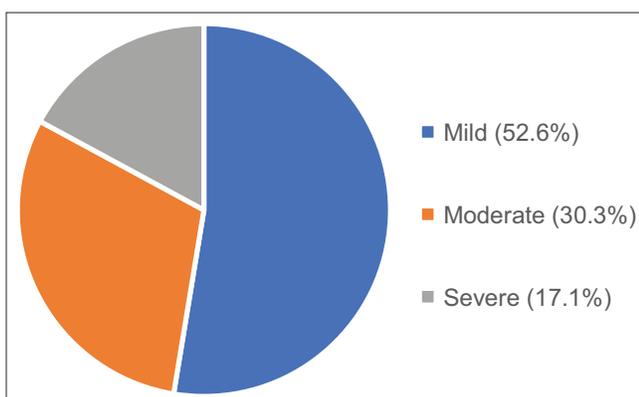
Depression (ZDS index score)	Caregivers of HIV-infected children, <i>n</i> (%)	Caregivers of HIV-negative children, <i>n</i> (%)	<i>P</i>	OR	95% CI for OR
Yes ( $\geq 50$ )	76 (43.2)	12 (6.8)	<0.001	10.387	5.381-20.049
No (<50)	100 (56.8)	164 (93.2)			
Total	176	176			

ZDS: Zung Self-Rating Depression Scale, CI: Confidence interval, OR: Odds ratio

**Table 3: Prevalence of depression according to the type of caregivers of the HIV-infected children**

Depression (ZDS index score)	Biologic caregivers, <i>n</i> (%)	Nonbiologic caregivers, <i>n</i> (%)	<i>P</i>	OR	95% CI for OR
Yes ( $\geq 50$ )	73 (47.1)	3 (14.3)	0.009	5.341	1.512-18.874
No (<50)	82 (52.9)	18 (85.7)			
Total	155	21			

ZDS: Zung Self-Rating Depression Scale, CI: Confidence interval, OR: Odds ratio

**Figure 1: Severity of depression among the caregivers of HIV-infected children**

is 43.2%, and it favorably compares with that of 38.5% documented by Santiesteban *et al.*<sup>[28]</sup> in Cuba, but is lower than the values of 65.2% and 64.5% reported by Abasiubong *et al.*<sup>[29]</sup> in Niger-Delta and Wainaina<sup>[23]</sup> in Nairobi, respectively.

The high prevalence in the study by Abasiubong *et al.*<sup>[29]</sup> may be attributed to the fact that their subjects included the caregivers of both HIV-infected adults and children while the participants in this study involved only the caregivers of HIV-infected children. Since their study of caregivers was on two populations (HIV-infected children and adults), there is a tendency to have a high prevalence of depression when compared to this study that involved only the caregivers of HIV-infected children. Furthermore, the difference in the prevalence between this study and that of Wainaina<sup>[23]</sup> may be attributed to the different sample sizes and psychometric tests administered. The participants in this study comprised 176 caregivers, whereas Wainaina<sup>[23]</sup> studied 228 caregivers. While this study used ZDS as the psychometric tool, Wainaina<sup>[23]</sup> used Becks Depression Inventory to assess depression. These may have resulted in the observed differences in their prevalence rates.

The effect of depression on the caregivers of children who have other chronic illnesses have been documented by the

**Table 4: Prevalence of depression according to the HIV status of the caregivers of the HIV-infected children**

Depression (ZDS index score)	HIV-positive caregivers, <i>n</i> (%)	HIV-negative caregivers, <i>n</i> (%)	Total
Yes ( $\geq 50$ )	57 (32.4)	19 (10.8)	76
No ( $< 50$ )	74 (42.1)	26 (14.8)	100
Total	131	45	176

$n=176$ ;  $df=1$ ;  $\chi^2=0.023$ ;  $P=0.880$ . ZDS: Zung Self-Rating Depression Scale

researchers.<sup>[18,41-43]</sup> Such documentations revealed an increase in the burden of depression, just like the HIV-infected caregivers. For instance, Ijezie *et al.*<sup>[18]</sup> in Enugu reported prevalence as high as 84% for depression in first-degree relatives with cerebral palsy, whereas Bhatia and Munjal<sup>[17]</sup> in a Kenyan reported 79% as the prevalence rate of depression in caregivers whose children presented with intellectual disability. Similarly, Lima *et al.*<sup>[42]</sup> in North-eastern Brazil documented 36.8% prevalence in caregivers whose children were undergoing renal replacement therapy. Furthermore, Altinda *et al.*<sup>[20]</sup> in Istanbul noted a significant difference in the burden of depression between mothers whose children had cerebral palsy and their controls. These observations are in keeping with the findings of this study. This may highlight the fact that caregivers whose children have chronic diseases (including HIV/AIDS), have a higher burden of depression when compared with others. This may be explained by the constant stress, lack of social support, and the severe financial challenge attached to the care of children with chronic illnesses.

The findings from our study also showed that there was a significantly high prevalence of depression among biologic caregivers of HIV-infected children. This observation has also been documented by some authors.<sup>[23,28,29]</sup> The high prevalence rate of depression among biologic caregivers may be explained by the role parents, especially women, play in the continuous provision of care and support to their HIV-infected and uninfected families, including children. They are generally the custodian of family health in the society. Our study also showed that, as high as 32.4% of the caregivers who had depression, also had an existing HIV infection. This was also noted by Santiesteban *et al.*<sup>[28]</sup> This may be explained by the stressful and rigorous burden of care and support both to themselves and their HIV-infected and HIV-negative family members. Despite this observation and to the researchers' surprise, this present study did not find any significant difference in depression prevalence between HIV-positive caregivers and their HIV-negative counterparts. The possible reason for this observation may be that, despite the possibility of HIV infection noted in the caregivers contributing to the depression burden in them, caring for the HIV-infected child may also trigger some stressors and result in psychological stress to the caregivers irrespective of their HIV status.

This study showed that 52.6%, 30.3%, and 17.1% of the caregivers of HIV-infected children had mild, moderate,

and severe depression, respectively. The high prevalence of depression severity was also reported by Santiesteban *et al.*<sup>[28]</sup> Sixty per cent and 40% of these caregivers in their study had mild and moderate depression, respectively, and none of them presented with severe depression.

## CONCLUSIONS

There is a high prevalence of depression among the caregivers of HIV-infected children in our environment. The biologic caregivers are more prone to depression burden more than the nonbiologic caregivers. Thus, there is a need to provide mental health assistance to families, especially first-degree relatives, affected by HIV/AIDS.

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## Conflicts of interest

There are no conflicts of interest.

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