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ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/dhiv20

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To cite this article: Charles Miyingo, Teddy Mpayenda, Ruth Nyole, Joan Ayinembabazi, Mujib Ssepuuya, Eddie Marvin Ssebuwufu, Sean Steven Puleh, Samson Udho & Amir Kabunga (2023) HIV Treatment and Care of Adolescents: Perspectives of Adolescents on Community-Based Models in Northern Uganda, HIV/AIDS - Research and Palliative Care, , 105-114, DOI: 10.2147/HIV.S405393

To link to this article: https://doi.org/10.2147/HIV.S405393

HIV/AIDS - Research and Palliative Care

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ORIGINAL RESEARCH

HIV Treatment and Care of Adolescents: Perspectives of Adolescents on Community-Based Models in Northern Uganda

Charles Miyingo[1], Teddy Mpayenda[1], Ruth Nyole[1], Joan Ayinembabazi[2], Mujib Ssepuuya[3], Eddie Marvin Ssebuwufu[4], Sean Steven Puleh[3], Samson Udho[1], Amir Kabunga[2]

[1]Department of Midwifery, Lira University, Lira City, Uganda; [2]Department of Psychiatry, Lira University, Lira City, Uganda; [3]Department of Public Health, Lira University, Lira City, Uganda; [4]Department of Medicine, Gulu University, Gulu City, Uganda

Correspondence: Amir Kabunga, Department of Psychiatry, Faculty of Medicine, Lira University, P.O BOX 1035, Lira City, Northern Uganda, Email akabunga@lirauni.ac.ug

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Background: Differentiated service delivery models for people living with HIV continue to be scaled up to expand access to HIV services and treatment continuity. However, there is a gap in information on adolescents' perspectives on community-based models. We aimed to explore the perspectives of adolescents living with HIV on community-based models in northern Uganda.

Materials and Methods: Between February and March 2022, we conducted a descriptive qualitative study at two health centres IV in Northern Uganda. Data was collected using an interview guide. The study had 25 purposively selected adolescents enrolled in community-based models for HIV care and treatment. The interviews were audio-recorded, transcribed verbatim, and translated. We analyzed data using a thematic approach.

Results: A total of 25 in-depth interviews with HIV-positive adolescents were conducted. More than half (52.0%) of the participants were females, 84.0% were not married, and 44.0% had no formal education. The mean age of the respondents was 15.6 (±1.9) years. The major themes were: community-based models currently accessed by adolescents, benefits, and challenges of the models. Although there are other community-based models (community pharmacies, home ART deliveries) our exploration only discovered two models used by these adolescents to access care, namely, Community Drug Distribution Point (CDDP) and Community Client-Led ART Delivery Groups (CCLADs). The benefits included reduced transportation costs, convenient service access, ART adherence, peer support, a comfortable environment and less stress. However, our results indicate that these models had some challenges, including lack of confidentiality and privacy, perceived stigma, and a lack of face-to-face interaction.

Conclusion: Our findings show that CDDP and CCLADs are the two CBMs used by adolescents in Lira District to access treatment and care. Adolescents benefited from these models through reduced transport costs, the convenience of accessing HIV care and treatment, and social support. The challenges associated with these models are lack of confidentiality and privacy, perceived stigma, and a lack of face-to-face interaction. The Ministry of Health should work with other implementing partners to strengthen the implementation of these models to improve HIV/AIDS service delivery for adolescents.

Keywords: adolescents, differentiated care, community-based model

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Background

HIV/AIDS continues to be a major public health concern, especially among adolescents.[1] Due to the transition stage of their development and the requirement to adjust to the biological, physical, and structural changes, adolescents are much more susceptible to contracting HIV than adults.[2] In 2021, of the 38.4 million people living with HIV globally, 36.7 million were adults and approximately 1.8 were adolescents aged 10–19 years.[1] In the same year, 1,750,000 adolescents were living with HIV, and 150,000 adolescents were newly infected with HIV.[3] Of 1.8 million adolescents aged 10–19 years with HIV globally, 59% were receiving antiretroviral therapy (ART) in 2021.[4] While greater focus on adolescents has resulted in improved services and outcomes, the rate of progress remains slow especially when compared

Received: 20 January 2023
Accepted: 9 March 2023
Published: 11 March 2023

to with the growing needs of adolescents living with HIV.[5] An estimated 1.74 million adolescents with HIV live in Eastern and Southern Africa, which accounts for 60% of the global burden,[5] indicating that there are gaps in the treatment cascade for adolescents living with HIV in low-income counties like Uganda that are not yet addressed.[5] Available information shows that close to 70% of adolescents were not retained in care.[6]

