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Research Article

Adolescent Girl's Experiences of Shame When Diagnosed with HIV/AIDS: A Qualitative Study in Zimbabwe

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Abstract

Despite the decline in HIV incidence, 2 out of every 7 new HIV infections globally in 2019 were among young people (15–24 years) and 1.7 million adolescents and 3.4 million young people are living with HIV(UNAIDS, 2021). Adolescent girls and young women are disproportionately more affected than their male counterparts.

A qualitative exploratory design explored the experiences of shame associated with a HIV/AIDS diagnosis for 10 adolescent women (aged 17-19) in Zimbabwe. In-depth semi-structured interviews were conducted in a familiar environment by a qualified psychologist in Harare, Zimbabwe. Data was thematically analysed and supported through a rigorous literature review of shame and PLHIV to contextualise the findings. The principles and theories of Self-Psychology were used to identify, interpret, and understand instances of shame in the data.

Overall shame is pervasive in every aspect of HIV infection. Individuals internalised societal cultural and moral prejudices and perceptions that exacerbated shame. Shame influenced self-esteem, decision making, set limits on who they could be, what they felt could be achieved and hoped for in life. Coping mechanisms were also identified.

The findings have implications for HIV policies, service provision and interventions that induce, promote and/or maintain shame in various spheres.

Keywords: Shame; HIV; Adolescents and Young People; Zimbabwe

Background

Human Immunodeficiency Virus (HIV) remains a major global health crisis with far-reaching implications [1]. As of 2023, an estimated 39.9 million individuals worldwide are living with HIV, including 2.38 million children and adolescents between the ages of 0 and 19 years [2]. Sub-Saharan Africa (SSA) bears the highest burden, with 65% of the global HIV-positive population residing in the region [3]. The primary mode of transmission is heterosexual intercourse, with women disproportionately affected compared to men [1].

Young women and adolescent girls aged 15–24 are particularly vulnerable, with around 4,000 new HIV cases reported each week

globally in 2023, 3,100 occurring in SSA [2]. This heightened risk for young women can be attributed to various factors, including age-disparate or transactional relationships, gender-based violence, patriarchal norms, limited educational opportunities, food insecurity, and practices such as genital mutilation [4]. Additionally, as of 2011, 92% of HIV-positive pregnant women were from Sub-Saharan Africa, highlighting a significant risk for mother-to-child transmission—with potential implications for shame experienced by adolescents who are either vertically or horizontally infected with the virus [5]. In Zimbabwe, 5.5% of people living with HIV are children aged 0–14 years, and 5.9% are adolescents aged 10–19 years [11]. Undiagnosed HIV is a leading cause of illness, hospitalisation, and mortality among adolescents in Zimbabwe, indicating that similar challenges may be present in other developing countries [9]. Delayed diagnosis often results in severe health consequences, such as stunted growth, tuberculosis, and other opportunistic infections, which are exacerbated by weakened immune systems during periods of increased social interactions [9].

Advancements in Antiretroviral (ARV) therapy have significantly improved the physical health outcomes for many children living with HIV, extending their life expectancy [6]. However, as these children transition into adolescence, they encounter new challenges related to managing a chronic illness [7]. This situation can be described as developmental trauma, where adolescents must cope with both the chronic condition and associated social or psychological burdens, such as threats of mortality and potential loss of family members—a scenario often observed in Southern Africa [7,8]. Consequently, adolescents face a heightened risk of mental health issues, decreased self-esteem, and difficulties in emotional regulation [9]. The psychological strain of living with HIV can also contribute to lower adherence to medication, challenges in forming and maintaining relationships, and struggles with self-acceptance, often exacerbated by the stigma associated with sexually transmitted diseases [9].

Despite significant improvements in physical health outcomes for individuals living with HIV, the emotional and psychological challenges associated with the condition remain profound and inadequately explored [9]. Existing literature predominantly focuses on stigma, a pervasive factor that hinders access to medical care and discourages the disclosure of one's HIV status [9]. To fully understand the psychosocial impact of HIV, it is crucial to differentiate between external stigma, internalised stigma, and shame—concepts that are often conflated [8]. According to Fortenberry., *et al*. (2002), external stigma refers to societal discrimination and its outward manifestations, while shame—a key component of internalised stigma—represents the internal emotional repercussions, leading individuals to view themselves as inherently flawed or defective [8,10]. Shame makes you feel as if your whole self is flawed and unworthy, often triggered by an incident, such as a personal failure or social rejection. Internalised stigma is when the negative societal beliefs about a particular identity or condition are internalised, affecting your self-worth. Shame is a self-conscious emotion that can be experienced as autonomous or heteronomous [24]. As an autonomous emotion, they can feel ashamed about their failures to meet personal standards or expectations of their character, morals, personality, identity, etc. Shame becomes a heteronomous emotion when others judge them or they fails to meet societal norms, values and standards. Therefore, enacted, internalized, and anticipated stigma causes shame as they trigger heteronomous and autonomous shame in people living with HIV [24].

