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ORIGINAL RESEARCH

Social Networks and Barriers to ART Adherence Among Young Adults (18–24 years) Living with HIV at Selected Primary Health Facilities of South-Western Uganda: A Qualitative Study

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Background: Young adults living with HIV (YALWH) struggle to maintain high levels of adherence to antiretroviral therapy (ART) because of numerous barriers. This study describes the social networks of YALWH (18–24 years), their barriers to ART adherence, and the perceived role of social networks in overcoming those barriers.

Methods: This study used a qualitative descriptive research design. Twenty-three (23) YALWH who were on ART for a period of greater than one (1) month and had consented to participate in the study were purposively selected from two primary health care facilities in southwestern Uganda. We held four (4) focus group discussions with the YALWH over 5 weeks between the 24th of July and 7th September 2020. Data were audio recorded, transcribed, and entered in Microsoft word 2010. Using the content analysis techniques, data were inductively coded and categories or themes developed.

Results: Most YALWH belonged to bonding (family, friends, and neighbors), followed by bridging (informal groups), and linking (health professionals) social networks, respectively. Most YALWH, irrespective of gender, had close connections with their mothers or elder sisters. The commonest form of bridging networks was informal community groups that provided financial services, whereas the linking ones comprised health professionals' directly involved in HIV patient care such as nurses, counselors, and their affiliates (expert clients or clinic based peer supporters), who occasionally acted as bonding networks. Structural barriers to ART adherence (eg, stigma) were the most cited, followed by medication- (eg, pill burden), and patient-related barriers (eg, non-disclosure of HIV status). Bonding networks were perceived to help overcome patient, medication, and structural barriers to ART adherence. Bridging networks overcame structural and medication-related barriers to ART adherence. Linking networks were perceived to help overcome some health systems and medication-related barriers to ART adherence.

Conclusion: Bonding social networks seem to play a prominent role in overcoming numerous barriers to ART adherence compared with bridging and linking social networks.

Keywords: HIV, ART adherence, barriers, social networks, YALWH, perceived role

Introduction

Over the last two decades, the use of antiretroviral therapy (ART) to treat the human immunodeficiency virus (HIV) has reduced the mortality of people living with HIV in low-and middle-income countries.[1] The use of ART has further led to an improved life expectancy and quality of life for people living with HIV.[2–4] ART

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can also reduce the risk of HIV acquisition by 96% if the person living with the HIV is virally suppressed.[5] However, among other factors, HIV viral load suppression depends on the type and dosing frequency of the ART regimens as well as ninety-five (95) or above percentage levels of ART adherence by people living with HIV (PLWH).[1,3,4,6,7]

Although the exact ART adherence levels for the young adults living with HIV (YALWH, 18–24-year-old) remain unclear, generally, research shows that YALWH (18–24 years inclusive), have lower ART adherence levels compared with older adults living with HIV.[6,9,10] For instance, a systematic review on the determinants of ART Adherence in sub-Saharan Africa found that younger patients (<35 years) compared with older adults (>35 years) with HIV had lower levels of ART Adherence.[9] In addition, YALWH are less likely to be initiated and maintained on ART compared with children and older adults.[11–13]

There are numerous reasons YALWH recode lower ART adherence levels.[13–16] The first reason relates to the uniqueness of the 18–24 years age group. Studies about industrialized communities such as the United States and Denmark have described young adults (18–25 years) as "emerging adults" who possess unique age-related behaviors that may interfere with ART adherence, such as binge alcohol drinking and illegal drug abuse.[14] The same age group may also have fewer job opportunities, hence, lower levels of income for HIV care; lack parental support; make health decisions alone without sufficient knowledge of their consequences.[13,15,16] Transition-related barriers from adolescent to adult HIV care also pose multiple challenges to ART adherence for those who perinatally acquired HIV.[2,17,18] Studies conducted in the USA, Uganda, and Tanzania have reported such transition barriers as (i) the fear of losing their HIV colleagues in adolescent HIV care and the abruptness in transition which leads to reluctance in transitioning from adolescent to adult clinic, compromising ART Adherence, ii) anticipated stigma in adult HIV care clinics iii) financial constraints in buying health insurance or ART, and iv) lower HIV care quality in the adult HIV clinic.[2,8,17,18] Indeed, research from the USA has shown that youth who had perinatally acquired HIV were more likely to experience ART adherence barriers than those who had behaviorally acquired HIV.[15] This is because the former had longer ART and other medication histories and an advanced stage of HIV which contributed to complicated ART regimens and multiple disabilities.[15] In addition, patient, structural, and medication-related barriers make ART adherence among YALWH difficult.[1,3–5,7,11–13,15,19–21] Although there are multiple overlaps associated with ART adherence barriers across developed and developing countries, previous studies among YALWH in developed countries point to patient-related factors (eg, depression, substance abuse, forgetting, and perceived self-efficacy) and medication-related factors (eg, side effects) as key barriers to ART adherence in this age group.[3,4,15] However, in developing countries such as Uganda, barriers to ART adherence tended to be structural and medication-related. For example, a study conducted among adolescents and YALWH in Uganda found poverty, lack of privacy at schools, unreliable family support, pill burden, and ART side effects as the most important barriers to ART adherence.[7]

Research evidence shows that social networks play a significant role in ART adherence by enabling PLWH (YALWH inclusive) to overcome barriers to ART adherence.[22] Indeed, in Botswana, a study by Nam et al[23] reported that those without their networks' support found it too difficult to adhere to ART. Social support to PLWH was also found to improve mental health and psychological wellbeing, quality of life, immune function, motivation, hope, and adoption of positive coping strategies.[24–29] Social support may also affect ART Adherence behavior, through meeting instrumental and informational needs of PLWH, improving motivation and hope, and influencing mood.[30] Support from social networks facilitates resilience to ART and is partly responsible for the high and sustained ART adherence rates in Africa.[31] Specifically, to overcome multiple barriers to ART adherence, previous studies indicate that bonding (intimate relationships), bridging (connections with people of adverse background), and linking (connections with people with a formal hierarchy) networks provided adult patients with HIV resources necessary for daily living such as money for transport, food, and medications, as well as food items, credit or encouragement.[21,31,32] In addition, evidence from randomized clinical trials conducted in Uganda, Nigeria, and South Africa indicate that interventions tailored to social networks such as ART treatment supporters and peer support groups are effective in improving ART adherence, reducing attrition rates from ART clinics, and improving clinic attendance among adults with HIV as a whole.[1,33–36]

However, little is known about the social networks and their perceived role in overcoming barriers to ART adherence among YALWH in sub-Saharan Africa. Above all, there is little specific data on YALWH (18–24), since it is often aggregated with that of children, adolescents, or older adults, which limits proper targeting of interventions meant to improve ART adherence among YALWH.[13,14] Therefore, the purpose of this study was to describe the social networks of YALWH (18–24 years), their barriers to ART adherence, and the perceived role of social networks in overcoming barriers to ART adherence. Knowing the linkages between social networks and ART adherence barriers will help stakeholders understand the type of networks that influence (overcome) specific categories of barriers to ART adherence among YALWH. Ultimately, this may inform future social network interventions to improve ART adherence for YALWH in Uganda and other low-income settings.

