HHS Public Access

Author manuscript

Afr J AIDS Res. Author manuscript; available in PMC 2020 September 01.

Published in final edited form as:

Afr J AIDS Res. 2019 September ; 18(3): 169–180. doi:10.2989/16085906.2019.1637912.

Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda

Scholastic Ashaba[1,*], **Christine Cooper-Vince**[2,3,*], **Dagmar Vořechovská**[2], **Godfrey Zari Rukundo**[1], **Samuel Maling**[1], **Dickens Akena**[4], **Alexander C. Tsai**[1,2,3]

[1]Department of Psychiatry Mbarara University Science and Technology, Mbarara Uganda
[2]Massachusetts General Hospital, Boston, MA, USA [3]Harvard Medical School, Boston, MA, USA
[4]Department of Psychiatry, Makerere College of Health Sciences, Makerere, Uganda

Abstract

Availability of and increased access to antiretroviral therapy (ART) has significantly reduced the morbidity and mortality associated with HIV. As a result, perinatally infected youth are increasingly able to reach adolescence. There is limited information about the psychosocial challenges facing adolescents living with HIV (ALWH) in rural settings of sub-Saharan Africa. We sought to understand psychosocial challenges facing ALWH in rural Uganda and their effects on mental health and HIV treatment outcomes. We conducted 5 focus group discussions and 40 one on one in-depth interviews in Mbarara, Uganda, with adolescents (aged 13–17 years) and adult women caregivers. All interviews were audio-recorded, transcribed directly into English, and coded using thematic analysis to identify themes related to psychosocial adversities and mental health. Adversities faced by adolescents included negative community perceptions (perceived aggression, presumed early mortality), HIV stigma (enacted and internalized), vulnerability factors (loss of parents, poverty), and health challenges (depression, ART non-adherence). In the conceptual model that emerged from the findings, negative community perceptions (about perceived aggression or presumed early mortality) predisposed ALWH to experience enactments and internalization of stigma that led to depression and ART non-adherence. The data also identified several protective factors, including counselling, family and religious support, and timely serostatus disclosure. Interventions to correct community misperceptions about HIV can potentially reduce stigma and thereby improve physical and mental health outcomes of ALWH.

Keywords

HIV; adolescents; stigma; mental health; psychological health; depression; social support; Uganda; sub Saharan Africa

---

Correspondence to: Scholastic Ashaba, sashaba@must.ac.ug, Mbarara, Uganda, +256752990070.

[*] Indicates co-first authorship

Competing interests
The authors have no competing interests to declare.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

BACKGROUND

Of the 2.1 million adolescents living with HIV worldwide, 82% live in sub-Saharan Africa (Bekker, Johnson, Wallace, & Hosek, 2015; UNAIDS, 2014), and this number continues to rise with increasing availability of and access to HIV antiretroviral therapy (ART), (Brady et al., 2010). Studies conducted in high-income countries, and in urban areas of low-income countries, show that adolescents infected with HIV perinatally are faced with challenges of living with a chronic, stigmatized disease, layered on top of emotional physical, and social challenges of adolescence (Birungi, Obare, Katahoire, & Kibenge, 2011; Edmonds et al., 2011; Mellins & Malee, 2013; Mellins et al., 2011; Palladino et al., 2009). As a result, adolescents living with HIV (ALWH) exhibit a greater rate of mental health problems, substance abuse, early sexual debut and HIV transmission risk behavior compared with adolescents in general population samples (Atwine, Cantor-Graae, & Bajunirwe, 2005; Kamau, Kuria, Mathai, Atwoli, & Kangethe, 2012; Mellins & Malee, 2013; Miles & Huberman, 1984; Musisi & Kinyanda, 2009; Vreeman, McCoy, & Lee, 2017; Woollett, Cluver, Bandeira, & Brahmbhatt, 2017). However, the individual and community-level factors that cause poor physical and mental health among ALWH are not well understood.

ALWH experience psychosocial adversities that are shaped by individual, family, peer, community, and societal factors, consistent with the social-ecological model (Feldacker, Ennett, & Speizer, 2011; Mburu et al., 2014). Understanding how ALWH interact with these domains within their social environments can inform how they cope with challenges associated with the illness, including HIV stigma (Skovdal & Daniel, 2012). According to Goffman (1963), stigma is an attribute that discredits and tarnishes the character of the individual who possesses it, leading to exclusion from social interactions and relationships. In the subsequent conceptualization by Link and Phelan (2001), interpersonal and structural aspects of stigma also feature prominently in explaining how it occurs. At the individual level, ALWH are faced with anticipated HIV stigma which impairs their ability to access HIV care (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Mutumba et al., 2015; Petersen et al., 2010). At the relationship level, ALWH commonly experience enactments of stigma through family neglect or social exclusion by peers (Mavhu et al., 2013; Mutumba et al., 2015; Strauss, Rhodes, & George, 2015). At the community level and societal levels, ALWH are adversely affected by other manifestations of enacted stigma, including community gossip (Bekker et al., 2015; Ntsepe et al., 2014) and discrimination in schools (Denison et al., 2015; Midtbø, Shirima, Skovdal, & Daniel, 2012; Nyogea et al., 2015). It is also important to note that stigma experiences are dependent on context, may shift over time, and can be successfully resisted (Abrahams & Jewkes, 2012).

Enacted stigma refers to the occurrence of discriminatory behaviors enacted against persons living with HIV specifically because of their seropositivity (Scambler & Hopkins, 1986). Internalized HIV stigma occurs when a person internalizes negative attitudes (about HIV or about persons living with HIV) from the public and accepts them as true and applicable to his or her own life (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Pantelic, Shenderovich, Cluver, & Boyes, 2015). Both enacted and internalized HIV stigma are common among ALWH (Cluver, Gardner, & Operario, 2008; Earnshaw & Chaudoir, 2009; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013). These forms of stigma have been

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

linked with depression and other manifestations of poor mental health among both adolescents and adults living with HIV (Casale, Boyes, Pantelic, Toska, & Cluver, 2019; Pope & Mays, 1995; Tsai et al., 2012). Among adults living with HIV, internalized HIV stigma has been shown to mediate the relationship between enacted stigma and depression (Simbayi et al., 2007; Turan et al., 2017; Zwick & Velicer, 1986). Among ALWH, enacted stigma and associated experiences (such as maltreatment, discrimination, and social rejection) are also associated with internalized HIV stigma, depressive symptoms, and poor quality of life (Boyes & Cluver, 2015; Breet, Kagee, & Seedat, 2014; Cluver & Orkin, 2009; Pantelic, Boyes, Cluver, & Meinck, 2017; Willis, Mavhu, Wogrin, Mutsinze, & Kagee, 2018).

Disclosure of HIV status among ALWH has also been associated with a range of stigma enactments, including loss of friends, social exclusion, bullying, being denied schooling and other opportunities (McHenry et al., 2017). As a result, ALWH struggle to conceal their seropositivity, and in the process, miss out on peer relationships which are much valued in this critical developmental stage (Ghoul, Niwa, & Boxer, 2013; Salmivalli, 2010). Yet benefits of disclosure have been reported in previous studies including social support that facilitates adherence to ART, better engagement with HIV care and improved mental health outcomes (Mutumba et al., 2015; Schenk, Kiragu, Murugi, & Sarna, 2014). Similar to adults living with HIV, access to ART and social support groups have enabled adolescents to limit internalization of the stigma they experience and live more confidently (Campbell et al., 2011; Maughan-Brown, 2010; Midtbø et al., 2012).

