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Challenges of the care of HIV positive adolescents in Jos, Nigeria

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The introduction of highly active anti-retroviral therapy (HAART) to children with perinatally acquired HIV has prolonged their lifespan to adolescence and beyond. These HIV positive adolescents on care face challenges as they undertake their treatment which this study aimed to determine. The study was a cross-sectional descriptive study of challenges faced by adolescents between the ages 10 and 19 years on routine follow up at the HIV Clinic of Jos University Teaching Hospital (JUTH) over a period of six months. Ethical approval was obtained from the Health Research Ethical Committee (HREC) of JUTH and permission was also obtained from the AIDS Prevention Initiative in Nigeria (APIN) center JUTH. Data obtained was entered into Epi Info version 7.2 and analyzed. Among the 147 subjects that were recruited, 56 (38%) were males, while females were 91(62%), M: F ratio of 1: 1.6. Of this, most were single (99%). Among the subjects, 81 (55%) were orphans, of which 53 (65%) were single orphan. Of the total patients studied, 68% lived with one or both parents, while 26% stayed with relatives and 5% lived in orphanages. Most were in school 137 (96%) and 85 (59%) were aware of their diagnosis. Discrimination was reported among 19 (13%) subjects by pupils/students, teachers, friends and/or family members, while 31 (21%) had thought of committing suicide. Among the subjects, 100 (70%) have considered stopping medication. HIV positive adolescents in our study suffer several challenges which include being orphans, discrimination and suicidal ideations. These challenges could interfere with retention in care and compliance with their antiretroviral drugs.

Key words: Adolescents, HIV, orphaned child, social discrimination, suicidal ideation.

INTRODUCTION

In 2017, United Nations Children's Fund (UNICEF) estimated that 1.8 million adolescents aged between 10 and 19 years were living with HIV and 250, 000 of those aged 15 to 19 years were newly infected with the disease (UNICEF, 2019). The estimated mortality for the adolescents aged 10 to 19 years was 38,000/year. With the introduction of the highly active anti-retroviral therapy (HAART) to children with perinatally acquired HIV; these

children now live to adolescence and beyond (WHO, 2014a; Patrice-Coy et al., 2016). The implication of this is that it allows these children to transit into adulthood. Generally, the use of HAART has reduced mortality of those who acquire the infection thereby transforming the disease from a debilitating and fatal one to a chronic and manageable one (Davies et al., 2009).

Adolescents and young people are a special group to consider in HIV control programs because of the high disease burden among them, their tendency for a care-free attitude, ignorance as well as high risk behavior which allows them to transmit the infection to other people (Abadia-Barrero and Castro, 2006). These HIV positive adolescents who are being cared for face challenges which bother on disclosure, adherence, psycho-social issues, reproductive health and stigma/discrimination among others (Willis et al., 2014; Naswa and Marfatia, 2010; Ledlie, 2004).

The Paediatric ART programme of Jos University Teaching Hospital (JUTH) started about 15 years ago with mostly children who had acquired HIV perinatally. These children on follow up in the clinic have reached adolescent years and may now be facing some additional challenges aside from those common to all adolescents. It has therefore become increasingly important in JUTH to look at the challenges that these special group of adolescents face as they are cared for in a pediatric setting and as they prepare to transit to adult medicine clinic to continue with their care. This study therefore, looked at the challenges of this cohort of patients that have been managed from childhood to adolescence in order to put in place measures necessary to address these problems so as to improve their wellbeing.

MATERIALS AND METHODS

Study setting

This study was carried out in the Aids Prevention Initiative in Nigeria (APIN) Centre of the Jos University Teaching Hospital (JUTH). APIN is a large treatment center for HIV patients supported by the Harvard School of Public Health, Boston USA and The President's Emergency Plan for Aids Relief (PEPFAR) USA. The center provides comprehensive HIV care, treatment and support for adults and children. Majority of the HIV positive children in APIN JUTH acquired their HIV infection perinatally and have been on regular follow up visits for drug pick-ups, treatment of common illnesses and prophylaxis and treatment of opportunistic infections, growth monitoring, treatment response and identification of treatment failures. Other services provided in the clinic are prevention of mother-to-child transmission of HIV (PMTCT), infant feeding counselling and support, HIV testing services (HTS), and adolescent HIV services. About two thirds of the children in the Paediatric ART programme have reached adolescence and some have even been transited to the adult ART programme.

Study population

Consecutive consenting/assenting children aged 10 to 19 years attending the pediatric and adult ART program of JUTH were enrolled into the study. The study was a cross-sectional descriptive study of these adolescents on routine follow up over a period of six (6) months (June to November 2018).

Data collection

A semi-structured interviewer-administered questionnaire was used to collect information from the respondents. The data collected included socio-demographic characteristics, history of discrimination, those whom they live with, whether they were orphans or not, educational history including school performance, suicidal ideation, and whether they had ever considered stopping ART.