Methods and Materials

Study Setting

The study was conducted in two purposively selected public primary health care facilities in southwestern Uganda: Kakoba health center three (III) is located in Mbarara city (urban, slightly densely populated), and Sanga health center three (III) in Kiruhura district (rural, more sparsely populated and largely cattle keeping community). According to Uganda's referral healthcare system, health centers threes (IIIs) are situated at every sub-county in a rural district or at a division in a city or municipality. South-Western Uganda has a higher prevalence of HIV (7.9%) compared to the national average of 6.2%.[37] The two health care facilities offered ART to a total population of 3219 HIV patients, with only 184 YALWH (18–24 years) on ART (Kakoba and Sanga health care facilities records, August 2020). ART services provided in the two health facilities included HIV testing and counseling, ART counseling and ART initiation (first and second-line ART), laboratory services (only sample collection for PCR, viral load, and CD4 count), substitution and switching of ART, post-exposure prophylaxis (PEP) services, prevention of mother-to-child transmission of HIV/AIDs (PMTCT), chronic HIV care (prophylaxis for opportunistic infections), and referrals of HIV patients.

Research Design, Sampling, Sample, and Sample Size

This study utilized a qualitative descriptive research design. Twenty-three (23) YALWH (18–24 years) who had been on ART for at least 4 weeks (>30 days) and consented were purposively selected to participate in this study. However, those who could not speak the local (Runyankole or Rukiga) or English languages (n=02) and the critically sick were excluded from this study (n=01). To examine whether variability in experiences existed across gender and setting, the research team ensured that participants who described themselves as staying in rural and urban settings were included in each focus group discussion (FGD) and later the FGDs were stratified by gender to minimize cross-cultural communication barriers. FGDs were utilized because of the desire to obtain consensus at minimal cost and time. Four (4) FGDs of YALWH were conducted separately-for males (2FGDs) and female (2FGDs) participants.

Data Collection Procedure

Data was collected over 5 weeks between the 24th of July and 7th September 2020. After approvals from the Mbarara University research ethics board (MUREC 22/01-20), Uganda National Council of Science and Technology (RESCLEAR/01), the district health officers of the respective districts, and the health facility managers', the research team contacted, briefed, and requested the ART clinic staff (counselors and nurses) to signpost the eligible study participants (18–24 years) to the research team (available at the health facility) during their respective clinic days. ART Clinic staff later identified and briefed the study participants individually about the study purpose and those that were interested were further linked to the research team. The research team screened the study participants against the inclusion criteria. Those that met the inclusion criteria, were subsequently informed verbally and in writing the details of the study using the information sheet and requested to take part in the study. Those that accepted to participate in the study were requested to sign a consent form. Focus group discussion (FGDs) were later conducted in private rooms attached to the ART clinic at the two health facilities, once an average of 4–5 participants (range=4–8) had consented and received that day's ART clinic services. The FGDs were conducted by the research team from the Mbarara University of Science and Technology and Bishop Stuart University that comprised a professional nurse and doctor (FGD facilitators) with over 5 years' of experience in research and nursing students (who audio recorded and took field notes). The open-ended questions on the FGD guide asked participants to describe the social networks they belonged to, explain their current barriers to ART adherence, and state how the social networks influenced those specific barriers to ART adherence. Before the study, the FGD guide was translated from English to the local language (Runyankole/Rukiga) and back-translated. This was pilot tested with 5 (five) participants at Mbarara University teaching hospital ART clinic. We also conducted one FGD weekly, transcribed the data and analyzed it before conducting another FGD. Each FGD took ~45 minutes (40–90 minutes). The research team provided refreshments to YALWH during the FGDs and thereafter transport refund (~$1.3).

Data Analysis

Data was inductively analyzed using the conventional content analysis technique, suitable for analyzing data that has been collected without the guidance of a theoretical framework.[69] We read word for word and coded data that had been collected using open-ended questions. Specifically, audio recorded discussions were manually transcribed and entered in Microsoft Word 2010. Raw data were entered in a table with two columns. The second column allowed the researchers to develop codes or marginal remarks of the raw data. Paragraphs or sentences in the transcripts that had similar meanings were color coded, transferred, and chunked together with their codes into another table. Data codes were revised and later organized into categories or themes (pattern coding). We further read and cross-checked the transcribed raw data once again to confirm the developed data codes and categories. A final matrix containing columns for selected raw data, codes, categories, and themes was developed in Microsoft Excel 2010. In addition, after observing minor differences in experiences across participants, the authors combined all FGD data for both genders during analysis and reporting.

Ethical Consideration

We conducted this study under the 1964 Declaration of Helsinki and its later amendments. The research team sought verbal and written consent from all study participants using the local language. Those illiterate, consent was obtained in the local language and confirmed with a thumbprint. All FGDs were conducted in the local language in a private adult ART clinic room. Codes were also used to identify study participants during FGDs. All participants identified during the FGDs to be non-adherent to ART were advised to seek support from the ART clinic counselors or nurses. In addition, participants consented to the publication of their responses as long as they were kept anonymous.

Study Concepts

Barriers to ART Adherence

This study asked YALWH to describe their current barriers or ART adherence challenges and how they affected their adherence to ART. To obtain the most relevant ART adherence barriers, all efforts were taken to ensure that FGD facilitators did not mention any specific barriers from literature to the study participants, during the FGDs.

Social Networks

Social networks were defined as a set of bonds (ties) among individuals or groups of the same interests and interactions.[38,39] Social networks were categorized into three namely: bonding, bridging, and linking networks.[40–42] Bonding networks were defined as those that involved "strong bonds or intimate relationships with people of the same background" that supported YALWH, such as family members, spouses, friends, and neighbors.[40–42] Bonding networks were indicated by individuals who were in close contact with the YALWH with whom they engaged in regular visits, talks, collaborative activities; considered confidants for HIV status disclosure and helped YALWH overcome barriers to ART adherence. On the other hand, bridging networks were defined as networks that involved weaker but more cross-cutting connections with "people of diverse backgrounds" organized in either local, regional, or national level networks of community groups. In addition, under the community groups, this study was interested in finding the type and number of groups the YALWH belonged to, their participation in the groups (activities and frequency), HIV status disclosure, and social support obtained from the groups following HIV status disclosure, that helped them overcome barriers to ART adherence. Linking networks were considered as "connections of people within a formal hierarchy" such as connecting with social workers, health care workers, counselors, or any other official at the health care facilities, directly or indirectly involved in their HIV care, with the ability or power to influence decisions, that indeed helped the YALWH to overcome barriers to ART adherence. This study was also interested in their relationship with YALWH, HIV status disclosure, and the social support obtained from those networks following HIV status disclosure that helped them overcome ART adherence barriers, through "leveraging information, ideas and resources from these formal institutions".[42]

Results

Selection Criteria, Demographic and Clinical Characteristics of Study Participants

During the data collection period, forty-two (42) participants (18–24 years) were identified and invited, but only thirty-one (31) were interested in participating in the study (Table 1). On screening, we excluded five (5) participants from the study who had been taking ART for less than 4 weeks. Among those eligible, we further eliminated three participants (03) because of sickness (n=01) and inability to speak the local languages (n=02). Twenty-three (23) YALWH took part in FGDs. The majority were aged between 20 and 24 years (n=20 years) and were female by gender (n=16). The most considerable number described themselves as living in rural settings (n=14). The majority were not yet married (single, n=15), out of school (n=20), and subscribed to the Christian faith (n=20). Apart from two participants who had perinatally acquired HIV, most of the participants had behaviorally acquired HIV (n=21) and had been diagnosed and initiated on ART within an average period of fewer than two (2) years. Some participants whose viral load results had not been returned and those with unsuppressed viral load were taking both ART and Cotrimoxazole (Septrin, n=10). Only one (1) participant was on second-line ART.

