Post HIV Status Disclosure Assessment of Behavioural and Mental Health Patterns among Adolescents and Young People Living with HIV

Ikenna Nwakamma[1,*], Carol Talla[2], Stephanie Erebi Kei [3] Kema Onu[4]

[1] African Centre for Health Leadership, Abuja, Nigeria
[2] Catholic Caritas Foundation of Nigeria
[3] School of Post Graduate Studies, Department of HIV Education and Management, National Open University, Abuja Nigeria
[4] AIDS Healthcare Foundation (AHF), Abuja, Nigeria

Contact:
amolabora2@gmail.com, +234 8066199289 (Ikenna Nwakamma*)

Abstract: Evidence suggests high rates of mental health/psychiatric disorder in young people with early or perinatal infection of HIV. As a result, some Scholars and professionals working with this group of young people now advocate for focus on factors that promote resilience and not just on pathologies. This Nigerian study seeks to add to body of knowledge and support evidence based HIV programming for adolescent and young people living with HIV. Qualitative data was collected from parents and care giver of the HIV positive adolescents and young people (AYP), from selected healthcare providers in HIV treatment centres and from AYP living with HIV. From the coding of the transcripts, seven themes and out of 787 identified clauses referring to 1 of the 7 themes, 71 (9.0%) were allocated to blame, 84 (10.7%) to academic performance, 210 (26.7%) on self-perception, while depression accounted for 81 (10.3%) of the clauses. Furthermore, clauses on post disclosure crises amounted to 201 (25.5%), treatment adherence accounted for 109 (13.9%), while sexual risk behavior was 31 (3.9%). In view of the global mandate of ending AIDS by 2030, and considering the observed behavioral and mental health complications among the AYP living with HIV in this study, it has become important to consider behavioral and mental health interventions as important components of the national HIV response.

Keywords: HIV Status, Post-disclosure, Mental Health, Behavioral Health, Adolescents, Youths, Young People, Nigeria

Introduction

In 2015, approximately 2.6 million children <15 years were living with HIV worldwide, nearly 90% of them in sub-Saharan Africa [1] and it was an estimated 28% increase in number of adolescents living with HIV since 2005 [2]. Nigeria had an approximated 41 000 new HIV infections among children in same year [3].

Advancement in antiretroviral treatment (ART) has improved survival rate of children with perinatal and early HIV infection, resulting to increase in the population of adolescents and young people living with HIV and transiting to adulthood [4]. This population faces a myriad of challenges as they age, sometimes triggered by factors like loss of caregivers and family members, self-stigma and discrimination, post HIV disclosure crises, and difficulties in coping with ART [5]. As a result, some Scholars and professionals working with this group of young people now advocate for focus on factors that promote resilience and not just on pathologies [6].

Evidence from a clinic based study suggests high rates of mental health/psychiatric disorder in young people with early or perinatal infection of HIV [7]. An American study of the behavioral health risks in a sample of perinatally HIV-infected (PHIV+) and perinatally HIV-exposed, uninfected (PHEU) adolescents discovered that nearly half of the participants met study criteria for at least one behavioral health risk, especially mental health problems (28%), early onset of sexual activity and substance abuse each reported by an average of 16% [8]. A multisite study on the psychological symptoms among 2032 youth living with HIV showed that 17.5% of the youth reported psychological symptoms trespassing the normative benchmark on the Global Severity Index with wide variety of symptoms reported [9].

Furthermore, qualitative studies conducted in Canada and South Africa [10, 11] identified psychosocial issues that could impact HIV positive youths' mental health, including problems developing a healthy sense of identity and sexuality in the context of the consciousness of their illness, difficulties with peer association, disclosure and social stigma among other factors. Another evidence from Thailand reports that adolescents with perinatally-acquired HIV-infection showed significant psychosocial and behavioral health situations that should warrant an urgent response. [12].

In view of the evident behavioral and mental health co-morbidities among adolescents and young people living with HIV, It has become important for the HIV programming landscape to recognize this emerging HIV related problem among the young ones who are likely to bear the longest burden of HIV. To mitigate the psychosocial challenges and improve treatment outcomes of this population and enable them lead a

long quality productive lives, it is important to understand the factors that affect the whole being of HIV-infected children and youths.

With the high burden of pediatric HIV in Nigeria and the continuous focus only on other HIV related pathologies, there is need for evidence to understand how the issues of behavioral and mental health situations are playing out among the young HIV positive population in Nigeria. This study seeks to meet the need for evidence as a way of proving information for evidence based HIV programming for adolescent and young people living with HIV.