Evidence of the high burden of HIV among adolescents underscores the need for appropriate interventions. However, the one-size-fits-all model of HIV does not work for all people living with HIV today. For example, stand-alone clinics were the preferred model of care for adolescents living with HIV and Peer support groups and youth corners in hospitals were appreciated innovations, but funding was a major barrier.[7] To better serve individual needs, maintain ART adherence, and lessen the unnecessary strain on the health system, differentiated service delivery (DSD), a novel adaptation to traditional HIV service delivery models, was endorsed by the World Health Organization (WHO)[8] and major global HIV donors to improve the quality of HIV care and treatment.[9] DSD models are client-centred approaches that focus on the needs and preferences of clients.[10] This aims to individualize care and treatment and address the context and clinical features of the clients using a public health approach.[11] For adolescents, DSD models attempt to address the disparities in access by increasing the acceptability, quality, and coverage of HIV care and treatment.[12] Several models have been employed, including community adherence groups, home-based ART, and multimonth dispensation. A growing body of evidence highlights how differentiated ART provides a significant opportunity to improve treatment adherence among adolescents living with HIV.[13]

Uganda, through the Ministry of Health, adopted the WHO recommendation on DSD models for people living with HIV.[14] Presently, five different approaches are being implemented: two facility-based models, two community-based models (CBMs), and one cross-cutting model. Community-led ART delivery strategies include CDDPs and CCLADs.[15] The facility-based models include facility-based individual management, fast-track drug refills and facility-based groups.[15] A survey in Uganda showed that only 6% of HIV patients nationwide regularly participate in CBMs groups, the majority of which are made up of women.[16] This has been linked to a lack of knowledge, an incorrect understanding of how these organizations function, stigma, privacy concerns, and a lack of benefits that are seen as being associated with participation.[17] However, because so few people in the general community are enrolled in the CBMs, there are still many fewer males and adolescents than women in these groups.[16]

Studies have reported positive results, particularly concerning expanding access to HIV testing and achieving desirable HIV treatment outcomes.[18,19] Previous research has shown that community-based ART delivery systems are as effective[20] or more effective[21] than facility-based models at achieving viral suppression and patient retention,[22] both direct indicators of ART adherence, reassuring that stable patients can be safely shifted to less intensive follow-up without compromising their clinical outcomes.[23] However, the reported health results have primarily been linked to barriers and facilitators relating to the health systems' organizational structure, even though the effectiveness of DSD models depends on continuous process assessments to understand clients' requirements, preferences, and behaviours.[24] The available literature is about clients' perspectives on DSD models and targets the general population of people living with HIV.[24,25]

While prior research has shown the benefits of incorporating DSD models into national HIV programs,[26] little research has focused on adolescents. Also, most of these studies focused on DSD implementation as a whole and paid scant attention to specific models and groups.[27] With over 67% of healthcare workers nationally trained in DSD delivery by 2019,[24] there is a lack of evidence on patient perspectives on HIV care, particularly among adolescents under CBMs. Adolescents aged 10–19 years[28] have unique challenges and are at increased risk of HIV infection compared to other groups.[29] Therefore, exploring their perspectives on how DSD models influence the utilization of services is critical. Their insights can help improve the availability and quality of HIV prevention and treatment programs for adolescents. Thus, we set out to explore the perspectives of adolescents living with HIV enrolled in CBMs in Lira district, northern Uganda, to guide strategies aimed at increasing access to HIV services and retention in HIV for adolescents.

Materials and Methods

Study Settings

This study was carried out in the outpatient public health facilities of Amach Health Centre IV and Ogur Health Centre IV in Lira District, northern Uganda. The health centres IVsin Uganda have workforce teams including medical doctors, nurses, non-physician clinicians, midwives and other staff. They serve 100,000 people and provide general health services and operate HIV clinics for the general population including adolescents. Lira district is located in the Lango sub-region. Each CDDP is envisaged to have not more than 60 clients receiving ART refills at a particular point.[30] The district is bordered by Otuke District to the northeast, Pader District to the north, Dokolo District to the southeast, Aleptong to the east, Kwania to the southwest and Kole District to the west. It is located about 337 kilometres by road, north of Kampala, the capital city of Uganda.