Shame and stigma are intertwined aspects of the psychosocial experience of being HIV-positive, with adolescents being more vulnerable to its effects when compared with other age groups [32]. However, research on effects of shame on the well-being of those infected remains limited [32]. As noted above, adolescent girls share a higher burden than their male counterparts. In Zimbabwe, adolescents between 15-19 years of age, compared to other age groups, reported the highest rates of feeling ashamed of having HIV (33.3%) and blaming others for infection (30.4%) [39]. This study addresses this research gap by addressing: 'What are the experiences of shame among adolescent girls living with HIV in Zimbabwe?'

Methods

Study design and recruitment

This study employed a qualitative exploratory design to investigate the experiences of shame among adolescent girls diagnosed with HIV. Semi-structured interviews were utilised to gather detailed data on their lived experiences of shame allowing for a thorough examination of how shame affects adolescents' self-

perceptions and worldviews. In-depth semi-structured interviews were selected to explore adolescents' experiences and facilitate the free flow of meaningful information [35]. Given the sensitivity of the topic, individual interviews were chosen to allow comprehensive and interactive exploration of personal experiences. A semi-structured interview guide with open-ended questions was created to encourage natural dialogue, enabling the interviewer to probe deeper and allowing participants to express their true thoughts and opinions, thereby generating rich data [35,42].

A purposive sampling method selected ten adolescents from the AFRICAIDs Zvandiri program in Harare, Zimbabwe. Zvandiri is a local private voluntary organization in Zimbabwe that delivers services at scale to young PLHIV through trained peers who connect with them and support them to survive and thrive. Zvandiri acted as the gatekeeper and the administrators facilitated access to potential participants. Recruitment occurred during support group meetings, with the gatekeeper introducing the researcher. The sample included low to middle-class black Zimbabwean females aged 17-19 years. Participants were included if they were living with HIV, able to provide consent or assent, and in good mental and physical health. Those unable to consent or with serious mental disorders, such as schizophrenia, were excluded. The interviews were conducted by the principal researcher, a qualified clinical psychologist, who is also fluent in the local language Shona.

Interested participants wrote down their names for scheduling appointments which were confirmed by phone. For those under 18, consent forms were provided for caregiver signatures and assent forms for the participants approval. Before the interviews, participants received an information sheet and consent/assent forms, and any ethical concerns were also raised before the interviews commenced. Interviews, lasting 60-90 minutes, were conducted at Zvandiri house to reduce stress and anxiety and in the local language Shona. Participants' questions were answered, and transport reimbursements were provided.

Data analysis

Thematic analysis was used to interpret the data, capturing complex meanings in qualitative research. An inductive approach allowed themes to emerge from the data without preconceived notions, providing insights into the research question and identifying broader patterns [33,34]. Interviews were transcribed and translated by the primary researcher (VM) who also conducted the interviews. Identifying information was removed, and initial codes developed. Codes were colour-coded, grouped, and examined for thematic connections, leading to the identification of the main themes and sub-themes.

Ethical considerations

The study adhered to ethical guidelines of, and received ethical approval from, the University of Cape Town, South Africa (VM was a registered postgraduate scholar with this university at the time of the research) and the Medical Research Council of Zimbabwe. Participants were informed about the research aims and provided consent before data collection, with clear communication about their right to withdraw at any time without repercussions. Confidentiality was strictly maintained, with access to identifiable information limited to the researcher. Personal identifiers were removed from transcripts to ensure anonymity. Zvandiri, the local voluntary organisation in Zimbabwe, was providing ongoing psychosocial support for all participants, but additional care options were made available if needed.-

Results

Three overall categories of data describe the responses from the participants in relation to shame: drivers of shame, reactions to HIV associated shame, and self-beliefs. Each of these categories is discussed with the themes that arose within them.

Drivers of shame

Association of HIV with sex

Participants were ashamed of their diagnosis because of the assumed mode of transmission, sexual activity and promiscuity. Worries about fault, blame and responsibility for HIV acquisition where drivers of shame.

"I cried all the way in the bus because I was hurting. I was like but it's not my fault– like you know the ways of transmission of HIV, mostly it's through sexual intercourse. The chances of using sharp utensils are fewer and so stuff …" (P 3).

