The Open Public Health Journal
DOI: 10.2174/0118749445396691250703054354, 2025, 18, e18749445396691
ISSN: 1874-9445
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RESEARCH ARTICLE **OPEN ACCESS**

Navigating HIV Disclosure: Voices of Young Women with Perinatally Acquired HIV

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Abstract:

Introduction: Human Immunodeficiency Virus (HIV) self-disclosure plays a crucial role in enhancing adherence to Antiretroviral Therapy (ART) and preventing secondary HIV transmission. Young women with perinatally acquired HIV face health and psychosocial challenges, including poor adherence and retention to treatment, poor viral load suppression, constraints in disclosing their HIV status to others, and acceptance by family members, peers, and intimate partners after disclosure. The objective of this study was to explore and understand the experiences of young women with perinatally acquired HIV in self-disclosure, providing insights to guide the development of strategies for professional nurses that support the disclosure process, empowering young women to make informed decisions about when and to whom they disclose.

Methods: A qualitative, exploratory, descriptive, and contextual research design employing a phenomenological method was used. The purposive sample included 18 young women with Perinatally Acquired HIV (PAH), aged 18-22, recruited from the Intermediate Hospital Katutura ART Clinic. Data were collected through in-depth, face-to-face, individual phenomenological interviews, transcribed verbatim and thematically analysed using the Braun and Clarke method. Themes and categories were generated from collected data by the researcher and an independent coder.

Results: Four themes emerged from the data that contributed to the experiences of HIV self-disclosure among young women living with perinatally acquired HIV. (1) a lack of awareness of their HIV status and had taken ART medication without comprehension of the infection, (2) demonstrated resilience and acceptance of their HIV status despite facing various challenges, (3) hesitance to disclose their condition due to fear of stigma and discrimination, (4) need for support and guidance on how to disclose their HIV status.

Discussion: Participants exercised considerable caution in disclosing their HIV status, confiding only in a limited and trusted few, primarily due to experiences of both enacted and anticipated stigma and lack of trust in others. They further expressed a critical need for support in the disclosure process, highlighting the essential roles of nurses and teachers in reducing HIV-related stigma, while also pointing to the limited community awareness regarding fundamental HIV knowledge. This study is the first of its kind conducted in Namibia, and its findings will contribute to the review of guidelines for adolescents and young people with PAH, promoting self-disclosure and enhancing both their mental and physical health outcomes.

Conclusion: The results revealed the complex challenges faced by young women with PAH regarding self-disclosure, underscoring the need for support and guidance on how and when to disclose their status to significant others. The findings of the study provide meaningful insights into the lives of young women with PAH. Future studies and policies should focus on the development of strategies to support HIV self-disclosure among young people living with HIV.

Keywords: HIV, Young women, Perinatally acquired HIV, Serostatus, HIV self-disclosure, Physical health outcomes.

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Cite as: Nalupe M, Downing C. Navigating HIV Disclosure: Voices of Young Women with Perinatally Acquired HIV. Open Public Health J, 2025; 18: e18749445396691. http://dx.doi.org/10.2174/0118749445396691250703054354

Received: March 01, 2025
Revised: April 29, 2025
Accepted: April 30, 2025
Published: July 11, 2025

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1. INTRODUCTION

An estimated 1.7 million adolescents and young people are living with HIV, with approximately 80% in Sub-Saharan Africa (SSA) [1]. In 2020, young people, including those within key populations, accounted for 27% of HIV infections [2]. In Sub-Saharan Africa (SSA), adolescents and young people with perinatally acquired HIV constitute 21% of the total population of people living with HIV (PLHIV), and the disease remains one of the top ten leading causes of death among adolescents aged 10-19 years [3, 4].

In 2023, women and girls of all ages accounted for 62% of all new HIV infections in sub-Saharan Africa. About 1.9 million adolescent girls and young women aged 15–24 were living with HIV, compared to 1.2 million adolescent boys and young men in the same age group in 2022 [5, 6]. Although adolescent girls and young women aged 15–24 years only make up 10% of the population in Eastern and Southern Africa, they account for 27% of all new HIV infections in the region [7].

In Namibia, compared to the general population, young people living with HIV face significant health and psychosocial challenges. These include poor adherence to treatment, poor retention in care, low rates of viral load suppression, and difficulty disclosing their HIV status. The viral load suppression rate among young people aged 15–24 stands at 65%, significantly lower than the 92% suppression rate among adults [8]. These challenges hinder the country's progress toward achieving the UNAIDS 95-95-95 targets set for 2030.

Existing literature emphasizes the benefits of HIV self-disclosure, including improved relationships, greater emotional relief, psychological well-being, reduced feelings of isolation, reduced HIV transmission risk, increased social support, and better adherence to Antiretroviral Therapy (ART) [9, 10].

