

HIV-Related Stigma Among Pregnant Adolescents: A Qualitative Study of Patient Perspectives in Southwestern Uganda

Amir Kabunga¹, Caroline Kambugu Nabasiye², Eustes Kigingi³, Halimah Namata⁴, Enos Mwiroti Shikanga⁵, Samson Udho², Anna Grace Auma², Jannat Nabaziwa⁶, Raymond Tumwesigye⁷, Marvin Musinguzi⁶, Ponsiano Okalo¹, Walter Acup⁶

¹Department of Psychiatry, Lira University, Lira City, Uganda; ²Department of Midwifery, Lira University, Lira City, Uganda; ³Department of Environmental Health and Disease Control, Lira University, Lira City, Uganda; ⁴Department of Mental Health, Makerere University, Kampala, Uganda; ⁵Department of Education Psychology, Moi University, Eldoret City, Kenya; ⁶Department of Community Health, Lira University, Lira City, Uganda; ⁷Department of Nursing, Mbarara University of Science and Technology, Mbarara City, Uganda

Correspondence: Amir Kabunga, Department of Psychiatry, Faculty of Medicine, Lira University, Uganda, P.O Box 1035, Lira City, Tel +256777929576, Email amirkabs2017@gmail.com

Background: The HIV epidemic disproportionately affects adolescents in Sub-Saharan Africa, with adolescent girls facing heightened vulnerability. Despite advancements in antiretroviral therapy, HIV-related stigma remains prevalent, particularly among pregnant adolescents. This qualitative study explores the perspectives of adolescents living with HIV in southwestern Uganda, seeking to understand the nature of HIV-related stigma in this context.

Methods: One-on-one narrative interviews were conducted with 28 pregnant adolescents living with HIV aged 14–19 receiving care at Mbarara Regional Referral Hospital. The qualitative approach allowed for in-depth exploration of participants' experiences. Thematic analysis was employed to identify recurring patterns in the narratives.

Results: Five overarching themes emerged from the analysis: Experiences of double stigma, social and cultural influences shaping stigma, healthcare system challenges, psychosocial impacts of stigma, and resilience and coping mechanisms. Double stigma, arising from societal prejudices related to both HIV status and teenage pregnancy, created a complex environment for participants. Despite these challenges, participants exhibited resilience through external support and internal strength.

Conclusion: This study reveals the pervasive double stigma experienced by pregnant adolescents living with HIV in southwestern Uganda, driven by societal biases against both HIV status and teenage pregnancy. Urgent targeted interventions are needed to address the intersectionality of stigma, cultural influences, healthcare issues, and psychosocial well-being for the betterment of this vulnerable population.

Keywords: adolescents, HIV-related stigma, social support, pregnant adolescents, qualitative study

Background

The HIV epidemic remains a critical public health challenge, especially in Sub-Saharan Africa, where adolescents bear a disproportionate burden. Over 88% of all adolescents with HIV reside in this region, and adolescent girls, in particular, face heightened vulnerability, accounting for the majority of new infections. The prevalence of HIV among adolescents is expected to rise by over 60% by 2030 if progress stalls.¹ Unfortunately, the advent of antiretroviral therapy (ART) has not shielded individuals from the pervasive issue of HIV-related stigma. Studies suggest a gender-based discrepancy, with women, especially pregnant adolescents, experiencing higher levels of HIV-related stigma.²

