

# 'You Are Always Worried and Have No Peace, You Cannot Be a Normal Adolescent': A Qualitative Study of the Effects of Mental Health Problems on the Social Functioning of Adolescents Living with HIV in Uganda

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## Abstract

Adolescents living with HIV (ALHIV) are at heightened risk of experiencing mental health problems. However, research on the impact of mental health problems on ALHIV's everyday life is scanty. This article explores the effects of anxiety, depression and suicidal behaviour on the social functioning of ALHIV in a low-resource setting. The three mental health conditions were screened using the Patient Health Questionnaire modified for adolescents (PHQ-A) and Screen for Child Anxiety Related Disorder (SCARED), while social functioning was defined by normative role expectations of adolescents in the study setting. We conducted in-depth interviews with 31 ALHIV receiving care at two hospitals in Central Uganda. Data were analysed using thematic analysis techniques. We found that mental health problems impair the social functioning of ALHIV by obstructing them from realising normative expectations of adolescents within their socio-cultural milieu, including academic excellence, maintaining amicable relationships and good physical health. In a context of scarcity, impaired social functioning has grave implications for ALHIV's physical, psychological and social and economic wellbeing and concomitantly HIV treatment outcomes in the immediate and long term. Integration of mental health into HIV care is imperative, if the global goal to end AIDS is to be achieved.

## Keywords

adolescents living with HIV, anxiety, depression, mental health, social functioning, suicidal behaviour, Uganda

## Plain Language Summary

### *The effects of mental health problems on the daily lives and functioning of adolescents living with HIV in Uganda*

Adolescents living with HIV (ALHIV) have an elevated risk of suffering from mental health problems particularly depression, anxiety and suicidal behaviour (which includes suicidal ideation, suicide attempts and self-harm) compared to their negative peers. In spite of the high burden of mental health problems among ALHIV, there is little research on how they impact their daily life and functioning. This article examines the effects of depression, anxiety and suicidal behaviour on ALHIV's ability to meet standards of behaviour, attitudes and roles and responsibilities expected of adolescents in their communities. Interviews were held with 31 ALHIV receiving HIV treatment at two health facilities in Uganda. We found that having suicidal behaviour and symptoms of depression and anxiety made it immensely difficult for ALHIV to live by expected standards for adolescents in their communities, including academic excellence, ability to initiate and maintain good relationships with others in their social network and looking physically healthy. In a low-resource setting, problems in conforming to expected social and behavioural standards increases ALHIV's risk for social isolation, poverty and poor physical and mental health and consequently poor HIV treatment adherence

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in the present and future. High levels of adherence to HIV treatment are critical for ending the HIV/AIDS epidemic. Therefore, it is important that the mental health needs of ALHIV are urgently addressed by integrating mental health into child and adolescent HIV care, if real progress towards achieving the global goal to end HIV/AIDS by 2030 is to be realised.

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## Introduction

Adolescence is a critical and formative stage of transition from childhood to adulthood.<sup>1</sup> The rapid physical, cognitive, emotional and social changes that occur during adolescence elevate the risk to mental health problems.<sup>2–4</sup> It is estimated that one in seven adolescents (about 166 million) aged 10–19 experience mental disorders globally.<sup>3,5</sup> Anxiety, depression and suicidal behaviour are among the leading causes of morbidity and disability among adolescents the world over.<sup>3,6,7</sup> According to the United Nations Children's Fund (UNICEF), the burden of anxiety and depression among adolescents aged 10–19 is as high as 40%.<sup>5</sup> This rate is mirrored by Shorey and colleagues who estimate the global prevalence of elevated depressive symptoms among adolescents at 34%.<sup>4</sup> In addition, suicide is the fourth leading cause of death for adolescent girls and boys aged 15–19,<sup>3,5</sup> while suicidal behaviour, including suicidal ideation, suicide planning and suicide attempt, is particularly common among adolescents in low- and middle-income (LMIC) countries.<sup>8</sup>

The risk of experiencing mental health problems is compounded for adolescents living with HIV (ALHIV). Several studies report a higher burden of mental disorders among ALHIV compared to their HIV-negative peers.<sup>9,10</sup> In the United States, Mellins and colleagues found that non-substance use psychiatric disorders were notably higher among ALHIV (61%) compared to their uninfected colleagues (49%), with anxiety being the most prevalent condition.<sup>9</sup> In sub-Saharan Africa (SSA), where about 85% of ALHIV live, studies comparing the prevalence of mental disorders among ALHIV and uninfected adolescents are limited.<sup>11</sup> However, available evidence portrays a high burden of psychiatric disorders among ALHIV in the sub-region. A systematic review found that 30%–50% of ALHIV in the region experience emotional and behavioural difficulties or significant psychological distress.<sup>12</sup> In Kenya, Kamau and colleagues found that approximately half (48.8%) of the surveyed children and adolescents in a resource-constrained urban area suffered from psychiatric morbidities, such as major depression and social phobia, with a higher burden among HIV-positive participants.<sup>13</sup>

Studies in the southern part of SSA further highlight the high burden of mental health problems among ALHIV. In Malawi, a cross-sectional survey found that 18.9% of ALHIV suffered from depression, while 7.1% had suicidal ideation.<sup>14</sup> In South Africa, Woollett and colleagues reported that 27% of HIV-positive adolescents had depression, anxiety or post-traumatic stress disorder, while 24% had experienced suicidal behaviour.<sup>15</sup> Similarly, in Botswana, a

high burden of depression (23%) and suicidal behaviour (18.9%) was reported among ALHIV.<sup>16</sup>

In Uganda, an older survey revealed that over half (51.2%) of ALHIV had significant levels of psychological distress (anxiety and depression), with 30% showing psychotic symptoms and 17.1% having attempted suicide within the preceding year.<sup>17</sup> A more recent study of children and adolescents attending a paediatric HIV clinic in Uganda reported a burden of suicidal ideation of 17%.<sup>18</sup> The high incidence of mental health problems among adolescents and the general population of people living with HIV (PLHIV) globally<sup>19–23</sup> is associated with the psychosocial stresses of living with HIV and the direct effects of the virus and its treatment on the central nervous system.<sup>24,25</sup> HIV is associated with neuropsychiatric complications such as mania, while its treatment may cause mental-related side effects on the central nervous system including depression.<sup>24,26</sup> Among perinatally infected children, the deleterious effects of the HIV virus on brain development endure into adolescence and young adulthood, heightening their risk to psychiatric disorders.<sup>27,28</sup>

Additionally, the news and consequences of HIV infection including stigma, loss of social support, uncertainty about the future and difficulties of coming to terms with their positive HIV diagnosis and adjusting to living with a lifelong infectious illness are cited as common causes of depression, anxiety and suicidal behaviour among PLHIV.<sup>19,22–24,29,30</sup> For ALHIV, these challenges are intensified by the complex developmental transitions of adolescence, which heightens their vulnerability to mental health problems. For instance, during adolescence, social relationships with peers and romantic partners gain importance.<sup>1,31,32</sup> As such, experience of stigma and rejection from peers can be particularly devastating.<sup>15,33–39</sup> Moreover, navigating dilemmas associated with HIV status disclosure, such as deciding when to tell and the fear of possible transmission of HIV to intimate partners, places extra psychological strain on ALHIV involved in romantic relationships.<sup>2,30,33,35</sup> For perinatally infected ALHIV, HIV status disclosure often coincides with the onset of adolescence<sup>40</sup> and a developing sense of identity.<sup>41</sup> Learning about their positive HIV status at this critical stage can be extremely distressing, distort their self-concept and strain familial relationships.<sup>11,30,40,42,43</sup> Several ALHIV are AIDS orphans, a status that deprives them of parental affection, support and guidance at a critical development stage.<sup>35,42,44</sup> The loss of a parent often triggers adolescents' own fears of death.<sup>2</sup> In addition, several ALHIV in resource-poor settings grapple with hunger and limited

access to education and healthcare services due to poverty and neglect from caregivers.<sup>12,34,44,45</sup>