ALWH in rural settings may be at even greater risk for experiencing the adverse effects of HIV stigma, relative to their urban peers. First, high rates of extreme poverty and AIDS-related orphanhood are observed in rural settings, both of which further compromise mental health outcomes among ALWH (Cluver et al., 2008; Kang, Delzell, Chhabra, & Oberdorfer, 2015; Menon, Glazebrook, Campain, & Ngoma, 2007; Tanney, Naar-King, MacDonnel, & Team, 2012; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013; Willis et al., 2018). Secondly, children and adolescents orphaned by HIV are commonly taken up by relatives and well-wishers or are living in child headed households which may predispose them to maltreatment and exploitation (Cluver et al., 2016; Meinck, Cluver, Boyes, & Mhlongo, 2015; Morantz et al., 2013). As a result, ALWH in rural settings are extremely vulnerable and are faced with uncertainty about the future, which predisposes them to involvement in high risk behavior and substance abuse (Campbell et al., 2016; Han, Ssewamala, & Wang, 2013; Tsai, 2015). While the drivers of stigma among adults living with HIV are well known, the drivers of stigma among ALWH have been less thoroughly explored. We therefore undertook this qualitative analysis to understand adversities facing ALWH in rural Uganda and their effects on mental health. The qualitative findings were then used to create a conceptual model linking the constructs that emerged, from the production of HIV stigma to its negative impacts on ALWH.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

METHODS

Study setting & data collection

We conducted the study in the Mbarara District of southwestern Uganda, which is located approximately 270 km from Kampala, the capital city. Mbarara Town is the area's commercial hub, with a population of 195,013 (Uganda Bureau of Statistics, 2014). Most district residents live in rural areas outside of Mbarara Town, where food and water insecurity are prevalent and where subsistence agriculture, animal husbandry, and local trading are the predominant sources of income (Tsai et al., 2011; Tsai et al., 2016). The prevalence of HIV among adolescents aged 15–19 years was 2.4% in 2011, an increase from 1.5% in 2004; similarly, HIV prevalence among youth aged 20–24 years increased from 4.7% to 5.4% over the same period (Uganda AIDS Indicator Survey (UAIS), 2014).

We conducted a qualitative study employing focus group discussions (FGDs) and one on one in-depth interviews with adolescents and adults from the Mbarara Regional Referral Hospital (MRRH) HIV clinic, psychiatry ward, and the local community site (Nyakabare Parish) (Ashaba et al., 2018; Cooper-Vince et al., 2017). All interviews were conducted between February and May 2016.

We recruited both adult women caregivers/parents and adolescent boys and girls, purposively sampling from clinics and the local community to obtain diverse perspectives on mental health problems faced by ALWH and HIV-affected adolescents in the local community. The rationale for using these 3 sites was that adolescents and adults recruited from the clinic sites would have personal or familial experience regarding HIV and mental health issues facing ALWH, while adolescents and adults recruited from the community site could describe general community perceptions of ALWH and the challenges facing ALWH.

Adult participants.—Adult women caregivers were recruited from the Mbarara Regional Referral Hospital (MRRH) HIV clinic and the MRRH psychiatry wards where their children were receiving care, as well as from a rural community site (Nyakabare Parish). Children and adolescents most commonly present to the MRRH psychiatry services for treatment of attention deficit hyperactivity disorder, intellectual disability, seizure disorders, and mood disorders. Although Ugandan men do participate in the rearing of children, most day-to-day care is handled by women (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007; Russell & Seeley, 2010; Taylor, Seeley, & Kajura, 1996). For this reason, only women caregivers were recruited to participate.

Adolescent participants.—Adolescent participants were recruited from the MRRH HIV clinic and the rural community site (Ashaba et al., 2018; Cooper-Vince et al., 2017). All ALWH who participated were fully aware of their seropositivity and were receiving care at the MRRH HIV clinic. Adolescent participants were not recruited from the MRRH psychiatry ward as most adolescents who present to the ward are experiencing acute psychiatric symptoms that would prevent them from fully participating in the FGDs and/or in-depth interviews.

Author Manuscript

Focus group discussions and one-on-one interviews

Adolescent focus group discussions.—We conducted two mixed-gender, adolescent-only FGDs (n=15) consisting of boys and girls aged 13 to 17 years, six of whom were emancipated (defined as adolescents below 18 years of age who were either married, had children, or were currently pregnant) (Uganda National Council for Science and Technology, 2007) or empowered minors (defined as those who were responsible for their own HIV care, per report of the HIV care provider). One adolescent FGD consisted of participants recruited from the community (2 boys and 5 girls, serostatus unknown). The other adolescent FGD consisted of participants recruited from the MRRH HIV clinic (2 boys and 6 girls, all ALWH).

Adult focus group discussions.—We conducted 3 adult FGDs which were comprised solely of adult women (n=25). The reason for this restriction, as explained above, is that while Ugandan men do participate in the rearing of children, most day-to-day care is handled by women and therefore they would be best positioned to provide information about their children’s day-to-day experiences. One adult FGD consisted of women recruited from the MRRH HIV clinic (n=8) who were primary caregivers of ALWH in care at the MRRH HIV clinic. The second adult FGD involved women (n=9, serostatus unknown) who were recruited from the MRRH psychiatric ward where their children were receiving mental health care. The third adult FGD involved women recruited from the community site (n=8, serostatus unknown) who were caregivers to adolescents 13–17 years of age.

Adolescent and adult in-depth interviews.—We conducted 40 in-depth interviews with adolescent boys and girls (n=10, including 6 emancipated or empowered minors) and with adult women (n=30). The 30 adult women included 5 recruited from the MRRH HIV clinic and 15 recruited from the MRRH psychiatry ward, where their children were receiving care; and 10 who were recruited from the community. All of these women were primary caregivers of adolescents 13 to 17 years of age. The 10 adolescents included 2 boys (1 from the community whose serostatus was unknown and 1 ALWH from the MRRH HIV clinic) and 8 girls (4 from the community whose serostatus was unknown and 4 ALWH from the MRRH HIV clinic).

We used both FGDs and in-depth interviews to gain complementary insights into perceived community norms and personal/family experiences. The interview guide was developed by reviewing relevant literature and with input from both local and international mental health experts. FGDs and in-depth interviews were guided by open-ended questions eliciting participants’ perspectives about major social problems facing ALWH and HIV-affected adolescents. These questions were followed by probes to explore the social contexts and consequences of these problems. To reduce any stress potentially associated with HIV serostatus disclosure, participants were not asked to report on their own serostatus or describe personal experiences related to their seropositivity, but were instead asked to share their general knowledge about these topics (specifically, ALWH participating in FGDs shared their perceptions about social problems facing ALWH in the community generally, and not with reference to their own personal experiences). Ugandan research assistants trained in qualitative methods and fluent in both English and the local language

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

(Runyankore) conducted the interviews. FGDs lasted an average of approximately 90 minutes, while in-depth interviews lasted approximately 60 minutes.

Ethical considerations

We interviewed participants after obtaining informed consent and, where applicable, assent. Adolescents who were under the care of their parents/guardians were interviewed only after written informed consent was obtained from the parent and assent obtained from the adolescent. Emancipated minors (i.e., adolescents below 18 years of age who were either married, had children, or were currently pregnant) (Uganda National Council for Science and Technology, 2007), and empowered minors (i.e., those who were responsible for their own HIV care, per report of the HIV care provider), were permitted to provide written informed consent to participate without involvement of a parent/guardian. Research assistants read consent forms to the participants in the local language, and participants were given a chance to ask questions for clarification before consenting. Research assistants received training and ongoing supervision in interviewing techniques, basic mental health knowledge, and eliciting sensitive questions. We received ethical approval for our study from the Research Ethics Committee of Mbarara University of Science and Technology and the Partners Human Research Committee. We also received clearance from the Uganda National Council for Science and Technology and from the Research Secretariat in the office of the President. Participants received 10,000 Ugandan shillings (approximately 3 USD at the time the study was conducted) to cover transportation costs.

Data analysis

Each of the FGDs and individual interviews was audiotaped, translated, and transcribed directly into English. Data analysis involved an iterative review of FGDs and in-depth interview transcripts to generate a code book that comprised the major themes discussed. Using the initial codebook, two of the investigators (SA, CCV) coded 5 individual interview transcripts in duplicate, compared their findings, and discussed and harmonized their differences until acceptable reliability in coding was achieved (Cohen's $\kappa = 0.68$). The remaining interview transcripts were coded independently. Data analysis was conducted using NVivo software (version 11, QSR International, Burlington Mass.).

RESULTS

Participant characteristics

The two adolescent FGDs included 15 adolescents (4 boys, 11 girls), of whom 8 were ALWH recruited from the MRRH HIV clinic. The three adult FGDs included 25 women, of whom 8 were primary caregivers of ALWH in care at the MRRH HIV clinic, 9 were primary caregivers of children in care at the MRRH psychiatric ward, and 8 were primary caregivers of adolescents with no other stipulation.