Young people, particularly young women with perinatally acquired HIV, face numerous barriers to disclosure. These include fear of stigma and discrimination, anticipated rejection, lack of disclosure support, and family influence discouraging disclosure due to fear of inadvertently revealing their own HIV status [11,12]. Nondisclosure has been associated with poor ART adherence, missed clinic appointments, and increased risk of HIV transmission due to the inability to negotiate safer sex [13, 14]

Despite global and regional literature on the benefits of HIV self-disclosure and its impact on the health outcomes of individuals living with HIV, there is limited research specifically exploring the lived experiences of young women with perinatally acquired HIV in Namibia. Although there is extensive literature on the role of health care workers in facilitating HIV disclosure from parents and caregivers to children and adolescents with perinatally acquired HIV, there is little guidance on onward disclosure among this subgroup. While the World Health Organization recommends supporting adolescents in making informed decisions about disclosure [15], there remains a gap in understanding how these recommendations are translated into practice in the Namibian context.

The aim of this study was therefore to address this gap by exploring the experiences of young women with perinatally acquired HIV related to self-disclosure to family members, peers, and sexual partners at the Intermediate Hospital Katutura ART Clinic.

2. MATERIALS AND METHODS

2.1. Study Design

A qualitative study design was employed to collect data from young women with perinatally acquired HIV. The design was used to answer questions about the complex nature of the phenomena of HIV self-disclosure from the participant's point of view [16]. It also aimed to gain an in-depth understanding of experiences that contribute to and influence engagement and decision-making in health-related behaviours [17].

2.2. Study Type

The study employed an exploratory, descriptive, and contextual design, utilizing a phenomenological approach. The researchers were able to systematically describe and interpret the phenomenon under study from the young women's point of view, generating new concepts and theories and gaining insight into the phenomenon [16, 18]. They further allowed the young women to be the source and interpreters of their experiences [19]. In phenomenological studies, it is essential to obtain detailed descriptions of participants' settings, experiences, and meanings they assign to them [20]. Participants were interviewed by the first author in their environment to gain insight into their experiences of the studied phenomenon within the context in which it occurred [21]. Participants were open to sharing their experiences in their context.

2.3. Study Setting

This study was conducted at the Intermediate Hospital Katutura (IHK) Antiretroviral Therapy (ART) Clinic in Windhoek, Namibia. Windhoek is Namibia's capital and biggest city, geographically centrally located in the Khomas region, with a HIV prevalence of 8.3% [22]. The clinic provides HIV services to patients living in Windhoek and those who live in the surrounding semi-urban settlements. This health facility was one of the first to provide ART services in the country since 2002 and caters to approximately 5,191 clients. The clinic offers HIV care and support, counselling and nutrition, and sexual and reproductive health services to about 600 clients between the ages of 0 and 24 years [23].

2.4. Participant Selection Criteria

The study included young women with perinatally acquired HIV aged 18-22 years, attending the Intermediate Hospital Katutura ART clinic, aware of their HIV serostatus for a period of five years or longer prior to the study, had been actively on ART for at least a year, and needed to be conversant in English. Participants who were not aware of their HIV serostatus were excluded from the study to avoid accidental HIV disclosure. The study also excluded those who disclosed less than five years prior to the study because they might not have had adequate experiences with self-disclosure.

2.5. Study Population and Sample Size

A population is a set of all members of a defined group that presents as a focus of the study [17]. The population of this study included all young women with perinatally acquired HIV enrolled for HIV care at the IHK ART Clinic in Windhoek. A total of 18 participants were recruited through a purposive sampling method. The sample size was appropriate for this study because, in qualitative research, the goal is to gain an in-depth understanding of the phenomenon rather than a broad range of information [21]. The research proposal, which included the sample size, was approved by the University of Johannesburg's Faculty of Health Sciences Higher Degree and Research Ethics Committee.

2.6. Sampling Method

The first author recruited participants with assistance from the nurses and adolescent peer supporters at both paediatric and adult departments during routine clinical follow days or ART refill days. The health facility team approached the young women who met the inclusion criteria to determine their interest in participating in the study. A QR code with inclusion criteria and the researcher's contact details was displayed on the notice board at the health facility. Snow-ball sampling was employed, whereby the researcher asked those interviewed to introduce the researcher to their friends living with HIV and determine if they were int-erested in participating in the study. Meetings and appoint-ments were scheduled with participants who met the eligibility criteria. Ten participants were recruited through the health facility's gatekeepers, while eight were recruited through the snowball sampling method.

The participants' parents permitted the young women to participate in the study. Three (3) participants initially agreed to participate in the study and later withdrew. One indi-cated that the parent was not comfortable with the inter-view, while the other two did not provide reasons for declining to participate in the study.