"I did not get into the bar to look for it so where did I get it? I wasn't promiscuous so where did I get it from?" (P 7).

Participants were also worried and ashamed of HIV acquisition in relation to future sexual relationships and disclosure.

"HIV positive people who want to indulge but especially if you are a girl, if you indulge, you lose your virginity then you want to get married, you can't disclose to your boyfriend or husband stuff…. coz they will ah say" you were sleeping around …how can I marry someone who was sleeping around? I don't know where you got that disease and stuff" (P 6).

Bodily capacity

The body was seen as providing proof of HIV infection thus exposing one's status to others, leading to shame, humiliation and social out casting.

… my face, everywhere it was just …. skin peeling, scars, ring worms all of that was on my body… in my family, the finger pointing was already there but at school, through seeing all that, they began to point fingers at me and say I am positive (P 7).

Being sick was seen as shameful as the body's capacity to do things was reduced. The weakness and abnormalities that the participants were experiencing induced shame.

"… she gave me a bottle to put phlegm… I failed to do it because I was weak, and I couldn't. I was truly sick at that time" (P 7).

Weight loss and stunted growth particularly late development of secondary sex characteristics were associated with the shame of being viewed as a child when one ought to be a woman.

"… Some other adolescents have very small bodies and yet their age will not comply to their bodies. So really dating can be a huge challenge because obviously a guy can't approach you seeing that you look thirteen". (P 9)

Participants were also mindful of how family members responded to them being sick with shame and humiliation being associated with ill health while acceptance was linked to health and wellbeing.

"… I was changing, skin it was clearing… to my surprise – my family – food that I would leave they started eating it …" (P 10)

Medication

Participants struggled with the burden of taking medication for life.

"… can you really survive like this, taking medication? … In the morning and in the evening umm it's hard" (P 2).

Taking medication both risked exposing participants' HIV status and was essential for managing the virus and related illnesses. This created internal conflict about taking it. Side effects like vomiting, weight loss, rashes, and delayed development made them worry about revealing their status. Despite these challenges, the medication also acted as a safeguard, preventing serious illness that could otherwise expose their condition and cause shame.

"…. I could have defaulted and maybe could have fallen very ill and then people could actually realize that I have HIV" … (P10).

Participants experienced anticipatory shame of peers discovering their medication in social settings resulting in humiliation and social out casting. One participant avoided going to a camp fearing that her HIV positive status would be exposed when she takes her medication.

"… I was afraid of taking the pill. You know how girls are "What's in your bag? Can I see?" Then she would start removing everything in the bag … And then suddenly the container of the pills can just fall out" (P 3).

Another participant was also uneasy about her teammates finding out about her status, thus she would device ways of taking her medication without them knowing about it.

"… Coming from breakfast it would be time for me to take my medication ... I would walk fast and tell others that I am rushing to do something in the room so that I could take my medication before they arrived… If they got to the room before me, I would make sure that I would be the last one to get out of the room..." (P 2).

The need to conceal and come up with excuses for taking medication, also point to the shame of exposure and others discovering one's status. The medicine containers were also a cause of concern.

"… I saw some of my friends suspecting because I did not change the containers of pills… I just took the pills without thinking about it or seeing that they were around … so there was just one friend who was like "ah that container?" … and I was like "no I couldn't find any useful container at home, so this one was more preserving than the right one" (P 6).

Family circumstances

Participants and their parents were judged and seen as being at fault or to blame for HIV acquisition, resulting in family members having little compassion for their plight.

"…My granny when she gets upset with me would say "that's why your mother died of HIV and was in the business of bringing sickness here!" (P 4).

Seventy per cent (n=?) of the participants where double orphans while 30% (n=?) had one parent who was still alive. This meant that most of the participants were looked after by siblings and other extended family members who worried about HIV acquisition. Most participants reported facing caregiving challenges and rejection which made them prone to shame about HIV acquisition.

".... My sister and brother-in-law used to constantly fight, "she should leave this place" with my sister saying, "No she is not going anywhere!" (P 7).

Participants expressed not receiving good parenting as often the families they joined had other caring responsibilities. Additionally, participants felt that their caregivers where ashamed of them being HIV positive resulting in exclusion from family events. This increased participants shame about HIV acquisition.

... When they are taking their children and going out … I couldn't go coz I was very thin – maybe they were ashamed of walking with me, I don't know [crying] (P 10).

Furthermore, their caregivers would treat the participants' differently to their siblings or other children. This isolated them from others worsening the feelings of being flawed which caused shame.