Stigma, as defined by Goffman, involves feelings of guilt, alienation, and rejection due to unfavorable social judgments. HIV-related stigma is perceptions, attitudes, and behaviors directed towards individuals living with HIV/AIDS, resulting in their social exclusion, discrimination, and internalized shame.³ The forms of HIV-related stigma

experienced by those living with HIV—externalized, internalized, and enacted—underscore its multifaceted nature.⁴ HIV-related stigma significantly hampers prevention, treatment, and care efforts, leading to decreased testing, disclosure reluctance, and poor ART adherence, contributing to increased mortality rates.^{5,6} Adolescents, already navigating the vulnerabilities of this developmental stage, are particularly susceptible to the negative effects of HIV-related stigma, including mental health issues like anxiety and depression.⁷ The intersection of adolescence, pregnancy, and HIV introduces a complex set of issues, with a critical concern being the pervasive stigma associated with the virus. HIV-related stigma among pregnant adolescents living with HIV exacerbates their vulnerabilities, affecting not only their own well-being⁸ but also influencing the health outcomes of their unborn children. Stigmatization not only hampers the mental health of these adolescents but also deters them from seeking essential healthcare services, thus impacting their overall reproductive health.⁸

Stigma and discrimination during teenage pregnancy present multifaceted challenges, as illustrated by research conducted by Paudel and Baral,⁹ revealing the significant obstacle posed by HIV-status disclosure for young women, exacerbating societal stigma. Similarly, Simbayi et al disclosed the intense self-stigmatization experienced by HIV-infected pregnant women.⁹ Additional studies, such as those examining HIV-infected pregnant women,¹⁰ further underscore the enduring impact of stigmatization, which manifests as depression and social isolation extending beyond childbirth. Moreover, in a study conducted in Thailand, stigma was observed among pregnant women living with HIV, regardless of age.¹¹ This indicates that adolescent mothers living with HIV encounter dual discrimination, stemming from both their age and HIV status. In response to these challenges, this study endeavors to explore the experiences of pregnant adolescents living with HIV, aiming to illuminate their unique journey and propose strategies to address stigmatization and discrimination within this vulnerable population.

Despite initiatives such as ART programs and awareness campaigns, pregnant adolescents encounter ongoing challenges in healthcare settings and communities.¹² Persistent stigmatizing behavior, coupled with interventions often overlooking their specific needs, contributes to social exclusion, discrimination, and internalized shame. The gaps in addressing these challenges include the absence of qualitative research capturing the perspectives of pregnant adolescents living with HIV. Various implemented initiatives have aimed to address challenges faced by these adolescents, focusing on improving access to ART, comprehensive sexual education, and support networks.¹³ However, the persistence of HIV-related stigma remains a significant obstacle fueled by societal attitudes, cultural beliefs, and limited HIV understanding.

Drawing upon the Social Ecological Model (SEM)¹⁴ and the Health Belief Model (HBM),¹⁵ which elucidate the interplay between individual, interpersonal, community, and societal factors in shaping health-related behaviors, it becomes evident that addressing HIV-related stigma requires a multifaceted approach. At the individual level, pregnant adolescents living with HIV face internalized stigma, manifested as feelings of shame and self-blame,¹⁶ which may deter them from seeking essential healthcare services and adhering to treatment regimens. Interpersonal relationships within families, communities, and healthcare settings can either mitigate or exacerbate stigma.¹⁷ Supportive social networks and positive relationships with healthcare providers can buffer against stigma, whereas judgmental attitudes and discriminatory behaviors perpetuate it. Community-level factors, including cultural norms, beliefs, and socioeconomic conditions, significantly influence HIV-related stigma.¹⁸ Cultural beliefs surrounding sexuality, morality, and gender roles contribute to the stigmatization of HIV-positive pregnant adolescents,¹⁹ exacerbating their vulnerabilities. Addressing stigma necessitates challenging these ingrained societal attitudes through targeted interventions and community engagement. Additionally, structural factors such as access to healthcare services, policies, and legal frameworks play a crucial role in shaping the experiences of HIV-positive pregnant adolescents.²⁰ Integrating the SEM and HBM frameworks into the study's theoretical framework provides a comprehensive understanding of the complex dynamics surrounding HIV-related stigma among HIV-positive pregnant adolescents in western Uganda.

