# Psychosocial challenges and adherence to antiretroviral therapy among HIV-positive adolescents attending an ART center in Kano, northwestern Nigeria

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## Abstract

Background: HIV-infected adolescents confront numerous psychosocial stressors in addition to coping with the developmental challenges of normal adolescent children. These may adversely affect their adherence to antiretroviral treatment.

Objective: To determine the psychosocial challenges of HIV-positive adolescents in Kano, Nigeria, and how they influence their adherence to antiretroviral therapy (ART).

Materials and Methods: Using descriptive cross-sectional design, we studied a random sample of 400 HIV-positive adolescents attending the ART center in Murtala Muhammad Specialist Hospital Data were analyzed using SPSS, version 16.0, computer statistical software.

Result: The mean age of the adolescents was 14.9 ± 3.15 years; majority of them were female subjects (54.8%) and from polygamous family setting (57.5%). More than half (54.5%) of them reported being anxious or depressed most of the times, commonly from fear of death (51.4%) or associated stigma (24.3%). Furthermore, 52.0% of them had lost a parent or spouse to HIV infection and about one-tenth reported being discriminated upon. More than one-third (38.5%) of them were out of school, of which 56.5% of them dropped out because the parents/quardians could not afford the combined burden of hospital costs and school. Most of them (90.5%) adhered well to prescribed medications. On multivariate analysis, anxiety or depression, loss of parent or spouse, and avoidance by friends/colleagues emerged as the independent psychosocial predictors of the adolescents' adherence to ART.

Conclusion: HIV-infected adolescents have varied and sensitive needs that must attract high-level understanding of program managers and the social environment to achieve an optimum level of adherence for ART.

KEY WORDS: HIV-positive adolescents, antiretroviral therapy, adherence, psychosocial challenges

# Introduction

Adolescence is the transitional period in the human life. which occurs between 10 and 19 years of age.[1] It is charac-

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terized by lots of experimentations and risk taking including behavior that predisposes to diseases. By the end of 2012, about 2.1 million adolescents globally were living with HIV, and over 90% were in sub-Saharan Africa.[2,3]

Adolescents living with HIV confront numerous psychosocial stressors in addition to having to cope with developmental challenges of normal adolescent children. HIVrelated challenges may start with the emotional trauma from disclosure of their HIV status, the fear of uncertainties from disease progression, deterioration of quality of life, and death or bereavement related to the death of loved ones on one hand; on the other hand, the stress of long-term treatment and coping with stigma and discrimination at the different levels

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of the society are also faced by them. They show concerns around emerging sexuality and the desire for relationships and families of their own. [4-6] If not properly handled, these fears and insinuations may culminate into loss of self-esteem with resultant psychological distress associated with illness, anxiety, withdrawal, depression, substance abuse, and fast deterioration of physical health and quality of life of the patients and their families. Furthermore, the adolescents' adherence to antiretroviral therapy (ART) may be adversely affected by the poor state of psychological health. Studies have shown that pyschosocial problems have independently been associated with poor adherence to ART.[7-9] Poor adherence to ART may lead to high viral load, increased vulnerability to opportunistic infections, more rapid disease progression, and the increased cost of management from resistance to firstline ART, which necessitates the need for a more expensive second-line treatment.

This study sought to determine the psychosocial challenges faced by HIV-positive adolescent children accessing care at Murtala Muhammad Specialist Hospital (MMSH) ART clinic and how these challenges influence their adherence to ART. Findings from this study would be useful to HIV program managers, development partners, and researchers in packaging strategies and/or interventions for reducing psychological stress and improving the quality of life of these victims and for normalizing HIV-related stigma and discrimination within the general public. This study did not assess the adolescents' or parents' characteristics associated with adherence.

### **Materials and Methods**

MMSH is the largest and most-attended secondary health facility in northern Nigeria, patronized by people from within and outside Kano State and from the neighboring Niger Republic. The ART center in MMSH is one of the earliest ART centers established by the Global HIV/AIDS Initiative (GHAIN) project in Nigeria. It operates a full range of HIV treatment, care and support services on the five working days of every week. There are approximately 8,000 adults and 10,000 pediatric clients presently on ART. On average, 40 adolescent children attend the clinic each working day.

We used a descriptive cross-sectional design to study a sample of 400 HIV-positive adolescent children attending the ART center in MMSH. The sample size was determined using an appropriate statistical formula for estimating the minimum sample size for descriptive studies<sup>[10]</sup> and using 56% prevalence of psychosocial problems among similar HIV-positive adolescent children attending ART clinic from a previous study in Zimbabwe.<sup>[11]</sup> The calculated minimum sample size was inflated by 10% to compensate for incomplete responses and nonresponses.