Methodology

Study Design

This is a qualitative study involving in-depth interviews of parents and care giver of the HIV positive adolescents and young people (AYP) and key informant interviews of selected healthcare providers in HIV treatment centers and some older AYP living with HIV. There were also two focus group discussions among adolescents and young people living with HIV. The age range of the AYP in this study was between 11 to 24 years, those considered as older AYP were between 20-24 years.

Study area

The data reported in this study emanated from surveys conducted in two locations in Nigeria: Abuja, Benue State. The respondents were purposefully selected to provide a mix of rural, peri-urban and urban settings.

Sample Size

A total of 65 participants were included in this study, 20 were adolescents and young people (AYP) living with HIV who participated in the focus group discussion (FGD), 10 older AYP living with HIV were involved in key informants interviews (KII), 20 care givers/parents participated in in-depth interviews (IDI) and 15 healthcare providers as key informants. The sample size was adopted based on convenience, with each of the study locations producing at least 30 participant s.

Data Collection and Analysis

The focused group discussions, in-depth and key informant interviews were guided by semi structured questionnaires addressing the issues around the perception of the respondents on how AYP cope with HIV

infections post HIV status disclosure experiences.

To maintain anonymity and establish a conducive atmosphere for discussion, participants were allowed to remain anonymous or chose an alias. The group discussions and interviews were done using a mix of English and local languages in the different locations to create an environment for easy communication considering the demographic characteristics of the populations. The discussions were audio taped after duly obtaining the consent of the participants, while the discussions and interviews lasted between 45 to 60 minutes.

The audio recordings from the interviews and focused group discussion were transcribed verbatim; sessions where local languages were used were transcribed into English and independently verified by two other people. The transcripts were read at first for the coders to deductively capture participants' answers to the different questions and the second review was to look for recurring themes in the text to inform development of codes used in analyzing transcript data. The transcripts were coded by three different people who reviewed each line, phrase, and paragraph of at least 4 different transcripts to identify the initial key codes. Subsequently, the three coders met with the principal investigator to review and harmonize the independently coded transcripts into a final document.

After the harmonization process, codes and themes were examined for content analysis in relation to the study and thematically according to the overall interview guide. The primary findings were then synthesized and summarized in analytic narratives.

Result

Interviews were held with 65 participants, 30 of them being AYP living with HIV, 20 care givers/parents and 15 health workers. All names were abbreviated to protect participants' confidentiality. The participants' characteristics are presented in Table 1.

From the coding of the transcripts, seven themes emerged including academic performance, perception of self, depression, blame and post disclosure crises. Others include treatment adherence and sexual risk behaviours. Out of 787 identified clauses referring to 1 of the 7 themes, 71 (9.0%) were allocated blame, 84 (10.7%) to academic performance, 210 (26.7%) on self-perception, while depression accounted for 81 (10.3%) of the clauses. Furthermore, clauses on post disclosure crises amounted to 201 (25.5%), treatment adherence accounted for 109 (13.9%), while sexual risk behavior was 31 (3.9%).

Blame

Some of the parents acknowledged that their children blamed them for the troubles of being HIV positive. The attitude was expressed more as they grew older and became more conscious of the implications of being HIV positive. In some cases, the HIV positive young people expressed their anger by being rebellious or kept to themselves once in a while.

"I knew it was going to happen. That was why it was difficult for us to disclose the HIV status, today my daughter reminds me at every provocation of how I have ruined her life. I feel so guilty" [a mother, IDI].

Some other parents who reported that their children had not expressed any form of blame feared that at one point they will begin to ask questions and eventually put the blame on them.

In the focus group discussions, there were varying responses to issue of blaming anyone for their HIV status. Even though majority of the AYPs could not air their opinion on the issue, those that responded pointed fingers at different directions, with more suspecting their fathers as the source of the infection.

"I know my mother is innocent, if it is from her then it maybe it was a mistake otherwise it maybe from my father. I can't say who I should blame" [a boy, FGD].

"My father has two wives, so how do I know. If he married only one wife maybe it would not have happened" [a boy, FGD].

Academic performance

Another issue that came up was how realization of HIV status affected the academic performances of the AYP. Most of the parents reporting that it did not affect the performance of their children were among those whose children's ages were less than 12 years. A good number of them reported some immediate or later impact of HIV status disclosure on the performances of the children. Some manifested in their academic results other were on their participation in school activities.

"*It was very clear, that very term his result was very bad that his teacher was really worried. The most difficult thing is that we cannot tell the teacher" [a father, ID].*

"You know the demands of healthcare may affect these young ones, for instance when they have important activity going on in school, they may be in the hospital for their drug refill or for any of the required medical assessments" [Male health worker, KII].