The sample of adolescent participants for in-depth interviews included 2 boys (1 from the community whose serostatus was unknown and 1 ALWH from the MRRH HIV clinic) and 8 girls (4 from the community whose serostatus was unknown and 4 ALWH from the MRRH HIV clinic). The sample of adult women caregivers for in-depth interviews included 10

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

women from the community, 5 from the MRRH HIV, and 15 from the MRRH psychiatry ward (all with serostatus unknown).

Conceptual model

Following thematic content analysis we identified 12 themes that emerged from the data, which we consolidated into five major categories: 1) negative community perceptions (perceived aggression and presumed early mortality), 2) HIV stigma (enacted and internalized), 3) vulnerability factors (loss of parents and poverty), 4) protective factors (counselling, family support, effective disclosure, and religious faith) and 5) health challenges (depressive symptoms and ART non-adherence). The qualitative findings were then used to create a conceptual model linking the constructs that emerged, from the production of HIV stigma to its negative impacts on the health and mental health of ALWH (Figure 1). Our conceptual model is a means to outline the relationship between negative community perceptions about ALWH, the ways ALWH internalize this stigma, and the mental health challenges expressed by ALWH that are indicators of depression. While the qualitative nature of our study and the data cannot show a causal relationship, we use this model to elucidate the experiences of ALWH to understand the adversities they face, particularly among those who had lost their parents or who were experiencing severe poverty.

1. Negative community perceptions

Presumed early mortality.—Negative perceptions among community members about early mortality and poor health outcomes for ALWH were also elicited. Participants reported that this generally caused parents/caregivers to neglect their children living with HIV in terms of general welfare, medical care, and educational opportunities.

> As a parent when you know that the child is HIV positive you care less about that child. Because you know even if you feed the child, the child won’t grow well. In case you have other children who are HIV negative, you put all the care on those because you know they will grow.
>
> -- Adult woman caregiver (serostatus unknown), 38 years old, community in-depth interview

Adolescent participants reported that ALWH are often told that they are about to die because they are HIV positive. Loss of hope was common among ALWH.

> Sometimes you find people saying that she or he (ALWH) is about to die because she is HIV positive. When you hear such things about you, you ask yourself why you should waste your energy in doing anything in life since you are about to die.
>
> -- Adolescent girl living with HIV, 15 years old, HIV clinic in-depth interview

Perceived aggression.—Both adult and adolescent community participants reported that ALWH are thought of as becoming “aggressive” towards both family members and others in the community, upon learning of their seropositivity. They reported, that it is commonly believed that ALWH who learn of their seropositivity become angry, blame their parents for

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

having infected them with HIV, and can become aggressive towards family members. Participants also reported that it is believed that ALWH engage in high risk behaviors, including substance abuse and having sexual intercourse with other children to intentionally infect them with HIV. Of note, these perceptions were mentioned by study participants irrespective of their serostatus: such perceptions were reported in both the community and ALWH-only adolescent FGDs, all of the adult FGDs, and the adolescent and adult in-depth interviews. As a result of these perceptions, some participants perceived ALWH to be a bad influence on their peers and being dangerous to the community.

> They [children living with HIV] are a bad influence to other children in the community. When they learn of their HIV status they start to behave badly towards others because they know they will die. They influence other children to go and drink alcohol, influence them into having sex with them to intentionally infect them.
>
> -- Adolescent boy (serostatus unknown), 16 years old, community in-depth interview

> Those [children] who are HIV positive, become desperate and hate themselves. They start being careless saying “let me have sex with whomever I see. I do not care whether I become pregnant or not since I will die soon”. Hmm… one may say “since I am HIV positive, let me infect others too so that we die many”.
>
> -- Adult woman caregiver (serostatus unknown), 39 years old, psychiatry ward in-depth interview

2. HIV stigma

Enacted stigma.—Accounts of unfair and harsh treatment, compared with HIV-negative children in the same household, were reported by ALWH. They reported that they were often blamed if household chores were not done as expected. Such differential treatment led ALWH to believe that they were not loved equally by their parents/caregivers.

> When there are other children in the family but you are the only one with HIV, you find that parents love those who are HIV negative, and hate you who are HIV positive. …they always blame you for everything in the home and beat you up instead of protecting you.
>
> -- Adolescent girl living with HIV, 16 years old, HIV clinic FGD

Harassment by peers and other members in the community was also reported by both ALWH and adult participants through FGDs and in-depth interviews. Participants stated that ALWH were avoided by peers. Adult women caregivers of ALWH also reported feeling sad about such exclusions.

> When a child is at school and other children learn that he is HIV positive, that child suffers a lot. Other children discriminate against him, they call him names “you are suffering from AIDS,” like that. So the child hates himself. You see people shouting loud at them “the person with AIDS.”

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

-- Adult woman caregiver (serostatus unknown), 37 years old, psychiatry ward in-depth interview

Internalized stigma.—The harsh treatment from peers and adults often led to negative emotions among ALWH, including feelings of shame, embarrassment and emotional pain. In anticipation of the social exclusion and the shame associated with their seropositivity, ALWH often isolated themselves to avoid being hurt by others.

> You may find that you are the only one who is HIV positive in the whole family, and the neighbors and their children know about your HIV status. If you ask to share anything with the children in the neighborhood, the children refuse to share with you because you are HIV positive. At that point you feel much pain in your heart.
>
> -- Adolescent girl living with HIV, 13 years old, HIV clinic FGD

> You start withdrawing from your friends. You stay in the house feeling lonely. You refuse to join peers because you know they will talk about a person who is HIV positive whom you [probably] stay with. You may even ask for permission to shift to another place….to another town to avoid them (friends).
>
> -- Adolescent girl living with HIV, 14 years old, HIV clinic FGD

3. Vulnerability factors

Loss of parents to HIV/AIDS.—Participants reported that ALWH who had lost their parents no longer had a caregiver to provide for their basic needs and essential development (e.g., education) or to model prosocial behaviours.

> Children who have lost their parents to HIV face many problems. Those children are disturbed in their studies and basic care. You find them loitering in the villages. Girls start interacting with men at an early age and end up sleeping with them to get money to support themselves.
>
> -- Adult woman caregiver (serostatuts unknown), 38 years old, community in-depth interview

Many participants reported that in families where the parents were living with HIV, family financial resources were often depleted to meet the parents' treatment and transportation costs. These financial burdens, placed their children even at greater economic risk. Accordingly, children who had lost their parents (or who were at risk of losing their parents) were described as vulnerable to dropping out of school and/or engaging in risky sexual behaviour to support themselves.

> You find that they [children who have lost their parents] do not have basic needs because they have lost both parents. They do not have a place to live, they were at most left with a small piece of land or none at all. You find them suffering and begging for everything. They do not go to school, they lack food.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

-- Adolescent girl (serostatus unknown), 16 years old, community in-depth interview

In addition, adolescents whose parents were living with HIV reported ongoing stress over worrying about the emotional and economic hardships involved in going through life without a parent.

> Your mind is not settled, you are thinking about many problems at the same time yet do not have solutions to these problems. You get stress. Like where you will get school fees if your parents die. Like how you will live without parents. You know living a life without parents is hell. Therefore when you keep thinking about such problems you become stressed.

-- Adolescent girl living with HIV, 16 years old, HIV clinic in-depth interview

Poverty.—Even among children who had not yet lost one or both parents, many reported that parents/guardians living with HIV could not work due to HIV/AIDS-related morbidity. Thus, many of the study participants reported that HIV-affected families were pushed into impoverished conditions with unmet basic needs, and children from HIV-affected families missed educational opportunities. Consequently children were pushed into informal employment to provide for themselves.

> Children lack basic needs. Parents are unable to provide for their children. They do not have food to eat and can’t afford school. They stay hungry or work so hard in other people’s gardens to get food. Some run away from home and go to look for jobs to support themselves.

-- Adolescent girl living with HIV, 15 years old, HIV clinic in-depth interview

Adult women caregivers described knowing of parents who had lost all hope in their circumstances due to their seropositivity and who had lost any interest in work or fulfilling caregiving responsibilities-- also necessitating that affected children drop out of school to provide for themselves.