Data entry and analysis

The data obtained were entered and analyzed using Epi Info version 7.2.0.1 (2016). Univariate analysis was carried out to describe the characteristics of the adolescents while bivariate analysis (Chi-Square test) was used to determine the association between the characteristics of these adolescents. P value of <0.05 was considered as statistically significant.

Ethical consideration

Written informed consent was obtained from the parents/ guardians/older adolescents (≥18 years) and assent from the younger adolescents (<18 years) before participating in the study. Participants were allowed to voluntarily withdraw at any stage of the study if they so desired. This did not affect their care in any way. All information obtained from the adolescents were kept confidential. Ethical approval was obtained from AIDS Prevention Initiative in Nigeria (APIN) authority and the Health Research Ethical Committee (HREC) of the Jos University Teaching Hospital (JUTH).

RESULTS

Of the 147 subjects, 56 (38%) were males, while females were 91 (62%), M: F ratio of 1: 1.6 with most of them being single (99%). The other socio-demographic characteristics of the subjects are shown in Table 1.

Among the subjects, 81 (55%) were orphans, of which 65% (53) were single orphan. Of the total patients studied, 68% lived with one or both parents, while 26% stayed with relatives and 5% lived in orphanages. Most of the respondents (68.7%) were aged 14 years and above and 62.5% of them are living in an urban area. About 96% were in school while 78.1% have had at least secondary school education. Of the adolescents studied, only 85 (59%) were aware of their diagnosis. Seven (4.8%) of the children were not granted permission by

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Table 1. Socio-demographic Characteristics of HIV Positive Adolescents Attending JUTH HIV Clinic.

Characteristics	Frequency (n= 147)	Percentage
Age group		
Early adolescents (10-13 years)	46	31.3
Middle adolescents (14-16 years)	71	48.3
Late adolescents (17-19 years)	30	20.4
Sex		
Female	91	61.9
Male	56	38.1
Address		
Rural	17	11.6
Semi-Urban	26	17.7
Urban	92	62.5
Urban slum	12	8.2
Marital status		
Married	1	0.7
Single	146	99.3

their schools to come for regular clinic visits while 11 (7.5%) do not usually ask for permission from their schools. Discrimination from pupils/students, teachers, friends and/or family members was reported among 13% of the study subjects, 31 (21%) had considered committing suicide. Among the study participants, 100 (70%) have also considered stopping their medication at some point (Table 2).

There was no statistical significant difference in the challenges faced when both sexes were compared (Table 3). There was however a significant association between knowledge of the disease and educational status when the aged groups were compared p-value <0.05 (Table 4).

When the association between orphan status and the characteristics of HIV positive adolescents attending JUTH HIV Clinic was explored, it was observed that where the orphaned child lives and if he or she was in school were also statistically significant p-value <0.05 (Table 5).

DISCUSSION

The introduction of HAART no doubt has led to the increase in the number of children with HIV that are transiting from pediatric care into adolescence and adulthood (Vijayan et al., 2009; Hussen et al., 2015; Machado et al,, 2016). The disease which used to be a debilitating disease with a fatal outcome is now a chronic disease that can be managed over a prolonged period of time (Davies et al., 2009). However, as the children developed into adolescents, they face different challenges because of the peculiarity of their physical and mental changes.

More than half of the subjects in this study were orphaned and majority are single orphans, a finding that is similar to the study by Nyamukapa et al. (2008). The orphaned and vulnerable children (OVC) especially those orphaned by HIV do face a lot of challenges. The odds are against the AIDS-orphaned children, as they are stigmatized, discriminated, psychologically distressed with no or poor access to basic health care and education (Willis et al., 2014). This study observed that there was a significant association between being orphaned and not being in school, as all the children who were not in school were orphaned. Additionally, about a quarter of the children in this study were living with relatives while 5% of them were living in orphanages and this may add to their psychological distress. This finding may have been as a result of loss of their parents and this is similar to what was reported by other authors (Parsons, 2012; Mavhu et al., 2013). Where the adolescents live was significantly associated with whether they were orphans or not.

In the present study, 21% of the respondents have had thoughts of committing suicide as a result of their HIV status or reasons unrelated to their disease. Mental and psychosocial problems are one of the challenges that children with HIV face and this usually comes from discrimination, fear of stigma, isolation and other social factors (Menon et al., 2007). These psychosocial problems can lead to suicide or having suicidal ideation. Studies have shown that perinatally HIV-infected youths

Table 2. Challenges and characteristics of HIV positive adolescents attending the JUTH HIV Clinic.