Research Design

This was a qualitative descriptive study to explore the perspectives of adolescents living with HIV and accessing CBMs. Data were collected between February and March 2022.

Study Participants and Sample Size Estimation

The study population included adolescents aged between 10–19 years seeking HIV-related care in the outpatient public health departments of Amach Health Center IV and Ogur Health Center IV in Lira District. The principle of data saturation was used to estimate the sample size of 25 participants for a comprehensive understanding of the phenomenon. Interviews continued until saturation was obtained as additional interviews did not lead to new information.[31]

Recruitment of the Participants

We purposefully selected two health centre IVs that had at least a two-year of experience implementing CBMs in Lira District. Thus, we purposefully selected Amach Health Center IV and Ogur Health Center IV in Lira District, northern Uganda. The centres were based on the information obtained from routine DSD data collected through a monthly management information system report. These health facilities were therefore considered to serve participants with rich information about their perspectives while receiving services through CBMs for adolescents. We purposively selected adolescent participants accessing ART services from CBMs. The files of the participants seeking HIV care services from these facilities were retrieved and those enrolled in CBMs were identified. Prospective participants were contacted by phone call and an appointment was made to meet with them in the community. The inclusion criteria involved being clinically stable adolescents living with HIV and enrolled in CBMs aged 10–19 years while the exclusion criteria involved emotionally unstable adolescents and those who could not speak either English or Luo language.

Data Collection Instruments

We developed an interview guide to collect data. The interview guide consisted of items aimed at exploring participants' accounts of CBM's model. Some of the items in the interview guide included "tell us about CBMs", tell us your experience with CBMs, and compare CBMs and FBMs and others). Also, the interview guide included socio-demographic information like age, sex, and education level. The interview guide was framed based on relevant literature on DSD models.[32] The items in the interview guide were pre-tested among participants who were not included in the study, and modifications were made accordingly.

Procedures

In-depth interviews were used to collect data from the selected participants to explore the perspectives of adolescents living with HIV on CBMs in Lira, northern Uganda. In-depth interviews were conducted by research assistants with backgrounds in psychology, public health, nursing, and midwifery. The research assistants were trained on study protocol and data collection tools. The research assistants had previous experience in qualitative interviews and HIV care. In-depth interviews were held with stable HIV clients enrolled in CBMs. We explained the purpose, risks and benefits of participating in the study and those who consented to participate were recruited. Interviews were conducted in English and/or the local language of the participants, audio-recorded, and translated into English as needed. Eligible participants were recruited after obtaining written informed consent and ascent from parents/guardians of the minors. The participants below the age of 18 years were recruited after the consent of their parents/guardians. Interviews were carried out in a private area. The interviews last 35–50 minutes.

Data Management and Analysis

Thematic content analysis, as defined by Braun and Clarke,[33] was used to manually process the data, and this process began concurrently with the data collection phase. Audio recordings of interviews were transcribed verbatim and translated and back-translated by the research assistants who collected data. We listened to the audio recordings and read the transcripts severally to gain an in-depth understanding of the data. After thorough discussion, meaningful words, sentences, and phrases related to the study aim were manually extracted in an Excel spreadsheet from each interview. AK, CM, and JA then created the first three codes. We later categorized all the key codes based on shared characteristics. To narrow down the code topics, we grouped all the codes that were either very similar or appeared repeatedly to form a sub-theme. Themes were made by combing the various sub-themes. Data credibility and reliability were both improved by the use of cross-checking. Discrepancies were resolved through team discussion, with an agreement between two of the three coders required. To ensure that the results truly reflect what the respondents intended, many direct quotes from the results were used.

Ethical Approval and Consent to Participation

The present study was conducted in line with the Declaration of Helsinki. This study was approved by the Gulu Research and Ethics Committee (GUREC-2021-169). Permission to carry out this study was obtained from local district leaders. Written informed consent was obtained from participants older than 18 years while caregivers for minors provided parental consent with minors providing assent. Following the Ugandan guidelines, we consulted participants below 18 years, to be part of the study. Then we sought parental consent for participants who allowed us to contact their parents. Finally, we sought the ascent of the minors who accepted to participate. Participants informed consent included the publication of anonymized responses.

Results

Socio-Demographic of Participants

We found that more than half (52.0%) of the participants were females, 84.0% were not married, and 44.0% had no formal education. The mean age of the respondents was 15.6 (±1.9) years, the median was 15.00 and the range was 8. This information is summarized in Table 1.