> Some parents who are HIV positive become desperate [hopeless] and stop taking care of their children. They stop providing necessities and sometimes they do not take ARVs and end up dying, leaving the children with problems. They [children] suffer a lot. If they are girls, they work as house helpers, and the boys go to take care of other peoples’ farms.

-- Adult woman caregiver (serostatus unknown), 35 years old, community in-depth interview

4. Protective Factors

Counselling.—Some participants reported that when ALWH experienced enacted and/or internalized stigma, they navigated these challenges more effectively when they received counseling in the context of HIV care.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

> When they come to the doctors, they are told that having HIV does not mean that you have come to the end of the world, you might study and get a degree, and you might live and have a future like any other people. We have people that were born with HIV and are now doctors, therefore after receiving that kind of counselling, you find that some children have overcome those bad situations and others have grown up to even produce children that are HIV negative.
>
> --Adult caregiver (serostatus unknown), 42 years old, HIV clinic in-depth interview

Family support.—In addition to the counseling provided by HIV care providers, participants also reported that it was very important for ALWH to get support from their parents and family members, including emotional support and instrumental support related to taking medication. Emotional support and identification of role models was noted to increase adolescents' hope for the future and reduce self-hatred, which in turn supported medication adherence.

> To tell you the truth, some commit suicide because myself one day I thought about it. All my step sisters and brothers do not know that I am HIV positive. So when I thought of committing suicide, I talked to my elder sister how I was feeling. She then counseled me and I got well. However those ones who do not get counselling commit suicide.
>
> --Adolescent girl living with HIV, 17 years old, HIV clinic in-depth interview

> If you want to make a child love taking HIV medicines, you must first show your child love by bringing your child to be close to you. Let us say you are to take your medicine, you tell your child to take his too, and at that time you can let the child know why she or he is taking medicine. You counsel your child and let the child know that many children take medicine and even old people are taking medicine, and thus that child will take medicines well. You encourage the child that many people are alive and living with HIV, so if you swallow your drugs, you will have no problem. This will help child to understand and have hope that since their parents are living with HIV, then this shows that "I can live too."
>
> --Adult caregiver (serostatus unknown), 42 years old, HIV clinic in-depth interview

Effective disclosure.—Participants reported that appropriate and timely disclosure of HIV status to children is a critical developmental step that enables ALWH to accept their diagnosis and adhere to ART. Participants reported that early disclosure enabled ALWH to understand the purpose and benefits of adhering to ART.

> The child refuses to take medicines by asking himself or herself that "why do I take these drugs every day yet I do not have malaria, nor any headache?" If a parent does not tell the child who is HIV positive that "I gave birth to you when you are HIV positive," and if you continue giving this child medicine without explaining why he or she is taking medicine, the child will not understand it. Therefore it is

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

> necessary that you tell your child, “I did not take you to the hospital when I produced you, but by the time I took you to the hospital I found that you were HIV positive”. That will help explain to the child why she or he is taking medicines every day. Therefore the child learns that he or she has to take medicine and survive.
>
> --Adult woman caregiver (serostatus unknown), 32 years old, community in-depth interview

> What mostly disturbs children is when a child takes medicine but without knowing why one is taking medicine. When a child is old enough to understand, but you continue taking this child to the hospital without telling the child the reason why she or he is taking medicines, the child will start isolating himself or herself. A child who has been loving himself or herself will start dodging school by giving small reasons like “I have a headache.”
>
> --Adult woman caregiver (serostatus unknown), 39 years old, HIV clinic in-depth interview

Religious faith.—Participants also described participating in religious worship (e.g., at a church or mosque) as being helpful for ALWH, because it enhances their ability to cope with the challenges of living with HIV. Specifically, it was noted that prayer renewed adolescents’ sense of hope for the future. The same 15-year old ALWH who described loss of hope and unmet basic needs described above, talked about the importance of religious coping.

> When children involve themselves in church activities like fellowshipping with others and attending overnight prayers, they realize that being HIV positive does not mean the end of the world. Therefore they start cooperating with others.
>
> --Adolescent living girl with HIV, 15 years old, HIV clinic in-depth interview

Adolescents also noted that they drew strength from and/or experienced a feeling of fellowship with personalities in the Bible-- who were also depicted as coping with significant adversity.

> Religion does [help]…, for example when you are told about the suffering that Saul experienced, or what other people in the Bible experienced, you also compare with what you are going through and see that you are experiencing the same. You are therefore told to continue praying to God. That helps you to remain close to God and praying to him.
>
> –Adolescent girl (serostatus unknown), 16 years old, community in-depth interview

5. Health challenges

Depressive symptoms.—Due to stigma enactments such as discrimination and gossip, some ALWH believed that they were inferior to their peers and that no one would want to associate with a person living with HIV. They reported being avoided by peers in school;

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

such acts of social exclusion brought shame and anger, and those affected sometimes contemplated suicide.

> HIV positive adolescents do not fit in with their peers. Let’s say you are walking towards them [peers], then you see them looking aside, trying to dodge you or ignore you, they move away from you. Then you feel guilty and angry, and start having recurrent thoughts of death: should I kill myself using rat poison, throw myself in the lake, or cut my neck and die? What can I do?
>
> -- Adolescent girl living with HIV, 14 years old, HIV clinic in-depth interview

Some ALWH also reported feelings of shame and low self-esteem after being subjected to gossip by their peers. Adults also participated in these enactments of stigma by warning other children not to associate with ALWH which was described as causing great psychological pain, feelings of sadness, and leading to self-isolation.

> HIV positive children are isolated. You find adults saying “don’t share your clothes with her because she will infect you with AIDS. It becomes so difficult to the infected child to go on with these insults. Such children become sad and they do not fit in society. They become so sad and hate everything around them. The whole world becomes like a box [feel trapped]. Some children may commit suicide by hanging or poisoning themselves.
>
> -- Adolescent girl living with HIV, 16 years old, HIV clinic in-depth interview

> They [HIV positive children] feel so sad because they are HIV positive and everybody talks about it [their HIV status]. Other children ask “I heard that you are HIV positive, is it true”? When you hear such things you become so sad. Such children are not happy and they isolate themselves from others. They are always thinking about their sickness [HIV status] and they do not associate with others, they are always sad.
>
> -- Adolescent girl living with HIV, 15 years old, HIV clinic in-depth interview

ART non-adherence.—Both ALWH and adult participants reported that ALWH experienced challenges adhering to ART, especially when living away at school. These challenges were commonly reported in the context of the themes previously described (stigma, fear of HIV serostatus disclosure, poverty, loss of parents). The same 42 year-old adult woman caregiver who described the importance of counselling and family support also described ART challenges.

> They [HIV positive children] do not take their drugs [ARVs] very well especially when they are at school. Other children make them uncomfortable when they see them taking medicine in the morning and evening. When they confirm that he/she is taking ARVs, they make him or her uncomfortable. The other children ask “where did you get HIV from” or say, “If you have HIV, don’t spread it to us”.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

-- Adult woman caregiver (serostatus unknown), 42 years old, HIV clinic in-depth interview

Most ALWH in school had difficulty taking their medications due to the fear that peers would learn their HIV status. These ALWH described it as shameful to be taking medicines daily and therefore often avoided taking medicines altogether. The same 15 year-old girl who described sadness resulting from gossip by their peers, talked about how stigma led to ART non-adherence.

> They [HIV positive children] have a problem of taking HIV medicine especially children in boarding school. They get difficulties in taking their medicine while others are watching. When you hide yourself to take your medicine and someone sees you, you start lying like "I have headache, that is why am taking this medicine". Sometimes you get tired of taking medicine.

-- Adolescent girl living with HIV, 15 years old, HIV clinic in-depth interview

DISCUSSION

In this qualitative study of ALWH, adult women caregivers, and community-residing adolescents and adults of unknown serostatus, we found support for a conceptual model linking negative community perceptions about ALWH, expressions of internalized HIV stigma, and depressive symptoms among ALWH (Figure 1). The conceptual model generates important insights into the social production of HIV stigma and its adverse consequences for ALWH. We found that ALWH were subjected to negative community misperceptions about their perceived aggression towards others and presumed early mortality. These negative community misperceptions often led to bullying, social isolation, feelings of shame, and internalization of stigma. Health challenges such as depressive symptoms and ART non-adherence frequently resulted (Katz et al., 2013; Willis et al., 2018). Other investigators have similarly reported that depressive symptoms and suicidal ideation resulting from stigma can manifest in refusal to take ART as a form of passive suicidality (Lall, How Lim, Khairuddin, & Kamarulzaman, 2015; Miles & Huberman, 1984; Mutumba et al., 2015; Pantelic, Boyes, Cluver, & Thabeng, 2018).