A systemic sampling technique was used for selection of the subjects based on the monthly clinic attendants of 800. With a sample interval of two (i.e., 800/400), one in every two adolescent children was selected until the required sample size was met. The starting point was determined by picking a random number from the clinic register between one and two. Subsequent respondents were identified by adding the sampling interval to the preceding respondents' serial number until the required sample size was met.

Pretested structured interviewer-administered questionnaires were used for data collection. The questionnaire consisted of sections that elicited the sociodemographic characteristics of the respondents, psychosocial problems of the HIV-positive adolescent children, and the effect of psychosocial problems on adherence to ART. The questionnaires were administered by four trained interviewers after obtaining an informed consent or assent from the adolescents or parents as appropriate. Literate respondents indicated acceptance by signing the consent form, while nonliterate participants affixed their thumbprint. Permission and ethical clearance for the study were also sought and obtained from MMSH and Ethical Committee of Kano State Hospital Services Management Board, respectively. Data were collected in June/July 2014.

Data were analyzed using SPSS software, version 16.0. Absolute numbers and simple percentages were used to summarize the categorical variables, whereas quantitative variables were summarized using mean and standard deviation (SD). The  $\chi^2$ -test and Fisher's exact probability test were used for bivariate analysis involving categorical variables; logistic regression analysis was used to determine the variables that predict the psychosocial challenges that influenced adherence to ART. A  $p \leq 0.05$  was considered statistically significant.

## Result

### Sociodemographic Characteristics of the Respondents

Majority of the adolescents studied were female subjects [219 (54.8%)] and were from a polygamous family setting [230 (57.5%)]. Their ages ranged from 10 to 19 years with a mean and SD of  $14.9 \pm 3.15$  years [Table 1]. Most of them came from the Hausa/Fulani tribes [344 (86.0%)] and were single [381 (95.3%)]. About half of the adolescents [197 (49.2%)] had attained at least secondary school level of education.

# Psychosocial Challenges of HIV-Positive Adolescent Children

The adolescents have been attending the ART clinic for an average duration of  $46.1 \pm 35.2$  months ( $3.8 \pm 2.9$  years), with 278 (69.5%) attending the ART clinic for not more than 120 months (5 years) [Table 2]. HIV infection occurred in other members of the adolescents' families and was more common among the biological parents (mother: 17.7%, father: 17.7%). More than half of the adolescents 218 (54.5%) reported being anxious or depressed most of the times—commonly owing to fear of death, because the disease has no cure 112 (51.4%), or based on the premise of the associated stigma 53 (24.3%) as depicted in Table 3. Furthermore, 208 (52.0%) of them had lost a parent or spouse to HIV

Table 1: Sociodemographic characteristics of the adolescents and their caregivers

Adolescents' characteristics	Frequency (%) ( <i>n</i> = 372)	Parents'/caregivers' characteristics	Frequency (%) (n = 372)
Sex		Family setting	
Male	181 (45.2)	Monogamous	170 (42.5)
Female	219 (54.8)	Polygamous	230 (57.5)
Age (years)		Educational status	
10–13	157 (39.3)	No education	17 (4.2)
14–17	119 (29.7)	Qur'anic education only	97 (24.3)
≥18	124 (31.0)	Primary education	92 (23.0)
		Secondary education	116 (29.0)
		Postsecondary education	78 (19.5)
Ethnicity		Occupations	
Hausa	300 (75.0)	Farmer	66 (16.5)
Fulani	44 (11.0)	Trader	190 (47.5)
Yoruba	19 (4.8)	Civil servant	73 (18.3)
Igbo	12 (3.0)	Others	71 (17.7)
Others	25 (6.2)		
Marital status		Number of children in family	
Single	381 (95.3)	1–10	291 (72.8)
Married	12 (3.0)	11–20	99 (24.8)
Divorced	3 (0.7)	21–30	7 (1.7)
Separated	1 (0.3)	31–40	3 (0.7)
Widowed	3 (0.7)		
Educational attainment		Relationship of caregiver with adolesc	ent
No education	3 (0.7)	Parent/spouse	229 (57.2)
Qur'anic education only	67 (16.8)	Guardian	159 (19.8)
Primary education	133 (33.3)	Husband	12 (3.0)
Secondary education	186 (46.5)		
Postsecondary education	11 (2.7)		

infection and more than one-tenth reported being discriminated upon at home in the form of deprivation from sharing domestic utensils with HIV-negative siblings [71 (17.7%)] and receiving unequal treatment with HIV-negative siblings regarding school and personal needs [41 (10.2%)]. More than one-third of the children [154 (38.5%)] were out of school, of which 87 (56.5%) of them dropped out because the parents/ guardians could not afford the combined burden of hospital costs and school. The reasons given by the adolescents for being out of school are summarized in Table 3. The adolescents also reported being avoided by friends/colleagues for intimate relationships 225 (56.3%) and during social interactions such as football, parties, or other social gatherings in the community [72 (18.0%)]. Other forms of discrimination experienced by the HIV-positive adolescents are summarized in Table 4.