"… I slept by myself … My own plate, a cup that was well known that it was (Participants name)" (P 8).

For participants who were being raised by their parents, mentioned that their caregivers' reactions to HIV acquisition had a bearing on their experiences of shame. A participant reflected on her mother's despair and shame about her own status which affected how she viewed herself and HIV.

"… If someone knocks at the door, she leaves to the other room and then stays there until the visitor leaves... So, she is really in great pain because if she wasn't she could still live like she did before she knew she has HIV..." (P 3).

Reaction to HIV related shame

Resistance to testing

Most of the participants did not get tested for HIV until they were very ill, often despite their parents' death. Parents whose children tested positive for HIV avoided being tested themselves.

"My father … I asked him a question "are you on treatment?" … Then he said, "I have not been tested." …He is the kind of person that does not want to be tested!" (P 9).

Shame made it difficult for parents to be tested for HIV and have their children tested as well. This delayed diagnosis and treatment, a huge challenge that causes infant mortality in Zimbabwe and Sub-Saharan Africa.

"… My mother when my dad died …. When she started feeling sick she went and got tested. She didn't think about taking her child to get tested because I was strong … then I started being sick as well…. they were just saying "it's just a child who is being troublesome because she is the youngest…" (P 4).

Some participants and their care givers also tried to avoid testing by attributing sickness to evil spirits and demonic manifestations.

At first, they were going to white garment churches seeking help … saying "our daughter is sick and we do not know what is causing the sickness". So, I was being given roots, herbs, and water … but it was not helpful" (P 1).

Denying sickness/associating illness with HIV

Despite the apprehension associated with being tested and the shame of being diagnosed, participants were often tested because of sickness. All the participants reported that they were constantly unwell, but their illness was misdiagnosed or dismissed. Although the sickness was quite serious, they generally did not attribute it to HIV.

Well [laughing] … it was something that I couldn't believe I was going to be. Like even if – no matter how sick I was I would never think that it would like lead into positive (P 9).

Participants had to be seriously ill or frustrated by misdiagnosis and always being sick for them to be tested.

.... Aargh [Irritation]. Ah then I shouted, "Ah I want to be tested". The nurse was like "ok, you want to be tested?" Let me put her words, ah she was like "what do you know about being tested, you?" and then I said "I want to be tested for HIV because I am always sick and each and every month I come here" ...(P 6).

Some of the participants were encouraged by others to be tested. This was in response to the various signs on the body that were associated with HIV.

... When I got herpes that is when my sisters' friend suggested that I should be tested, and I was found to be positive" (P 8).

"My mom just said ... I started developing a rash and then she said "this rash I usually see it on others, this rash" ... that was the proof" ... (P 2).

Secrecy, hiding and withdrawal

Participants felt they had to hide their status and do everything possible to avoid exposure. Fears of exposure were supported by the law as nonconsensual disclosure of HIV is a crime.

"... She knows that if you disclose someone's status you will be imprisoned" (P 7).

Secrecy or hiding included participants wearing clothing that covered parts of their bodies with rashes suggesting infection.

"... Some also grew hepatitis B, and that is the actual symptom of HIV so they cannot wear those clothes that can reveal their shoulders. If it's on the hands, they are only usually in long sleeves...." (P 5).

At school, some participants had letters explaining that they had other diseases and should be excused from certain activities thus concealing their status and averting shame.

"... Like they wrote a letter in my school saying that I had chest problems ... and the fact that I had HIV was not mentioned ..." (P 6).

Those who did disclose their status at school had the misfortune of having it spread around, validating the need for secrecy.

"That's the only one I could tell but the teacher was not trustworthy ... but told the headmaster ... and then the whole school knew about it. It was ... bothering me until I got transferred from the school" (P 8).

Even in family, friendships and interpersonal relationships secrecy was valued because of fear of exposure. Living with HIV was a close family secret kept from the infected and affected.

"Ah it was a family secret that was just known by my grandmother and her children only" (P 1).

"I was told that the tablets you are drinking are for fish disease in that if you eat fish you have a skin reaction to it" (P 9).

"My brother doesn't know... If we fight over anything he will start revealing those things he would know that I don't want my gran and my mom to find out. So that's what made me kept it from him" (P 3).

Even in cases where participants were sick and required medical attention, shame caused them to remain secretive about HIV to healthcare providers.

".... Like I didn't say anything at the hospital ... you know how nurses are like ... well sometimes they are just [pause] talking and they are like "do you know that this child is positive?" ... then maybe that nurse is not a secret keeper, she goes on and tells the next person ..." (P 3).