Perception of self

Internalized stigma was very pronounced among the AYPs. Though a few maintained a high spirit and expressed conviction that they could achieve their dreams, a good number of them spoke of their concerns about how people will accept them, if they can marry and have their own children. A few insisted that they did not want to marry or have children.

"Sometime I just imagine it that HIV is living in my body and I just feel dirty. I cannot marry because I don't want to tell anyone about my HIV status and I cannot imagine having children and they have HIV. I will just kill myself" [female AYP, FGD]

"Yes, people try to console me and assure me that all is well. I don't think all is well, I know they want me to feel okay, but I don't know if I will live long, I even don't see reason why I have to go to school and face all those troubles when I am not even sure how I will be tomorrow" [male AYP, KII]

The health workers' opinions were not far from the responses given by the AYPs, they acknowledged that there was need to focus on mental health given that they AYPs are facing a difficult moment in their lives.
"It is difficult to counsel these young people without being emotional yourself. There was a time I was speaking to a girl that was always defaulting in her treatment, she broke into tears and asked me if I knew what it meant to worth nothing because someone gave you HIV, I couldn't say anything" [Female health worker, KII].

Depression

From the responses of the parents and care givers, the AYPs seemed to be more prone to depression as they grow older. Though their understanding of clinical definition of depression may be argued, a good number of parents/caregiver reported that their wards sometimes remained incommunicado for days and some refused to eat. The health worker agreed that there have been cases of depression among the older HIV positive AYPs

"Some time ago, my daughter refused to talk to anyone, she kept to herself and she was not even crying to make me feel she was having problems. I became afraid because I did not know what to do" [a Mother, ID].

"We have had cases of depression among the young people. Unfortunately, little attention is paid to that

in the National HIV program and there is no provision for documenting them in the monitoring and evaluation system. I can say the poor adherence we record in the age group is connected with depression, we need to look into that in the program" [male health worker, KII]

Treatment adherence

Treatment adherence was among the major issues that emerged from the discussions. The AYPs, their parents/care givers and the health workers agreed that adherence was a problem in the age group. Poor adherence was also recorded more in the older group, and from the responses of the parents/care givers and the health workers, the girls adhered more to treatments.

"It was easy for me to convince my son to take his drugs when he was younger, since he came to know his status; I have lost control of him. He abandons his drugs for days and you cannot do anything about it" [a mother, IDI]

"The age group is the worst in terms of adherence, but it is understandable. The stage in their life comes with certain temperaments naturally, you know generally young people hate drugs and hospitals, in their case it is being compounded by a sudden realization of this problem they will have to carry all their lives" [female health worker, KII].

Sexual risk behaviors

There were varying views among the AYPs on sexual risk behaviors, particularly with regards to informing their sexual partners of their HIV status. Eight (3 male, 5 female) of the AYP acknowledged to have had sex without condom in the last six month and majority of them expressed concerns about informing their boyfriends and girlfriends of their HIV status as well as using condoms. Some of them had the views that no boy or girl in their age will agree to date them if they are aware of their status, as such; they would rather not disclose their status.

"I have had sex without condom. I told the guy to use condom but he refused, it was not my fault" [female HIV positive youth, KII].

"I hear how my friends talk about HIV, that's why I said I will never tell any of them, I will not tell anybody apart from my family. If I have a boyfriend and he insists on having sex with me, I will not tell him. If he gets it, fine" [Female AYP, FGD]

The health workers reported that they had counselled some HIV AYP who acknowledged being sexually active without using condom. A health professional suspected some of them maybe doing it deliberately

out of frustration.

"You know, some of these young ones may be battling with a lot of emotional problems and the burden of silence is huge for them. As a way of getting back at a world that rejected them, they want to do anything. If people can do suicide bombing in anger, or cause serious harm to people in anger, it will not be surprising that this group can do same in anger, but in their case, the harm will not be visible immediately" [Male Health worker, KII].

The parents acknowledged that the much they could do was to advise them, what they do, like in other young people in the age group, is usually covert. They however agreed that they should not be made to feel too bad by always too closely following up on them and probing too much about their sexual activity as that may reinforce internalized stigma.

Table 1. *Description of respondents in the study*

Description of Respondents	Number (%)
HIV positive AYP	30(46.2)
Care givers/Parents	20(30.7)
Health workers	15(23.1)
11-18 year of age	12(18.5)
19-24 years of age	18(27.7)
≥25	35(53.8)
Male	31(47.7)
Female	34(52.3)

Post-disclosure Crises

One theme that was discussed prominently was post HIV status disclosure crises among the AYPs. The parents and care-givers expressed how challenging it is to disclose HIV status to their young ones. While some reported to have disclosed the status themselves, other had to involve health workers in the disclosure. There were varying ages in which the statuses of the AYPs were disclosed ranging between 8 to 10, some of the older AYPs got to know their status themselves while undergoing medical treatments.