In Uganda, where more than 170,000 adolescents live with HIV,²¹ addressing HIV-related stigma is crucial. However, existing studies seldom focus on the unique challenges faced by pregnant adolescents living with HIV, who grapple not only with their HIV status but also the societal stigma attached to pregnancy.²² The burden of HIV-related stigma is particularly pronounced in settings with high prevalence rates, such as western Uganda.²³ Adolescents face a double layer of stigma—first for being pregnant at a young age and second for being HIV-positive.²⁴ This dual stigma creates a hostile environment that may hinder the effective management of HIV during pregnancy and exacerbate existing health

disparities among this vulnerable population.²⁴ Limited research on the aspects of HIV-related stigma leaves a crucial gap in understanding the lived experiences of these adolescents, hindering optimal care. The psychosocial implications of living with HIV during adolescence and pregnancy necessitate a deeper exploration to bridge existing gaps in understanding the challenges faced by these individuals. Therefore, this study explores the perspectives of adolescents living with HIV in southwestern Uganda, seeking to understand the nature of HIV-related stigma in this context.

Methods

Study Design

We used a phenomenological research design in our study. The research explores the lived experiences of individuals, aiming to comprehend the essence of those experiences as they are perceived by the participants themselves. By adopting this design, we captured the subjective perspectives surrounding the intersection of HIV-related stigma and pregnancy stigma. Phenomenological research allows for a deep exploration of how participants interpret and make sense of their experiences, shedding light on the complex interplay between societal attitudes, personal beliefs, and lived realities.

Study Settings

The study was carried out at the Mbarara Regional Referral Hospital (MRRH), which serves as the Southwestern region's referral hospital. The hospital treats patients from the surrounding districts that make up south western Uganda and neighboring countries of Tanzania and Rwanda. At the adolescent HIV clinic, close to 400 adolescents receive care and treatment.²⁵ MRRH is located in Mbarara City, the second-largest city in Uganda after Kampala, is located in the Western Region. The distance between Kampala, Uganda's capital and oldest city, and Mbarara is roughly 270 kilometers (168 miles) by road.

Participants

The study participants comprised pregnant adolescents living with HIV aged 14–19 years receiving HIV care at MRRH in Mbarara district in south western Uganda. This study targets pregnant adolescents living with HIV aged 14–19 years who are confirmed to be living with HIV. Participants had to be currently pregnant and receiving care at MRRH in the Mbarara district of western Uganda. We excluded individuals who are critically ill or mentally unable to participate in an interview at the time of the study. Additionally, participants who do not provide explicit consent to be part of the study were not included.

Sample Size Estimation

The participants were consecutively sampled until reaching data saturation; a point when no substantially new information emerged from the interviews.²⁶ We collected enough data to thoroughly explore the topic and that further interviews were unlikely to provide additional insights. We ensured that we captured a comprehensive range of perspectives and experiences related to HIV-related stigma among pregnant adolescents living with HIV in southwestern Uganda. In total, 28 pregnant adolescents living with HIV participated in the study were selected.

Sampling Procedure

A consecutive sampling technique was used to select the participants attending MRRH and we included a maximum variation among the interviewees. A consecutive sampling technique refers to a method of participant selection where every eligible individual who meets the criteria for inclusion is invited to participate until the desired sample size is reached. In the context of this study, consecutive involved systematically recruiting HIV-positive pregnant adolescents until a sufficient number of participants were enrolled.

Data Collection Tool

The data collection tool utilized in this study was an interview guide crafted through the lens of narrative interviewing techniques. This guide was specifically designed to foster an environment where participants felt encouraged to openly share their experiences, thereby facilitating a comprehensive exploration of HIV-related

stigma among HIV-positive pregnant adolescents in western Uganda. Structured as a series of open-ended questions, the interview guide commenced with an invitation for participants to reflect on their lives shortly before receiving their HIV diagnosis. This initial inquiry was intended to prompt narrative responses, enabling a deeper understanding of participants' personal experiences and perspectives. Moreover, the interview guide featured a predefined list of items aimed at guiding discussions on specific facets of HIV-related stigma, particularly those arising from the intersection of HIV status and pregnancy. Additionally, tailored prompts were included to assist participants in articulating their thoughts and reflections on navigating the complexities of living with HIV while being pregnant. To enhance the effectiveness and suitability of the interview guide, we conducted a pilot test among pregnant adolescents living with HIV who were not part of the study cohort. This iterative process enabled us to refine the interview guide based on invaluable feedback, thereby ensuring its capacity to capture the experiences and perspectives of the target population accurately.