On the other hand, we also found that counseling, family support, timely disclosure, and religious participation enabled ALWH to cope with stigma and its adverse mental health effects. These resilience resources also helped ALWH establish hope for a full life and adhere to ART (Mutumba et al., 2015; Petersen et al., 2010). Social support from parents has also been documented to improve adherence to ART among perinatally HIV infected youth (MacCarthy et al., 2018; Naar-King et al., 2013). Religion and spirituality have been reported as coping mechanisms among adults living with HIV (Ashaba et al., 2017). Our data consolidate these findings into a single unified model of ALWH well-being that links community determinants, HIV stigma, resilience resources, and mental health.

Our findings that there remains a persisting misperception in the community that ALWH are likely to aggressively spread HIV through HIV transmission risk behavior is similar to what has been reported in previous studies (Ezekiel, Talle, Juma, & Klepp, 2009; Keogh et al.,

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

2012; Maughan-Brown, 2010). The stigma experienced by ALWH was rooted in instrumental concerns about secondary transmission of HIV in addition to expectations of early mortality that led to neglect and reduced support from family and peers (Strydom & Raath, 2005; Turan et al., 2016). In some cases, study participants expressed beliefs about early mortality that is clearly not consistent with the available scientific evidence (Anglemyer et al., 2014; Group, 2015; Kitahata et al., 2009; Mills et al., 2011).

Our findings do not suggest as has been previously described that that the increasing availability of ART and associated improved physical health would reduce the stigma associated with HIV (Chan, Weiser, et al., 2015; Farmer et al., 2001). Participants' descriptions of negative attitudes in the community, and stigma associated with taking ART, indicate, to the contrary, that stigma has persisted, at least in this specific context (Chan, Tsai, & Siedner, 2015; Chan, Weiser, et al., 2015; Treves-Kagan et al., 2016). It is possible that less stigma may be experienced by ALWH in urban settings, as stigma experiences may be worse among ALWH in rural settings characterized by the communal living and lack of privacy (which may facilitate gossip through social networks) (Amuri, Mitchell, Cockcroft, & Andersson, 2011). Additionally, the lower education levels and wide spread poverty common in rural settings may also contribute to elevated HIV stigma (Bond, 2006; Tsai et al., 2013).

The negative impacts of stigma on adolescents' mental health were further compounded by poverty and parental death consistent with previous research (Abubakar et al., 2017; Cluver et al., 2008; Cluver, Orkin, Gardner, & Boyes, 2012; Pantelic et al., 2018; Willis et al., 2018). Hence, stigma adversely affected those who were most vulnerable. Poverty and financial difficulties are common among HIV-affected families, due to low economic productivity associated with HIV-related morbidity and mortality. In turn, affected children may be less likely to seek formal employment, more likely to miss school and more likely to experience other adversities, including neglect, sexual abuse, hopelessness, and depression (Abubakar et al., 2017; Cluver, Orkin, Boyes, Gardner, & Meinck, 2011; Cluver et al., 2012; Lowenthal et al., 2014; Nyamukapa et al., 2010; Pufall et al., 2014). Poverty and parental loss have also been documented to increase the risk of internalized HIV stigma and depressive symptoms (Cluver et al., 2008; Pantelic et al., 2018; Tanney, Naar-King, & MacDonnel, 2012; Tsai, 2015; Willis et al., 2018).

Interpretation of our findings is subject to several limitations. First, we interviewed only adolescents 13 to 17 years of age and their caregivers and interviews focused on the emotional experiences of ALWH. Our findings may not extend to younger children or to the emotional experiences of the caregivers themselves. However, due the high fertility rates in Uganda it is common for families to have multiple children spanning from early childhood through adolescence, so it is likely that the views expressed by the caregivers in our sample may also reflect challenges faced by younger children living with HIV. Future work should explore these themes in younger children.

Second, the adolescent FGDs were mixed-gender. The mixed-gender design could have limited participants' abilities to express their opinions freely. In the context of our study site in Mbarara, Uganda, adolescent boys may feel more empowered than girls to share their

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

opinions in a mixed-gender group. However, it should be noted that the majority of the adolescents in the FGDs were girls (and that could have limited the boys' ability to freely express their opinions). Nonetheless, the perspectives obtained in the FGDs were consistent with the perspectives obtained in the in-depth interviews, providing some reassurance about the quality of the data obtained.

Third, the interview questions were posed in such a way that participants would not feel compelled to disclose their own HIV status if they were not comfortable doing so. While many participating ALWH did in fact provide first-person accounts during the FGDs the majority of participants responded to questions in the third person. Any potential stifling of responses, could have limited the richness of the data obtained.

Fourth, only adolescents, and their female caregivers were interviewed for this study. Overrepresentation of girls in the FGDs and in-depth interviews resulted from the fact that there were fewer boys in these venues meeting our inclusion criterion of being 13–17 years of age. Our recruitment experience is consistent with the local sex ratio among adolescents as well as the local epidemiology of both HIV and depression.

Given that women in Uganda traditionally have had greater involvement in the day-to-day aspects of their children's lives, it is unclear if the views expressed are also held and promoted by men. Men typically assume leadership roles within the household and community and may be better positioned to influence community beliefs. Therefore, further research is needed to clarify if the present findings can be generalized to men in the study setting.

Conclusions

This qualitative analysis shows that ALWH are still vulnerable to HIV stigma despite availability of ART. Their vulnerability is worsened by community misperceptions about ALWH which contributes to the production of HIV stigma and subsequent worsened mental health and other health challenges among ALWH. These effects are further exacerbated in the setting of vulnerability factors like poverty and orphanhood. HIV care programs for ALWH in rural settings should address the challenges of stigma, disclosure of HIV, and formation of peer support groups to improve mental health outcomes and ART adherence. Interventions to correct community misperceptions about HIV, including early mortality and drivers of risky behavior, can potentially reduce HIV stigma, and thereby improve physical and mental health outcomes among ALWH.

Acknowledgements

We acknowledge the contributions of our research assistants to data collection and logistical support: Patricia Tushemereirwe, Patrick Gumisiriza, Allen Kiconco and Elizabeth Namara. We also thank the participants whose voices made this study possible.

Funding

The study was funded by the U.S. National Institutes of Health (Fogarty International Center (FIC), National Institute of Mental Health (NIMH), and National Institute of Neurological Disorders, and Stroke (NINDS)) under award D43TW010128. Dr. Tsai acknowledges salary support through R01MH113494–01, and Dr. Cooper-Vince also acknowledges salary support through T32MH093310.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

References

Abrahams N, & Jewkes R (2012). Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. Journal of the International AIDS Society, 15(2), 10.7448/IAS.7415.7442.17330.

Abubakar A, Van de Vijver FJ, Hassan AS, Fischer R, Nyongesa MK, Kabunda B, … Newton CR (2017). Cumulative Psychosocial Risk is a Salient Predictor of Depressive Symptoms among Vertically HIV-Infected and HIV-Affected Adolescents at the Kenyan Coast. Annals of Global Health.