2.7. Data Collection Method

An interview guide was developed and administered in person by the first author and piloted with two young women with perinatally acquired HIV to ascertain reliability. The pilot test was conducted using the two central questions. All 18 in-depth interviews were conducted between September 2022 and May 2023. Before each interview, participants reviewed the participant information sheet and provided written informed consent for participation. All in-depth phenomenological face-to-face interviews were conducted in English and audio-recorded with the participants' permission. Interviews were conducted in the privacy of the participants' homes, which were naturalistic settings, to understand their experiences of HIV self-disclosure in the context in which it occurred [21]. Some participants opted to be interviewed at the clinic or the researcher's workplace over weekends due to a lack of privacy at their homes. Two central questions posed to all participants were: "What are your experiences of HIV serostatus disclosure to family members, peers, and sexual partners?" and "How can HIV serostatus disclosure be facilitated among young women with perinatally acquired HIV to family members, peers, and sexual partners?" Follow-up questions and probing were used to obtain in-depth and descriptive responses from the participants. All participants were interviewed during a time that was convenient for them. Interviews were conducted in a private room to ensure participants' privacy. Each interview lasted 30-45 minutes and was audiotaped with the participants' consent. Data were collected until data saturation was reached. Field and observation notes were compiled during and after each interview session. The field notes were analysed with verbatim responses during data analysis to enrich the collected data and credibility. Peer debriefing meetings were conducted between the researcher and supervisor to mitigate biases.

2.8. Data Management and Analysis

The researcher recorded and transcribed interviews verbatim after data collection. Data were analysed concurrently with data collection using the Braun and Clarke method. The first author developed a table with columns where the main research questions were inserted in the first row of the first column, and participant responses were noted in the corresponding rows. The researcher coded the data and recoded it after two weeks to ensure the results were identical. During the data coding process, the researcher read and reread participants' transcriptions and observational notes to identify deeper meanings and coded similar responsive patterns. Similar responses to a specific question were clustered in a single rich statement. Thereafter, themes were developed by identifying and categorising collected data and verifying and drawing conclusions from the data.

An independent coder with a PhD qualification in Psychiatric Nursing, and 13 years of experience in qualitative research data coding, coded the collected data. Thereafter, the researcher and the independent coder met on a virtual platform to discuss and verify the themes that emerged from the data and reached a consensus. The independent coder compiled a coding report on the final themes and categories.

The primary author held a Master of Philosophy in HIV Management and a postgraduate diploma in Nursing Education. The primary author was employed as a Regional Coordinator for the Namibia Adolescents Treatment Supporters (NATS) at the regional level within the Ministry of Health office. The second author, who holds a PhD, has expertise in qualitative research methods, reviewed the collected data and the process of data analysis to ensure its rigor. Both authors had extensive experience in qualitative research. The participants identified the primary author as a student and researcher. None of the authors had any supervisory or patient-provider relationships that could have influenced the data collection process.

2.9. Ethical Considerations

The study was conducted after approval was obtained from the University of Johannesburg's Faculty of Health Sciences Higher Degree and Research Ethics Committee and the Research Management Committee through the Ministry of Health and Social Services in Namibia. Permission was requested and granted from the Intermediate Hospital Katutura, where the study was conducted. Participation in the study was voluntary. Written consent was obtained from adolescents aged 18 years and above, and verbal consent was obtained from parents or caregivers before participation. Data collected were stored on a password-protected computer and backed up on password-protected hard drives and cloud storage. No personally identifiable information, such as names, identity numbers, or residential addresses, was collected to ensure the confidentiality of participants' information and to respect their privacy and dignity.

2.10. Trustworthiness in Qualitative Research

The researcher ensured the study's trustworthiness using the four criteria proposed by Guba and Lincoln (1985) [24]. These criteria applied to ensure the study's rigour were credibility, dependability, transferability, and confirmability. The credibility and trustworthiness of the study were ensured by prolonged engagement with the young women with perinatally acquired HIV. The researcher remained in the field collecting data until data saturation was achieved. The researcher's continuous engagement through the piloting of the interview guide and the data collection stage helped refine the quality of questions in the data collection tools and the quality of subsequent data obtained from the in-depth interviews. The researcher verified unclear information with participants on the transcripts before data analysis. The credibility of the study was enhanced by selecting participants who met the inclusion criteria.

3. RESULTS

3.1. Demographic Characteristics of Participants

A total of 18 young women (n=18) with perinatally acquired HIV participated in this study. All participants were between 18 and 22 years old, had known their HIV serostatus for five years, and had been actively receiving ART for at least a year. Six participants were in the range of 18 years. Seven participants were 19 years old, while three were 20 years old. The remaining two were 22 years old. All participants were conversant in English. Hence, no translation was required during the data collection process. The demographic characteristics of the participants are presented in Table **1**.