Challenge and characteristic	Frequency (n= 147)	Percentage
Living with whom?		
Husband	1	0.7
Orphanage	7	4.8
Parent(s)	101	68.7
Relatives	38	25.8
Orphan		
No	66	44.9
Yes	81	55.1
Orphan type (n= 81)		
Double	28	34.6
Single	53	65.4
Know the disease you are treated for?		
No	59	40.1
Yes	88	59.9
Are you in school?		
No	6	4.1
Yes	141	95.9
Educational status		
Drop out	1	0.7
Primary	31	21.2
Secondary	105	71.9
Tertiary	5	3.4
Completed secondary	4	2.8
Boarding school		
No	145	99.0
Yes	2	1.0
Change school in the past?		
No	106	72.1
Yes	41	27.9
Change school because of your HIV status (N=41)		
No	35	85.4
Yes	6	14.6
School performance		
Average	130	88.4
Excellent	15	10.2
Poor	2	1.4
Discrimination		
No	128	87.0
Yes	19	13.0
Thought of suicide		
No	116	79.0
Yes	31	21.0
Felt like stopping ART drugs		
No	47	32.0
Yes	100	68.0

Table 3. Association between sex and characteristics of HIV positive adolescents attending JUTH HIV Clinic (n=147).

Characteristic	Sex		Chi square	P-value
	Female	Male		
Living with whom?				
Husband	1	0	4.4015	0.2212
Orphanage	5	2		
Parent(s)	57	44		
Relatives	28	10		
Orphan				
No	40	26	0.0857	0.7697
Yes	51	30		
Orphan type (n= 81)*				
Double	17	11	0.0928	0.7606
Single	34	19		
Know the disease you are treated for?				
No	33	26	1.4908	0.2220
Yes	58	30		
Are you in school?				
No	4	2	0.0601	0.8062
Yes	87	54		
Educational status				
Drop out	1	0	1.5870	0.8111
Primary	19	12		
Secondary	64	41		
Tertiary	4	1		
Completed secondary	2	3		
School performance				
Average	81	49	0.1522	0.9267
Excellent	9	6		
Poor	1	1		
Discrimination				
No	77	51	1.2839	0.2571
Yes	14	5		
Thought of suicide				
No	70	46	0.5676	0.4512
Yes	21	10		
Felt like stopping ART drugs				
No	25	42	2.1071	0.1466
Yes	66	34		

have a higher tendency to developing a mental problem than perinatally HIV-exposed but uninfected youths (Malee et al., 2011; Mellins and Malee, 2013). Midtho et al. (2012), however demonstrated that children who attend peer support-support groups help them to cope well with their disease by gaining knowledge about HIV, talking and sharing experiences which leads to positive perception of the disease and adherence to medications. Additionally, social support can minimize depression, isolation as well as help to improve self-confidence

Table 4. Association between age group and characteristics of HIV positive adolescents attending JUTH HIV Clinic (n=147).

Characteristic	Age group			Chi square	P-value
	Early	Middle	Late		
Living with whom?					
Husband	0	0	1	6.5481	0.3647
Orphanage	3	2	2		
Parent(s)	33	47	21		
Relatives	10	22	6		
Sex					
Female	30	39	22	3.3404	0.1882
Male	16	32	8		
Orphan					
No	27	29	10	5.6330	0.0598
Yes	19	42	20		
Orphan type (n= 81)					
Double	8	16	4	2.5848	0.2746
Single	11	26	16		
Know the disease you are treated for?					
No	37	19	3	47.7175	0.0000
Yes	9	52	27		
Are you in school?					
No	0	0	6	24.3957	0.0000
Yes	46	71	24		
Educational status					
Drop out	0	0	1	89.9237	0.0000
Primary	26	5	0		
Secondary	20	66	19		
Tertiary	0	0	5		
Completed secondary	0	5	5		
School performance					
Average	40	65	25	3.0097	0.5562
Excellent	6	5	4		
Poor	0	1	1		
Discrimination					
No	41	63	24	1.6802	0.4317
Yes	5	8	6		
Thought of suicide					
No	41	52	23	4.3501	0.1136
Yes	5	19	7		
Felt like stopping ART drugs					
No	19	16	6	6.3758	0.0413
Yes	25	54	22		

Table 5. Association between orphan status and the characteristics of HIV positive adolescents attending JUTH HIV Clinic (n = 147).