Table 1 Socio-Demographic of Adolescents Living with HIV in Lira District (N= 25)

Variables	Category	Frequency n (%)	Mean (SD)	Median	Range
Age			15.36	2.00	8
Gender	Male	12(48.0)			
	Female	13(52.0)			
Marital status					
	Married	4(16.0)			
	Not married	21(84.0)			
Education level					
	No formal education	11(44.0)			
	Primary	8(32.0)			
	Secondary	6(24.0)			

Adolescent Perspectives of Community-Based Models in Lira District

We explored the participant perspectives of CBMs in Lira District. We derived unique codes, themes and sub-themes. From the results analyzed three major themes arose from the present study. These themes are community-based models currently accessed by adolescents, the benefits of participation in CBMs, and the challenges of community-based models.

Theme 1: Community-Based Models Currently Accessed by Adolescents

Based on the participants' descriptions, we inferred that the community-based DSD models accessed by the adolescents living with HIV were the community-led ART delivery model and CDDPs, most especially drop-in centres. Notably, the community-based DSD models that were not mentioned were community pharmacies, outreach programs, and home ART deliveries. Nevertheless, some of these were recommended and preferred by adolescents. We deduced that they were using the two models as per the narratives below:

> When my medicine is over, I come to the centre to get others. I grab my medicine here first thing in the morning and then head back home. But if I fail to pick up my medications, the nurse will pack them up and give them to a boda-boda (motorcycle), and my mother will pay the rider when he gets here. (15-year-old male)

> One of the members (peers) picks the drugs we take, sometimes it is me picking the drug or another member will pick for us. I just give my number (ART number), and they will get medications from the facility. (17-year-old female)

Theme 2: Benefits of Community-Based Models

The study participants narrated the benefits obtained from CBMs compared to the services provided at health facilities. This theme yielded five sub-themes described below;

The Convenience of Getting Services

Many of the participants said that community-based DSD models offer easier access to the services they offer. As they work and live close to the Drop-in Centers, adolescents have unrestricted access to medication at any time of day; healthcare professionals are reachable; and drop-in centres operate on flexible schedules. The precise phrases are as follows:

> Since the drugs are readily available in a village near my home, I can use them anytime. The approach means that if I forget to pick up my drugs, I can quickly go back and get the drugs. These centres make it easy to seek help. Having easy access to care that is close to my home is very good. It's possible to leave and come back on the same day. (18-year-old female)

> My mother used to take me to a hospital (health centre) which is far away from home and walking for a long time. She sometimes carried me on her back (because I was weak and tired). But these days, my mother sends me alone to get drugs (11-year-old female)

ART Adherence

Many participants mentioned that CBMs improved ART adherence as drugs were administered without fail. Participants indicated that the CBMs improved retention for most of them. Adolescents who require care get it with shorter wait times, and they no longer need to go to the facility, both of which enhance adherence. The participants believe that this approach has proven successful in improving patient outcomes. On-time drug delivery and administration for a full three months are guaranteed. Those who are not available when their medications are supposed to be delivered will still get their refills. Thus, community-based approaches have responded to the diverse needs of people living with HIV. This is illustrated by the quotes below:

> We don't miss drugs these days. Drugs are always delivered on the expected date; every month or two or three months (1–3 months refills) I pick my drugs and I don't miss them. (13-year-old male)

> Whenever we get together in our community groups, we encourage one another, and if someone has forgotten to pick up their medicines, the other members will remind them. Therefore, we make sure we take our drugs. (15-year-old female)

Reduced Transportation Costs

Several respondents were pleased with community-based models because they cut down on the time and money they spent travelling to and from medical facilities to get their ART refills at community outreach centres (CDDPs). Participants in the CCLAD model were grateful for the chance to share the expense of getting to and from clinics to get their ART refills. Quotes from some of the participants are below;

> We decided to keep sending one or two of us to pick up our medicine instead of all of us, saving so much in transportation costs. (18-year-old male)
>
> Travelling from home to the health was always difficult because I didn't have money for transport. Sometimes I would not go because my parents did not have money. But, today (as a result community-based approach) the services are closer to home and more convenient. My parents use that money for buying and preparing good meals or doing other things. (16-year-old male)

Support from Peers is Easily Accessible

When asked about their experiences getting ART refills, participants who indicated a preference for receiving care in drop-in centres voiced strong opinions about the peer support they had received. This was especially true because these adolescents face the burdens of living with HIV and stigma in society.