While research on the mental health of ALHIV has increased in the last decade, much of it focuses on the prevalence and correlates of mental disorders.<sup>9,10,14,15,35,44,46</sup> Research on the impact of mental health problems on the social functioning of ALHIV is limited.<sup>10,47</sup> Yet budding evidence associates mental health disorders with impaired social functioning.<sup>48–52</sup> For instance, data from a longitudinal study of depression and anxiety in the Netherlands revealed increasing levels of social dysfunction among affected individuals, with patients with comorbid anxiety and depressive disorders showing the most severe impairments.<sup>53</sup> Another study found significant and negative association between social functioning and psychiatric disorders among youth who presented with early-stage psychiatric symptomatology.<sup>52</sup> The negative association of mental health problems and social functioning does not augur well for HIV treatment outcomes. Indeed, mental health problems have been associated with poor HIV treatment outcomes,<sup>24,25,54</sup> which may be a corollary of social dysfunction. In a study of adolescents and adults living with HIV in South Africa, Haas and colleagues found that mental health diagnoses increased the risk for poor antiretroviral therapy (ART) adherence and viral non-suppression, particularly among adolescents and young adults.<sup>55</sup> Similarly, a systematic review and meta-analysis identifies depression and substance and alcohol abuse as significant barriers to ART adherence among children, adolescents and adults living with HIV globally.<sup>56</sup>

Adequate social functioning is critical for human wellbeing and survival<sup>53</sup> and in the era of ART-positive treatment outcomes. Therefore, lack of evidence on how social functioning is affected can undermine the development of interventions to prevent and respond to mental health issues among ALHIV, due to limited appreciation of their gravity. Evidence is particularly critical in resource-limited settings where gaps in integrating mental health into the care for HIV are apparent.<sup>21</sup> Moreover, integration of mental health with HIV services is one of the key priority actions in the global AIDS strategy 2021–2026.

This article provides insights into the lived experiences of ALHIV (here defined as individuals aged 10–19) grappling with suicidal behaviour and symptoms of anxiety and depression. It explores how suicidal behaviour and symptoms of anxiety and depression affect the social functioning of ALHIV. Social functioning defines an individual's interactions with their environment and the ability to fulfil the role expectations associated with their status within such settings.<sup>57,58</sup> In this article, social functioning is conceptualised as ALHIV's ability to realise the values that define a normal adolescence within their socio-cultural settings. These values shape the normative behaviour and roles and responsibilities adolescents are expected to assume in their communities. The article addresses two main research questions: (1) how do ALHIV define a normal adolescence within their socio-cultural settings and (2) how does suicidal behaviour and symptoms of anxiety and depression affect ALHIV's ability to realise a normal adolescence as defined within their socio-cultural settings?

## Materials and Methods

### Study Design, Setting and Population

This article draws on primary data from a study that aimed to examine mental resilience among ALHIV experiencing symptoms of anxiety and depression and suicidal behaviour. A descriptive study design was employed to provide a detailed account of how suicidal behaviour and symptoms of anxiety and depression affected ALHIV's social functioning, that is, their ability to realise values that they conceived as defining a normal adolescence within their socio-cultural settings.<sup>59</sup> Grounded in interpretivist epistemology and constructivist ontology, the study took a qualitative approach that enabled deep insights into the lived experiences of ALHIV suffering from mental health problems and the meanings they attached to them.<sup>60</sup>

The study population included ALHIV aged 10–19 who were manifesting symptoms of anxiety and depression and experiencing suicidal behaviour within 6–12 months preceding the study. These adolescents were enrolled on the HIV treatment programmes of Mukono and Naggalama general Hospitals, both situated in Mukono District in Central Uganda. ALHIV constitute a small fraction (6.3%) of the population of PLHIV in Uganda,<sup>61</sup> which necessitated the focus on two treatment centres to generate a considerable number of ALHIV to screen for the 3 mental health problems (anxiety, depression and suicidal behaviour) of interest.

Mukono is the seventh most populous district in Uganda, with a population of about 596 804 people.<sup>62</sup> The district has a high prevalence of HIV, of about 7%,<sup>63</sup> which is higher than the national average of 5.1%.<sup>64</sup> Mukono and Naggalama are the largest health facilities in Mukono District. They attract PLHIV from the surrounding districts, including Kampala City, which is about 20 km away. From the records of the two hospitals, the population of ALHIV aged 10–19 enrolled for HIV treatment programmes was estimated at 226 at the time of the study.

### Sampling

Sampling was preceded by the screening of 169 ALHIV, 72 being clients of Mukono Hospital and 97 from Naggalama Hospital, for the three mental health conditions. The two health facilities lacked a register of ALHIV with mental health problems because they were yet to integrate routine screening for mental disorders in their HIV treatment programmes. Therefore, as one of the preliminary activities, we conducted screening to generate a list of eligible ALHIV (with symptoms of anxiety, depression and suicidal behaviour) from which to select participants for the study. The initial step in the screening process was the assembling of a register of ALHIV enrolled in the treatment programmes of Naggalama and Mukono general hospitals with the assistance of health workers and records personnel. The identified ALHIV were then contacted and arrangements made for them to visit the respective health facilities for screening. The ALHIV were

screened for symptoms of anxiety, depression and suicidal behaviour in the 6–12 months preceding the study. The screening was conducted over a 2-week period by four psychiatric clinical officers who were experienced in diagnosing mental health conditions among children and adolescents. Anxiety was assessed using the Screen for Child Anxiety Related Disorder (SCARED), while depression and suicidal behaviour were screened via the Patient Health Questionnaire modified for adolescents (PHQ-A). The PHQ-A scoring system ranges from 0 to 27, with scores of 10 and above classified as a positive indicator. For the SCARED, a score of  $\geq 25$  indicates a positive result. Both tools are accessible free of charge and commonly used in psychiatric facilities in Uganda. The PHQ-9 has been validated among Ugandan adolescents and adults.<sup>65</sup> However, the SACRED is yet to be validated.

Following the screening, a total of 32 (16 per health facility) out of the 75 who scored positive for SCARED and/or had depression symptoms ranging from mild to moderate and severe were selected to participate in the study. However, only 31 responded. Guest and colleagues demonstrate that about 12 cases are enough to reach data saturation.<sup>66</sup> Therefore, the sample size of 31 participants was sufficient to attain data saturation while capturing the variations that exist among ALHIV with mental health problems.

The participants were selected using a purposive sampling methodology. The selection criterion was maximum variation on the basis of age, gender, mental health condition (including suicidal behaviour, depression, anxiety or their combinations), health facility and schooling status. This selection criterion provided us broad insights into the diverse experiences of ALHIV suffering from mental health problems. The selected adolescents were contacted and facilitated to come to the treatment centre for interviews.

