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Original Research Article

Problem and pro-social behaviour among adolescents living with HIV/AIDS and perception of healthcare workers on available medical and social support in Sokoto, northern Nigeria

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ABSTRACT

Background: Adolescents living with HIV/AIDS (ALHIV) are likely to have behavioural, social, cognitive, and emotional problems. Early detection and treatment of these psychological issues in ALHIV is precarious to comprehensive HIV management. This study aimed to assess problem and pro-social behaviour among and to identify available health facility and social supports for ALHIV in Sokoto State, Nigeria.
Methods: A cross sectional study with mixed methods of data collection was conducted among 236 adolescent-caregiver pairs. Key informant interviews were conducted among four health care workers. Quantitative data were analyzed using IBM SPSS version 23 while content analysis along thematic lines was done for qualitative data.
Results: Mean age of adolescents was 14.6±2.2 years while mean age of caregivers was 37.9±7.2 years. Prevalence of pro-social behaviour among ALHIV was 6.4% (self- report) and 15.2% (caregiver report). Seventy-eight (33.1%) caregivers reported peer problems and 15 (6.4%) emotional problems among their ALHIV. Based on self-report, 160 (67.8%) ALHIV reported experiencing peer problems and 3 (1.8%) emotional problems. Eleven (4.7%) adolescents reported having low social support, 136 (57.6%) had moderate and 89 (37.7%) high social support. Viral suppression showed significant association with SDQ scores.
Conclusions: The Sokoto State Ministry of Health and other organizations supporting HIV programs should ensure community enlightenment programs on HIV in order to reduce stigma associated with the disease.

Keywords: Adolescents, HIV/AIDS, Problem behaviour, Prosocial behaviour

INTRODUCTION

HIV/AIDS is a biopsychosocial disease whose impact extends far beyond its physical symptoms. Stigma, social and economic factors, and political environment contribute to the burden of HIV/AIDS.[1] Studies have shown that adolescents living with HIV (ALHIV) are more likely to report high levels of anxiety and behavioural problems as compared to adolescents without HIV.[2,3] The causes of behavioural problems among ALHIV include pre-morbid mental conditions, effects of the virus on the central nervous system (CNS), the psychological impact of living with HIV, breakdown of family structure as a result of multiple losses, side effects

of medication and consequences of social stigma and discrimination.[4]

Early identification and management of emotional and behavioural problems in ALHIV is central to a comprehensive approach to HIV management.[5] Poor management of emotional and behavioural problems can result in a range of social and health problems which include poor adherence to treatment, increased progression of HIV symptoms, increase in risky behaviour. The very nature of adolescence with accompanying behaviour changes and mood swings makes the diagnosis of emotional and behavioural problems difficult. Some conditions are easily managed through support and counselling, while others which result in impaired functioning or harm to themselves and/or others will need more specialised interventions.

A systematic review of the literature on the mental health of adolescents living with HIV found few studies on psychiatric diagnoses in HIV-infected adolescents and the existing studies suggest that psychiatric disorders such as depression and anxiety are prevalent among HIV infected adolescents.[2,6,7] A study from Zambia in 2018 showed that about 25% of the adolescents living with HIV had depressive symptoms.[8] Another study in South Africa showed that mental health problems were prevalent in almost half (46.3%) of the ALHIV.[9] A study carried out in Nigeria showed that the prevalence of depression was higher among children and adolescents living with HIV infection than those without HIV infection. Older age group (14-16 years), children who experienced academic failure, the orphans, and those who had more than one hospitalization were more likely to experience depression.[10]

Empirical research on mental health among ALHIV lags considerably behind that of adults, particularly in poorly-resourced and HIV endemic communities.[2,11,12] Given the far-reaching social and mental health problems of HIV-related stigma in other populations, there is a critical need to better understand the emotional and behavioural well-being of ALHIV.[12,13] Despite the fact that systematic reviews on mental health of ALHIV have been carried out, there is a dearth of literature on mental health among ALHIV and the availability of supports for them especially in Northern Nigeria. This study therefore aimed to assess problem and pro-social behaviour among ALHIV, to identify health facility support for ALHIV in Sokoto State, Nigeria and to determine the relationship between ALHIV/caregiver characteristics and SDQ scores.