Table 1 Selection Criteria, Demographic and Clinical Characteristics of Study Participants

Characteristic	n
Selection criteria	
# Invited to participate	42
# Assessed for eligibility	31 (n=05, were on ART for <4 weeks)
# Eligible	26 (n=02, could not local languages, n=01, were sick)
# Consented & participated in FGDs	23
Gender	
Male	07
Female	16
Residence	
Urban	09
Rural	14
Marital Status	
Single	15
Married/cohabiting	08
School status	
In school	03
Out of school	20
Religion	
Christian	20
Others	03
HIV acquisition	
Behaviorally	21
Perinatally	02
Drugs	
ART only	13
ART & Septrin	10
Average period on ART (median years)	1.8 (3 months–2 years)

Abbreviation: ART, Antiretroviral therapy.

Social Networks

Bonding Networks

Regardless of their gender, most of the YALWH were from nuclear families, had more contact (ties) with either their mothers or older sister, and these also acted as their confidants. One participant said:

> My close relative is my mother and my sister... Currently, I stay (rent) with my elder sister but my mother is in the village… Sometimes when I am sick… she calls our mother to inform her... [Female, 21 years, Urban]

Some YALWH preferred fathers (men) and grandparents (older) as close confidants because of the perception that they kept secrets related to HIV status, thus protecting them from stigma.

> I always tell my father all my problems with ART. He is the only one I have ever disclosed my serostatus to because men don't talk like women… if it's a man, he will think about the implications of telling your HIV status to his friends, first... [Female, 22 years, Urban]

The other close family members rarely mentioned by YALWH as confidants included their fathers, grandparents, aunts, older brothers, spouses, and uncles. On the other hand, most friends to YALWH were people within their neighborhoods (fellow tenants and village colleagues), workmates, peers (HIV diagnosed), and fellow students. Thus, they frequently interacted with these daily or weekly.

> My close friend is the one whom I work with and is the one who brought me here to test for HIV… We even stay (rent) together. [Male, 23 years, Rural]

Daily or weekly communication among YALWH that stayed alone (especially urban dwellers) was achieved via phone calls or occasional visits to or by their close relatives or friends. On some occasions, YALWH interacted with their bonding networks during specific activities, such as farming, weddings or funeral rites, and cooking.

Overall, the choice of confidants across the various bonding networks was based on several reasons such as the trust built over time (years), the ability to keep their HIV status a secret, those tolerant in attitude, peers relationships with the YALWH, and their ability to support the YALWH with daily basic needs or any other care (comfort, advice, and love).

> When I need something, I get it from my friend. I also share all my troubles with her... So you choose somebody who will keep your secret and comfort you thereafter, and that person becomes your second doctor. [Female, 19 years, Rural]

Since HIV status disclosure is paramount to receiving support from bonding networks, many YALWH disclosed their HIV status to only their confidants. However, a greater number of YALWH had not disclosed their HIV status to their spouses because of the perceived or previous experiences of rejection, harm, and stigma (enacted stigma).

> We hide it (HIV status) completely from our boyfriends because if you tell them, they will just abandon you or if he has had sex (live) with you for a week, he can cut you with a big knife (a machete)! [Female 21 years, Urban]

However, HIV status disclosure to new sex partners or spouses was much easier for those who had lived with HIV for a long time and were well known by many people in their communities.

> I have been with HIV for some time (close to 8 years)… When I meet a man, I ask him to love me the way I am or leave me so that I remain single. [Female, 24 years, Rural]

Besides, sometimes YALWH were compelled to disclose their HIV status against their will to the other non-confidant bonding networks (especially relatives) during severe sickness and when they anticipated they might need prompt care during emergencies.

> I first hid my HIV status from my friend. But when I was sickly, she kept asking me why? I opened up finally. I told her I was diagnosed with HIV. [Male, 22 years, Urban]

In summary, the support obtained after HIV status disclosure was through direct solicitation of help by the YALWH or a third party (one close relative to the other), and through inquiry (concern) and observations of the dire situations of the YALWH.

Bridging Networks

Most YALWH belonged to informal community groups that provided financial services (savings and loan associations) and were formed within their vicinity (village, town, or similar ethnic community).

> …In my group, we collect money from all group members and give it to one member on a monthly rotational basis… [Female, 24 years, Rural]

The other groups' YALWH belonged to included: peer support groups, funeral rite fundraising groups, groups created around an economic activity (banana selling group), food fundraising groups, and religious groups that offered spiritual support (prayers and love) following disclosure of their HIV status. Most of the groups comprised a mixture of young adults diagnosed with HIV and those without HIV, although some groups were formed only for YALWH (peer support groups), and these assigned no names to their groups to avoid attracting stigma.

> We formed our group after realizing that we were all diagnosed with HIV from the same place (village) with a problem of transport. We formed it and did not give it a name to avoid people noticing us. [Male, 23 years, Rural]

To join these groups' members were required to pay membership fees, a first installment, or both. Members of the groups met weekly or monthly to collect savings, dispatch loans, and share profits with their colleagues. Failure to save or pay loan installments regularly attracted a fine for some groups. However, members had access to all their savings when they failed to save.

Except for the peer support groups, most participants had disclosed their HIV status to only a close friend and confidant in their group to avoid the perceived group stigma. One participant said:

> I can only disclose to all group members if they are all diagnosed with HIV,… If you tell everyone, you may even

> not get anybody to offer you a cup of water! [Female, 21 years, Urban]

Similarly, some YALWH who disclosed their HIV status to their confidants, who were group leaders, obtained support (empathy). Such support comprised offering time off the group's economic activity to pick ART, deferred payments of their monthly installments, and even provided financial support.

> We disclosed our HIV status to our group leader. He has told nobody and has been very supportive of us. On the day of picking ART (at the ART clinic), he tells us not to work, but he still gives us some money to buy food.... [Male, 19 years, Rural]

Linking Networks

Some YALWH knew and had closer connections with a counselor, nurse, or expert client at the health facility who provided special care to some of the YALWH. Some of these were relatives, friends, or neighbors. Therefore, some of the linking networks acted as bonding networks.

> There is an uncle of mine who is a nurse in Mbarara (city), whenever I have treatment issues, I call him... [Male, 22 years, Rural]

However, YALWH disclosed their HIV status to their linking networks that were related to them as relatives, friends, or neighbors and those directly involved in their care.