Participants expressed that public hospitals had a high likelihood of exposing HIV acquisition making them anticipate shame and humiliation in those settings.

"...I go to a private clinic; I am not facing challenges there. But some other peers say when you go to a local clinic or a general hospital, they will be like ah "Those that take HIV medication come and stand here". What if someone in your neighbourhood is there and that person sees you going that way, what would they think?" (P 4).

Opting to go to a private clinic speaks to the fear of exposure, and the real or imagined reactions of others, and reinforces the decision to hide their status due to shame.

Blaming source of infection/Assigning blame

To defend themselves from the shame and negative personal and social labels associated with HIV infection, many of the participants wanted to know the source of infection and apportion blame for their status. Some required that their parents be tested as confirmation that they were not responsible for infection.

"… So, getting my mother tested was just a way of knowing "where did I get it from?" (P 3).

"I asked him "where did I get the virus? "…he was shocked and said, "Ah I don't know!" … "Ah you leave me alone!" … "If you refuse to tell me this time, I will look for a way to kill myself! "Then he said "my sister you were born with it, it's not your fault, just live with what is there" (P 7).

Many of the participants insinuated that their HIV infection was because of sexual indiscretions by their fathers. They presented their mothers as victims who were also paying for the recklessness of their fathers.

"I wouldn't blame her as such coz she is also paying for something she did not … you know. I wouldn't know parents really, but I am sure it only came with my dad, being passed on to my mom and being passed on to me" (P 3).

"…and I blamed my father saying that if he didn't have three wives – they are not even three maybe there are even three more besides my mom. My mom was the last one. …. Could it be that ah he knew his status and wanted to spread it, or could it be that he didn't know his status and he was only doing his thing…?" (P 4).

Another participant also alluded to their father being responsible for transmission, linking his rank, income and social status to the possibility of HIV infection as these are some of the attributes that enable men to have multiple sex partners.

"… Maybe my dad was the one who had it because he was a brigadier…" (P 2).

Assigning blame for HIV acquisition enabled participants to express their feelings towards their parents for vertical transmission and avert shame.

"… for my parents like I really grew that – that ice in my heart especially for my dad who passed away, he had done all he had to do with his life, and he left me with the disease, you know. So, I don't want to lie, I had been hating on my parents. It took me a while to forgive them" (P 10).

Beliefs of HIV related shame

As I am

Participants viewed themselves as being HIV and all its negative moral and social labels being a part of their identity as opposed to having a condition that does not define them.

"My dad and grandmother called me … and they told me that that is what I am" (P 1).

"… I just accepted "ah that's just how I am" (P 5).

Statements such as "what I am or who I am" were used by all the participants to describe themselves in relation to HIV acquisition. This suggest that they have introjected HIV to be part of their identity making the negative labels a part of their identity inducing shame.

Worthlessness and low value

The belief that one is fundamentally undeserving of love or incapable of being loved was expressed and underpinned by the assumption of low inherent worth. Many of the participants felt no one would love and accept them because of their HIV infection.

If you say it as it is then he will tell you the absolute truth that "he does not date people like that" and dump you (P 1).

"…Then it came out that he wanted to tell his parents about my HIV status, and I didn't like that. So, I was like God this is the reason I am breaking up with him". I don't want to mess up my life and I don't want to mess up his life …I know that parents do not want their children to get married to HIV positive people (P 6).

The participant refused to marry a man who was accepting of her and HIV because she was convinced that she was unlovable and that she would be abandoned by her partner and his family. The shame of disclosing her HIV acquisition, a blemish on the self, was seen as an attack to the self which she defended against by ending the relationship.

Participants lived in anticipation of being shamed or rejected by others for their status.

".. I am thinking about telling him a story "you know my friend had a boyfriend and she was HIV positive and then she told her boyfriend about her status and the boyfriend dumped her. If it was you in that situation, what would you do?" Then I will listen to the answer that he would have given me to see if he will accept or reject me" (P 1).

The participants were guarded about talking about their status with their boyfriends as they anticipate being rejected. They tried to gauge the reactions of others by tell stories about infection hoping to ascertain the responses of others, protecting herself from shame.

Inadequacy and low self-esteem

Participants also exhibited low self-esteem in that they evaluated themselves as lacking, inferior and not good enough in comparison to others, thus, to be chosen by another for interaction greatly shocked and moved them as they were shameful and unworthy in their own eyes.

Why not just get a real – real girl and then really…. A real – real girl who is negative and not one …… but [sic] the problem is that when you are HIV positive – it just shocked me … (P 8).