> The group service is my favourite since it fosters social interaction. I walk with a friend and this makes me feel well. She sometimes calls to remind me to take my drugs. Being able to confide in my peers about my struggles has helped me to feel less isolated. My friend (peer) tells me how to take my drugs (17-year-old male)
>
> I meet other people when I come to get my drugs and we talk about many things. When others talk about how long they've been doing well on ART, it motivates me to do the same. Being able to confide in my peers about my struggles has helped me to feel less isolated. (16-year-old female)

Comfortable Environment and Less Stress

Participants who opted for CBMs reported feeling less burdened by the planning process because they did not have to account for a long time away from home. Participants benefited from not having to make major adjustments to their schedules; they could get to the drug distribution centres at the start of their day as usual. Participants also noted that the community-based settings were less hectic than the health centres, leading them to characterize them as "comfortable".

> The strategy (community-based models) makes me happy, I used to feel bad (anxious) before my scheduled appointments at the health facility. (13-year-old female)
>
> Before, I was always nervous that the health centre I was visiting was providing me with drugs. I knew I had to tell myself, "oh the day has come, I must visit the health facility and pick up the drugs". But these days, am not stressed as I don't have to wait in line at a health facility. (15-year-old male)

Theme 3: Challenges of Community-Based Models

Many of the study's participants said they wanted to use CBMs to get services and had various benefits. However, the participants experienced many. The analysis produced three sub-themes and these are presented below.

Lack of Privacy and Confidentiality

Many participants had negative views about CBMs because they were afraid of a lack of confidentiality among group members. The participants' anxiety was so great that they admitted they would switch to a different healthcare provider if healthcare professionals insisted on their joining such models. The members of the group in question were those who might not be able to maintain confidentiality and might reveal the HIV status of other members of the group.

> People may start spreading rumours that you have HIV if they see you frequenting the centres (drop-in centres), which are recognized to provide HIV care services to those living with HIV. Members of the community will see me and will laugh at me or reject me. (16-year-old male)

> I wish we could be inside and meet the nurses to get our drugs rather than waiting outside where anyone passing by could see us. Everyone in the neighbourhood can see us, and the fact that these nurses come here to give us drugs is common knowledge. We are exposed, and it's an embarrassment. (18-year-old female)

Perceive Internalized Stigma

A lack of interest in CBMs was largely attributed to the stigma associated with HIV. Adolescents living with HIV are reported to be fearful of joining CBMs out of concern that their community members will know their HIV status. They feared being stigmatized and isolated by the community if they received HIV care in their community, and some preferred to visit the health facilities that were away from home.

> I wish there was another way; I don't like this kind of service (community-based models) because everyone is seeing me as I collect my drugs. People may treat me differently (stigmatize me). I do not want the other person to know that I am sick. Here, people will know that I have HIV, and they will hate me if they know my status. (19-year-old female)

> I don't want to get my drugs in a public place like this. People will laugh at me and say bad things about me (because of my sickness). My friends will stop playing with me. I don't want people to avoid me when they see me. (13-year-old female)

Lack of Face-to-Face Interaction

Some participants believe that CBMs entail at least some disengagement from the formal healthcare system. They prefer face-to-face interaction with healthcare workers due to their professionalism, expertise, and respect for patient privacy. They mentioned other services provided at health facilities, like counselling services, verification of the drug's efficacy, and checkups of health status and weight.

> While I appreciate the time saved due to approaches (community-based services), as an individual I would like to receive more assistance and a hands-on approach from my doctor. I need someone to privately, I have issues that disturb me. Like last week I had issues with my boyfriend and I needed someone to listen to me (psychological support). I don't get the same assistance if I don't visit the health facility. (19-year-old female)

> If you want to know how I'm doing (medically) and if the drug is helping, I think it's best if the doctor sees me in person. I should not simply get drugs and walk away. I need to talk to a doctor about my issues and get checkups to see how I'm doing—I want to know whether am I doing well or badly. (17-year-old male)