> When I asked my uncle (nurse) to tell me why I was always sickly, he advised me to go and test for HIV. Once I was diagnosed with HIV I had to disclose it to him because I knew I needed him to cope with the disease… [Male, 22 years, Rural]

Barriers to ART Adherence

In this section, ART adherence barriers are organized and presented under the patient, structural, and medication-related categories (Table 2). Overall, structural barriers to ART adherence (eg, stigma, drug stock-outs, long lines, undifferentiated care services, and financial constraints) were the most frequently cited, followed by medication- (eg, pill burden), and patient-related barriers (eg, non-disclosure of HIV status and forgetting to take ART).

Patient-Related Barriers to ART Adherence

Non-Disclosure of HIV Status

In this study, most of the YALWH had never disclosed their HIV status to their non-close social networks' because of the fear of perceived and anticipated stigma from them, loss of customers for those involved in business, and the lack of skills to break this news. Non-disclosure of one's HIV status raised suspicions because of the change in eating habits, frequent healthcare-seeking habits, daily drug intake, and self-isolation. As a result, participants stopped taking ART to quell those suspicions that occasionally occurred when they paid or were paid a visit by friends and relatives.

> Sometimes when you visit your parents' or relatives' home, and you do not want them to know that you were diagnosed with HIV and on ART, but when they see you taking a jug of porridge every evening to your room, they ask, "Is she pregnant?", so you end up missing some days without taking pills to quell the suspicions. [Female 19 years, Urban]

Forgetfulness

Some YALWH forgot to take ART because of sleep and a busy schedule at their workplace or schools. Above all, such YALWH lacked colleagues to remind them.

> When you carry it (ART) at the place of work, you even cannot get time to take it, since you are busy the whole day and did not tell anybody to remind you!… You lay on your bed waiting for the scheduled time to swallow your drugs, but you end up sleeping off. [Female 20 year, Urban]

Change in Daily Routine

Changes in daily routine, such as visiting a relative, attending a wedding or funeral rite, and changing or obtaining a new job (especially for wage earners) were responsible for the skipping of ART doses for some YALWH. On such occasions, YALWH rarely carried the ART with them since they expected to return home in time before their next ART dose.

> As a house builder, you go somewhere thinking that you will return that day …, but you fail to return, so you miss that day's dose... [Male, 24 years, Rural]

Medication-Related Barriers

Several ART pill-related barriers in this section were most experienced by YALWH that had just started ART. Except for the ART side effects, the other ART adherence barriers

Table 2 Major Themes, Categories, and Codes Derived from Data About Barriers to ART Adherence

Themes	Categories	Subcategories/Codes
Patient related barriers	Non-disclosure of HIV status	Non-disclosure to non-close networks Non-disclosure was because of perceived and anticipated stigma Non-disclosure raised suspicions
	Forgetfulness	Sleep and a busy work schedule Lack of colleagues to remind them
	Change in daily routine	Abrupt change in daily routines Never carried ART
Medication-related barriers	Pill burden	The daily intake of ART Treatment fatigue Drug holidays
	Bigger pill size	Size of the pill Perceived difficulty in swallowing the tablets Improved community understanding of HIV treatment
	Noisy pill packages	Noisy on opening pill packages Noisy during transportation/movement Noise raises suspicions
	ART side effects	Side effects, such as dizziness, general malaise, headache, in somnolence etc. Lack of heavy drinks and food worsened the side effects
Structural-related barriers	Stigma	Persistent enacted stigma Stigma follows actual or accidental HIV status disclosure Lack of privacy and fear of being frequently discussed by others
	Financial constraints	Limited finances to buy medicine Limited finances to buy food
	Health system-related barriers subcategories	
	Drug stock-outs	Receive fewer drugs Fewer drugs attracted frequent ART clinic visits Additional transport costs Frequent ART clinic visits raised suspicions among employers Occasional requests for permission to pick ART Picked ART from a secondary site
	Long queues and waiting times	Long waiting times and queues Hunger Early Booking Delegating a colleague to pick ART Skipping the long queues
	Undifferentiated health care services in the adult HIV clinic	Open waiting spaces Easier recognition as a patient with HIV Proximity and the limited time spent with a health worker Poor communication from the health care workers
	Delay in health facility transfers	Lack of smoothness in the transfer Back and forth movement

raised suspicions that occurred in circumstances of HIV status non-disclosure.

Pill Burden

Pill burden was the most cited medication-related barrier to ART adherence in this study. The daily intake of ART caused a feeling of treatment fatigue, which subsequently led to drug holidays (stopped taking ART for some time). In addition, because daily intake of ART raised suspicions among workmates, family members, sex partners, and relatives, participants often avoided taking pills with them during visitation to avoid attracting stigma.

> Sometimes I feel tired of the daily intake of pills. You cannot move with them at the place of work, you don't even visit because of the ART pill, you cannot even leave them in your small bag there when you go to the toilet because kids might check in your bag and reveal them to everyone. It is like carrying a cross! So you give yourself a break… [Female 22 years, Urban]

Bigger Pill Size

The size of the pill was one of the most important barriers to ART adherence, according to several YALWH. This was because of the perceived difficulty in swallowing the tablets. In addition, since Uganda has dealt with the HIV pandemic for close to three decades, the community's understanding of HIV and its treatment has improved. Thus, anyone with HIV can be recognized by the look or size of the pill they are carrying (ART pill). Therefore, participants avoided taking the ART pills with them in certain public places to avoid being recognized by the community members-hence missing their ART doses.

> The ART pill is so unique, it's big. Even when one has never seen it he/she can suspect that you were diagnosed with HIV by looking at the pill you are carrying… [Female 22 years, Urban].

Noisy Pill Packages

YALWH value their privacy, and anything that compromises it could affect ART adherence. The noise created by the ART pills during the opening of their packages and during transportation on the motorbike (public transport means in Uganda) was one of the most cited barriers to ART adherence since it caused suspicions among friends, family, and motorcycle riders. This consequently impeded their movement with ART. One participant explained:

> When you open the tin with the medicine (ART), you use a lot of effort (strength). It makes a great noise. Even when you are on a Boda Boda (motorbike)… To avoid being recognized, I avoid or limit carrying the drugs with me when traveling or visiting. [Female 21 years, Urban]

ART Side Effects

ART-related side effects such as dizziness, general malaise, headache, insomnolence, nausea, anorexia, among others that occurred when some YALWH took ART without enough drinks or food, led to a tendency to miss ART doses on occasions when they did not have them.

> ART is too tough. It does not require you to take it with water alone. When you take it without food and heavy drinks, it makes you feel dizzy. You feel weak and sleepy… So I have to first find food before I can take it. Without it, I have to miss that day's dose until I find food... [Female 24 years, Urban]

Structural Barriers to ART Adherence

In this study, cultural (stigma), economic (financial constraints), and institutional (health systems related) barriers were the three (3) main structural barriers to ART adherence experienced by YALWH.

Stigma

Persistent enacted stigma from the family members and the community following actual or accidental HIV status disclosure by some YALWH led to skipping ART doses. Those YALWH who stayed close to their kin experienced rejection, harassment, verbal insults, quarrels, and daily lamentation from relatives. These further caused YALWH stress and depression that led to missed ART doses.