METHODS

This study was conducted in Sokoto State. Sokoto is one of the oldest states located in Northern Nigeria. It came into existence in 1976 with Sokoto as the capital city. Fourteen health facilities are involved in the provision of comprehensive HIV/AIDS treatment and support services to both children and adults. A cross sectional study design with quantitative (questionnaire survey) and qualitative (key informant interview) methods of data collection was employed. The purpose of the qualitative aspect of the study was exploratory in nature. The study was conducted among 236 adolescent-caregiver pairs and four HCWs. Data were collected over a six months' period from April 2020 to September 2020.

ALHIV who had been on ART for at least 12 months before the commencement of the study, caregivers who lived in the same house with the child under treatment and had the main responsibility for regularly taking care of them including giving them their medications for at least 12 months and HCWs providing HIV care and treatment services who had worked for at least 12 months in the selected health facilities were recruited into the study.

ALHIV who were critically ill, ALHIV who had an existing psychiatric illness and caregivers who spent ≥2 weeks in 6 months away from the children were excluded from the study.

Sample size was calculated using prevalence of depression (16.9%) among adolescents from a previous study.[14] Two hundred and thirty-six (236) ALHIV-caregiver pairs were recruited into the study via a two-staged sampling technique from ART clinics across the State. In the first stage, eight ART clinics (one tertiary, four secondary and three primary health care facilities) out of 14 were selected using simple random sampling by balloting while in the second stage, systematic sampling technique was used to recruit eligible ALHIV and their caregivers into the study. Four healthcare workers participated in the KII and they were recruited purposively based on their willingness to participate and share their views. This selection was done with the aid of the HCWs in the selected facilities.

Emotional and behavioural problems were measured using the strengths and difficulties questionnaire (SDQ) while social support was measured with multidimensional perceived social support scale (MPSSS).

The SDQ is a 25-item scale that measures emotional and behavioural problems in children and adolescents. It comprises five sub-scales that screen for: (1) emotional problems; (2) conduct difficulties; (3) hyperactivity/ inattention symptoms; (4) peer relationship problems and (5) pro-social behaviours. Total SDQ is based on the summation of scores from emotional symptoms, conduct problems, hyper- activity/inattention, and peer relationship problems.[15] The parent version (for children 4-17 years) and the youth/self-version (for adolescents 11-17 years) were utilized in this study.

The MPSSS is a 12- item measure of how much support a person feels they have of their family, friends and a special person. Each of these forms a separate subscale, a

total social support score is based on summation of these three subscales.

KII guide was adapted from previous studies on healthcare workers' perception of emotional and behavioural problems among ALHIV, and availability of supports for ALHIV with emotional and behavioural problems.[16-21]

Trained study staff used a structured interviewer-administered questionnaire to collect quantitative data on an electronic platform designed on open data kit (ODK). The questionnaire was used to collect data on the sociodemographic and clinical parameters of the ALHIV and their caregivers

In order to ensure appropriate ALHIV-caregiver pairing for the questionnaire, the caregiver section was coded "A" while the adolescent section was coded "B" (for example: 1A for caregiver and 1B for ALHIV).

Questions on healthcare workers' perception of emotional and behavioural problems among ALHIV and availability of supports for ALHIV were asked. Probe questions were included in the KII guide for further exploration of the subject matter. The lead researcher (AZE) facilitated all interviews in English language while a research assistant audio-recorded all proceedings. All the participants for the qualitative aspect of the study completed the interviews.

Emotional and behavioural problems of ALHIV were assessed using 20 questions. There were three possible responses: Not true, somewhat true and certainly true. Point values were assigned as follows: not true =0, somewhat true =1, certainly true =2. Some of the correct responses were reverse-scored to avoid response bias. Somewhat true was always scored as 1, but the scoring of not true and certainly true varied with each question, for example, the appropriate responses to the questions: I'm usually obedient and do as I am told, other people generally like me and have at least one good friend will be reverse scored (0→2, 1→1, 2→0). The possible score for each respondent ranged between 0 and 40. The responses were graded as normal, borderline and abnormal for the caregiver and self- reports as follows: self-report- normal =0-15, borderline =16-19, abnormal =20-40. Caregiver report- normal =0-13, borderline =14-16, abnormal =17-40.[22]

Social support was assessed by twelve questions on measures of perceived support from three domains: family, friends and significant others (health care workers). Respondents were to indicate their agreement with items on a 7-point Likert-type scale, ranging from very strongly disagree to very strongly agree where 1= very strongly disagree, 2= strongly disagree, 3= mildly disagree, 4= neutral, 5= mildly agree, 6= strongly agree, 7= very strongly agree. All the scores of the 12 items were added together and divided by 12. Thus giving each respondent a mean total score of 7. The responses were graded as low, moderate and high for the caregiver and self- reports as follows: low =1-2.9, moderate =3-5, high =5.1-7.[23]

Health facility support were assessed by the proportion of ALHIV with counselling, home visits, support groups for both caregivers and ALHIV.