3.2. Experiences of HIV Serostatus Disclosure among Young Women with Perinatally Acquired HIV

The study revealed four themes, (1) a lack of awareness of their HIV status and had taken ART medication without comprehension of the infection, (2) demonstrated resilience and acceptance of their HIV status despite facing various challenges, (3) lack of trust and hesitance to disclose due to fear of stigma and discrimination and (4) need for support and guidance on how to disclose their HIV status, as summarized in Table **2**.

3.2.1. Theme 1: Experienced a Lack of Awareness of their HIV Status and took ART Medication without Comprehension of the Infection

Young women with perinatally acquired HIV reported that they lacked awareness of their HIV status. As a result, they were unaware of the reasons for taking ART.

Table 1. Socio-demographic characteristics of young women living with perinatally acquired HIV, Namibia, 2023 (N=18).

#	Participant Code	Current Age (in years)	Level of Education	Ethnicity	Source of HIV Disclosure	Age (in years) of Disclosure
1.	YW1	19	Vocational training student	Oshiwambo	Grandmother	8
2.	YW2	20	Grade 11	Oshiwambo	Mother	12
3.	YW3	18	Grade 11	Oshiwambo	Aunt	13
4.	YW4	22	2nd year University student	Oshiwambo	Mom and elder sister	11
5.	YW5	18	Grade 10	Oshiwambo	Mom	10
6.	YW6	19	Grade 12	Oshiwambo	Healthcare workers	15
7.	YW7	19	University student	Oshiwambo	Mother disclosed	13
8.	YW8	19	Grade 12	Oshiwambo	Nurses and mom together	8

(Table 1) contd.....

#	Participant Code	Current Age (in years)	Level of Education	Ethnicity	Source of HIV Disclosure	Age (in years) of Disclosure
9.	YW9	18	Grade 11	Oshiwambo	Counsellor in the presence of mother	12
10.	YW10	22	3rd year University student	Oshiwambo	Aunts	7
11.	YW11	18	2nd year University student	Rukwangali	Aunt	12
12.	YW12	18	Grade 11	Oshiwambo	Accidental disclosure	11
13.	YW13	18	Grade 11	Oshiwambo	Accidental disclosure	13
14.	YW14	20	1st year university student	Rukwangali	Teen club	14
15.	YW15	20	University student	Oshiwambo	Mother	10
16.	YW16	19	Grade 11	Oshiwambo	Teen club	10
17.	YW17	19	Grade 10	Oshiwambo	Health worker	14
18.	YW18	19	2nd year University student	Oshiwambo	Parents	7

Table 2. Themes and categories for young women with perinatally acquired HIV.

Themes	Categories
1. Experienced a lack of awareness of their HIV status	1.1 Participants were unaware of their status or that of their parents for a long time. 1.2 Experienced the misfortune of being the sibling living with HIV. 1.3 Participants Described the Daily Intake of Medication as Inconvenient and with its own Challenges
2. Demonstrated resilience and acceptance of their HIV status despite facing various challenges	2.1 Participants had great hopes and dreams despite facing myriad challenges. 2.2 Experienced living with HIV as a journey of acceptance made possible with support from the teen club.
3. Lack of trust and hesitance to disclose due to fear of stigma and discrimination	3.1 Confided in a very limited circle of selected people and were discouraged from disclosing it to others. 3.2 Experienced both enacted and anticipated stigma and not trusting others, as significant barriers to disclosing their status. 3.3 Assessment of the attitudes of individuals they planned to disclose to, to gauge potential outcomes of HIV disclosure.
4. Needed support and guidance on how to disclose their HIV status	4.1 A desire for support during the disclosure process. 4.2 Nurses' vital role in mitigating HIV stigma and facilitating disclosure among young women. 4.3 Teachers' role in mitigating HIV stigma among young women living with HIV. 4.4 Lack of awareness in the community about basic information about HIV.

3.2.1.1. Experienced being Unaware of their Status or even their Parents' Status for a Long Time (years)

Participants were disclosed primarily by their biological parents, caregivers, or healthcare workers. However, several others learned about their HIV status by reading through their hospital records and during support group meetings. The following quotes narrate experiences on how they found out about their HIV status.

"My mom didn't tell me that I was HIV positive. She just used to take me to the hospital to get pills, and I drank. When I asked her, she just always told me that I was sick when I was small. But she didn't tell me what really it was. Until one day, I started going alone to the clinic and then I took my file and read. I saw ARV." (YW12, 18 years old)

"I never asked her why I was drinking my medication because I did not feel like questioning her on anything like that. And I only recently found out when I joined the teen club that I was HIV positive. And I did not really know why I was taking medication." (YW14, 20 years old, disclosed in the teen club)

3.2.1.2. Experienced the Misfortune of being the Sibling Living with HIV

In this category, participants reported feeling unfortunate for being the only sibling born with HIV in the family. They reported feeling depressed, particularly when they had to take medication while their siblings did not.