# **Psychosocial Challenges and Adherence to ART**

Adherence to ARTs among the adolescents was assessed by considering their consumption of prescribed drugs in the preceding 3 months. We found that most of them [362 (90.5%)] adhered well to the prescribed medications. The reasons given by the remaining 38 (9.5%) for not being consistent on their drugs are summarized in Table 3. About two-thirds of the nonadherent adolescents [22 (57.9%)] have lost confidence on the drugs, because of the notion that it does

On bivariate analysis, it was observed that the adolescents' adherence to ART was significantly influenced by the adolescents' self-perceived state of general health, feeling anxious or depressed most times, not receiving equal treatment at home with other HIV-negative siblings regarding school and personal needs, deprivation from using the same domestic utensils with HIV-negative siblings, avoidance by friends/colleagues during social interactions, and avoidance by friends/colleagues in intimate relationship(s) [Table 4]. Lack of schooling ( $\chi^2 = 1.39$ , p = 0.24) and receiving less attention from teachers (Fisher's exact, p = 0.50) and from friends/colleagues at school (Fisher's exact, p = 0.50) were not significantly associated with the adolescents' adherence to ART. On further statistical analysis using a logistic regression model that comprised all the significant psychosocial challenges that influenced the adolescents' adherence, feeling anxious or depressed most times (p = 0.02), loss of a parent or spouse (p = 0.05), and avoidance by friends/colleagues in intimate relationships (p = 0.05) emerged as the independent psychosocial predictors of the HIV-positive adolescents' adherence to ART [Table 4].

Table 2: Psychosocial challenges of HIV-positive adolescent children

Challenge	Frequency ( $n = 400$ )	Percentage (%)
Other family member(s) with HIV infection		
Mother	71	17.7
Father	70	17.5
Stepmother	18	7.8
Siblings	47	11.7
Self-perception of general health condition		
Good/fair	368	92
Poor	32	8
Self-perception of state of mind		
Happy/stable most times	182	45.5
Anxious most times	86	21.5
Depressed/feel like committing suicide most times	132	33
Loss of intimate relationships		
Lost father to HIV infection	183	45.7
Lost mother to HIV infection	114	28.5
Loss of spouse/intimate partner to HIV infection	3	0.7
Lost a parent or spouse to HIV infection	208	52
Discrimination at home		
Receive unequal treatment with HIV-negative siblings regarding school and personal needs	41	10.2
Deprived from sharing domestic utensils with HIV-negative siblings	71	17.7
Discrimination in schooling		
Do not attend school	154	38.5
Receive less attention from teachers	8	3.3
Receive less attention from friends/colleagues	8	3.3
Discrimination in community		
Avoided by friends/colleagues most of the time during social interactions such as football, parties, or other social gatherings	72	18
Avoided by friends/colleagues in intimate relationships	225	56.3

Table 3: Reasons given by the HIV-positive adolescents' for feeling anxious or depressed, not schooling or not adhering to prescribed ART

Reasons for feeling anxious or depressed	Frequency ( <i>n</i> = 218)	Percentage
Associated stigma	53	24.3
Fear of death because disease has no cure	112	51.4
Uncertainty about marriage/future intimate relationship(s)	34	15.6
Fed up	19	8.7
Reasons for not schooling	Frequency ( <i>n</i> = 154)	Percentage
Parents/ guardians cannot afford combined burden of hospital costs and school	87	56.5
Fear of stigma and discrimination from friends and colleagues	4	2.6
Frequent sickness	19	12.3
Completed secondary school/awaiting admission into postsecondary school	23	14.9
Not interested	21	13.6
Reasons for not being adherent to ART	Frequency $(n = 38)$	Percentage
Lost confidence in drug because it does not cure	22	57.9
Challenge with transport money to the hospital	8	21.1
Do not want people to know my HIV status	4	10.5
Forgetfulness	4	10.5

Table 4: Psychosocial challenges influencing the adolescents' adherence to antiretroviral medications

Challenge	Adherence		Bivariate, χ² ( <b>p</b> )	Logistic regression	
	Good/Fair, frequency (%) (n = 362)	Poor, frequency (%) (n = 38)		Z (p)	OR (95% CI)
Perceived having poor state of general health	25 (6.9)	7 (18.4)	6.20 (0.03)*	0.70 (0.48)	
Feeling anxious or depressed most times	190 (52.5)	28 (73.7)	6.23 (0.01)*	2.34 (0.02)*	
Lost a parent or spouse to HIV infection	108 (29.8)	12 (31.6)	4.54 (0.03)*	1.94 (0.05)*	0.38 (0.17-0.85)
Not equally treated with HIV-negative siblings regarding school and personal needs	86 (23.7)	19 (50.0)	12.23 (0.0001)*	1.38 (0.17)	0.47 (0.23–0.95)
Deprived from using same domestic utensils with HIV-negative siblings	59 (16.3)	12 (34.2)	5.50 (0.02)*	0.09 (0.93)	
Avoided by friends/colleagues most of the time during social interactions such as football, parties, or other social gatherings	59 (16.3)	13 (34.2)	7.48 (0.01)*	0.58 (0.56)	
Avoided by friends/colleagues in intimate relationships	198 (54.7)	27 (71.0)	3.74 (0.05)*	1.94 (0.05)*	0.46 (0.21–1.01)

<sup>\*</sup>Statistically significant.