Quantitative data were analyzed using IBM SPSS version 23.0 Armonk, NY: IBM Corp. For quantitative analysis, first, we summarized sociodemographic data with descriptive

statistics, e.g. proportions and mean±standard deviation. Chi square test was used to test for association between some ALHIV (e.g. age, clinical stage, viral suppression etc.)/ caregiver characteristics (such as educational level) and SDQ scores. Level of significance was set at p values of <0.05. Qualitative data were transcribed verbatim and analyzed using thematic analysis by the lead researcher who is a public health physician. Thematic analysis was based on both pre-determined and emergent themes.

RESULTS

Quantitative results

Mean age of the ALHIV was 14.6±2.2 years; 142 (60.2%) were females; while 108 (37.6%) were in secondary school. Clinically, a majority (n=224, 94.9%) of the ALHIV were in WHO clinical stage 1 (Table 1). Among 236 caregivers, mean age was 37.9±7.22 years and 72.5% (n=171) were female. Seventy-three (30.9%) caregivers had Quranic education and 18 (7.6%) had primary education. Slightly more than two-thirds (n=153, 64.8%) of caregivers were biological mothers of the ALHIV, and 183 (77.5%) of the caregivers' self-reported as being HIV-positive (Table 2). Fifteen (6.4%) ALHIV had abnormal total SDQ scores by self- report and 36 (15.2%) by caregiver report respectively. Prosocial behaviour represents the strengths among these adolescents and care-givers assessment of their strengths was lower (80.9%) than self- assessment (83.9%). Seventy- eight (33.1%) caregivers reported peer problems, 15 (6.4%) emotional problems and 17 (7.2%) conduct problems among their ALHIV. One hundred and sixty (67.8%) ALHIV reported experiencing peer problems, 3 (1.8%) emotional problems and 12 (5.1%) conduct problems (Figure 1). Almost all the ALHIV 226 (95.8%) reported receiving counselling, 46 (19.5%) home visits 111 (47.0%) support group for ALHIV, support group for caregiver 44 (18.6%) and 30 (12.7%) referral (Figure 2). ALHIV who had viral suppression (VL≤20 copies/ml), had a higher proportion of those with normal SDQ scores 105 (98.1%) as compared to those who did not have viral suppressed (VL>20 copies/ml) 91 (90.1%) and the difference was statistically significant (χ^2=6.165, p<0.013) (Table 3).

Table 1: Socio-demographic characteristics and clinical parameters of ALHIV.

Variables	n=236 ALHIV	
	N	%
Age group (years)		
11- 14	123	52.1
15-18	113	47.9
Sex		
Male	94	39.8
Female	142	60.2
Family religion		
Christianity	36	15.3
Islam	200	84.7
Current educational level		
None	15	6.4
Quranic	17	7.2
Primary	70	29.7
Secondary	120	50.8
Tertiary	10	4.2
Ethnicity		
Hausa	187	79.2
Fulani	13	5.5
Ibo	21	8.9
Yoruba	5	2.1
Others	10	4.2
Disclosure status		
Disclosed	58	24.6
Not disclosed	178	75.4
WHO clinical stage		
I	224	94.9
II	12	5.1
III	0	0.0
IV	0	0.0

Table 2: Socio-demographic information of caregivers.

Variables	n=236 caregivers	
	N	%
Age group (years)		
18-29	23	9.7
30-39	114	48.3
40-49	84	35.6
50-59	13	5.5
≥60	2	0.8
Sex		
Male	65	27.5
Female	171	72.5
Educational level		
None	30	12.7
Quranic	73	30.9
Primary	18	7.6
Secondary	59	25.0
Tertiary	56	23.7
Occupation		
Civil servant	36	15.3
Trader/business	82	34.7

Continued.