"Sometimes I feel depressed. As I am the only person who is drinking pills in the house, and like the pressure is too much. The people around me are just fine, and then I look at them and they are not always concerned that I didn't take my pills, and for me, I have to." (YW9, 18 years old, disclosed by a counsellor in the presence of the mother at 12 years.

Participants Described the Daily Intake of Medication as Inconvenient and Fraught with Challenges

"And then I also have siblings, like I had one of my brothers that I used to stay with, and I'm wondering now, why is he the firstborn and he doesn't take medication, and I'm the one ... I'm the last born and I have to take medication." (YW17, 19 years old, disclosed by healthcare workers at 14 years)

3.2.1.3. Participants Described the Daily Intake of Medication as Inconvenient and Fraught its Challenges

Antiretroviral Therapy (ART) has changed HIV from a life-threatening condition to a chronic, manageable disease. However, participants experienced daily intake of ART as challenging, with reported unpleasant taste and side

effects, as well as the burden of taking medicine daily. These challenges resulted in non-adherence at some point in their lives.

"Sometimes it was very hard to swallow the pills. Sometimes I drink, sometimes I don't drink. And they do test my viral load, and it's very high. And then they do ask me sometimes, and I'm like, I do drink. Sometimes I do lie that I do drink, but myself I don't drink. And sometimes, if I drink, I just feel like throwing up. Maybe it's just that I don't like pills themselves." (YW7, 19 years, disclosed by mother at 13 years)

They also expressed being uncomfortable taking their medication around people they have not disclosed to, especially those in hostel settings. In such situations, they sought out privacy to take medication to avoid being seen and being asked questions.

"When I was in the hostel, my roommates would have this awkward silence when I wanted to take my pills, but now they know. When I tried to take my pills, they were all quiet in the room. And after a while of me realising what was happening, I had the idea of not taking my medicine." (YW11, 18 years old, disclosed by guardian at 12 years)

3.2.2. Theme 2: Demonstrated Resilience and Acceptance of their HIV Status despite Facing Various Challenges

Young women living with perinatally acquired HIV expressed their experiences in terms of how they endured and became resilient despite the various challenges they faced on their journey with HIV. Participants further expressed that attending the teen clubs allowed them to accept their status by sharing their experiences with others who had the same condition.

3.2.2.1. Participants had Great Hopes and Dreams despite Facing Myriad Challenges

Participants demonstrated remarkable resilience despite coming from disadvantaged backgrounds. Disadvantaged backgrounds include living in informal settlements, absent father figures in their lives, growing up as orphans or raised by single mothers, and others by extended families. The following participant expressed her enthusiasm for the future.

"I want to get better marks, and I am determined. I have decided for myself that no matter how negative thoughts come through, I will always distance myself from negative thoughts. Because they won't help me, but they will just bring me down. They won't even push me where I want to be. So, I want to distance myself from them." (YW2, 20 years old, disclosed by mother at 12 years).

Maintaining a positive mindset is important in living with HIV, as expressed by one participant.

"I don't really care, I have this type of thing, you can say whatever you like, you can say bad things to me, you can say…you can call me names, but then I just don't care, you see, I don't care, like I don't take those things to my heart because you know, I have a positive mindset, let me say, ja." (YW13, 18 years old, accidental disclosure at 13 years)

3.2.2.2. Experienced Living with HIV as a Journey of Acceptance, made Possible with the Positive Support from Teen Clubs

Living with a chronic condition such as HIV can be overwhelming and stressful for adolescents and young people. Participants sought support from teen clubs and learned how to live positively with HIV. They were encouraged to take medications daily to remain virally suppressed, which translated into physical health. Participants acknowledged the support from attending teen clubs:

"I started attending teen club, and then I saw a lot of young people who were also attending, and I saw no, everyone in this room is HIV positive. That's when I started to gain my courage, like yo, I am not alone, we are a lot and there's nothing to be sad about." (YW18, 19 years old, disclosed by parents at 7 years)

Another participant said:

"Teen club is a group where we motivate and encourage each other, like a group of people who live with HIV, where they teach us to take care of ourselves and how to disclose our status…" (YW12, 18 years old, accidental disclosure at 11 years)

3.2.3. Theme 3: Experienced a Lack of Trust and Hesitance to Disclose due to Fear of Stigma and Discrimination

The participants shared general mistrust regarding their disclosure to others, citing anticipated and enacted stigma and discrimination. Consequently, participants' HIV status was only known by a few family members. Some participants personally experienced stigma and discrimination, while others heard or saw how their peers were discriminated against and stigmatised based on their HIV status. As a result, their parents and guardians discouraged the young people from disclosing to others. The participants also indicated that they presented scenarios related to their condition to those they planned to disclose to, before disclosing their HIV status, to assess the reactions of individuals.