> Ever since my mother…, found those ART pills, she has been quarreling daily, and she even hates me! She instead says, I did not give birth to you with it (HIV)!, so look after yourself! When I think about it, I feel like leaving ART so that I can die! [Female, 24 years, Urban]

For those in school because of the lack of privacy and fear of being frequently discussed by others (perceived stigma), YALWH sneaked out of class to take their ART. This was not always easy; as a result, some YALWH missed their ART doses.

> Students rumormonger about you…, so because of the fear of being seen taking my medications, I always sneak out

> of class into the dormitory to take them. Sometimes I forget or cannot sneak out, which makes me miss that day's dose. [Male, 18 years, Rural]

Financial Constraints

Limited finances to buy medicine (HIV-related medicine like septrin), food, or pay for transport costs was one of the most cited barriers to ART among YALWH. Food was a major challenge for the YALWH from urban settings. Meanwhile, the shortage of money to pay transport costs was a major challenge for YALWH from rural settings. This was because most of them lived far away from the health facilities where they collected ART.

> …, there is a time when you have no money for food or drinks to take ART or even transport to pick the ART. [Male, 24 years, Urban]

Health System-Related Barriers

Drug Stock-Outs

Despite governmental and non-governmental investment in free ART services for patients with HIV in Uganda, ART stock-outs are still common. Because of these ART stock-outs and some YALWH having recently initiated ART, ART was received monthly from their respective ART clinics. This prompted frequent visits to the ART clinic and attracted additional transport costs, leading to skipping ART doses.

> Like me, I came here last month, am here now, and will be here next month to pick ART, yet I have been on ART for a year now! They give us a few ART pills …! [Female, 18 years, Urban]

Frequent visits to the ART clinic were also of concern to those who were employed in businesses. This was because they not only arouse suspicions among managers and staff, but also created a false impression of incompetence, which subsequently led to dismissals from their jobs.

> Every time you have to be at the hospital and your boss keeps asking you where are you going? So, he/she suspects maybe you do not want to work, so he/she ends up dismissing you! [Male, 22 years, Urban]

To prevent losing their jobs, some YALWH feared to ask for permission to pick ART on some occasions, could not carry their ART to their places of work, and even when they took ART to their places of work, they would not take it. This was because of the busy work schedule and the fear of being asked about the ART they were carrying or taking. On occasions when there were stock-outs of ART or septrin, YALWH were requested to move and obtain them from the nearby health facility or ART Center. Since those health facilities were far away from their places of residence and that some YALWH had insufficient finances to get there, they ended up missing picking or taking ART.

> They (nurses) tell us to buy septrin. Sometimes there is no ART, so they give us half of the treatment, like today! So you end up coming twice a month or going to the other treatment center for ART, which means you spend twice, yet transport disturbs us! [Female, 23 years, Rural]

For some who could afford to bear the transport costs, the healthcare workers sometimes communicated the decision to move to the nearby health facility late. This led to hunger and still a failure to obtain ART at the right time.

> Sometimes we come here and spend the entire day waiting for ART, yet there is no ART, and the nurses do not tell us immediately. We even end up going hungry sometimes without medicine. [Female, 23 years, Rural]

Long Queues and Waiting Times

As mentioned earlier, all participants at the two study sites revealed that long waiting times and queues, coupled with hunger, contributed to missing that day's ART. Participants who had limited working times ended up either coming very early or delegating a colleague to pick ART for them. Despite this effort, they ended up picking ART late because of older (senior) patients with HIV skipping the long queues.

> You sit and stay there (at the ART clinic) the whole day. Even you get hungry. You see some patients jump the queue... [Female 23, rural]

Undifferentiated Health Care Services in the Adult HIV Clinic

In some primary public health facilities of Uganda, because of the lack of infrastructure or issues related to infrastructure design, patients' waiting areas in adult ART clinics are held in open spaces or even in tents with very little privacy. Likewise, in the two study sites, the adult ART clinic was held in a private room, but patients waited for treatment in an open space outside or in a tent, where older adults, children, women, young adults, and adolescents with HIV obtained ART as a group. This ART clinic setup was a barrier to ART adherence in three ways. First, those who recognized people they knew from their locality at ART clinic changed and started receiving ART from a nearer to far away ART reception center (especially men), hid and waited until those they knew had received ART and had left, or even they had to leave the ART clinic without taking ART to avoid being noticed as an HIV diagnosed client.

> When I had just started picking ART from this center, there was an elderly HIV diagnosed lady who found me here. She told everybody in my village that she saw me at the ART clinic… The next time I saw her at the ART clinic, I slowly took off.... Today whenever I find her at the ART clinic, I hide within the health facility premises until she has left, then I pick my ART. [Male 24 years, urban]

Second, because of the proximity and the limited time spent between the YALWH and the health workers during each clinic visit, YALWH neither shared their ART-related challenges nor received counseling. As a result, some YALWH struggled with ART side effects, hence non-adherence to ART.

> You cannot share all your ART-related challenges with the health worker because they have no time for you (they are ever busy). [Female, 18 years, Urban]

Third, poor communication from the health care workers (lack of feedback and disrespect) prompted participants not to pick ART.

> I used to have low confidence after being diagnosed with HIV. There was a nurse who used to condemn us… and reveal to anyone your HIV status. So each time I thought of going to the ART clinic, I would fear (get a headache). I would feel low confidence and bad, so I ended up missing picking my medicine, sometimes. [Male, 23 years, Rural]

Delay in Health Facility Transfers

Although cited by few YALWH, the lack of smoothness in the transfer from one ART reception center to the other led to the back-and-forth movement to collect or obtain the drugs (ART) documentation to effect the transfer. In that process, those participants missed many days without taking their ART.

> I came from Kiruhura (rural) to Mbarara (city)…, but my medicines got over, so I came here to pick them. But the nurses sent me back to my previous ART reception center to pick up my documents… all those last days I have taken no medicine. [Male, 20 years, Urban]

The Perceived Role of Social Networks

The Perceived Role of Bonding Networks

There were five ways or mechanisms through which bonding networks helped in overcoming the patient, medication, and structural barriers to ART adherence, namely, 1) the provision of instrumental support to YALWH, 2) provision of informational and emotional support, 3) provision of ART intake reminders, 4) peer-to-peer support among YALWH, 5) protection from stigma (Table 3).

Provision of Instrumental Support

To overcome the structural barriers, YALWH received instrumental support in the form of finances from close family members or friends on either request or when they observed the YALWH direly needed this resource. YALWH spent these funds on food and transport costs to and from the ART reception centers.

> Sometimes my friend provides me money when I don't have it, to buy food. [Male, 24 years, Urban]

These funds were also used to buy HIV-related medications on occasions when they were out of stock at the ART clinic.

> My sister and mother help me a lot, as you see here (ART clinic) there are sometimes drug stock-outs of septrin, so they are the ones who buy for me those drugs. [Female, 19 years, Urban]

When bonding networks of YALWH could not provide financial resources, they gave food, drinks (millet flour, porridge, or milk), and herbs, which enabled participants to overcome ART side effects.