### **Data Collection**

Data were collected in September 2022, strategically timed before the commencement of the new school term in Uganda, to enable meaningful participation of in-school ALHIV. The data were collected with the assistance of two research assistants with experience in conducting qualitative research among children and adolescents. Face-to-face in-depth interviews were held with each of the 31 ALHIV using a guide. The guide was generated on the basis of themes from the study objectives and the resilience theory.<sup>67</sup> According to the theory, resilience is an outcome of a dynamic interaction of risk and protective factors.<sup>68,69</sup> In this case, the theory enabled us to capture the psychosocial risks the three mental health conditions posed for the realisation of the values that define a normal adolescence by ALHIV. The guide comprised open-ended questions to enable the participants express their views and narrate their experiences in their own words. The interviews lasted approximately 40 min and tackled questions on adolescents' conceptualisations of a normal adolescence in their socio-cultural milieu and how the mental health conditions of anxiety, depression or suicidal behaviour affected the

fulfilment of these expectations. Probes and prompts were used to seek clarifications or deeper descriptions and explanations where necessary. The interviews were held at the treatment centre. The interviews were conducted primarily in Luganda, the main language used in the central region of Uganda, to ensure comprehension and accurate interpretations of questions asked. In instances where participants were not proficient in Luganda, English, another widely spoken language in Uganda, was used. The discovery-oriented approach offered by the interviews enabled an in-depth exploration of the experiences, feelings and perspectives of study participants.<sup>70</sup> Interviews were audio recorded with the consent of the participants.

### **Data Management and Analysis**

Each in-depth interview was transcribed verbatim and where necessary, translated into English. The resultant transcripts were then word processed and imported into NVivo version 12, a qualitative data analysis software, for further management. The analytical approach was thematic, employing both deductive and inductive strategies.<sup>71</sup> Deductive thematic analysis drew upon predetermined themes generated from the study objectives, theoretical framework and research questions. In contrast, inductive analysis focused on themes and categories that naturally emerged from the data. Themes were initially generated during transcription and refined through iterative coding as the analysis unfolded. The analysis process involved repeatedly reading individual transcripts and coding the relevant sections, paragraphs and words according to categories and themes generated from the research questions and the data.

### **Ethical Approval and Informed Consent**

Ethical approval was obtained prior to the commencement of the study. Written informed assent was obtained from minors aged 10–17, as well as informed consent from their caregivers. In addition, written informed consent was obtained from adolescents aged 18–19. The consent process involved a detailed explanation of the study purpose, selection criteria, the potential benefits and risks of participation and their right to voluntary participation and to withdraw from the study at any point, where they could address any complaints about the study, as well as permission to audio record the interviews. The fact that their refusal to participate or withdrawal from the study would not in any way affect access to services at the treatment centre was emphasised. Informed consent to participate in the study was obtained once. Participants who consented to the screening were also asked to provide consent to participate in the main study, if they were identified with any of the mental health conditions of interest. Steps were taken to observe and maximise confidentiality, privacy and anonymity of study participants. Interviews were conducted in private spaces within the treatment centre to minimise our conversations being overheard. Access to data by unauthorised people was minimised by locking computer files with passwords and deleting the audio

interviews after transcription. The participants were assigned pseudonyms to conceal their identities. Accordingly, only pseudonyms are used in this article. To facilitate ALHIV's access to mental health care, we referred all the study participants with a positive diagnosis to social workers at the two treatment centres for linkage to care. In addition, a list of ALHIV with symptoms of any of the 3 conditions but had not been selected for the study was compiled and submitted to social workers at the treatment centres for follow-up and linkage to mental health care. All the referrals were effected with the consent/assent of the concerned adolescents and their caregivers, where applicable.

## Results

### Characteristics of Study Participants

Sixteen out of the 31 ALHIV identified as female. Most (20) were older adolescents aged 15–19. Most (18) were enrolled in educational institutions. Of these, only 2 were in vocational school, while the rest were in formal school. Six of the out-of-school ALHIV were engaged in various forms of employment such as casual labour, petty trade, hairdressing and construction work. In regard to mental health, most (14) participants had symptoms of both anxiety and depression, 8 had co-occurring symptoms of anxiety, depression and suicidal behaviour (including suicide attempts and suicidal ideation), 4 had only depression and 1 participant suffered from only anxiety (see Table 1).

### Themes and Sub-Themes

The article is based on two major themes and three sub-themes as summarised in Table 2. Main theme 1 (conceptions of normal adolescence) includes a myriad of values that stipulate the

**Table 1.** Characteristics of study participants.

Characteristic	Frequency (N = 31)	%
Gender		
Female	16	51.6
Male	15	48.4
Age (years)		
10–14	11	35.5
15–19	20	64.5
Schooling status		
In-school	18	58.1
Formal (16)		
Vocational (2)		
Out of school	13	41.9
Employed (6)		
Not employed (7)		
Mental health problem		
Depression and anxiety	14	45.2
All 3 conditions	8	25.8
Depression	4	12.9
Depression with suicidal behaviour	4	12.9
Anxiety	1	3.2

acceptable attitudes and behaviours expected of adolescents within the study setting, as reflected in categories such as enrolling and excelling in school. Main theme 2 (effects of mental health problems on social functioning) consists of two sub-themes: mental health problems categorised as anxiety, depression and suicidal behaviour and poor social functioning reified in ALHIV's inability to conform to normative expectations and standards, such as educational and economic success as reflected in the categories of the sub-theme (acceptable behavioural and attitudinal standards) of main theme 1.

In the subsequent sections we present data on the two main themes: ALHIV's conceptions of normal adolescence and how anxiety, depression and suicidal behaviour affected ALHIV's social functioning (the realisation of the values that define a normal adolescence as conceptualised by ALHIV).

### Conceptions of Normal Adolescence

ALHIV in our study outlined a range of values that typify a normal adolescence within their socio-cultural setting. The categories include enrolling and excelling in school and working hard to earn a living if out-of-school, contributing to household chores, discipline and good behaviour, good relationships with people, good personal hygiene and physical health, abstinence from sexual relationships and being God fearing. However, the categories are not mutually exclusive. For instance, contribution to household chores, abstinence from sexual relationships and maintaining good relationships with people were commonly described as part of the good behaviour expected of adolescents.

*Enrolling and Excelling in School and Working Hard to Earn a Living If Out of School.* There was general consensus that adolescents should be in school, whether formal or vocational – where they are learning a trade such as tailoring or carpentry. Adolescents were also expected to not only concentrate in class, work hard and excel but also remain in and complete the school cycle. Acquiring an education was seen as a critical ingredient in their future success as one participant explained:

She [adolescent] should be in school. She has to work hard at school and also learn vocational skills. They have to remain in and complete school. With today's employment situation they cannot employ someone who doesn't have an education. It becomes easy for someone who has an education to get a job and be successful. (IDI with 14-year-old female)

They [normal adolescents] should be in school and concentrate in class. They should read their books and perform well at school. (IDI with 14-year-old female)

They [normal adolescents] don't miss school or class work given by teachers... They report to school on time. (IDI with 15-year-old male)

Adolescents who were not in school were expected to work hard to earn an honest living rather than turn to criminal activity such as stealing for survival:

**Table 2.** A summary of themes and sub-themes.

Main theme 1	Sub-theme	Categories
Conception of normal adolescence	Acceptable behavioural and attitudinal standards	<ul style="list-style-type: none"> <li>• Enrolling and excelling in school</li> <li>• Working hard to earn a living</li> <li>• Contributing to household chores</li> <li>• Discipline and good behaviour</li> <li>• Good relationships with people</li> <li>• Good personal hygiene and physical health</li> <li>• Abstinence</li> <li>• Being God fearing</li> </ul>
Main theme 2	Sub-theme	Categories
Effect of mental health problems on social functioning	Mental health problem	<ul style="list-style-type: none"> <li>• Anxiety symptoms</li> <li>• Depression symptoms</li> <li>• Suicidal behaviour</li> </ul>
	Poor social functioning	<ul style="list-style-type: none"> <li>• Poor educational outcomes</li> <li>• Low economic achievement</li> <li>• Poor physical health and ART adherence</li> <li>• Impaired ability to perform domestic chores</li> <li>• Strained relationships</li> <li>• Being labelled poorly behaved</li> </ul>

The most important thing should be, if they are not in school, they should work to earn a living. They should work hard and not steal people's property or beat people to rob them of their property. Rather, they should be good adolescents who want to work and sustain themselves. (IDI with 18-year-old male)

**Contributing to Household Chores.** All the adolescents indicated that they were expected to contribute to household chores, including cleaning the house, washing dishes and gardening and farm work for those from households relying on agriculture for a livelihood. Contributing to household chores was perceived as a demonstration of good behaviour and responsibility:

He [adolescent] should fetch water, help out in cultivating, cooking food, washing dishes, washing clothes, mopping the house, sweeping the courtyard and grazing the animals if they are to be well behaved and responsible. (IDI with 18-year-old male)

They [adolescents] should do all the chores at home; not to leave all the work to parents. They should sweep the compound, mop the house, slash the compound, fetch water and anything else they can do at home to make their parents proud of them. (IDI with 19-year-old male)

However, some participants indicated that ALHIV could only help out with light tasks given their medical condition. This was based on the advice of ART providers, who generally counsel PLHIV to avoid strenuous work.<sup>72</sup>

There is some hard work we should not do as [HIV] infected people. Like fetching water and carrying jerrycans. But the rest we do, like attending to animals kept at home, sweeping the compound and cleaning of animal shelters, washing clothes and dishes, cooking food, but not heavy work. (IDI with 16-year-old female)

**Discipline and Good Behaviour.** Adolescents were expected to be disciplined and well behaved at home, school and community settings. Key components of discipline and good behaviour were being respectful towards self, parents, peers, teachers and other relations and avoiding destructive behaviour such as substance abuse, violence and criminality:

They [adolescents] should be disciplined and have good manners. They should be respectful towards teachers and friends. You go to school and you don't have bad peer groups. Some adolescents have bad groups and take alcohol and drugs which is not good for them. Such adolescents should also respect themselves and the little children they interact with. (IDI with 10-year-old male)

They [adolescents] have to act respectably before their parents and friends without causing trouble and engaging in fights and other evil acts like raping young girls. (IDI with 19-year-old female)

He [adolescent] must be well behaved. Should not be abusive, not be violent and not a murderer. Don't abuse or fight with your friends but relate well with all of them. He should not steal other people's property. (IDI with 18-year-old male)

Respect for parents and teachers tended to be conceived as adolescents' acknowledgement of their authority. Adolescents were expected to listen to and obey instructions from their parents and teachers as well as seek their permission before undertaking certain activities:

[An adolescent] should respect his parents and do what they tell him to do. When they send you to go and get something, you should oblige. He should pay attention to what his parents tell him. Also, they should not disobey teachers. (IDI with 10-year-old male)

They [adolescents] should be respectful towards parents. Even when you want to go somewhere, you seek their permission. (IDI with 16-year-old female)

Adolescents were also expected to be respectful as they communicated with others. According to Leila, respect should be reflected in the way adolescents talk to people, which had connotations of being polite:

The way they talk to people should be respectful. (IDI with 17-year-old female)

Discipline and good behaviour also involved possession of social skills such as ability to initiate relationships, greeting parents and elders and helping and sharing with others. It also involved proactiveness and taking initiative, rather than idleness, contribution to and prioritisation of collective activities such as household chores rather than personal interests, avoiding trouble by discerning right from wrong and setting boundaries such as on when to return home and where to eat:

Don't loiter around the community aimlessly and come home late. Do chores at home before you do your own things. Don't go eating from other people's homes. (IDI with 16-year-old female)

Adolescents should be disciplined and behave well. Greet people and parents. Do chores at home. Share what you have with others and they also share with you. They [normal adolescents] don't loiter around aimlessly and don't move at night. (IDI with 15-year-old male)

He [adolescent] should make friends and encourage them to do different things. For example, when at school, he should encourage them to revise their books. (IDI with 19-year-old male)

Even minding and taking care of herself knowing the right thing to do and what she shouldn't do that might land her in trouble. That will help her to be a good adolescent. (IDI with 18-year-old female)

**Good Relationships with People.** Adolescents were expected to nurture good relationships with people. This primarily involved being friendly and loving towards their relations, as well as avoidance of conflict and ill treatment of others:

Adolescents should relate well with people. They should make friends and not abuse them, love each other and share with others. They should be friendly and not bully their colleagues. (IDI with 13-year-old male)

They [adolescents] should relate well with people and make friends. Should love his friends; and play with them without fighting or abusing them. You should not overlook people; accept them the way they are. (IDI with 16-year-old female)

**'An Adolescent Must Take Good Care of Themselves to Look Good': Good Personal Hygiene and Physical Health.** Participants

collectively stressed the importance for adolescents to maintain good personal hygiene and physical health as vital components of a positive public image. For ALHIV, looking physically good and healthy entailed showing no symptoms of AIDS. This meant that they had to take responsibility to adhere to the ART regimen to avoid progression to AIDS. Therefore, ART adherence was a key value expectation for ALHIV:

She [adolescent] must look after herself in each and every way. She should have good personal hygiene to be neat and clean. She has to look good. This means adolescents with HIV should not skip days without taking medication to avoid looking like they have the disease [AIDS]. (IDI with 19-year-old female)

They [ALHIV] have to live healthy, whereby no person can notice that they have HIV. They have to adhere to medication just as the health workers direct them. They should try to avoid stress and depression. No need to take overdoses or underdoses to avoid death. They should eat well and have a balanced diet so that the drugs work well. Don't skip appointments when told to return to the hospital. That way they can be seen as normal [adolescents]. (IDI with 15-year-old male)

#### ***Abstinence from Sexual Relationships and Being God Fearing.***

Some participants reported that adolescents were expected to abstain from sexual relationships to avoid negative consequences, particularly unwanted pregnancies and HIV infection:

Adolescents should not engage in sexual relationships. You never know whether someone is infected [with HIV]. They can end up with early pregnancies as boys keep lying to young girls. (IDI with 19-year-old female)

If they are girls, they should avoid sexual relationships with men. Even boys should avoid sexual relationships with women or girls until they finish their studies. They should take care of themselves to avoid sexual relationships at a young age as they can end up infected [with HIV]. (IDI with 19-year-old male)

Several participants mentioned being God fearing as a core value for a normal adolescence, which underscores the centrality of religion in their communities:

An adolescent must be God fearing. They should be prayerful and obey religious teachings. (IDI with 14-year-old female)

#### ***Effects of Mental Health Problems on Realisation of a Normal Adolescence***

ALHIV were asked to explain how the various mental health conditions they experienced affected their realisation of the values that define a normal adolescence in their socio-cultural settings. Results indicate that the symptoms of depression and anxiety as well as suicidal behaviour hindered ALHIV from fulfilling several societal expectations. The symptoms derailed the realisation of expected values through undermining educational

outcomes and economic success, creating misunderstanding, straining social relationships and escalating stigma against ALHIV with mental health problems, undermining performance of household chores and contributing to poor physical health and ARV adherence as described below. A conspicuous exception was their relationship with God, which appeared to be unaffected as they tended to turn to prayer to deal with their symptoms.