3.2.3.1. Participants Confided in a very Limited Circle of selected People and were Discouraged from Disclosing to Others

Participants trusted only a few family members who were already aware of their status and had taken responsibility for caring for them since they were young. They regarded HIV as a secret that should only be known by those close to them, including friends they could trust.

"I don't like telling people my secrets, so ja, I would just tell my family members, but not basically family members like all of them, only people who are close to me, like my sisters and brothers, not all my family members, only my mum or sisters." (YW3, 18 years old, disclosed to by aunt at 13 years)

Fear of being exposed was central to the participants' non-disclosure, as narrated in the following quote:

"What if I tell them and they go and spread? That is one thing I also don't want and everything… one thing about my

location is that if they hear a small thing and it is bad, everyone will hear about it, so, even when I am talking to my friend, I make sure, even when I am coming to the hospital I don't say that I am going to the hospital. I tell them that I am going out." (YW14, 20 years old, disclosed in the teen club)]

3.2.3.2. Participants Experienced both Enacted and Anticipated Stigma, and not Trusting others, as Significant barriers to Disclosing their Status

Young people inherently value friendships. Therefore, participants were concerned that disclosing their status might result in exclusion from their circle of friends or schoolmates or lead to bullying by others. One participant expressed her concerns about stigma if she shared her HIV status with others as follows:

"I feel like if I share with them, then they will just tell everyone that I am HIV positive, and it will go out of proportion, and when I walk and pass by everyone, they will be like stay away from that girl, she has a virus, don't sleep with her. Those kinds of things." (YW14, 20 years old, disclosed in the teen club)

Another participant shared her experience of rejection by an intimate partner after she disclosed her status.

"*After disclosing my status to him, the communication also started to decline, whereby, like, he started dodging. For me, I already know why you're dodging, you know. I just asked him what is going on, and I just want to conclude. This person literally went and just disappeared." (Y16, 19 years old, accidentally disclosed in the teen club)*

Some participants reported that the school setting was a place where they experienced stigma and discrimination. The following participant narrated how peers and teachers stigmatised her:

"Because I used to be very sick, my sister had to tell the teachers what to expect and what to do if I felt sick. And then I got bullied again. I got discriminated against. I don't know how or from where the kids got to know about it, maybe one of the teachers, yes, then I got discriminated against." (YW4, 22 years old, disclosed by mother and elder sister at 11 years)

3.2.3.3. Assessment of the Attitudes of Individuals they Planned to Disclose to in Order to Gauge Potential Outcomes of HIV Disclosure

Young women with perinatally acquired HIV assessed individuals by providing hypothetical scenarios similar to HIV and checked their reactions to those scenarios. By introducing scenarios to those they intended to disclose to, participants were reassured that their partners would accept them after HIV disclosure. This was common when disclosing to peers and intimate partners.

"*I will tell you two things, but you should pick the truth.' I told him that I once had an abortion, and I told him that I am HIV positive. So, he is there, like seated, and he is like 'No, the truth is that you had an abortion.' And then he was like, 'No, I am HIV positive.' And then I'm like, I am there smiling, because I wasn't going to give in too easily. He was like, 'No, you had an abortion.' I was like, 'No, that was the lie. The truth is that I am HIV positive." (YW10, 22 years old, disclosed by her aunts at 7 years old)*

"What I did with my previous partner, I actually brought up the topic to see how he would react, so maybe I am going to do the same, like … what if … I would come like, what if it happens that if you found yourself in a situation where you are dating an HIV positive girl, how are you going to react, what are you going to do. And then, those responses will give you a lot of answers to decide whether to tell the person or not." (YW10, 22 years old, disclosed by her aunts at 7 years old)

3.2.4. Theme 4: Participants required Guidance on how to Disclose their Status to Significant Others

Participants expressed the need for nurses to provide emotional support to prepare them for the disclosure process. They emphasised the role of nurses, teachers, and the general community to mitigate stigma and discrimination against young people living with HIV.