"I saw myself …I can say just a person who is walking around without any value and without anything that they can try to do to be valuable" (P 9).

Perinatal HIV acquisition can cause cognitive difficulties in childhood [23] and being ill for long periods resulted in absenteeism at school. Therefore, most participants did not do well at school and felt bad about it, worsening feelings of inadequacy and incompetence.

"Right now, I am sitting at home. I wrote O' Level last year. I wrote five subjects, but I passed only two (P 5)".

"… Those that know me; if they find out that I have Ds they would say "are those (participant's name) results?" Yes, I really wanted to pass, and I didn't want to get married without passing, No! If you would be asked by your in laws "what did you bring?", you can just bring out your certificate …" (P 2).

Failing at school made participants feel that they had many shortcomings that they had to make up for, including HIV, making them unacceptable to others and causing shame. Feelings of incompetence often stem from the belief that "I can't do things right" or "I am incapable." This belief can become self-fulfilling as it undermines efforts to succeed or improve. Academic struggles together with living with HIV worsened the negative self-image that participants had about themselves inducing shame.

Self-loathing and hatred

Self-hatred, a belief-driven emotion, was expressed through views about being inherently bad, flawed, or unacceptable. Participants preferred dating HIV negative people because those who were positive would disclose their status. This revealed how much they disliked themselves and having HIV. They were ashamed of themselves, their status and being linked with those that were HIV positive.

"Never! Never! … I can't say they didn't come. They came but I don't want positive guys. I want a negative guy… The reason is that ah I don't want. I want to explore the world, right? What if that person is known in their neighbourhood that they are HIV positive? That means I am also going to be known that the lady she is dating is HIV positive as well. I don't prefer positive guys at all since I got to know my status … as for me, ah as (participants name), I don't want them" (P 6).

The participants who viewed themselves as dirty and repulsive were apprehensive about being intimate with others as they feared that they would pass the infection or dirt to others.

"Ah the thing that I don't like is kissing … because I am a person that is easily disgusted …diseases can be passed through saliva… I was afraid of passing the disease" (p 7).

The reactions of others in not touching them or not eating food that they touched also communicated that they were tainted or dirty, thus a consciousness was expressed about eating in a smart way or not being messy.

"… Whatever food I might have left, even if I had not touched it or eaten in a messy way like children do, no I would eat in a smart way, just because it was eaten by someone who is positive, just to touch it, they would decide to sleep without eating …even if I have left it" (P 5).

In addition to being seen as dirty, participants were viewed as dangerous, reflecting beliefs such as, "I am a threat to others" or "I cannot be trusted." These feelings often stem from guilt or fear related to past actions. Participants linked this stigma to traditional caring roles women often fulfil—such as cooking and sewing—making them feel inadequate. The shame associated with these duties further exposed them to humiliation for their status and their inability to perform feminine roles.

"… Even cooking, people wouldn't allow me to cook. I don't know what they were afraid of …" (P 8).

"… It was like if I sewed my dress and I didn't even prick myself, people would not even touch that needle". (P 10).

Despair and hopelessness

Despair often arises from the belief that "nothing will ever improve" or "there is no hope for me." This belief fuels feelings of helplessness and resignation. The weight of the above beliefs and the environment in which the participants lived resulted in some participants believing that nothing could be done – that HIV was a stain on the self that could not be removed.

"It bothered me … but I tried to be strong and tried to accept it because there was nothing I could do about it" (P 7).

"Ah-ah, I just think that this is what I am and there is no one to deny it to. So, I will just survive like that" (P 4).

Discussion

Shame was pervasive in adolescent girls' experiences of living with HIV. Drivers of shame such as the link between sex and HIV acquisition, bodily incapacitation due to illness, potential exposure due to using ARVs and family circumstances made it a reality in participants' experiences. The above-mentioned drivers of shame led to reactions such as resisting testing, denying illness or looking for alternative explanations or solutions, secrecy, hiding and withdrawal, together with assigning blame on others for HIV acquisition. These drivers and reactions to shame are crucial to understanding the lived experiences of adolescent girls living with HIV as they have a bearing on care and support services offered to this group.

Poor access to services, retention in care and high mortality have been reported among AYPLHIV, particularly during the transition from paediatric to adult care [29]. The findings of this research suggest that shame is an unaddressed barrier to testing, acceptance of HIV diagnosis, access to services, adherence to medication and retention in care. Particularly for adolescents who are developmentally transitioning to adulthood which comes with physical and psychological changes that can induce shame [14,28,29]. Having HIV in adolescents can be conceptualized as a developmental trauma that affects maturation and worsens the shame experienced by young people during this period. Participants in the study indicated that they did not fully understand the meaning of having HIV in childhood. However, this changed in adolescents because of maturation and being given more selfcare responsibilities including clinic visits and adherence to medication [23]. Maturation and increased selfcare responsibilities exposed adolescents to negative familial, community and social narratives about HIV acquisition, resulting in shame.