Amuri M, Mitchell S, Cockcroft A, & Andersson N (2011). Socio-economic status and HIV/AIDS stigma in Tanzania. AIDS care, 23(3), 378–382. [PubMed: 21347901]

Anglemyer A, Rutherford GW, Easterbrook PJ, Horvath T, Vitoria M, Jan M, & Doherty MC (2014). Early initiation of antiretroviral therapy in HIV-infected adults and adolescents: a systematic review. AIDS, 28, S105–S118. [PubMed: 24849469]

Ashaba S, Kaida A, Burns BF, ONeil K, Dunkley E, Psaros C, … Matthews LT (2017). Understanding coping strategies during pregnancy and the postpartum period: a qualitative study of women living with HIV in rural Uganda. BMC Pregnancy and Childbirth, 17:138. [PubMed: 28482821]

Ashaba S, Kakuhikire B, Vořechovská D, Perkins JM, Cooper-Vince CE, Maling S, … Tsai AC (2018). Reliability, validity, and factor structure of the Hopkins symptom checklist-25: population-based study of persons living with HIV in rural Uganda. AIDS and Behavior, 22(5), 1467–1474. [PubMed: 28667469]

Atwine B, Cantor-Graae E, & Bajunirwe F (2005). Psychological distress among AIDS orphans in rural Uganda. Social Science & Medicine (1982), 61(3), 555–564. [PubMed: 15899315]

Bekker LG, Johnson L, Wallace M, & Hosek S (2015). Building our youth for the future. Journal of the International AIDS Society, 18, 20027. [PubMed: 25724512]

Birungi H, Obare F, Katahoire A, & Kibenge D (2011). HIV infection and schooling experiences of adolescents in Uganda. Social and Psychological Aspects of HIV/AIDS and their Ramifications. Rijeka: InTech, 73–88.

Bond V (2006). Stigma when there is no other option: understanding how poverty fuels discrimination toward people living with HIV in Zambia. AIDS, poverty, and hunger: Challenges and Responses, 181–197.

Boyes ME, & Cluver LD (2015). Relationships between familial HIV/AIDS and symptoms of anxiety and depression: The mediating effect of bullying victimization in a prospective sample of South African children and adolescents. Journal of Youth and Adolescence, 44(4), 847–859. [PubMed: 24996836]

Brady MT, Oleske JM, Williams PL, Elgie C, Mofenson LM, Dankner WM, … Team, P. A. C. T. G. C. (2010). Declines in mortality rates and changes in causes of death in HIV-1-infected children during the HAART era. Journal of Acquired Immune Deficiency Syndromes (1999), 53(1), 86. [PubMed: 20035164]

Breet E, Kagee A, & Seedat S (2014). HIV-related stigma and symptoms of post-traumatic stress disorder and depression in HIV-infected individuals: Does social support play a mediating or moderating role? AIDS care, 26(8), 947–951. [PubMed: 24666226]

Campbell C, Andersen L, Mutsikiwa A, Madanhire C, Nyamukapa C, & Gregson S (2016). Can schools support HIV/AIDS-affected children? Exploring the ‘Ethic of care’amongst rural Zimbabwean teachers. PloS One, 11(1), e0146322. [PubMed: 26790103]

Campbell C, Skovdal M, Madanhire C, Mugurungi O, Gregson S, & Nyamukapa C (2011). “We, the AIDS people…”: how antiretroviral therapy enables Zimbabweans living with HIV/AIDS to cope with stigma. American Journal of Public Health, 101(6), 1004–1010. [PubMed: 21164081]

Casale M, Boyes M, Pantelic M, Toska E, & Cluver L (2019). Suicidal thoughts and behaviour among South African adolescents living with HIV: can social support buffer the impact of stigma? Journal of Affective Disorders, 245, 82–90. [PubMed: 30368074]

Chan BT, Tsai AC, & Siedner MJ (2015). HIV treatment scale-up and HIV-related stigma in sub-Saharan Africa: a longitudinal cross-country analysis. American Journal of Public Health, 105(8), 1581–1587. [PubMed: 26066939]

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

Chan BT, Weiser SD, Boum Y, Siedner MJ, Mocello AR, Haberer JE, … Bangsberg DR (2015). Persistent HIV-related stigma in rural Uganda during a period of increasing HIV incidence despite treatment expansion. AIDS (London, England), 29(1), 83.

Cluver L, Meinck F, Yakubovich A, Doubt J, Redfern A, Ward C, … Mpimpilashe P (2016). Reducing child abuse amongst adolescents in low-and middle-income countries: A pre-post trial in South Africa. BMC Public Health, 16(1), 567. [PubMed: 27919242]

Cluver L, & Orkin M (2009). Cumulative risk and AIDS-orphanhood: Interactions of stigma, bullying and poverty on child mental health in South Africa. Social Science & Medicine, 69(8), 1186–1193. [PubMed: 19713022]

Cluver L, Orkin M, Boyes M, Gardner F, & Meinck F (2011). Transactional sex amongst AIDS-orphaned and AIDS-affected adolescents predicted by abuse and extreme poverty. Journal of Acquired Immune Deficiency Syndromes, 58(3), 336–343. [PubMed: 21857361]

Cluver LD, Gardner F, & Operario D (2008). Effects of stigma on the mental health of adolescents orphaned by AIDS. Journal of Adolescent Health, 42(4), 410–417. [PubMed: 18346667]

Cluver LD, Orkin M, Gardner F, & Boyes ME (2012). Persisting Mental Health Problems among AIDS-Orphaned Children in South Africa. Journal of Child Psychology and Psychiatry, 53(4), 363–370. [PubMed: 21883206]

Cooper-Vince C, Kakuhikire B, Vořechovská D, McDonough A, Perkins J, Venkataramani A, … Bangsberg D (2017). Household water insecurity, missed schooling, and the mediating role of caregiver depression in rural Uganda. Global Mental Health (Cambridge, England), 4, e15–e15.

Denison JA, Banda H, Dennis AC, Packer C, Nyambe N, Stalter RM, … McCarraher DR (2015). “The sky is the limit”: adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. Journal of the International AIDS Society, 18(1), 19358. [PubMed: 25591915]

Earnshaw VA, & Chaudoir SR (2009). From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. AIDS and Behavior, 13(6), 1160. [PubMed: 19636699]

Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, & Copenhaver MM (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS and Behavior, 17(5), 1785–1795. [PubMed: 23456594]

Edmonds A, Yotebieng M, Lusiama J, Matumona Y, Kitetele F, Napravnik S, … Behets F (2011). The effect of highly active antiretroviral therapy on the survival of HIV-infected children in a resource-deprived setting: a cohort study. PLoS Med, 8(6), e1001044. [PubMed: 21695087]

Ezekiel MJ, Talle A, Juma JM, & Klepp K-I (2009). “When in the body, it makes you look fat and HIV negative”: The constitution of antiretroviral therapy in local discourse among youth in Kahe, Tanzania. Social Science & Medicine, 68(5), 957–964. [PubMed: 19136190]

Farmer P, Léandre F, Mukherjee JS, Claude MS, Nevil P, Smith-Fawzi MC, … Sachs J (2001). Community-based approaches to HIV treatment in resource-poor settings. The Lancet, 358(9279), 404–409.

Feldacker C, Ennett ST, & Speizer I (2011). It’s not just who you are but where you live: an exploration of community influences on individual HIV status in rural Malawi. Social Science & Medicine, 72(5), 717–725. [PubMed: 21316134]

Ghoul A, Niwa EY, & Boxer P (2013). The role of contingent self-worth in the relation between victimization and internalizing problems in adolescents. Journal of Adolescence, 36(3), 457–464. [PubMed: 23489658]

Goffman E (1963). Stigma Notes on the Management of Spoiled Identity. New York: Simon and Shuster: Inc.

Group ISS (2015). Initiation of antiretroviral therapy in early asymptomatic HIV infection. New England Journal of Medicine, 373(9), 795–807. [PubMed: 26192873]

Han C-K, Ssewamala FM, & Wang JS-H (2013). Family economic empowerment and mental health among AIDS-affected children living in AIDS-impacted communities: evidence from a randomised evaluation in southwestern Uganda. Journal of Epidemiology and Community Health, 67(3), 225–230. [PubMed: 23410851]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Hodgson I, Ross J, Haamujompa C, & Gitau-Mburu D (2012). Living as an adolescent with HIV in Zambia–lived experiences, sexual health and reproductive needs. AIDS care, 24(10), 1204–1210. [PubMed: 22380932]

Kamau JW, Kuria W, Mathai M, Atwoli L, & Kangethe R (2012). Psychiatric morbidity among HIV-infected children and adolescents in a resource-poor Kenyan urban community. AIDS care, 24(7), 836–842. [PubMed: 22292795]

Kang E, Delzell DA, Chhabra M, & Oberdorfer P (2015). Factors associated with high rates of antiretroviral medication adherence among youth living with perinatal HIV in Thailand. International Journal of STD & AIDS, 26(8), 534–541. [PubMed: 25080289]

Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, & Tsai AC (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. Journal of the International AIDS Society, 16(3).