Characteristic	Orphaned		Chi square	P-value
	No	Yes		
Living with whom?				
Husband	0	1		
Orphanage	0	7		
Parent(s)	61	40		
Relatives	5	33	31.7984	0.0000
Know the disease you are treated for?				
No	32	27		
Yes	34	54	3.4748	0.0623
Are you in school?				
No	0	6		
Yes	66	75	5.0969	0.0239
Educational status				
Drop out	0	1		
Primary	18	13		
Secondary	45	60		
Tertiary	3	2		
Completed secondary	0	5	6.87	0.1429
School performance				
Average	59	71		
Excellent	7	8		
Poor	0	2	1.661	0.4358
Discrimination				
No	58	70		
Yes	8	11	0.0688	0.7910
Thought of suicide				
No	53	63		
Yes	13	18	0.1394	0.7089
Felt like stopping ART drugs				
No	24	19		
Yes	43	61	2.4747	0.1156

(Wang et al., 2018). The various components of suicidal behaviors include suicide ideation (thinking about killing oneself), planning suicide, attempting suicide and suicide itself (WHO, 2014b). In the present study, 31 (21%) had thoughts of committing suicide out of which 20 were females. Though this was higher in females, this finding was not statistically significant. However, Nock et al. (2008) documented that suicide ideation often emerges in adolescence and is prevalent among adolescent females. With 21% considering suicide, this finding is significant especially considering the recent increase in cases of suicide as reported by the media in this country (Muanya et al., 2019). HIV/AIDS and suicidal behavior have increasingly presented major public health challenges and has become a burden to society. In recent years, mental health problems have gradually come to the fore as a critical issue among people living with HIV/AIDS (PLWHA), and such problems may cause them to develop suicidal ideation, thus leading to higher mortality (Wang et al., 2018). It has also been reported that

suicidal ideation is more common in HIV-positive patients than in the general population (Keiser et al., 2010; Onyebueke and Okwaraji, 2015; Ogundipe et al., 2015). Therefore, the need to prevent, or identify early these group of children cannot be overemphasized.

In this study, only about 60% of the adolescents know their HIV status. This shows that the level of disclosure of HIV status in our environment is still low. However, a similar study in Zambia (Okawa et al., 2017) showed higher disclosure rate but Hayfron-Benjamin et al. (2018) in Ghana showed lower disclosure rate. More of the adolescents in the middle and late stages know their status compared to those in the early stage. This may be as a result of the fact that the health care providers utilize a tailored and developmental counselling approach to disclosure, as each adolescent is unique (WHO, 2013).

This low level of status awareness could affect them psychologically as they daily take medications which they are not aware of the reason for doing so. This could also adversely affect adherence to the medications. A proper disclosure to the adolescents will help them to know their HIV status, learn and access information about HIV infection which will be beneficial.

The fact that most of our subjects (96%) are in school, will in addition aid learning and understanding of their condition. When the challenges faced by these adolescents were compared between the males and females respondents, there was no statistical difference between them.

Despite the increase in knowledge of HIV/AIDS in the society, reported cases of discrimination still abound as shown in this study. This discrimination is orchestrated by school mates, teachers, friends and family members. Over a quarter of the study participants have changed schools in which some of them were as a result of stigma and discrimination because of their HIV status while others were due to other reasons such as financial constraint and the need to relocate to another home. The implication of this is that it may affect their academic performance. In addition, stigma and discrimination associated with HIV may prevent many adolescents from disclosing HIV status even when involved in a sexual relationship. Also, about 99% of the patients who are in secondary school attend day schools though majority of them preferred boarding school. The caregivers/parents preferred them in day schools because they are afraid their school mates will be aware of their HIV status and that will lead to stigmatization and discrimination. Additionally, the issue of ensuring adherence to ARVs has denied them the opportunity to live in a boarding house in order to experience an independent-life like their peers. From the study, some of the children were denied permission to come for regular clinic follow up visits probably because the school authority were not aware of their HIV status and frequent absenteeism may be interpreted as truancy. In addition, this discrimination orchestrated by school mates, teachers, friends and family members demonstrates poor social support which will ultimately affect the adherence to antiretroviral drugs and consequently leads to treatment failure.

A high percentage (70%) of our patients has considered stopping their medication. This can lead to skipping of medication which can lead to poor viral load suppression and drug resistance. Non-adherence to medication has also been shown to be the single most significant challenge to the successful management of the HIV infected individual. Therefore, there are barriers as well as facilitators to adherence at individual, family/caregiver and hospital levels. This may include any combination of structural, patient-related, provider-related, medication-related, disease-related, and psychological barriers. A well-developed intervention support for this category of patients can go a long way in helping with adherence (Agwu and Fairlie, 2013; Galea et al., 2018).

LIMITATION

Data was generated by interviewing the adolescents; there could be the possibility of bias in some of their responses.

Conclusion

HIV positive adolescents in the present study face many challenges which include being orphans, discrimination and suicidal ideations. These challenges may interfere with retention in care and the compliance with taking of their antiretroviral drugs. The development of intervention support, the improvement in the counseling, establishment of peer support group as well as orphans and vulnerable children (OVC) services to this category of adolescents could help to reduce these challenges and improve their quality of life. These could encourage retention in care and treatment as well as reduce the transmission of HIV infection to the populace.

CONFLICT OF INTERESTS

The authors have not declared any conflict of interests.

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