Variables	n=236 care givers	
	N	%
Unemployed	24	10.2
Other (student + housewife)	94	39.8
Relationship to ALHIV		
Mother	153	64.8
Aunt or uncle	69	29.2
Sibling	8	3.4
Stepmother	5	2.1
Father	1	0.4
HIV Status of caregiver		
Negative	52	22.1
Positive	183	77.5
Unknown	1	0.4

Table 3: Relationship between ALHIV/caregiver characteristics and SDQ scores.

Variables	SDQ scores		
	Normal	Abnormal*	Test statistics and p value
Viral load (in copies/ml)			
Viral suppression (≤20)	105 (98.1)	2 (1.9)	χ^2=6.165
No viral suppression (>20)	91 (90.1)	10 (9.9)	p=0.013
Clinical stage			
I	209 (93.3)	15 (6.7)	Fisher's Exact
II	12 (100.0)	0 (0.0)	p=1.000
Duration on ART (in years)			
≤5	209 (93.5)	15 (6.7)	Fisher's Exact
>5	12 (100.0)	0 (0.0)	p=1.000
Social support			
Good*	212 (94.2)	13 (5.8)	Fisher's Exact
Poor	9 (81.8)	2 (18.2)	p=0.149
Caregiver at assessment			
Mother	139 (93.3)	10 (6.7)	χ^2=0.086
Non-mother	82 (94.3)	5 (5.7)	p=0.770
Educational level of caregiver			
Formal	193 (94.6)	11 (5.4)	Fisher's Exact
Informal	28 (87.5)	4 (12.5)	p=0.129

*Abnormal SDQ score= borderline + abnormal * Good social support= moderate + high.

Qualitative results

Most of the HCWs mentioned that they identify ALHIV with emotional and behavioural problems by observing their moods and asking questions or parents complaints. The supports rendered were counselling and referral to psychiatrists.

"*Sometimes the parents come and complain to us that the child is withdrawn, always sad, doesn't want to go to school or the school grades are dropping, so we try to find out what the problem is and continue counselling. However, there are times when the depression is so severe that we have to refer to the psychiatrists. So far, we've had to refer 2 children this year*" (KII 1: adherence counsellor, female).

"*We are used to most of our clients here, so we observe their moods and start asking them or their parents questions*" (KII 2: treatment support specialist, female).

"*The way to deal with emotional and behavioural problems in ALHIV is proper counselling*" (KII 4: paediatric ART nurse, male).

"*Sometimes when we go on home visits to see how our clients are faring, the parents aren't happy to see us because they think our presence in their homes will make people know they have HIV since we are identified with HIV care in our different health facilities*" (KII 2: treatment support specialist, female).

"*Home visits are key in giving good support to our clients. we don't do it anymore because of finances.*

Sometimes you finish counselling the child & his parents & they agree to do what you have said, you still need to follow up at home to see if there's a problem, sometimes there are problems at home which you will never notice until you visit them" (KII 4: pediatric ART nurse, male).

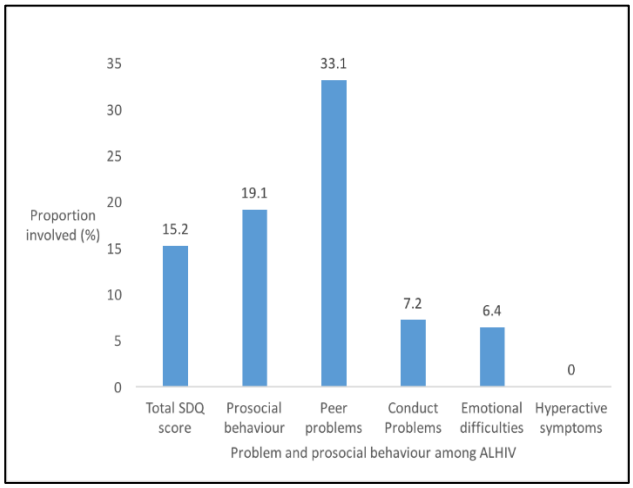

Figure 1: Caregiver report of problem and prosocial behaviour among ALHIV.