3.2.4.1. A Desire for Support during the Disclosure Process

Participants expressed that most nurses were caring and made them feel relaxed when visiting health facilities. They highlighted various strategies nurses could utilise to provide support and assist them with the disclosure process:

"I will need deep emotional support because disclosing is not easy, and it is always the thought that what if this person doesn't like me just because of this condition. Yeah….and then regretting telling them." (PW15, 20 years old, disclosed by mother at 10 years)

Participants also suggested that nurses were able to destigmatise HIV by educating and empowering young women on the importance of disclosure and living positively with HIV:

"It is just good that nurses advise the young women on how to disclose their status and just how to live happily with HIV. They should be told that HIV is just a normal thing, the treatment is there as long as they are adhering to their medications." (YW16, 19 years old, disclosed at the teen club at 10 years old)

3.2.4.2. Nurses' Vital Role in Mitigating HIV Stigma and Facilitating Disclosure among Young Women

Professional nurses could play an important role in reducing the stigma associated with HIV. Participants indicated that nurses should provide counselling focusing on the importance of self-disclosure and preparing them when they intend to disclose.

"They can help by telling us the advantages or benefits of disclosing yourself. I mean, what can we do?" (YW13, 18 years old, accidental disclosure at 13 years)

Participants also suggested that nurses provide counselling to young women first to make sure that those they wanted to disclose to were mature and trustworthy:

"*Maybe they can just tell us young women not to disclose our status to anybody that comes, without like knowing the person, because some people are mature but*

not trustworthy." (YW6, 22 years old, disclosed by health care workers at 15 years)

3.2.4.3. Teachers' Role in Mitigating HIV Stigma among Young Women Living with HIV

In this category, participants suggested that teachers should stay informed about the latest general information on HIV and teach learners with accurate and updated information in schools. School textbooks contained outdated information on HIV, which required regular updates.

"In the textbooks, we are taught that if you sleep with someone with HIV, they will immediately get it. But as we are being taught now, that's not how it happens. Only if your viral load is high that's when you get it. If my viral load is not detected, I cannot pass it on to someone else. But if your viral load is detected, you can pass it on to someone else. So, maybe the teachers and the textbooks for life skills should be updated about that." (YW14, 20 years old, disclosed in the teen club)

3.2.4.4. Lack of Awareness in the Community about Basic Information about HIV

Participants identified a lack of knowledge among community members on HIV, which led to stigma. Therefore, they suggested that mass education campaigns to educate community members on the basic facts of HIV should be conducted. Additionally, the participants identified social media platforms where young people look for information to stay updated on the latest information on HIV.

"Like on World AIDS Day, they should share information on the walls, Facebook, WhatsApp, and Instagram since the youth are on those platforms, that you will not get HIV or anything like that." (YW14, 20 years old, disclosed in the teen club)

4. DISCUSSION

This qualitative study sought to explore and understand the experiences of young women with perinatally acquired HIV's experiences on HIV self-disclosure to family members, peers, and intimate partners. The study findings revealed numerous challenges faced by young women with HIV. However, it highlighted their resilience and optimism in facing daily hardships as a result of this condition.

Young women with perinatally acquired HIV experienced a lack of awareness of their HIV status through the stages of childhood to adolescence due to delayed disclosure. As a result, some participants found out their status during the adolescence stage, and others through accidental disclosure by either reading through hospital records or while attending support group meetings. Delayed disclosure was prevalent in this study, with most young people disclosing after the targeted disclosure age of nine years [25]. In previous studies, parents and caregivers cited varying reasons for delayed disclosure to children and adolescents living with perinatally acquired HIV. Caregivers' delayed disclosure due to fear of being blamed, stigma, discrimination, and fear that the child would not keep the HIV serostatus a secret [25, 26]. This study only included young women and excluded their parents and guardians, and as a result, reasons for delayed disclosure were not provided.

Participants reported instances where they hid their medication due to fear of disclosing their condition, which had led to some participants missing doses. They further cited challenges such as the pill burden and unpleasant ART side effects, such as gastrointestinal tract complaints, during their treatment journey. These challenges affected adherence as some of them defaulted from taking their medication, which can lead to poor health outcomes [4,26]. Young women in this study also expressed their misfortune of being the only siblings born with HIV in their families, which caused distress and a feeling of being unfortunate. Some participants regarded themselves as unfortunate to live with HIV, which has led them to feel hurt, frustrated, and angry [27, 28].

Despite the challenges they faced, participants demonstrated remarkable resilience despite coming from disadvantaged backgrounds, where some were raised by single mothers and lived in informal settlements [28, 29].

The study revealed that participants regarded teen clubs as a source of hope and acceptance. The platform provided a supportive environment where young women shared their experiences with others and improved adherence to ART. Through attending teen clubs, young women had an opportunity to accept their seropositive HIV status. These findings concur with similar studies [29, 30].