Discussion

In this study, we set out to explore the perspectives of adolescents living with HIV on CBMs in Lira, northern Uganda. The major themes were: community-based models currently accessed by adolescents, benefits and the challenges of the models. Although there are other community-based models (community pharmacies, home ART deliveries) our exploration only discovered two models used by these adolescents to access care, namely, CDDP and CCLADs and the two models are beneficial to the adolescents. However, our results indicate that these models had some challenges, including a lack of confidentiality and privacy, perceived stigma, and a lack of face-to-face interaction. Nonetheless, our results show that adolescents enrolled in the CBMs did not struggle with ART adherence. The approach alleviated several of the previously stated barriers to involvement with the health system, such as travel, changes in routine, and being too busy to attend.[34] It is becoming increasingly important for DSD to make patients' preferences the focal point of service design as the healthcare system moves toward retention mechanisms for lifelong care.[35] Incorporating ART into daily life is facilitated by refill intervals, which can also improve the efficacy of current community-based models.[36]

Our results also showed that there was significant interest in obtaining care from CBMs because of the convenience of drop-in centres, the lower costs of transportation, and the convenience of operation. This suggests that adolescents have more faith in community-based approaches, a view supported by previous research.[15] However, some adolescents showed a desire to be attended to by healthcare professionals at health facilities. This suggests that some adolescents may need to switch between CBMs and FBMs. Earlier studies in Uganda, Tanzania, and Kenya emphasized the need to implement a comprehensive package of treatment at the community level for better health outcomes and more access to HIV care.[15,37,38]

Another important result was that adolescents were worried about a lack of privacy and confidentiality in CBMs such as CCLADs that rely on group interaction. The adolescents also reported feeling uneasy about entrusting their medicines to other members of the group, suggesting that they did not have faith in the group's DSD models. The mistrust stemmed from the inability to keep the HIV status of others confidential and the habit of spreading rumours about others' personal lives. Studies in Malawi, Uganda, and Tanzania found that a lack of confidentiality, privacy, and trust concerns were important factors in the failure of group DSD models.[15,37,39] Because of the changing nature of engaging adolescent peers and patient support groups, which poses a new issue in maintaining confidentiality, understanding service delivery ethics should be explicitly encouraged for everyone involved in informal service delivery. Our findings highlight the importance of addressing confidentiality concerns connected to the actual sites where CBMs are conducted.

Our findings demonstrated that internalized stigma was a major challenge and was consistently mentioned as a hindering factor to the utilization of CBMs. Therefore, it is important to develop interventions within the framework of CBMs to combat perceived stigma and discrimination. Counselling and providing social support for adolescents may be implemented to get timely and appropriate health care.[40] Other studies have found that stigma is a major barrier to receiving HIV care in the community.[15,22] Our findings highlight the importance of attending to stigma concerns connected to the actual sites where CBMs are conducted. CBMs can help adolescents overcome internalized stigma and gain unrestricted access to treatment, provided the right environment, space, and location are identified for them.

Strengths and Limitations of the Study

This study was limited to two health centers fours in Lira District. Also, interviews were conducted in English and the local dialect only, thus excluding adolescents who speak other languages. However, the participants had diverse backgrounds thus, representing the broad characteristics of adolescents. Also, this study provides critical information based on the perspectives of adolescents living with HIV on CBMs. This may contribute to the successful application of the CBMs.

Conclusion

CDDP and CCLADs are the two CBMs used by adolescents in Lira District to access treatment and care. Adolescents benefited from these models through reduced transport costs, the convenience of accessing HIV care and treatment, and social support. The challenges associated with these models are lack of confidentiality and privacy, perceived stigma, and a lack of face-to-face interaction. The Ministry of Health should work with other implementing partners to strengthen the implementation of these models to improve HIV/AIDS service delivery for adolescents.

Data Sharing Statement

The datasets used and/or analyzed during the present study are available from the corresponding author on reasonable request.

Acknowledgment

We acknowledge all the participants in this study. We also acknowledge Prof Celestino Obua, Prof Edward Kumakech, Dr. Moses Ochan and Dr. Edith Wakida for their technical support during data analysis and manuscript writing.

Author Contributions

All authors made substantial contributions to the conception and design, acquisition of data or analysis and interpretation of data; took part in drafting the article or revising it critically for important content; agreed to submit it to the current journal; gave final approval for the version to be published; and agreed to be accountable for all aspects of the work.

Funding

Research reported in this publication was supported by the Fogarty International Center (US Department of States Office of the US Global AIDS Coordinator and Health Diplomacy [S/GAC] and the President's Emergency Plan for AIDS Relief [PEPFAR]) of the National Institutes of Health under Award Number R25TW011210. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Disclosure

The authors declared no conflict of interest in relation to this work and no potential conflict of interest concerning the research and/or publication of the article.

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