> After taking ART, in the morning I wake up without appetite for food, with also nausea or pica. When I get those problems, I always tell my mother about them. Later, she searches for herbs in the bushes for me to take… [Female, 24 years, Rural]

The above instrumental support and more were further provided to the YALWH when they were sick, pregnant, or during periods of joblessness to allow for the smooth intake of ART during periods of distress. One participant mentioned that a close relative linked her to a job opportunity in the urban setting.

> When I told my aunt my HIV status and my need to take care of myself, she immediately linked me to a job opportunity in Kampala (capital city). [Female 21 years, Rural]

Table 3 Major Themes, Categories, and Codes Derived from Data About the Perceived Role of Social Networks

Themes	**Categories**	**Subcategories/Codes**
The perceived role of bonding networks	Provision of instrumental support	Provide funds to purchase food Provide funds to cover transport costs to ART clinic Provide funds to purchase HIV-related medications Provide food stuff Pick herbs to manage ART side effects Support during pregnancy Job linkage
	Provision of informational and emotional support	Counseling/advice Concern/love and care Encouragement
	Provision of ART intake reminders	Frequently inquire about ART intake Remind YALWH
	Peer to peer support among YALWH	Reciprocity Collaborated to reduce transport costs
	Protection from stigma	Acceptance of their HIV status Non-disclosure of their HIV status to others Hide away ART for them Provide secretive moral (counseling) Provide secretive financial support
The perceived role of bridging networks	Provision of instrumental support, such as financial loans.	Food loans Loan to cover transport costs Loans to cover hospital bills or pay for HIV-related medications School fees loans Enterprise loans
	Peer-to-peer financial assistance among group members to pick ART	Group members to set up teams to pick ART for their colleagues Raise finances for transport to and from ART reception centers
	Provision of informational support.	Advice from the group Invite health workers or expert clients for group support
The perceived role of linking networks	Provision of informational and emotional support	Support beyond working hours or official mandate Encouragement Visiting (love and Care) Counseling/Advice Promptly provided ART during illness
	Provision of ART intake reminders	ART intake reminders Reminders to pick ART
	Keeping or reserving ART for their clients	Keeping ART aside for YALWH Sending ART to YALWH

Peer to Peer Support

Unlike with close relatives, YALWH observed the principle of reciprocity when sharing financial resources with friends. In fact, sometimes YALWH formed their bonding networks around their HIV status. This peer-to-peer collaboration helped to reduce transport costs to ART clinics through picking ART for each other.

> My friend and I got to know each other's HIV status from here (ART clinic). Coming from the same village… we talked about the challenge of finding funds to cover transport costs… we agreed to apportion days to each other when to pick it. So we pick it for each other in turns… [Female, 23 years, Rural]

Informational and Emotional Support

YALWH frequently cited informational and emotional support as counseling, advice, concern, or encouragement as forms of support from friends, family, or neighbors that mainly helped them in overcoming medication-related barriers to ART adherence. Participants received advice about the importance of lifelong ART and how to cope with the side effects of ART through dietary modifications. Family members and friends advised YALWH who had just started ART to eat and drink a lot of fluids if their ART side effects they experienced were to disappear.

> My friend provides me with advice on the importance of ART, that if I take it, I will live longer… he also visits me when I am stressed and provides comfort and advice on how to move on. [Male 18 years, urban]

Some family members cautioned some YALWH to desist from risky behaviors, such as alcohol intake (patient-related barrier) that would compromise ART intake.

> My aunt (diagnosed and living with HIV) who knows my HIV status regularly advises me to leave alcohol, and a habit of engaging in sex with multiple partners… [Female 21 years, Rural]

ART Intake Reminders

To reduce chances of forgetting, most close family members and friends frequently inquired about ART intake and reminded YALWH to take ART promptly or pick ART on the scheduled days of the week or month, to avoid missing out on their daily ART doses.

> After clinic visits, I receive a call from a friend asking me when I am next going back to the ART clinic (re-visit)… On that particular scheduled day of the re-visit, I again receive a call reminding me to go back and pick my drugs. [Male, 23 years, Urban]

Protection from Stigma

Some relatives accepted their children's HIV status, and instead further protected them from the stigma, through non-disclosure of their HIV status to other members of the family deemed hostile to the YALWH, hiding (keeping) for them ART, and ensuring they took it secretively, providing secretive moral (counseling), and financial support.

> When I visited my relatives…, my brothers checked my bag and found my medicine (ART). They started laughing…! So, I kept on denying it. When I told my father (confidant), he asked me to keep and swallow the medicine in his room…. [Female, 19 years, Urban]

The Perceived Role of Bridging Networks

There were three mechanisms through which bridging networks overcame structural and medication-related barriers to ART adherence, namely: 1) provision of instrumental support, such as financial loans, 2) peer-to-peer financial assistance among group members to pick ART, and 3) provision of informational support.

Provision of Instrumental Support (Financial Loans)

Since most groups YALWH were engaged in were providing financial services, these community groups provided them small financial loans to buy food, pay for transport to pick ART, pay the hospital bills or HIV-related medications, pay for other needs (school fees), and to set up small agricultural developmental activities among others.

> …When you are in our savings group, you cannot lack anything… You can borrow the money which you use to hire a casual laborer to till your land for you, buy food, pay school fees, or even transport you to the ART clinic. [Female 24 years, Rural]

Peer-to-Peer Financial Assistance for ART

Some groups of solely YALWH (peer support groups) also used their group members to set up teams to pick ART for their colleagues. This was through raising finances for transport to and from ART reception centers.

> We formed our group after realizing that we were all diagnosed with HIV from the same village with a problem of transport… In the group, we collect 10,000/

> = (≈2.7 dollars) from each person monthly. We then give it to one person who goes to collect for us our treatment at the ART clinic. [Male, 23 years, Rural]

Provision of Informational Support

Besides, peer support groups were also a source of informational support (In the form of advice, comfort, and building confidence for each other). To overcome medication-related barriers, health workers or expert clients would be invited sometimes to guide the groups on ART adherence.

> We invite the expert client or counselor to talk to us about ART adherence strategies, alcohol intake, and sexual relationships. [Male, 23 years, Rural]

Overall, YALWH did not perceive the bonding and bridging networks to be very helpful in overcoming most health services and system-related barriers to ART adherence. This was because of the lack of knowledge and skills on how to disclose those barriers to their networks and the perception that their networks would do nothing about them following disclosure (perceived ineffectiveness).

> We do not tell those clinic issues to our friends, family members, relatives, or groups. Those are our problems and the health facility. How do you tell them? Even if you tell them, they will not help you!… [Female, 24 years, Urban]

The Perceived Role of Linking Networks

Although it is now the role of the ART clinic staff in Uganda to ensure HIV clients irrespective of age are retained in HIV care through strategies such as telephone call reminders (to attend scheduled ART clinics days) and home visits (for those HIV patients that have defaulted), study participants indicated that staff involved in the care of some YALWH played some of these roles beyond their assigned working time frame or official mandate. Therefore, 1) the provision of informational and emotional support, 2) provision of ART intake reminders and 3) keeping or reserving ART for their clients were the only three ways in which linking networks helped overcome structural (health systems) and medicine-related barriers. Specifically, these barriers were mitigated through visiting the YALWH outside the official working time frame to offer encouragement and counseling on ART, reminding YALWH to come for ART, keeping ART aside for them to pick in their own time, sending ART to them via public transport or through close friends, and providing ART promptly for some of them when they visited the ART clinic feeling sickly.