"*It became difficult to keep the secret from him, I and his father discussed and we had to tell him. It was not easy, initially he did not understand very well but later started asking many questions. He was about 11 years and about to enter secondary school, suddenly he told us he was not going to school again [a mother, KII].*

"Things were ok until she was told her she is HIV positive, she just asked us if we were also HIV positive and we said yes and she kept quiet. It was after some days that she started crying and asked me why we even gave birth to her" [a mother, KII]

Discussion

This study has brought to fore front a rarely discussed problem among HIV positive AYP. The discussions suggest that the parents, the health workers and the AYP themselves are in agreement that HIV positive AYP are largely at risk of behavioral and mental health problems. The dominant themes from the coded transcripts were self-perception 210 (26.7%), post disclosure crises 201 (25.5%), and treatment adherence 109 (13.9%).

A good number of the young people responded in a way to suggest that the HIV positive AYP experience low self-esteem, with some wondering how they will be accepted by their peers. Self-esteem is an important component of one's mental, emotional and social health, originating from infancy and manifesting all through one's life [13]. In a study conducted in the United States of America, it was discovered that young HIV positive women changed their interactions with others that were HIV-negative based on their perception of their self-worth and value in the community as being inferior and ''negative" [14]. Evidence from a study suggests that low self-esteem was reported to be a statistically-significant multivariate predictor of involvement in HIV risk [15]. This situation poses a great public health risk for the HIV positive AYP and the general population as engagement in high risk behavior may impede the drive for prevention of new HIV infections. Low self-esteem may also be responsible the reported poor performances in academic activities as have been reported in another studies [16].

Post HIV status disclosure crises was acknowledged as a challenge in managing HIV positive AYP by all the parents/care givers and health workers. The information corroborates responses from a study conducted in Uganda in which parents hesitated to inform their HIV positive children about their sero-status, partly based on fear of blame and the belief that the children were too young to comprehend matters related to HIV and AIDS, while others wanted to avoid worrying their children for the fear of triggering psychological problems in them [17]. In this study, participants acknowledged that the AYP experienced various forms of behavioral and mental health challenges on realization of their HIV status and the implications of living with HIV. The American Academy of Pediatrics Committee on Pediatrics AIDS hold a strong opinion that adolescents should know their diagnosis in all cases [18] and it has been acknowledged that when young people are fully aware of their health status, they can make informed

decisions regarding their actions and life choices[19]. It is, however, important to strengthen capacity of health workers and parents/care givers of these young people in appropriate disclosure modalities and support for the young ones to adjust to the normal life.

The other themes that emerged from this study all point to the need to develop and incorporate psycho-social development support for this population of AYP to ensure that they adjust to a healthy life and achieve their full potentials. With some of the AYP acknowledging to be sexually active and eight of them reporting to have had sex without condom in the last six months, it is clear that without close attention to them, the many young people living with HIV will remain major public health concern to the country. Furthermore, the poor adherence to therapy as reported in this study, which has been identified in other studies [20, 21], remains an issue in managing HIV among AYP and stumbling block to eliminating AIDS related deaths.

Conclusion

Over the years, a lot has been invested in the HIV response, particularly in the areas of anti-retroviral therapy and HIV prevention. A lot of achievements have also been recorded in preventing new infections and AIDS related deaths. These achievements have led to high survival of infants perinatally infected with HIV, a good number of them already in their adolescence and older. In view of the global mandate of ending AIDS by 2030, and considering Nigeria's burden of HIV among the adolescents and young people, it has become important to consider behavioral and mental health interventions as important component of the national HIV response. This will ensure that these AYP are psychologically stable to adhere to their therapies and maintain good behavior that will not put themselves and others at risks.

References

[1] Dodd PJ, Gardiner E, Coghlan R, Seddon JA. Burden of childhood tuberculosis in 22 high-burden countries: a mathematical modelling study. Lancet Glob Health. 2014;2(8):e453–9.