Keogh S, Urassa M, Roura M, Kumogola Y, Kalongoji S, Kimaro D, … Zaba B (2012). The impact of antenatal HIV diagnosis on postpartum childbearing desires in northern Tanzania: a mixed methods study. Reproductive Health Matters, 20(39 Suppl), 39–49. [PubMed: 23177679]

Kipp W, Tindyebwa D, Rubaale T, Karamagi E, & Bajenja E (2007). Family caregivers in rural Uganda: the hidden reality. Health Care for Women International, 28(10), 856–871. [PubMed: 17987457]

Kitahata MM, Gange SJ, Abraham AG, Merriman B, Saag MS, Justice AC, … Brooks JT (2009). Effect of early versus deferred antiretroviral therapy for HIV on survival. New England Journal of Medicine, 360(18), 1815–1826. [PubMed: 19339714]

Lall P, How Lim S, Khairuddin N, & Kamarulzaman A (2015). Review: an urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. Journal of Inernational AIDS Society, 18, 41Á53.

Link BG, Cullen FT, Struening E, Shrout PE, & Dohrenwend BP (1989). A modified labeling theory approach to mental disorders: An empirical assessment. American Sociological Review, 400–423.

Link BG, & Phelan JC (2001). Conceptualizing stigma. Annual Review of Sociology, 27(1), 363–385.

Lowenthal ED, Bakeera-Kitaka S, Marukutira T, Chapman J, Goldrath K, & Ferrand RA (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. The Lancet Infectious Diseases, 14(7), 627–639. [PubMed: 24406145]

MacCarthy S, Saya U, Samba C, Birungi J, Okoboi S, & Linnemayr S (2018). “How am I going to live?”: exploring barriers to ART adherence among adolescents and young adults living with HIV in Uganda. BMC Public Health, 18(1), 1158. [PubMed: 30286746]

Maughan-Brown B (2010). Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. Social Science & Medicine, 70(3), 368–374. [PubMed: 19892454]

Mavhu W, Berwick J, Chirawu P, Makamba M, Copas A, Dirawo J, … Corbett EL (2013). Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. PloS One, 8(7), e70254. [PubMed: 23894625]

Mburu G, Ram M, Oxenham D, Haamujompa C, Iorpenda K, & Ferguson L (2014). Responding to adolescents living with HIV in Zambia: a social–ecological approach. Children and Youth Services Review, 45, 9–17.

McHenry MS, Nyandiko WM, Scanlon ML, Fischer LJ, McAteer CI, Aluoch J, … Vreeman RC (2017). HIV Stigma: Perspectives from Kenyan Child Caregivers and Adolescents Living with HIV. Journal of the International Association of Providers of AIDS Care (JIAPAC), 16(3), 215–225. [PubMed: 27655835]

Meinck F, Cluver LD, Boyes ME, & Mhlongo EL (2015). Risk and protective factors for physical and sexual abuse of children and adolescents in Africa: a review and implications for practice. Trauma, Violence, & Abuse, 16(1), 81–107.

Mellins CA, & Malee KM (2013). Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. Journal of the International AIDS Society, 16(1), 18593. [PubMed: 23782478]

Mellins CA, Tassiopoulos K, Malee K, Moscicki A-B, Patton D, Smith R, … Seage George R. III, f. t. P. H.-A. C. S., (2011). Behavioral health risks in perinatally HIV-exposed youth: co-occurrence of

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

sexual and drug use behavior, mental health problems, and nonadherence to antiretroviral treatment. AIDS patient care and STDs, 25(7), 413–422. [PubMed: 21992620]

Menon A, Glazebrook C, Campain N, & Ngoma M (2007). Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: implications for peer-support programs. JAIDS Journal of Acquired Immune Deficiency Syndromes, 46(3), 349–354. [PubMed: 17721397]

Midtbø V, Shirima V, Skovdal M, & Daniel M (2012). How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. African Journal of AIDS Research, 11(3), 261–271. [PubMed: 25860100]

Miles MB, & Huberman AM (1984). Qualitative data analysis: A sourcebook of new methods.

Mills EJ, Bakanda C, Birungi J, Chan K, Ford N, Cooper CL, … Hogg RS (2011). Life expectancy of persons receiving combination antiretroviral therapy in low-income countries: a cohort analysis from Uganda. Annals of Internal Medicine, 155(4), 209–216. [PubMed: 21768555]

Morantz G, Cole D, Vreeman R, Ayaya S, Ayuku D, & Braitstein P (2013). Child abuse and neglect among orphaned children and youth living in extended families in sub-Saharan Africa: What have we learned from qualitative inquiry? Vulnerable Children and Youth Studies, 8(4), 338–352. [PubMed: 24563656]

Musisi S, & Kinyanda E (2009). Emotional and behavioural disorders in HIV seropositive adolescents in urban Uganda. East African Medical Journal, 86(1), 16–24. [PubMed: 19530544]

Mutumba M, Bauermeister JA, Musiime V, Byaruhanga J, Francis K, Snow RC, & Tsai AC (2015). Psychosocial challenges and strategies for coping with HIV among adolescents in Uganda: a qualitative study. AIDS Patient Care and STDs, 29(2), 86–94. [PubMed: 25607900]

Naar-King S, Montepiedra G, Garvie P, Kammerer B, Malee K, Sirois PA, … Nichols SL (2013). Social ecological predictors of longitudinal HIV treatment adherence in youth with perinatally acquired HIV. Journal of Pediatric Psychology, 38(6), 664–674. [PubMed: 23629146]

Ntsepe Y, Simbayi LC, Shisana O, Rehle T, Mabaso M, Ncitakalo N, … Naidoo YD (2014). Perceptions about the acceptability and prevalence of HIV testing and factors influencing them in different communities in South Africa. the Journal of Social Aspects of HIV/AIDS:, 11(1), 138–147. [PubMed: 25059467]

Nyamukapa C, Gregson S, Wambe M, Mushore P, Lopman B, Mupambireyi Z, … Jukes M (2010). Causes and consequences of psychological distress among orphans in eastern Zimbabwe. AIDS care, 22(8), 988–996. [PubMed: 20552465]

Nyogea D, Mtenga S, Henning L, Franzeck FC, Glass TR, Letang E, … Geubbels E (2015). Determinants of antiretroviral adherence among HIV positive children and teenagers in rural Tanzania: a mixed methods study. BMC Infectious Diseases, 15(1), 28. [PubMed: 25637106]

Palladino C, Bellón JM, Jarrín I, Gurbindo MD, De José MI, Ramos JT, … Amo JD (2009). Impact of highly active antiretroviral therapy (HAART) on AIDS and death in a cohort of vertically HIV type 1-infected children: 1980–2006. AIDS Research and Human Retroviruses, 25(11), 1091–1097. [PubMed: 19895191]

Pantelic M, Boyes M, Cluver L, & Meinck F (2017). HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. Journal of the International AIDS Society, 20(1), 21771. [PubMed: 28853517]

Pantelic M, Boyes M, Cluver L, & Thabeng M (2018). ‘They Say HIV is a Punishment from God or from Ancestors’: Cross-Cultural Adaptation and Psychometric Assessment of an HIV Stigma Scale for South African Adolescents Living with HIV (ALHIV-SS). Child Indicators Research, 11(1), 207–223. [PubMed: 29497463]

Pantelic M, Shenderovich Y, Cluver L, & Boyes M (2015). Predictors of internalised HIV-related stigma: a systematic review of studies in sub-Saharan Africa. Health Psychology Review, 9(4), 469–490. [PubMed: 25559431]

Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, … Mellins C (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. AIDS care, 22(8), 970–978. [PubMed: 20229370]

Pope C, & Mays N (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. British Medical Journal, 310(6996), 42–46.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Pufall EL, Nyamukapa C, Eaton JW, Campbell C, Skovdal M, Munyati S, … Gregson S (2014). The impact of HIV on children’s education in eastern Zimbabwe. AIDS care, 26(9), 1136–1143. [PubMed: 24625293]

Russell S, & Seeley J (2010). The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. Social Science & Medicine, 70(3), 375–382. [PubMed: 19914756]

Salmivalli C (2010). Bullying and the peer group: A review. Aggression and Volent Behavior, 15(2), 112–120.