Procedure

Trained research assistants conducted interviews between March and April, 2023 using hybrid and narrative format.²⁷ The research assistants had worked in the HIV section for close to 5 years and had expertise in conducting interviews to obtain personal narratives. We explained the purpose, risks, and benefits of participating in the study, and then we recruited individuals who gave their consent. Interviews were done in English or the participants' native language, recorded, and when necessary translated into English. After acquiring written informed consent and assent from the minors' parents or guardians, eligible participants were recruited. After receiving parental or guardian agreement, researchers recruited participants under the age of 18. Interviews were conducted in a private setting. The interviews take 40 to 50 minutes.

Data Management and Analysis

A transcriber who had signed confidentiality agreement recorded and transcribed verbatim every interview. Data were assessed for themes on stigma interactively and inductively,²⁸ using a thematic approach.²⁹ The themes emerged through a rigorous thematic analysis process following data collection. This involved systematically organizing and interpreting the data to identify recurring patterns and key concepts related to HIV-related stigma among pregnant adolescents living with HIV. Rather than imposing pre-determined themes onto the data, an inductive approach was employed. This allowed themes to naturally emerge from the participants' narratives and experiences, ensuring they were grounded in the data and reflective of the participants' perspectives. The data were initially coded line-by-line, and codes were then grouped into broader categories based on similarities and relationships. Through iterative analysis and constant comparison, these categories were refined and consolidated into overarching themes that encapsulated the main findings of the study. The authors developed, debated and discussed emerging major themes in order to produce a solid draft analysis and comprehension of the findings.

Trustworthiness

Trustworthiness was ensured through various strategies aimed at enhancing credibility, transferability, dependability, and confirmability. Initially, collaboration among multiple authors facilitated rigorous analysis, with each step documented and consensus reached on thematic categories through meetings. Additionally, the study methodology was meticulously described, including participant selection criteria and data analysis procedures, while rich contextual descriptions were provided to facilitate transferability assessment. Extensive documentation of the research process, including data collection, coding decisions, and analytical memos, established dependability. Peer debriefing further ensured consistency and rigor in data analysis. Furthermore, reflexivity was fostered through reflexive journaling to acknowledge and mitigate biases, and negative case analysis addressed contradictory evidence. Finally, thematic findings were detailed with supporting quotes, including translations for original quotes in Runyakitara, employing the forward-backward approach by bilingual researchers, to enhance confirmability.

Ethical Considerations

In conducting this study, we adhered to the ethical guidelines outlined in the Helsinki Declaration.³⁰ Each participant provided a comprehensive written consent form at the time of their interview. In cases involving minors, consent was

typically obtained from both a parent or legal guardian as well as assent from the minor themselves. Ethical approval for this study was obtained from the Lira University Research Ethics Committee (LUREC-2023-23). All participants informed consent and assent included publication of anonymized responses.

Results

Demographics

Table 1 provides descriptive characteristics of the respondents in the study. The average age of the respondents is 6.9 years, with a standard deviation of 3.5 years. There were 16 singles, accounting for 57.2%. Among the 28 participants, 19 (67.8%) were currently attending school. Out of the total participants, 10 (35.7%) had both parents alive, 13 (46.5%) had lost one parent, and 5 (17.8%) had lost both parents.