## **Discussion**

The successes recorded in the battle against HIV/AIDS in the last few decades has witnessed an increasing number of infected children, who have survived into the adolescent stage of life, a unique stage in human development fraught full of developmental challenges. Nigeria has a HIV seroprevalence rate of 3.0% and about 60.4 million growing population of young people that contribute more than one-third of its population.[3] Diagnosis of HIV infection in low-resource settings is often in later childhood or adolescence[12], as reflected by the findings of this study that majority of the adolescents started attending the ART clinic in their adolescence stage and not from childhood, probably from the slow progression of the disease.

Although a majority of the respondents in this study (92.0%) perceived their general state of health as good/fair, it was obvious from the study that, from the WHO definition of health, which refers to a state of physical, mental, and social well-being, many of them were mentally and socially unwell. More than half (54.5%) of them reported being anxious, depressed, or feeling like committing suicide most of the time. These feelings are not unexpected as the respondents were subjected to psychological assaults at all fronts: at home, in school, and in the community. Theses assaults took several forms including stigmatization, discrimination, avoidance, not sending to school, being offered unequal treatment as compared with their siblings. Sadly, more than one-third (38.5%) of the adolescents was not attending school, and this may have long-term consequences on the society.

Across several studies, anxiety and depression have been noted to be the psychosocial factors consistently associated with nonadherence.[10,13] Current estimates of adherence in developed and developing countries have shown that, despite fears and concerns over the latter, adherence levels

are similar or higher in developing countries when compared with developed countries. The level of adherence observed in this study is high and comparable with the pooled estimate of sub-Saharan African patients of 77% (95% confidence interval: 68%-85%)[14] and adherence in developing countries of >75% (range: 45%–100%).[15] However, reported adherence for developed countries are lower, with majority <75% (range: 20%-100%).[14,16]

Nonadherence has been described as the single most significant challenge to the successful management of HIVinfected individuals, especially adolescents.[12,17] Factors contributing to nonadherence are multidimensional and may be patient related, provider related, medication related. disease related, or owing to psychological barriers;[13,18] with the psychological factors being more consistent with nonadherence.[13] This was obvious in this study as perception of having a poor state of health, anxiety, depression, loss of parents, and various forms of discrimination all contributed to poor adherence. Albeit the fact that this study indicated a good adherence to ART in the adolescents examined, it is, however, worrisome that about one-tenth were not consistent on their drugs. It is on record that adolescence is a period of risk taking including high risk behaviors for HIV transmission.[19] In the midst of pyschological stressors, avoiding temptations for risky transmission behaviors and further spread of a more disastrous drug-resistant strain of the virus may not be guaranteed. Thus, the observed association of the adolescents' adherence with varying psychosocial stressors rekindles hope that addressing the factors is likely to guarantee optimum adherence to ART and ensure safer behavior of the adolescents.

HIV-infected adolescents have varied and sensitive needs that must attract high understanding and commitment of program managers and the social environment to achieve the desired level of adherence to ART. With the complex range of factors associated with psychological challenges and adherence in adolescents, multiple modalities would need to be explored in their management, as hitherto many interventions have focused on infected adults and children. Training of health-care professionals in adolescent care, formal establishment of coping mechanisms to deal with loss of loved ones and initiating/maintaining intimate relationships, caregiver education, telephone follow-up, and the use of multidisciplinary treatment teams (case manager, doctors, nurses, psychologists, and support group) among others would need to be included as part of routine management of HIV in adolescents.

Although caregivers are often ill equipped to manage this unique group of people<sup>[13]</sup> and play negative roles that contribute to the adolescent's psychological stress, they can also play an indispensable role if well equipped. A family-centered support program was shown to be successful and reduce stigma, discrimination and depression, and further boost adherence in Zimbabwe.<sup>[17]</sup> This multiple components program addresses psychological determinants of adherence and factors such as knowledge, skills, and environment that affect adherence directly. This program should be locally adapted and sustained in Nigeria and other countries with similar challenges.

### Conclusion

HIV-infected adolescents have varied and sensitive needs that must attract a high-level understanding of program managers and the social environment to achieve the optimum level of adherence to ART.

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