Diseases are social constructions, and HIV has been conceptualized as an illness of sexual immorality and deviance [18]. This construction comes with a narrative of fault and blame for HIV acquisition which causes shame [39]. The participants in the study felt ashamed because of the link between sex and HIV acquisition. They also felt ashamed about their parents' sexual behaviour which they believed caused their HIV acquisition. The reactions of their parents and guardians with or without HIV - secrecy, hiding and withdrawal - socialized them to be ashamed of living with HIV. Narratives of fault and blame together with feeling ashamed because of mother to child transmission of HIV suggests that adolescents might feel even more ashamed if they sexually acquired the virus. The findings of this study show that shame has adverse effects on HIV testing, acceptance of diagnosis, access to services, adherence to medication and retention in care. This is a huge concern in SSA, including Zimbabwe, which has a high HIV acquisition rate among adolescents, with girls disproportionately affected [31]. Addressing HIV related shame could be the missing link to meeting the 95-95-95 care and treatment goals among AYPLHIV.

Additionally, the socially constructed HIV narrative also uses language that causes shame and negatively affects PLHIV. Findings from other studies have indicated that using words like vertical or horizontal infection and key populations caused stigma,

discrimination and poor mental health outcomes among PLHIV [44]. In this study, participants used words like "I am HIV positive", "you are HIV positive", "this is what I am" to describe living with HIV. "I am "and "You are" are identity makers that suggest that a person is their disease, together with the negative social constructions of HIV, causing shame. Shame related to assigning the negative attributes of a disease to one's identity has been highlighted in mental health literature. For example, people with mental illness have been identified by themselves and others by saying "I am a schizophrenic, or You are schizophrenics", linking their sickness to their identity causing shame [40]. This language is distinct to HIV and mental illness, diseases that are highly stigmatised in society and which induce high levels of shame for those diagnosed with and affected by them [40]. Social constructions relating to other diseases conceptualize them as conditions one has, for example -you have cancer, hypertension, sugar diabetes etc. This separates negatives attributes of an illness from one's character and identity reducing shame and stigma. In mental health research, linking attributes of a disease to a person's identity results in shame which causes people to avoid being assessed for mental illness, struggling to accept diagnosis, poor access to services, poor adherence to medication and poor retention in care [26]. Findings which are supported in this study.

Identity formation is a key developmental task in adolescence [19,27]. Due to the HIV narrative and language, participants could not separate the negative social labels from their character. Participants characterised themselves as inadequate, with low self-esteem, worthlessness, dirty, dangerous, flawed, untrustworthy, bad, incompetent and self-loathing. Participants inability to separate HIV and its negative personal and social labels from their identity caused them to feel ashamed and to experience despair. As HIV is incurable, it was seen as a flaw on the participants character or identity which could not be removed causing hopelessness about being good, desirable and acceptable to others. This finding is crucial in that adolescence are self-conscious, want to fit in and need to be seen as desirable and acceptable by peers [25]. Having a spoiled or flawed identity due to HIV resulted in shame and greatly affected the adolescents' developmental needs, impacting on physical and psychological growth. Despair and hopelessness also resulted in suicidal thoughts and attempts made through various means, including defaulting ARVs for long periods. In other studies, HIV related shame was seen to cause depression and suicidal thoughts among adolescents and young people living with HIV [15,17,41].

The immutability of HIV as a flaw on the participants character was also reinforced by cultural norms of societies, like Zimbabwe, which use shame as a tool for social control [15]. In these societies, shaming is an active behaviour used to reprimand, deter or punish people for violating norms, values or morals [22,38]. There are two types of social shaming which include stigmatic and reintegrative [38]. Stigmatic shaming labels the individual as a bad person while reintegrative shaming deplores the act but allows the individual the opportunity to be redeemed in the eyes of society [21,24]. Stigmatic shaming denigrates and destroys a person's bond with society for the rest of their life while reintegrative shaming creates opportunities for rehabilitation and re-admission into society. People living with HIV experience stigmatic shaming which has a greater impact on adolescents and young people as they developmentally need to be guided, accepted and supported by society, in various sectors, to grow optimally. Findings from the Zimbabwe stigma index 2014 report showed that adolescents experienced higher levels of HIV related shame and avoided social interactions when compared to other age groups [22]. Adolescents raised in a culture of shaming can see stigma, discrimination and humiliation as normal or acceptable consequences for socially deviant behaviour of acquiring HIV. This has a dual impact as it empowers societies to justifiably punish people with HIV for acquiring the virus and simultaneously strengthens the negative self-beliefs among people living with HIV about having a flawed identity, entrenching despair, which results in poor physical and mental health outcomes.