> I know of a counselor at the clinic who helps me whenever I have a problem. He calls and reminds me to come and pick my ART, and keeps aside ART when I miss or delay to pick it. Since I stay nearer to him, he calls me before he comes to visit me. Once he comes, we talk about ART adherence and living positively with HIV. Sometimes, he brings the ART for me. At the clinic, once he sees me sickly and, in a long line, he calls me to get medicine first. [Male, 24 years, Rural]

Discussion

Prior to this study, research showed that YALWH (18–24 years) struggle to adhere to ART because of multiple barriers. However, because of the aggregation of data, it was unclear if there were differences between YALWH and other groups of PLWH in terms of the barriers to ART adherence, composition of their social networks, and the perceived role of social networks in overcoming multiple barriers to ART adherence. In this study, we found that most barriers to ART adherence were structural and inclined towards the general barriers experienced by the older adults' (>24 years) on ART in sub-Saharan Africa. In addition, most YALWH belonged to bonding networks, and these networks seemed to play the leading role in overcoming multiple barriers to ART adherence. These findings and many more provide an insight into various ways stakeholders could leverage on the connections and benefits of social networks of YALWH to help them overcome barriers to ART adherence, with a goal of improving ART adherence.

Social Networks

We found YALWH had the most contact with family members, followed by friends, and last, with their neighbors. Our findings are similar to those of other studies conducted in Brazil, Zambia, and Kenya among adults (>18 years) with HIV, where again friends and family and not neighbors were the dominant forms of social networks.[27,71,73,75] However, in the USA, social networks of older adults with HIV (50+yrs) were mostly composed of smaller (fragile) networks of older friends (often living with HIV), whom they relied on than family members for support.[43–46] Previous literature on HIV indicates that women were more likely to care for PLWH than men.[1,21] This study also found that most YALWH, regardless of gender, had most contact with either their mothers or older sisters whom they regularly turned to, for support. Similarly, adolescents living with HIV in Uganda had connections and drew support largely from biological parents, followed by grandparents-who were most likely to be women.[22] However, family support networks of older adults with HIV in the USA comprised children and to some extent spouses, who only took over the supportive roles following the loss of their older friends, because of sickness (HIV) or death, retirement, or relocation.[25,44] In this study, the choice of the close contacts and confidants by YALWH was based on trust, the ability to keep their HIV status a secret, a tolerant attitude, peer relationships, and the ability to support YALWH with daily basic needs or any other care. Similarly, trust was key in selecting ART treatment supporters of the adults (23–69yrs) living with HIV in Uganda, who were close family members, lived nearer, and provided support.[1,69]

Within bonding networks, many YALWH in this study disclosed their HIV status to their confidants (especially relatives) only. Similar studies show that YALWH are more likely to disclose their HIV status to their neighbors, family members, and partners compared with their older counterparts (50+yrs).[47–50] However, literature is contradictory about whom older adults (50+yrs) disclose their HIV status;[46] some disclosed to their kin and others to non-kin bonding networks,[46] although much more evidence points towards disclosure to their kin. In the USA and Nigeria, studies show that older adults with HIV are more likely to disclose their HIV status to family members (spouses) compared with non-relatives.[47–49,51] Some YALWH were compelled to disclose their HIV status against their will to the other non-close bonding networks when they anticipated the need for prompt care during emergencies and severe sickness. Similarly, because of ART side effects and HIV wasting syndrome, older PLWH in the USA and sub-Saharan Africa were compelled to disclose their HIV status against their will.[45,46,49,50] Although HIV status disclosure to new sex partners or spouses was much easier for those known by their communities to be living with HIV, fewer participants of this study disclosed their HIV status to their partners, because of the fear of anticipated or enacted stigma, the same reasons cited by older women with HIV in sub-Saharan Africa.[28,51]

Regarding bridging networks, YALWH belonged to a network of non-formal supportive community groups within their vicinity, with many of these groups providing financial services. Likewise, bridging networks of adults with HIV in Ethiopia and Zimbabwe mainly comprised non-formal (indigenous community initiated) groups and rarely formal groups (linked/facilitated by governmental and non-governmental organizations).[67,68,71] This study demonstrates that non-formal community groups may play a supportive role to YALWH on ART in places where formal community groups are scarce, like in Sub-Saharan Africa.[24] Like in a previous study,[23] peer support groups were also found to help YALWH to live positively and come to terms with the HIV disease. This was partly attributed to the non-judgmental culture embedded in such groups. However, because it was a prerequisite for YALWH to pay a fee to join the community groups, those with limited finances missed the benefits that those belonging to community groups obtained. In this study, except for the peer support groups, most participants that belonged to groups disclosed their HIV status to a close friend in their group to avoid the perceived group stigma. Similarly, in previous studies, because of the constant burden of remembering whom they disclosed to and the lack of assurance from those they disclosed to, that they shall keep their HIV status confidential, PLWH rarely disclosed their HIV status to everyone in their groups.[23,50]

In terms of linking networks, some of the YALWH had connections with counselors, nurses, or expert clients at the health care facilities where they obtained ART. In addition, some of these networks acted in more than one role as bonding and linking networks, consistent with studies conducted in Uganda, Kenya, and Zimbabwe among adults and youth with HIV (>18 years) where health professionals acted concurrently as bonding and, or bridging networks.[21,68,72] In addition, YALWH in this study disclosed their HIV status to only those linking networks they were related to as relatives, friends, or neighbors and those directly involved in their care. Similarly, the literature from developed countries shows that younger adults with HIV are more likely to disclose their HIV status to health professionals than older adults (50+years).[43,47]

Barriers to ART Adherence Among YALWH

In this study, we found the most cited barriers to ART adherence among YALWH to be structural (eg, stigma and drug stock-outs), followed by medication (eg, pill burden) and patient-related barriers (eg, non-disclosure of HIV status and forgetting to take ART). This pattern of barriers to ART adherence was similar to one observed among older adults with HIV in sub-Saharan Africa.[52–59] but very different from that in developed countries. Barriers to ART adherence among adults with HIV in the developed countries were mainly patient-related followed by structural and lastly medication-related barriers, with the health care services and system-related barriers the least reported sub-category of structural barriers.[60]

The findings of our study also have some similarities and differences with barriers to ART adherence among adolescents and children with HIV. Like barriers to transition from adolescent to adult HIV care clinic,[2,17,18] we found that because of lack of privacy, the undifferentiated care services in the adult HIV care clinic negatively influenced ART adherence among YALWH. However, a recent systematic review among adolescents in sub-Saharan Africa found that most barriers to ART adherence were patient-related, followed by caregiver-related barriers, health system-related barriers, and medication-related barriers.[65] In addition, in sub-Saharan Africa, because children depend on their caretakers to adhere to ART, most of the barriers to ART adherence are caretaker-related, followed by child-related ART adherence barriers.[61–64]

Perceived Roles of Social Networks

This study found that support from bonding networks was perceived to play a significant role in overcoming structural, medication, and patient-related barriers. Specifically, support extended to YALWH by bonding networks as instrumental, informational, and emotional support, reminders, and peer-to-peer support helped overcome barriers to ART adherence such as financial constraints, medication side effects, forgetfulness, and drug stock-outs. This finding agrees with the literature from Ethiopia, Uganda, Kenya, Zimbabwe, and Mozambique, about adults and youth with HIV where again family and friends provided among others, food, money, encouragement and love, and reminders that helped them overcome multiple barriers to ART adherence.[27,67,71,72,75] Consistent with findings from the USA and South Africa among adult and older patients (50+) with HIV [47,68], this study also found that bonding networks, particularly family members, were also key in protecting some of YALWH against stigma and also helped them cope with HIV.