*'You Cannot Perform Well': Undermining Educational Outcomes and Economic Success.* Educational and economic success were key values that defined normal adolescence in the study setting. Yet, several adolescents reported that symptoms of depression and anxiety such as poor concentration, excessive worries, restlessness and panic attacks had negatively affected their performance and retention in school as well as caused them financial losses at work. Some in-school ALHIV reported difficulty in remaining attentive during classes largely due to distracting thoughts and in some cases panic attacks. For example, Sharon a primary seven student – who presented with symptoms of depression and anxiety disorders – narrated how the constant worries and thoughts she experienced always distracted her during classes, resulting in poor grades:

When they [the thoughts] come, they can make me miss what is being taught because I do not give it my whole attention. A teacher can be teaching and my eyes are on her but when the mind is not on what she is saying. She might even ask me what she has just said and I immediately panic because I have no idea; my mind was far away. When given exams, I end up failing because I am not always attentive in class. (IDI with 14-year-old female)

Like Sharon, Betty, who presented with symptoms of depression, anxiety disorders and suicidal thoughts, associated her poor academic performance with inattentiveness in class caused by excessive worries. She related how threats to publicise her HIV status from a few peers at school had trapped her in a constant state of worry that had hindered her from being attentive in class, leading to examination failure. Her experience demonstrates the intricate link between HIV-related stigma, poor mental health and social dysfunction:

I am always in a worried state. Some students always scare and threaten me...Those who know that I am on [HIV] medication, they always threaten to inform others about it, which makes me scared and worried all the time. This prevents me from being attentive in class. I end up failing exams. (IDI with 14-year-old female)

For Tina, the inattentiveness was triggered by sudden panic attacks that put her in a momentary state of confusion:

I get sudden panic attacks; the heart starts racing, I feel unsettled and confused. I feel like something wrong has happened at home. In that moment, I feel like leaving school and going back home. But eventually I recollect myself and calm down, then I focus on what the teacher is saying. (IDI with 16-year-old female)

Patrick also reported failing to concentrate and complete his assignments due to excessive fear and worries. He intimated that the struggle with concentration had pushed him on the verge of dropping out of school:

It can affect me; I even fail to write down class work because I am in too much fear and worry. When the teacher gives too many assignments, I cannot finish them because I am worried all the time... I try so hard to remain in school but sometimes I feel it is useless because I just can't concentrate in class. (IDI with 13-year-old male)

Other in-school ALHIV reported missing classes and experiencing difficulties in revising their books due to symptoms associated with anxiety and depression. Yudaya, a secondary school student, related how she sometimes failed to revise her books due to sudden changes in her mood. She nevertheless indicated that the sudden mood swings due to moderate depression had not significantly impacted her grades, as they occurred occasionally:

My mood can just change all of a sudden...I fail to read my books even when I try to force myself...I am lucky they [mood swings] don't commonly disturb me in class. (IDI with 16-year-old female)

Fadison reported often missing classes because of symptoms associated with anxiety and particularly school avoidance. While he reported that frequent absence from class had minimal effect on his academic performance, this behaviour usually put him in trouble with his teachers:

You can be there and hear as if someone [a voice] is telling you to do this and the other...That don't go to school today. And while you are there, then it will tell you, now you go. So, you stay confused like that with such thoughts until you decide to go to school at once. While you're in class, it [the voice] will tell you to go out and play or go to the toilet and you end up disorganized. The teachers will not be happy with you; they will say you are not concentrating. If it tells you to do something and you don't, you feel confused. Sometimes something tells me to run out of class; then I run out and go to play or sit alone somewhere. By the time I come back, the teacher has finished the lesson. But I read through my friends' work and understand it better than those who have been attending the class, so I pass my exams. Only that I get in trouble with teachers for having incomplete work. (IDI with 10-year-old male)

The poor academic performance and trouble with teachers exacerbated the emotional difficulties of some of the affected ALHIV, especially when they blamed themselves for their predicament, while others dropped out of school. Moses provided a poignant account of the emotional turmoil and frustration he endured stemming from his failure to concentrate in class and pass exams:

I feel bad because I cannot concentrate. I am always thinking about the bad things people say to me and have nothing to do [about it], so I end up hating myself and feeling useless! For example, when we



are taught, then it means I will not learn anything, and when they give us exams and I fail them, I feel bad because content was taught but I have failed. I feel bad because the teacher will blame me [for not being attentive]; then I get even more upset. (IDI with 18-year-old male)

While Moses persevered and remained in school, his age-mate Grace was not so resilient. She reported getting discouraged by her poor grades and eventually dropping out of formal school and later her vocational training course:

I can't concentrate when the teacher is teaching, even when given an assignment I can't complete it. I was always failing my exams and repeated one class for years until I got tired and refused to go to school [dropped out]. Some organization supported me to enroll in a vocational training course. But even there, I couldn't concentrate; I was always worried. I was failing assignments. I tried hard to fight and overcome the thoughts, but I failed. I ended up giving up on attending the course because I was tired. (IDI with 18-year-old female)

Whereas adolescents out of school are expected to work hard to sustain themselves, some of them reported losing economic opportunities and income due to acts of commission and omission associated with poor concentration and mood swings. For example, Racheal, who struggled with poor concentration, spoke of the significant financial loss and embarrassment she had suffered out of mistakes committed in the course of running her hairdressing business:

It [poor concentration] has affected me seriously. I have lost money on several occasions because I am working on a customer and at the same time my thoughts are wandering. I end up damaging her hair then she refuses to pay me. On top of that, she will abuse and shame me, which also affects me a lot. (IDI with 17-year-old female)

John illustrated the repercussions of his mental health problems on professional prospects, expressing regret at the loss of economic opportunities. He described situations where due to low moods, he failed to respond appropriately to greetings from community members, leading to misplaced perceptions of him as badly behaved. This, in turn, resulted in a damaged reputation that minimised his chances of gaining employment through community referrals:

Sometimes people greet me when I am not feeling okay [in a low mood] then I do not respond. They always ask what has happened to me and whether I want to learn bad manners. Some label me big headed and that I have no manners. This has affected me in some way; it is hard to find job opportunities these days because no one wants to recommend me. When one person wants to give me a job, another one can tell them that I can't work, that I have bad manners, just because they think I behaved badly towards them. (IDI with 19-year-old male)

*'You're a Bad and Disrespectful Child': Being Misunderstood, Strained Relationships and Escalation of Stigma.* Adolescents were expected to exhibit respectful and non-destructive

behaviour, as well as foster positive relationships with those around them. However, several of our interlocutors reported that symptoms of depression and anxiety as well as suicidal behaviour frequently led to misconceptions about their conduct, resulting in tension that strained their relationships with family, friends and other relations. Such symptoms included sudden mood changes, irritability and anger, isolation, excessive worries and suicidal ideation and attempts. An example was Yudaya who was diagnosed with moderate depression with suicidal thoughts. She related how the sudden changes in her mood had strained several of her friendships, including the closest. She explained that she usually felt like being alone during depressive episodes and was hostile towards friends who attempted to associate with her. Several of them got angry and distanced themselves from her, because they thought she was deliberately ignoring them:

I don't have many close friends. Whenever you are depressed, you reach a point and you don't want to relate with your friends well. My mood can just change all of a sudden when I am with my friends. They can come to me then I chase them; I ask them to leave me alone. Even if it is my best friend, I just push her away. Sometimes I just want to isolate myself and be alone. Some of my friends get angry with me, thinking that I am ignoring them. So, some of them are no longer as close as they used to be. (IDI with 16-year-old female)

Nicholas reported that he isolated himself and was angry and irritable whenever he experienced suicidal ideation. He observed that while in this state, he was easily angered and had verbal altercations with his siblings, which in turn contributed to the deterioration of their relationship:

I don't relate well with my siblings. It is like he [my father] wants me to die. So, I end up feeling bad about everything in life. I feel I should die. Whenever I get those bad [suicidal] thoughts, I don't want to be with people, but alone. I feel angry. I end up quarrelling with and abusing my siblings at home. I can keep quiet and be alone but eventually I feel so bad; then I quarrel with and abuse them. (IDI with 18-year-old male)

Being irritable and angry had also strained Grace's relationship with her daughter. She explained that the irritability and anger she experienced during depressive episodes often culminated into abusive outbursts, which led to her daughter's rejection and refusal to stay with her:

They [depressive episodes] have caused me not to be with my child, because even right now I am not with her and she also doesn't want to be with me. She is with my mother, she doesn't want to be with me because she knows that for example when I am in my low mood then she comes to me, I end up beating or shouting at her. (IDI with 18-year-old female)

Patrick reported getting involved in fights he would probably have avoided if his anxiety symptoms had been managed. He related that his peers avoided him because they perceived him

as a ‘violent and bad child’, which had affected his ability to make friends:

I feel so lonely. My peers don’t want to associate with me. They think I am bad because I have a lot of anger. When I fail to control the anger, I end up fighting with my friends, even where I wouldn’t have wanted to. Such fights are normally aggressive; some of my victims lose their teeth. So, they [my peers] avoid me thinking I am violent. (IDI with 13-year-old male)

Besides their peers, symptoms of anxiety and depression as well as suicidal behaviour also bred misunderstandings and strained relationships between ALHIV and adults in their social networks. Like the peers, the adults tended to perceive ALHIV with mental health problems as destructive and badly behaved, rather than people who were suffering and needed psychiatric help. For example, Juliet grappled with suicidal ideation and had attempted suicide four times by the time we conducted the study. She reported that instead of her caregiver, her elder sister empathising with and seeking help for her following these incidents; she had been bitter and even wished she would die once and for all, which had exacerbated her emotional problems:

They don’t care about me. People annoy me; then I feel like I should just die. I feel so bad; I am not happy at all... I have tried to kill myself four times. I wanted to use a rope. I was going to tie it around my neck and die but some people stopped me. When my sister found out, she was angry. She scolded me and the last time it happened, she told me, ‘Why don’t you die once and for all and go?’. I got so angry and depressed; the bad [suicidal] thoughts came back again. (IDI with 14-year-old female)

Similarly, Leila often found herself in trouble with her caregiver – her aunt – because she was sometimes absentminded due to excessive worries. Instead of her caregiver engaging to understand the cause of her odd behaviour, she beat and harassed her whenever she failed to respond to her calls promptly, because she thought that she was deliberately being disrespectful:

I may be in deep thoughts when my aunt is calling me because she wants something. When I delay to respond, she just comes and beats me up and insults me without caring to know what I am going through. She calls me names; that I am a bad child, big headed and disrespectful. (IDI with 17-year-old female)

These misconceptions sometimes escalated stigmatisation and discrimination of ALHIV experiencing mental health problems. For example, Leila reported being discriminated against and chased away from home because of her behaviour. Asked how her mental health problems had affected her relationships, she remarked:

They have caused me very many problems. For example, I have been beaten, chased away from home and at times discriminated against. (IDI with 17-year-old female)

We have also seen that John (see section on educational outcomes and economic success above) was labelled ‘badly behaved’ and denied job opportunities by community members. These cases underscore the compounding effect of mental health problems on the stigmatisation and discrimination of ALHIV, which can undermine access to vital treatment support.

Other adolescents reported isolating themselves from the broader community due to social and separation anxiety, which constrained them from socialising and making friends as expected. Abraham grappled with intense fears of impending danger to himself and his caregiver – the grandmother – due to separation anxiety. He revealed that he followed his grandmother around to avoid staying home alone and that he could not hang around in the community due to persistent fears of being attacked. As a result, he avoided not only going to school but also interacting with peers in the community, which hindered him from making friends:

I am always worried; I don’t want grandmother to leave me alone. We go to cut grass for the cows together and that is also not good for my health. All the time I worry that something bad will happen to me or my grandmother. I end up fearing all places in the village. So, I don’t want to stay alone. I fear getting out of the home; so, many times I don’t go to school or play with my peers in the community. I worry that a person can come and attack me... You are always worried and have no peace; you cannot be a normal adolescent. (IDI with 15-year-old male)

Then there was Daniel who largely avoided interacting with people due to intense and persistent fears of unintentionally disclosing his positive HIV sero status. He indicated that he preferred being alone, and when he interacted, he proactively sought out those aware of his HIV status. The social anxiety had undermined his ability to initiate and nurture relationships with people, including his siblings. This increased his risk for social isolation and poor treatment outcomes, as social networks are critical for HIV treatment success in contexts of scarcity:

Of course, some youths are not sick [HIV positive]; I can’t associate with them because a positive one can come along and inquire whether I have taken my medicine, and that means the others will find out. That is why these days, I just want to interact with only those youths who are also positive and know my status. Even at work, I do not want to interact with colleagues; I just want to be alone. We talk but I avoid getting close to them. I also do not always spend a full day where I rent [a room], because there are a lot of neighbours. I go to my friend’s home whom I told about my [HIV] status and only return to my place to sleep at night. When I go to the village [natal home], I only interact with those who know my status like my parents. Some of my siblings don’t know so I avoid them... It [avoidant behaviour] affects me in such a way that I don’t have friends. Even those few I have, I don’t want to be so much around them. Yet there are things they know which I don’t know which they would teach me but if I become close to them, they will ask me questions [about my

status], that's why I don't want to be around them. (IDI with 19-year-old male)

Daniel was also selective about the health workers that attended to him whenever he visited the treatment centre. He indicated that he only received care when those particular health workers were available because they were the ones he trusted. This inflexibility was a potential threat to treatment adherence, in the event his preferred health workers took extended leave:

There are health workers whom I go to straight in case I am at the [HIV] treatment centre. They are the ones who know how to handle me, so when I enter that [consultation] room and find another health worker, I get out and wait until the one I want comes... If they are not around, I go back home and return when at least one of them is around. (IDI with 19-year-old male)

Essentially, the symptoms of anxiety and depression as well as suicidal behaviour curtailed ALHIV from realising the standards of good behaviour expected of them including being sociable, obedient and respectful. They also posed a risk to HIV treatment adherence, which was a key expectation of ALHIV, primarily through adverse effects on their social support network.