This is a particularly relevant in Zimbabwe which has a culture of shaming for social control [36] evidenced through Shona idioms and proverbs about shame like "kushaya ganda kumeso", which means having no shame and "nyadzi dzinokunda rufu" meaning shame surpasses or is worse than death [36]. Adolescents raised in this society where being shameless is bad can be easily prone to experiencing shame especially when diagnosed with HIV which has been socially constructed as a disease of sexual immorality which society abhors. In addition, living with the belief that shame surpasses or is worse than death can be a social catalyst

for resisting testing for HIV, accepting diagnosis, accessing services and medication adherence, all of which can lead to premature death. Therefore, HIV related shame in this context could be the unaddressed challenge driving the high rates of treatment failure and mortality among adolescents and young people living with HIV in Zimbabwe and Sub-Saharan Africa, which share similar culture, values and norms.

The impact of shame driven by cultural and societal norms affects all adolescents and young people living with HIV; however, it might be greater on girls [13]. Findings from the study indicated that patriarchal beliefs extended to social constructions and narratives of fault and blame regarding HIV acquisition were gendered. Society is seen to excuse the sexual deviance of men while severely punishing women for the same transgressions [16,43]. As this study only interviewed adolescent girls, we do not know if they are experiencing more shame about HIV acquisition when compared with their male counterparts. However, having HIV was described as an indictment of a girl's character and reputation as it went against societal constructions of feminine chastity and purity. It also affected the full execution of feminine gender roles like cooking and sewing because of the fear of spreading HIV to others. The participants also felt that HIV affected their identity as women because they could not have unprotected sex and have children without medical support or intervention. This caused shame and beliefs of inadequacy, low value, worthlessness, incompetency, feeling dirty, tarnished, dangerous and untrustworthy in their eyes and those of society. These findings are like those of other studies in Sub-Saharan Africa, where inequalities have been identified in experiences of stigma and discrimination between man and women living with HIV [30]. In patriarchal societies, including Zimbabwe, women have a diminished status in society which is worsened by HIV acquisition [43]. Adolescent girls might experience worse outcomes than adult women [30,37]. This is of particular concern because adolescent girls have the highest rate of HIV acquisition in Sub-Saharan Africa where existing vulnerabilities and shame might exacerbate the poor physical and mental health outcomes that are being seen in this age group.

Conclusion

Shame affects the mental and physical health of adolescents and young people living with HIV. Interventions are needed to address shame to improve HIV testing, acceptance of diagnosis, access to services, medication adherence, and retention in care among this key population. The importance of examining shame, beyond stigma, in public health interventions and policymaking has been discussed in recent years, following the COVID-19 pandemic [45]. These studies have stressed the need to look at shame and its impact on public health, ideologies of shaming and blaming people for acquiring certain health conditions, shame sensitivity in policy making, evidence-based approaches to the consequences it has on health outcomes, long term effects of pandemic shame and cultural contexts [45]. Our study highlights the importance of these recommendations.

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Declaration of Interest Statement

The authors report there are no competing interests to declare.

Data Availability Statement

Due to the sensitive nature of the data collected and no agreement with the participants to share their transcripts the only available data is included as quotes in the body of this article.

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Appendix 1: Interview Guide

Introduction:

Getting to know the participant. Age, academic levels attained, family structure, physical address etc. (Brief bio data).

Length of time they have been with Zvandiri and the programs that they have been part of. Also get a sense of how they feel about those programs and how helpful they have been.

Past and present issues of infection:

How did they find out that they were HIV infected?

When did they find out that they were HIV infected?

How did they feel about it when they first found out?

Was there anyone to whom they first disclosed that they were HIV infected?

How did they respond to the news? If they did not tell anyone, what made them keep it a secret?

Are there any differences in the way they live their lives now in comparison to how they lived before they knew about the HIV infection?

Are they in any interpersonal relationships or are they dating anyone at present or in the past?

Are they sexually intimate with their partners?

How do they spend their time, do they have any hobbies or do they socialize with others?

Any other information:

Anything else about their experience that they would like to share that I might not have asked?