Instrumental, informational, and peer-to-peer support from bridging networks of the YALWH in this study helped to overcome structural barriers such as lack of finances for food and transport. This finding corroborates findings in Ethiopia, Mozambique, and Zimbabwe where non-formal groups were a key source of financial, nutritional, and psychosocial support among many others.[67,68,71–74] However, fewer participants of this study thought that bridging and bonding networks had a role in overcoming health system-related barriers. This was partly because of the inability to disclose health system-related barriers to their networks, second to a perception that they would do nothing to change them.

In addition, we found that informational and emotional support, reminders, and keeping or reserving ART for their clients were the commonest forms of support from linking networks that helped overcome structural (health systems) and medicine-related barriers. In Uganda, Kenya, and Zimbabwe, linking networks that composed of doctors and nurses were also found to be helpful in access to scarce financial resources, providing regular reminders, informational, and emotional support to take ART, and contributed to the reduction in stigma among adults and youth with HIV.[24,67,72]

Implications and Recommendations of the Study

The study findings discussed in this section have future implications for YALWH, government, and non-governmental organizations (NGOs, public and private), healthcare workers (HCWs), and all other stakeholders dealing with HIV. There is a need to build the capacity of YALWH, especially those that behaviorally acquired HIV and have never attended adolescent clinics, on how to disclose their HIV status to others and prepare them to handle the short- or long-term consequences that come with HIV status disclosure. YALWH need to be encouraged and supported by the healthcare team to disclose their HIV status to a wider network of family and friends in order to obtain more support from those networks. However, this requires that family level barriers such as stigma and misconceptions about HIV and its treatment are mitigated first. Therefore, there is also a need for community-related interventions targeting stigma in the networks of YALWH; as well as, how to support YALWH upon HIV status disclosure. These interventions should target the informal networks (family, friends, and groups), and small enterprises (salons, bars, and restaurants) where most of the YALWH work.

In addition, to help mitigate some of the health system and medication-related barriers to ART adherence, adult ART clinics' managers may allocate and train a youth-friendly clinician or a youth expert client or all the ART clinic staff to provide youth-friendly services, routinely, identify and counsel those who are most risk of low ART adherence, and also act as rights advocates for the YALWH in those health care units. In order to alleviate barriers to ART adherence such as financial constraints, long waiting lines and times, and issues related to drug stock outs, the ART clinic staff may need to organize YALWH into peer groups and link them to governmental and non-governmental organizations providing ART (health facilities) for support or use them to obtain ART for their colleagues rotationally.[67,72] It is also worth noting, that despite the global effort towards mitigating barriers to ART such as side effects, pill burden, and pill size, negative community perceptions about these barriers to ART adherence still exist as observed in this study, thus additional counseling and teaching are needed to change the minds and hearts of PLWH at an individual level. Our findings also show gaps in current strategies to mitigating ART adherence barriers, such as moving with ART in case of changes in daily routines. In situations of community stigma, non-disclosure of HIV status, and noisy pill packages as reported in this study that may be difficult to achieve, thus it is important that YALWH are advised and taught how to re-package their medicines upon movement. Also, as shown in this study, in overcoming forgetfulness among the newly diagnosed YALWH on ART, YALWH may need to complement telephone reminders with reminders from a treatment supporter who may be part of their close network, to provide encouragement to take ART.

In conclusion, future social network group interventions created by policymakers, non-governmental organization (NGOs), researchers, and health care workers (HCWs) should ensure that they respond to the ART adherence needs of YALWH through the provision of resources (loans, social or psychological support). Where possible, stakeholders may also help YALWH to join existing or start-up their groups, manage and grow them. Social network groups created should preferably be diverse, include young adults irrespective of their HIV diagnosis to reduce stigma, or comprise peers of YALWH. These peer groups could be attached to the adult ART clinics to advocate for YALWH. Besides, these groups should have no or lower membership fees, to avoid discouraging many from joining. Stakeholders should train these groups of YALWH on how to handle challenges of HIV status disclosure by their colleagues and how to support YALWH, group development, and advocacy skills. In the end, these groups should be able to attract YALWH, provide support to them, collect ART for their colleagues (especially those who are busy, sick, or cannot afford transport costs), and advocate (engage) for their health rights at the health care units (formal structures), to overcome health systems related barriers.

There are limitations to this study that may influence its conclusions. Because of the COVID-19 pandemic, we changed the sites of data collection from a district hospital and regional referral hospital to the nearby primary health care facilities. The findings of this study may not also be generalized to a wider HIV population of YALWH, since this is a qualitative study. In addition, most of our participants were newly diagnosed and had just started taking ART, thus the findings of our study may not represent YALWH who are on long-term ART or enrolled in chronic HIV care. Although a considerable amount of time was invested in the data collection process, it is possible that during the conduct of this study we might not have reached the saturation point of data owing to the smaller number of FGDs (04). In addition, with FGDs, there may be a tendency for some participants to be influenced by what other participants say, particularly when the topic is sensitive like in this study, thus introducing bias. Last, data were not analyzed by urban/rural stratification or by sex/gender as these characteristics might have influenced the barriers to ART adherence reported in this study. Nevertheless, we provide a full description of the study participants, contexts, and a thick description of their verbatim accounts, allowing researchers in the field to compare and contrast these study findings with other age-groups or YALWH in other contexts.

Conclusions

Overall, most YALWH belonged to bonding networks compared with bridging or linking networks. Thus, YALWH not connected to such networks (bridging and linking) were more likely to miss out on the support they provide, which is important in overcoming multiple barriers to ART adherence. In addition, we found the most cited barriers to ART adherence among YALWH to be structural, followed by medication and patient-related barriers. Given that bonding networks were perceived to help mitigate many barriers to ART adherence, except for health systems-related barriers, we suggest that bonding networks seem to play a prominent role in overcoming patient, medication, and other structural-related barriers to

ART adherence compared with bridging and linking social networks. However, future studies (especially quantitative research) are needed to further explore or confirm the relationships and conclusions made in this study among YALWH from various contexts.

Abbreviations

YALWH, young adults living with HIV; ART, antiretroviral therapy; PLWH, people living with HIV/AIDs; FGD, Focus group Discussion.

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Disclosure

The authors declare no conflicts of interest in this work.

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