*'You Feel Tired and Can't Do Any Work at Home': Undermining Performance of Household Chores.* While adolescents were expected to contribute to household chores as a demonstration of discipline and responsibility, symptoms of anxiety and depression often undermined realisation of this goal. Several participants reported that symptoms such as tiredness, low mood and excessive worries and fear commonly disrupted their execution of household chores. Yudaya narrated how the sudden onset of depressive episodes which were punctuated by loss of energy and worries often compelled her to abandon domestic tasks mid-way:

Like I told you, my moods change all the time. I can be in the middle of something; then I suddenly feel weak and fall into deep thoughts. This commonly disturbs me when I am doing [household] chores at home. When it happens, I can even stop washing dishes half way; then I go to sleep and wake up later when I am energized. (IDI with 16-year-old female)

While Yudaya reported experiencing no issues with her caregivers due to her nonconforming behaviour, Abraham was not as fortunate. He often got in trouble with his grandmother when he failed to tend to the cows, due to his intense and persistent fears of danger. He indicated that his fears had extended to the cows, so he couldn't get close to them, and that he sometimes felt too tired and sleepy to do anything:

Sometimes I get nightmares, which increase my fears and panic attacks. I had a bad dream when I had stolen then they beat me badly. From that time, I feared to move away from home any more. I also had a dream when a cow was following me

persistently. When I jumped a big ditch, it stood at a distance and watched me. I ended up fearing those cows at home. I fear to feed them and when grandmother comes back, she quarrels with me, which is not good. And when your life is full of worries, you sometimes don't want to wake up. You feel lazy and can't do any work at home; you oversleep; then grandmother gets angry with you. (IDI with 15-year-old male)

*'You Can Overworry and Stop Taking Medicine': Poor Physical Health and Adherence to HIV Medication.* Some adolescents with depression and anxiety reported experiencing physical symptoms such as headaches and stomach aches. For example, Edward reported feeling headaches whenever he worried too much:

When I worry a lot, I start feeling headache and this makes me feel very bad about myself. (IDI with 18-year-old male)

Similarly, Abraham reported getting headaches and stomach aches when he experienced panic attacks. He indicated that the headaches and stomach aches had contributed to disrupting his learning at school:

I can be in class then I get panic attacks. I become restless; my stomach starts paining. I get headaches. I cannot concentrate; all the time I am running to the toilet and the headache cannot allow me to focus on what the teacher is saying. You miss everything the teacher says; you cannot perform well. (IDI with, 15-year-old male)

Besides physical symptoms, others reported that they often missed their antiretroviral medicine (ARV) doses. For example, Leila reported that the excessive worries, fears and panic attacks she experienced had driven her to self-hatred and poor ARV adherence:

Those feelings [excessive worries, fear and panic attacks] make me hate myself, so sometimes I refuse to take medicine [ARVs] and just sleep. (IDI with 17-year-old female)

Similarly, Sharon revealed that her excessive worries sometimes culminated into hopelessness and then she stopped taking medication. Asked how her mental health condition had affected her HIV treatment, she remarked:

You can overworry and stop taking medicine [ARVs]. When I worry too much, I sometimes become hopeless and stop taking [HIV] medication. (IDI with 14-year-old female)

Sharon further revealed that during anxiety episodes, she usually slept to avoid associating with her peers and felt sick afterwards:

When I have worries, I feel like being alone. I isolate from others; even at school I do not usually hang out with my friends. I isolate myself and decide to go to sleep. This makes me fall sick; I wake up feeling weak and lonely. (IDI with 14-year-old female)

Moreover, some of the participants shared that depressive symptoms such as low moods sometimes inhibited adolescents' access to health care by constraining their communication with health workers:

It [depression] is bad. When you're in a low mood, you may be asked something when you don't feel like talking to them [health workers]. It makes it hard for the health workers to help you. Some are short tempered; once you don't respond, they will not help you. (IDI with 19-year-old male)

As shown, mental health problems directly and indirectly affected HIV treatment outcomes. They discouraged ART adherence, triggered psychosomatic symptoms and undermined the quality of client-provider communication that is critical for effective HIV treatment and care.

## Discussion

We have presented data on ALHIV's conceptions of normal adolescence and how symptoms of anxiety and depression as well as suicidal behaviour affect the realisation of the values that define a normal adolescence within their socio-cultural settings. The aim was to provide insights into the effects of mental health problems on the social functioning of ALHIV. It is our hope that these findings will contribute to evidence on the gravity of mental health problems for the general social functioning and wellbeing of ALHIV and the urgent need to integrate mental health into HIV care, particularly in low-resource settings where gaps are apparent.

### *ALHIVs' Conceptions of Normal Adolescence*

ALHIV identified a range of values that define a normal adolescence within their socio-cultural settings. These include academic excellence and schooling, working to earn an honest living if out of school and discipline and good behaviour including deference for parents and teachers and avoiding anti-social behaviour. Others include contribution to household chores, maintaining good social relationships, good personal hygiene and physical health, abstinence from sexual relationships and being God fearing. The identified values generally encompass the biological and social constructs of adolescence – as associated with onset of puberty and a stage of life between childhood and adulthood, respectively.<sup>73</sup> For instance, the value of abstinence from sexual relationships denotes reproductive maturation. Other values allude to changes in responsibilities from those expected of younger children. These include the expectation for out-of-school adolescents to work to earn a living, contributing to household chores, managing social relationships and taking charge of their treatment if on ARVs. They were also expected to manage their relationship with God and exercise rationality and self-regulation to conform to acceptable behavioural standards. Moreover, emphasis on specific values was commonly justified by associating them with the future success of adolescents in their adulthood. It was, for instance,

contended that schooling and academic achievement were important because they were critical to economic success and employability in the future. This pattern lends itself to the view that societal expectations for adolescents reflect skills and qualities deemed important for success in adult roles.<sup>74</sup>

On the whole, the identified values mirror cherished traditional African social, moral, political, religious and economic cultural values.<sup>75</sup> These include respect for authority including parents, teachers and other elders, hard work, moral uprightness (through avoiding immoral behaviour including criminal activity and illegitimate sex) and centrality of religion in daily life. Others include collective and humane behaviour such as sharing with and caring for others, harmony and peaceful co-existence, maintaining good and cooperative relationships with others, contributing to collective responsibilities such as domestic chores and subordinating individual for collective interest.<sup>75–77</sup> In addition, the identified expectations for adolescents incorporate more contemporary values such as the value for formal education and schooling and respect for others including peers and younger children. In the era of ART, adherence to the treatment regimen to achieve good physical health is also viewed as a key expectation for ALHIV. This attests to the diffusion of traditional African culture with values from other societies.<sup>75</sup> The forces of globalisation and colonialism are key factors in the diffusion of traditional African culture with predominantly western values.<sup>78</sup> Thus, the values that define adolescence in a given setting are more dynamic than static. They are shaped by shifting cultural, social, economic and even political situations within adolescents' environments.<sup>79</sup> This is consistent with the socio-cultural perspective on adolescence which views it as a dynamic and variable development phase emerging from the interaction of individuals and their changing social environments over time.<sup>79</sup>

### *Mental Health Problems and the Social Functioning of ALHIV*

Data show that anxiety, depression and suicidal behaviour affected ALHIV's social functioning (as measured by their ability to realise the values that define a normal adolescence in their socio-cultural settings) negatively. Manifestations of the 3 mental health problems rendered it immensely difficult for our participants to fulfil the standards of conduct, roles and responsibilities expected of adolescents in their socio-cultural settings. Several of them were unable to concentrate and excel in school, while others eventually dropped out. Mental health problems are generally associated with poor educational outcomes for school-going children and adolescents. As shown in our study, mental health problems increased the risk of repeating a grade, truancy, lower academic performance and achievement and dropping out of school.<sup>80–85</sup>

Contribution to household chores, performance in the work place and access to employment opportunities were undermined by various symptoms of anxiety and depression. These symptoms also commonly spoiled relationships with resourceful social networks. Like in our study, anxiety and depressive

symptoms have been associated with unemployment and decreased work performance elsewhere.<sup>48,86,87</sup> Symptoms of anxiety and depression also undermined the physical health of ALHIV by increasing the risk for somatic symptoms such as headaches and stomach aches, failure to access appropriate care in the event of illness and poor ART adherence. As shown, excessive worries sometimes evoked negative emotions such as hopelessness and self-hatred that discouraged ART adherence. Negative impacts of mental health problems on ART adherence among ALHIV have also been reported in previous studies.<sup>36,55,88–91</sup> In addition, our study shows that mental health problems may impede access to quality health care due to their deleterious effects on communication between ALHIV and health workers.