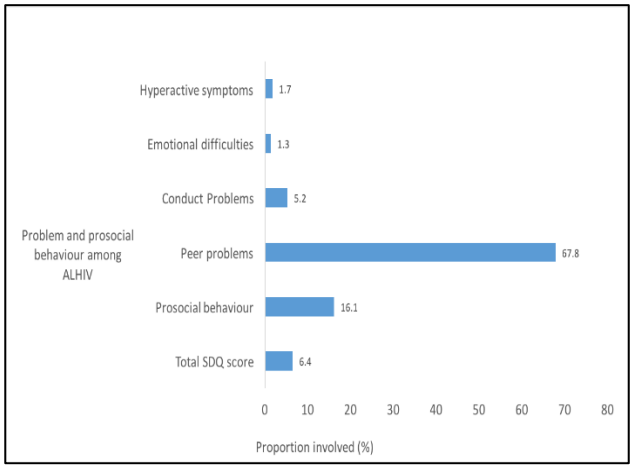

Figure 2: Self report of problem and prosocial behaviour among ALHIV.

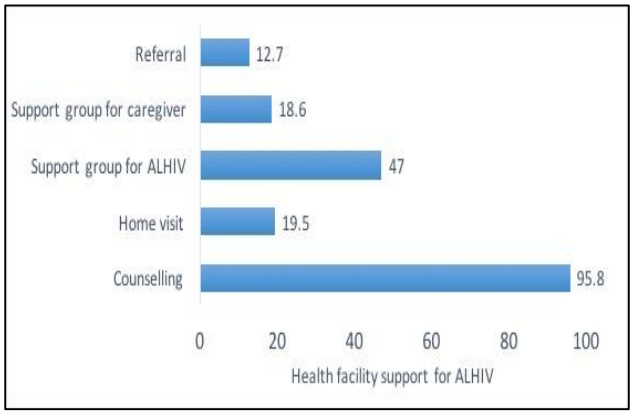

Figure 3: Health facility support for ALHIV.

DISCUSSION

This study aimed to assess problem and pro-social behaviour among adolescents living with HIV/AIDS (ALHIV), to identify available health facility and social supports for ALHIV in Sokoto State, Nigeria and to determine the relationship between ALHIV/caregiver characteristics and SDQ scores. The prevalence of pro-social behaviour among ALHIV was 6.4% (self-report) and 15.2% (caregiver report). Seventy-eight (33.1%) caregivers reported peer problems and 15 (6.4%) emotional problems among their ALHIV. Based on self-report, 160 (67.8%) ALHIV reported experiencing peer problems and 3 (1.8%) emotional problems. Psychosocial support available for ALHIV in the health facility were counselling, referral, home visit and support group. Viral suppression was significantly associated with SDQ scores.

The findings on problem behaviour sub-scales are comparable to the Uganda study where emotional and behavioural problems was reported by over half (52%) of the respondents.[24] Another study in Rwanda reported that 20% of the CLHIV were reported to have attempted suicide or engaged in self-harm in the past 6 months compared to 13% of HIV-uninfected.[25] The prosocial behaviours reported in this study could be because substantial percentage of ALHIV experienced significant peer problems and counselling methods may need to be improved upon. This is in contrast to a study in South Africa where all the respondents received home-based counselling with significant reduction in the emotional and behavioural problems in the children.[26] Another study conducted in Ilorin, also in Northern Nigeria reported a higher prevalence of emotional and behavioural problems, the children did not have access to counselling.[27]

HIV is a disease which affects the psychological health of people infected and affected by it. Caregivers may feel stressed by the burden of the illness on their children-frequent clinic visits, giving children medicines every day etc. The mental health of the caregiver invariably affects that of the child because a mentally unstable caregiver will not be able to adequately cater to the child's needs. A study in Rwandan showed that children whose caregiver's reported having mental health problems were two to three times more likely to have suicidal ideation.[25] The presence of counselling where HCWs explore the emotional health of the children and their caregivers in order to find out their challenges and arm them with skills to cope with the disease is a big boost. This goes a long way in reducing the distress both caregivers and children feel. Reduced emotional and behavioural problems could result in improved academic performance, healthier relationships with parents, peers, reduction in juvenile delinquencies and a better society at large.