Scambler G, & Hopkins A (1986). Being epileptic: coming to terms with stigma. Sociology of Health & Illness, 8(1), 26–43.

Schenk KD, Kiragu K, Murugi J, & Sarna A (2014). If you build it, will they come? A qualitative investigation into community barriers to accessing paediatric HIV services in Kenya. Children and Youth Services Review, 45, 18–27.

Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, & Mqeketo A (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Social Science & Medicine, 64(9), 1823–1831. [PubMed: 17337318]

Skovdal M, & Daniel M (2012). Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa. African Journal of AIDS Research, 11(3), 153–164. [PubMed: 24482634]

Strauss M, Rhodes B, & George G (2015). A qualitative analysis of the barriers and facilitators of HIV counselling and testing perceived by adolescents in South Africa. BMC Health Services Research, 15, 250. [PubMed: 26123133]

Strydom H, & Raath H (2005). The psychosocial needs of adolescents affected by HIV/AIDS: a South African study. International Social Work, 48(5), 569–580.

Tanney MR, Naar-King S, & MacDonnel K (2012). Depression and stigma in high-risk youth living with HIV: a multi-site study. Journal of Pediatric Health Care, 26(4), 300–305. [PubMed: 22726715]

Tanney MR, Naar-King S, MacDonnel K, & Team ATN f. H. A. I. P. (2012). Depression and stigma in high-risk youth living with HIV: a multi-site study. Journal of Pediatric Health Care, 26(4), 300–305. [PubMed: 22726715]

Taylor L, Seeley J, & Kajura E (1996). Informal care for illness in rural southwest Uganda: the central role that women play. Health Transition Review, 49–56. [PubMed: 10163411]

Treves-Kagan S, Steward WT, Ntswane L, Haller R, Gilvydis JM, Gulati H, … Lippman SA (2016). Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. BMC Public Health, 16(1), 87. [PubMed: 26823077]

Tsai A, Bangsberg D, Frongillo E, Hunt P, Muzoora C, Martin J, & Weiser S (2012). Food insecurity depression and the modifying role of social support among people living with HIV/AIDS in rural Uganda. Social Science and Medicine, 74(12).

Tsai AC (2015). Socioeconomic gradients in internalized stigma among 4,314 persons with HIV in sub-Saharan Africa. AIDS and Behavior, 19(2), 270–282. [PubMed: 25572833]

Tsai AC, Bangsberg DR, Emenyonu N, Senkungu JK, Martin JN, & Weiser SD (2011). The social context of food insecurity among persons living with HIV/AIDS in rural Uganda. Social Science & Medicine, 73(12), 1717–1724. [PubMed: 22019367]

Tsai AC, Bangsberg DR, Kegeles SM, Katz IT, Haberer JE, Muzoora C, … Weiser SD (2013). Internalized stigma, social distance, and disclosure of HIV seropositivity in rural Uganda. Annals of Behavioral Medicine, 46(3), 285–294. [PubMed: 23690283]

Tsai AC, Kakuhikire B, Mushavi R, Vořechovská D, Perkins JM, McDonough AQ, & Bangsberg DR (2016). Population-based study of intra-household gender differences in water insecurity: reliability and validity of a survey instrument for use in rural Uganda. Journal of Water and Health, 14(2), 280–292. [PubMed: 27105413]

Turan B, Rogers AJ, Rice WS, Atkins GC, Cohen MH, Wilson TE, … Wentz EL (2017). Association between Perceived Discrimination in Healthcare Settings and HIV Medication Adherence:

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Mediating Psychosocial Mechanisms. AIDS and Behavior, 21(12), 3431–3439. [PubMed: 29081045]

Turan B, Smith W, Cohen MH, Wilson TE, Adimora AA, Merenstein D, … Metsch L (2016). Mechanisms for the negative effects of internalized HIV-related stigma on antiretroviral therapy adherence in women: the mediating roles of social isolation and depression. Journal of Acquired Immune Deficiency Syndromes (1999), 72(2), 198. [PubMed: 26885803]

Uganda AIDS Indicator Survey (UAIS). (2014). Uganda HIV and AIDS Country Progress report. Kampala, Uganda.

Uganda Bureau of Statistics. (2014). The population of the regions of the Republic of Uganda and allcities and towns of more than 15,000 inhabitants. Kampala: Citypopulation

Uganda National Council for Science and Technology. (2007). National guidelines for research involving humans as research participants. UNCST Kampala, Uganda:.

UNAIDS. (2014). HIV/AIDS JUNPo, The Gap Report. Geneva, Switzerland.

Vreeman R, McCoy B, & Lee S (2017). Mental health challenges among adolescents living with HIV. Journal of the International AIDS Society, 20(Suppl 3), 21497–21497. [PubMed: 28530045]

Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, & Nyandiko WM (2013). Disclosure of HIV status to children in resource-limited settings: a systematic review. Journal of the International AIDS Society, 16(1), 18466. [PubMed: 23714198]

Willis N, Mavhu W, Wogrin C, Mutsinze A, & Kagee A (2018). Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. PloS One, 13(1), e0190423. [PubMed: 29298326]

Woollett N, Cluver L, Bandeira M, & Brahmbhatt H (2017). Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg. Journal of Child Adolescent Mental Health, 29(1), 11–26. [PubMed: 28287023]

Zwick WR, & Velicer WF (1986). Comparison of five rules for determining the number of components to retain. Psychological Bulletin, 99(3), 432.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

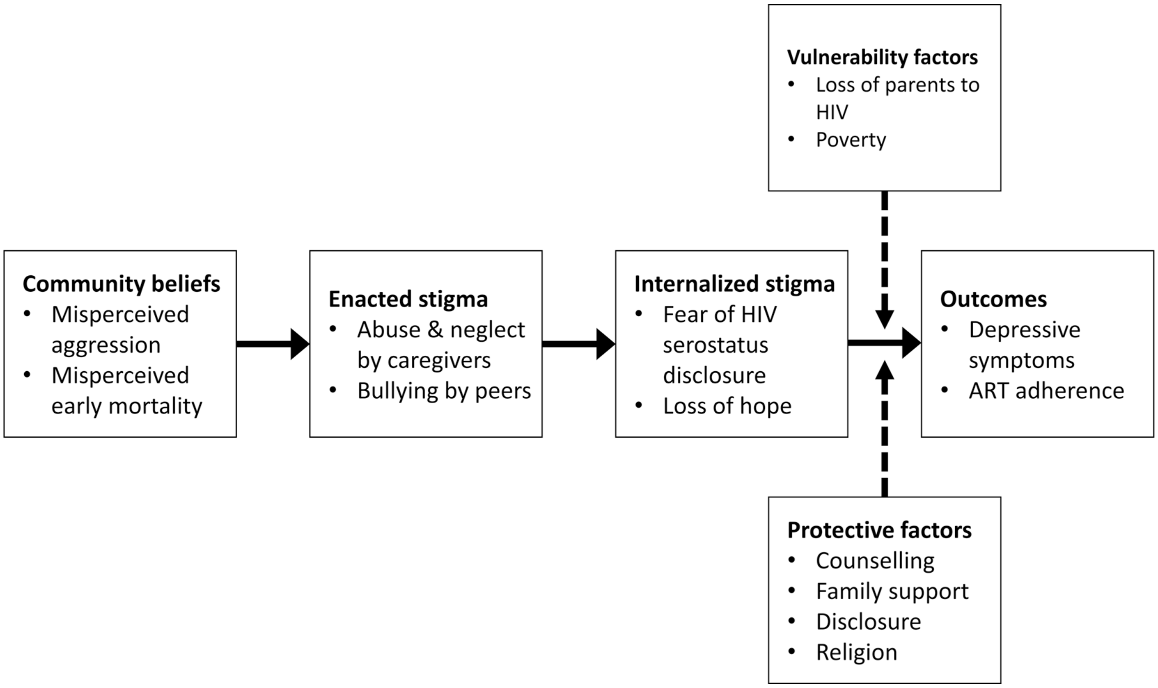

Figure 1:

Conceptual model linking community beliefs, HIV stigma, and health outcomes among adolescents living with HIV