Participants in this study did not want to disclose their status to others for various reasons, including a lack of trust. They disclosed information solely to close family members and peers, citing mistrust, fear of stigma and discrimination, and the concern that they would tell others as reasons for non-disclosure [10, 27, 31-33]. On the contrary, some studies reported that adolescents and young women living with HIV experienced emotional support after self-disclosure [34, 35]. In addition, parents discouraged self-disclosure and would tell the young women not to disclose to people they did not trust, instructing them to keep the information within the family [9]. In order to prevent possible rejection, stigma, and discrimination, participants tested the attitudes of those they intended to disclose to before disclosing to form a judgement about the likely outcome after disclosure [36-38].

This study revealed that young women lacked the necessary skills to disclose and needed support to improve disclosure outcomes [31,39]. Therefore, they suggest targeted interventions for young women about when and how to disclose their HIV status [9, 38]. Furthermore, health workers should customise and integrate HIV disclosure with mental health support for young people [31].

Other gatekeepers, such as teachers, must stay up-to-date with new information and share it with learners [39, 40]. Similarly, to provide appropriate support, continuous sensitisation of all school stakeholders is needed to reduce HIV-related stigma and promote self-disclosure by young people living with HIV [41].

Lastly, participants indicated that community members lacked basic information on HIV, which contributed to stigma [2, 42]. There is a need for mass education of community members. They further asserted that, for strengthening interventions to reduce stigma and promote

support for young people living with HIV, continuous community sensitization and education must be provided [12, 39, 43].

5. STRENGTHS AND LIMITATIONS OF THE STUDY

Specific limitations that can affect the generalisation of the study were noted. The study was conducted at a single health facility and cannot be generalised. The study focused exclusively on young women with perinatally acquired HIV, thereby excluding young women with behaviourally acquired HIV as well as young men living with HIV. Furthermore, this study was conducted in a semi-urban area, and the findings might not represent the views of young women in rural Namibia. The parents and caregivers of the participants, as well as healthcare providers and other stakeholders, were not included in the study. However, the study's findings offer valuable insights into the lives of young women with perinatally acquired HIV and can inform the development of strategies to support HIV self-disclosure among young people living with HIV.

CONCLUSION

This study explored the experiences of young women with perinatally acquired HIV regarding HIV self-disclosure at the Intermediate Hospital Katutura ART Clinic, highlighting the numerous challenges they faced daily. These challenges included delayed disclosure and non-disclosure by parents of participants' HIV status, mistrust and fear from perceived stigma and discrimination, pill burden, and ART side effects. By identifying the challenges faced by this subpopulation, the study offers an opportunity to develop tailored interventions that can positively influence the health outcomes of young people living with HIV. Participants highlighted various interventions that can mitigate the stigma and discrimination associated with HIV disclosure, such as enhanced emotional support from nurses, community awareness, and education through diverse media platforms, which can increase environmental support for people living with HIV.

The study findings provide meaningful insights into the lives of young women with perinatally acquired HIV regarding HIV self-disclosure. Future studies and policies should focus on the development of strategies to support HIV self-disclosure among young people living with HIV.

AUTHORS' CONTRIBUTIONS

The authors confirm contribution to the paper as follows: M.N. and C.D.: Contributed to the conceptualization, methodology, and validation of the study; M.N.: Collected the data; M.N. and C.D.: Performed the analysis, data curation, and prepared the original draft; M.N.: The manuscript was written and reviewed; C.D.: Editing and supervision provided by CD. All authors have read and approved the final version of the manuscript.

LIST OF ABBREVIATIONS

AYPLHIV	=	Adolescents and Young People Living with HIV
AGYW	=	Adolescents Girls and Young Women
ART	=	Anti-Retroviral Therapy
CDC	=	Centre for Disease Control
MoHSS	=	Ministry of Health and Social Services
HIV	=	Human Immunodeficiency Virus
PAH	=	Perinatally Acquired HIV
PLHIV	=	People Living with HIV
PMTCT	=	Prevention of Mother-to-Child Transmission
SSA	=	Sub-Saharan Africa
UNAIDS	=	United Nations AIDS
UNICEF	=	United Nations International Children's Emergency Fund
UNAIDS	=	Joint United Nations Programme on HIV/AIDS
WHO	=	World Health Organisation

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by University of Johannesburg's Faculty of Health Sciences Higher Degree and Research Ethics Committee, South Africa, with a reference number HDC-01-83-2021, and the Research Management Committee through the Ministry of Health and Social Services in Namibia with reference number 17/3/3/MNN.

HUMAN AND ANIMAL RIGHTS

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or research committees and with the Declaration of Helsinki of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Written consent was obtained from adolescents aged 18 years and above, and verbal consent was obtained from the parents or caregivers.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

All the data and supporting information are provided within the article.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

Special thanks to Ms Ilke Hay for their insightful feedback and guidance, which greatly enhanced the quality of this manuscript. Finally, we would like to extend our appreciation to the participants for their time and cooperation.

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