It has been reported that caregivers usually perceive a higher level of distress than their children report.[28,29] This

resonates with what has been reported in this study. Most of the Problem behaviour sub-scales are higher among care-givers' report. A study in Uganda reported mixed findings where caregivers report for behavioural problems in children was 9.2% and 14.5% by child report, in the same study, caregivers indicated that 54.8% of the children met criteria for an emotional problem whereas 36.9% of the children self-reported emotional problems.[30]

In this study, the proportion of children and caregivers who reported having a support group is small. This implies that some health facilities do not have support groups for both children and their caregivers. This could be because the funding to support HIV programs including support group activities has reduced and the support groups have not become self-reliant in the absence of these funds. The importance of support groups was cited by HCWs, caregivers and children. Some caregivers in this study mentioned that their children learnt about a lot of things from the support group including how to be adherent, keeping the sickness secret and how to cope with the disease. In support groups, children, as well as caregivers, are likely to see other children and their caregivers who have similar or even worse challenges than them. They also get to meet other people with the same illness and so they know that they are not alone and this gives them a sense of courage and belonging. This was corroborated by a study in South Korea where most of the FGD participants agreed that they felt connected and accepted by other peer supporters and felt they had a place where they belonged and people who care about them. They appreciated the opportunity to interact with other peer supporters, discuss their common interests, and share their experiences with the group.[31] This was supported by another study in Zambia where participants mentioned that social support groups do not only reduce the isolation associated with stigma, but also are the most effective avenue for dissemination of useful information on accepting the HIV positive status, coping with the HIV virus and adhering to treatment.[32] The children in this study also reported being able to share their problems without feeling judged, they also learn how to cope with their challenges by listening to other people's stories and learning from them.

Children who had viral load <20 copies/ml were almost 6 times more likely to have good SDQ scores. This may be because if a child's viral load is <20 copies/ml, the HCWs commend the child and caregiver, are told that viral suppression is a sign of treatment success, they are also encouraged to keep up the good work while still emphasizing on good ART adherence. This gives the caregiver and the child a general sense of well-being. Almost all the children in this study were either in clinical stage 1 or 2. They may generally feel healthy and not fall ill as often as before, so they may have a positive perception of the illness. Availability of counselling and support groups was cited by HCWs as being key to reducing negative emotions and behavioural problems in ALHIV.

A small proportion of ALHIV with emotional and behavioural problems in this study received home visits. Some of the HCWs cited the importance of home visits during the KII, they emphasized the fact that there are some problems that a HCW may not notice within the health facility until he/she visits the child at home. The major challenge to home visits is limited funding and stigma as cited during the KII. The HCWs who work in the ART clinics are well-known in the health facilities and their surrounding communities. Any household where these HCWs visit is usually seen to be a household where people living with HIV reside. Some of the caregivers of these ALHIV resist home visits from these HCWs because of stigma of being associated with HIV. This is in line with findings from a study in South Korea where peer supporters who conduct home visits cited stigma as a major barrier to their work; they expressed difficulty working because their patients feared their HIV status would be evident to their neighbours because of the peer supporter home visits.[31] The peer supporters in the South Korean study were also well-known in the community and some of them were HIV positive. The implication of this is that HCWs may stop home visits and the child's home environment will not be evaluated. Hence, some simple interventions which the HCW would have been able to put in the child's home to assist the child and his/her caregivers will be missed out. This finding reinforces the negative of impact of HIV-related stigma on the lives of children living with HIV, their caregivers and even the HCWs as the quality of care given to these children is reduced and the burden of care on both their caregivers and HCWs is increased.

Efforts are still needed to overcome HIV-related stigma, which remains prevalent worldwide. Evidence indicates that HIV-related stigma can be lessened through comprehensive community interventions-consisting of workshops for people living with HIV/AIDS (PLWHA) and people living nearby, namely partners, children, close family members, close friends, spiritual leaders, and community members.[33]

The study may have been prone to recall and social desirability bias, since information was obtained through self or caregiver report. This was minimized by training the research assistants not to be judgemental while asking the questions and also by reassuring the respondents that the survey was purely for academic purpose.

CONCLUSION

The level of pro-social behaviour among ALHIV was low. Peer problem represent a significant behavioural problem among the population studied, a phenomenon that may be associated with self-perceived stigma. Almost all the adolescents reported receiving counselling, while a small proportion had home visits. The Sokoto State Ministry of Health and other organizations supporting HIV programs should ensure community

enlightenment programs on HIV in order to reduce stigma associated with the disease.

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