[2] UNICEF, For Every Child End Aids, Seventh Stocktaking Report, 2016

[3] UNAIDS Global Country Factsheet, Nigeria 2016. Access via http://www.unaids.org/sites/default/files/media/documents/UNAIDS_GlobalplanCountryfactsheet_nigeria_en.pdf

[4] Collins IJ, Jourdain G, Hansudewechakul R, Kanjanavanit S, Hongsiriwon S, Ngampiyasakul C, Sriminiphant S, Technakunakorn P, Ngo-Giang-Huong N, Duong T, Le Coeur S, Jaffar S, Lallemant M, Long-term survival of HIV-infected children receiving antiretroviral therapy in Thailand: a 5-year observational cohort study. Clin Infect Dis. 2010 Dec 15; 51(12):1449-57

[5] McCleary-Sills J, Kanesathasan A, Brakarsh J, Vujovic M, Dlamini K, Namisango E, Bowsky S. Foundation for the future: meeting the psychosocial needs of children living with HIV in South Africa and Uganda. J HIV/AIDS Soc Services. 2013;12:49–62

[6] *Skovdal M,* Pathologising healthy children? A review of the literature exploring the mental health of HIV-affected children in sub-Saharan Africa. Transcult Psychiatry. 2012 Jul; 49(3-4):461-91.

[7] Gaughan DM, Hughes MD, Oleske JM et al Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection. Pediatrics. 2004 113:e544-551.

[8] Claude A. Mellins, Katherine Tassiopoulos, Kathleen Malee, Anna-Barbara Moscicki, Doyle Patton, Renee Smith, Ann Usitalo, Susannah M. Allison, Russell Van Dyke, and George R. Seage III, for the Pediatric HIV-AIDS Cohort Study. AIDS Patient Care and STDs. June 2011, 25(7): 413-422. https://doi.org/10.1089/apc.2011.0025

[9] The ATN 086 Protocol Team for The Adolescent Medicine Trials Network for HIV/AIDS Interventions. Psychological **Symptoms Among 2032 Youth Living with HIV: A Multisite Study**. AIDS Patient Care and STDs. Apr 2015, Vol. 29, No. 4: 212-219

[10] Fielden SJ, Sheckter L, Chapman GE, Alimenti A, Forbes JC, Sheps S, Cadell S, *Frankish JC.* Growing up: perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV*; AIDS Care. 2006 Nov; 18(8):1050-3*

[11] Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, McKay M, Mellins C. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation; *AIDS Care. 2010 Aug; 22(8):970-8*

[12] Manaboriboon B., Lolekha R., Chokephaibulkit K., Leowsrisook P., Naiwatanakul T., Tarugsa J., Durier Y, Aunjit N., Punpanich W, Vandepitte, V. Boon-yasidhi. Psychosocial needs of perinatally HIV-infected youths in Thailand: lessons learnt from instructive counselling, AIDS Care. Dec 2016, Vol. 28, No. 12: 1615-1622

[13] Macdonald, G. Self-esteem and the promotion of mental health. In Trent, D. and Reed, C. (eds), *Promotion of Mental Health*. Avebury, Aldershot, 1994 vol. 3, pp. 19–20.

[14] Sybil Hosek., Jennifer Brothers., Diana Lemos, What HIV-Positive Young Women Want from Behavioral Interventions: A Qualitative Approach. AIDS PATIENT CARE and STDs 2012 Volume 26, Number 5,

[15] Klein, H., Elifson, K. W., & Sterk, C. E. Self-Esteem and HIV Risk Practices among Young Adult "Ecstasy" Users. Journal of Psychoactive Drugs, 2010 *42*(4), 447–456.

[16] Adams, M.J. Youth in crisis: an examination of adverse risk factors effecting children's cognitive and behavioral–emotional development, children ages 10–16. Dissertation Abstracts International A: Humanities and Social Sciences , 1996 56(8-A), 3313

[17] David Kyaddondo, Rhoda K. Wanyenze, John Kinsman, Anita Hardon. Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment; SAHARA-J: Journal of Social Aspects of HIV/AIDS 2013 Vol. 10 , Iss. sup1,

[18] American Academy of Pediatrics Committee on Pediatrics AIDS. Disclosure of illness status to children and adolescents with HIV infection. Pediatrics. 1999;103:164–6.

[19] Vranda, M. N., & Mothi, S. N. Psychosocial Issues of Children Infected with HIV/AIDS. Indian Journal of Psychological Medicine, 2013 35(1), 19–22. http://doi.org/10.4103/0253-7176.112195

[20] Rudy BJ, Murphy DA, Harris DR, Muenz L, Ellen J, Adolescent Trials Network for HIVAI. Prevalence and interactions of patient-related risks for nonadherence to antiretroviral therapy among perinatally infected youth in the United States. AIDS Patient Care STDS. Feb 2010;24(2):97-104.

[21] MacDonell K, Naar-King S, Huszti H, Belzer M. Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. AIDS Behav. Jan 2013;17(1):86-93. Available at http://www.ncbi.nlm.nih.gov/pubmed/23142855.