Suicidal behaviour and symptoms of anxiety and depression such as anger, low mood, excessive worries and fear also curtailed study participants from being the humane, sociable, respectful, obedient, cooperative and peaceful adolescents they were expected to be. This strained their relationships with significant others – including caregivers, siblings, friends and general community members. Strained relationships threatened ALHIV's ability to fully integrate into their communities, at the detriment of their development. Developmental psychologists show that adolescents' relationships with parents, peers (siblings and friends) and community are crucial for their personal and social development.<sup>92</sup> For example, dysfunctional family relationships are associated with negative impacts on children and adolescents' emotional and social competences which often endure into adulthood.<sup>93</sup> Research shows that children and adolescents who experience dysfunctional family relationships are more likely to have poor social relationships in adulthood.<sup>94,95</sup> In a context where social networks are not only critical for physical and psychological wellbeing<sup>96</sup> but also daily survival,<sup>97</sup> strained relationships may compound ALHIVs' vulnerability to physical, economic and psychological risk, in the present and future. Indeed, strained relationships with close relations such as caregivers had exacerbated the emotional difficulties of some of the study participants, while others were unable to leverage existing community networks for job opportunities. Moreover, social anxiety threatened initiation of new social networks and uptake of health care services by affected adolescents.

Therefore, neglected mental health problems may trap affected ALHIV in a lifetime cycle of poor mental health, social isolation and poverty.<sup>93</sup> Poverty, weak social support and poor mental health are all associated with poor ART adherence and treatment outcomes among PLHIV.<sup>98</sup> Therefore, unrecognised mental health problems are inimical to ending the AIDS epidemic.<sup>21,99</sup> There is an urgent need to address the specific mental health needs of ALHIV, given their elevated risk for mental health problems<sup>9,10</sup> and the grave implications for their development trajectory.<sup>100</sup> Integration of routine mental health screening in child and adolescent HIV care is imperative to enable early detection and intervention. Early detection and intervention is crucial for averting likely immediate- and long-term adverse effects of mental health

problems on the social functioning and treatment outcomes of ALHIV. Effective intervention also requires that structural barriers in the provision of mental healthcare services to PLHIV and the general population are addressed. These include limited funding, human resource constraints and the stigma of mental illness among service users, health workers and policy makers.<sup>21</sup> Advocacy to increase public expenditure on mental health interventions from a paltry 1% of national health budgets on average<sup>101,102</sup> is critical to provide the financial resources required to facilitate integration of mental health into primary care. This will not only increase the availability of mental health professionals to directly support HIV treatment programmes but also improve access to mental health care at the community level. Campaigns to raise mental health awareness among PLHIV, healthcare workers, policy makers and the general community may help to address misinformation and normalise mental illness.<sup>103,104</sup>

The failure to conform to normative adolescent behaviour may escalate stigmatisation and discrimination of ALHIV, since they are perceived as breaking culturally based norms. For instance, some participants were maltreated and denied job opportunities because their nonconforming actions were misconstrued as being 'big headed' and 'disrespectful' towards adults. Other participants were labelled 'bad', 'violent' and 'unfriendly' and isolated, yet others were judged for attempting to commit suicide or scolded for failing to fulfil their domestic obligations. Such misinterpretations of behavioural expressions of people with mental disorders by their significant others are not uncommon.<sup>48</sup> However, the reported lack of effort to engage and secure professional help for the affected ALHIV, even in incidences of life-threatening suicide attempts, suggests limited awareness and appreciation of mental health issues affecting adolescents by their significant others. Indeed, studies show that mental health literacy in the general population of LMICs is low,<sup>105</sup> including Uganda.<sup>106</sup> This partly explains the limited utilisation of and prioritisation accorded mental health services in these countries.<sup>102</sup>

Increasing utilisation of mental health services by ALHIV requires that both adolescents and their caregivers are educated about the mental health issues that affect adolescents and where to seek help. This could be achieved by integrating topics on the intersections between HIV and mental health into education talks and counselling sessions provided to ART clients on routine treatment days. Improved mental health awareness may enhance uptake of available services and consequently early detection and intervention. As earlier indicated, early detection and intervention is critical to reduce the risk for mental, social and vocational problems in ALHIV's adulthood.<sup>107</sup> Mental health awareness may also increase care and support for ALHIV grappling with mental health issues, thereby improving ART adherence. Such support may also help to address underlying social drivers of poor mental health such as stigma and violence,<sup>15,30,33,35,38,44</sup> as well as protect ALHIV who have received mental health care from relapsing.

A limitation of our study is that it included ALHIV from ART programmes of two health facilities within one district in Central Uganda. Therefore, the reported findings may not reflect the experiences of ALHIV in other parts of the country. Nevertheless, it provides insights into the impact of mental health problems on the social functioning of ALHIV in a low-resource setting.

## Conclusions

We have shown that the values that define a normal adolescence are a blend of traditional African culture and more contemporary values that reflect the shifting cultural, social, economic and political environment in the study setting. While adolescents are expected to conform to the attitudes and behaviours dictated by these values, mental health problems hinder ALHIV from fulfilling these expectations, with debilitating effects on their social functioning. In a context of scarcity, impairment in social functioning has grave implications for ALHIV's physical, psychological, social and economic well-being and concomitantly HIV treatment outcomes in the immediate and long term. This is because it strains their social relationships. Yet, social networks are critical not only to their daily survival but also physical, psychological and economic wellbeing both now and in the future. Therefore, neglecting mental health problems among ALHIV will expose them to a lifetime of physical, economic, social and psychological risks, all of which do not augur well for ART adherence and treatment outcomes. In this regard, the negative impact of mental health problems on the social functioning of ALHIV is detrimental to the optimisation of the treatment and preventive benefits of ART to obliterate the HIV/AIDS pandemic. This calls for urgent interventions to address the mental health problems of ALHIV, if significant progress towards the global goal to end AIDS as a public health threat by 2030 is to be realised.

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## Author Contributions

E.K.N. participated in designing the study, contributed to data collection and analysis, secured the funding and served as the lead author for the manuscript. A.K. participated in designing the study and contributed to data analysis and drafting of the manuscript. R.N. contributed to data analysis and drafting of the manuscript. J.T.S. participated in designing the study and contributed to data analysis and drafting of the manuscript. D.K. participated in designing the study, secured the funding and contributed to drafting of the manuscript. All the authors read and approved the final manuscript.

## Consent to Participate

All participants provided written informed consent/assent prior to participating. In addition, written informed consent for the minors aged

10–17 to participate in this study was provided by the participants' legal guardians/next of kin.

## Data Availability

The data supporting the conclusions of this article are available on request from the corresponding author.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethical Considerations

This study received ethical approval from the Makerere University School of Social Sciences Research Ethics Committee (approval number: MAKSSREC10.21.515) on October 28, 2021, and the Uganda National Council for Science and Technology (approval number: SS1307ES) on June 15, 2022.

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