Themes

In our research, we identified five overarching themes, namely: Experiences of double stigma, Social and cultural influences shaping stigma, challenges within the healthcare system, psychosocial impacts of stigma, and resilience and coping mechanisms (Table 2).

Theme 1: Experiences of Double Stigma

Double stigma refers to the compounded discrimination and judgment faced by individuals who not only carry the burden of being HIV-positive but also navigate the societal stigma associated with teenage pregnancy. The participants not only grapple with the societal prejudices surrounding their HIV status but also confront additional layers of discrimination related to their pregnancy. The intertwining of these dual stigmas creates a unique and complex environment that significantly impacts the lives of these young women. The participants express the overwhelming sense of being marked and singled out, illustrating the intersectional challenges they face.

One participant, expressing the overwhelming weight of this dual burden, stated,

It is like I'm carrying two burdens, you know? People look at me, and they see the virus, and then they see my belly. It is hard to escape the judgment, and it feels like the whole world is against me. (Participant B)

Another participant highlighted the transformative nature of the double stigma, stating,

Table 1 Descriptive Characteristics of Respondents

Variables	N=28 n(%)
Age (Mean/SD)	6.9 (3.5)
Gender	
Married	12 (42.8)
Single	16 (57.2)
Education	
In school	19 (67.8)
Out of school	9 (32.2)
Orphan hood Status	
Had both parents alive	10 (35.7)
Had lost one parent	13 (46.5)
Had lost both parents	5 (17.8)

Table 2 Themes

Codes	Sub-Themes	Major Themes
"double stigma", "societal judgment", "overwhelming burden"	<ul style="list-style-type: none"> • Overlapping burdens of HIV and pregnancy • Feeling marked and singled out • Disappointment in lack of community support 	Experiences of double stigma
"lack of community support", "cultural beliefs", "social norms", "perception of promiscuity", "expectations of a 'good girl'", "fear of ostracization", "... HIV is a death sentence"	<ul style="list-style-type: none"> • Association between HIV and immoral behavior • Societal expectations on behavior of "good girls" • Perception of HIV as a death sentence 	Social and cultural influences shaping stigma
"stigmatization within healthcare settings", "no confidentiality and privacy"	<ul style="list-style-type: none"> • Stigmatization within healthcare settings • Lack of confidentiality and sensitivity 	Challenges within the healthcare system
"impact on mental health", "self-esteem issues", "doubt and self-worth", "feeling of loneliness", "impact on relationships and aspirations"	<ul style="list-style-type: none"> • Mental turmoil and constant scrutiny • Impact on self-esteem and self-worth • Feelings of loneliness and isolation • Impact on relationships and aspirations 	Psychosocial impacts of stigma
"family and social support", "peer support", "internal resilience"	<ul style="list-style-type: none"> • Family and social support as a shield against stigma • Peer relationships as sources of strength • Self-worth as armor against discrimination 	Resilience and coping mechanisms

It is not just about being HIV-positive anymore; it is being pregnant adolescents living with HIV. That's when you realize you're on your own. (Participant A)

Furthermore, one participant expressed disappointment in the lack of anticipated community support, sharing,

I thought my community would support me during this difficult time, but no. The gossips are unbearable. I'm not just dealing with being a young mom; I'm also grappling with being labeled as 'that girl with HIV. (Participant D)

Theme 2: Social and Cultural Influences on Stigma

The narratives shared by the participants collectively shed light on the profound impact of cultural beliefs and social norms on the stigma experienced by pregnant adolescents living with HIV. Through their accounts, participants clearly articulated the prevailing cultural beliefs and social norms.

The participants categorically articulate a prevalent association between HIV and immoral behavior within their community. This connection, often linked to promiscuity, becomes particularly stigmatizing when applied to pregnant adolescents with HIV, creating a perceived stain on their character as highlighted by the following quote;

In our community, HIV is often linked to immoral behavior. People associate it with promiscuity, and this perception extends to pregnant adolescents with HIV. It is like a stain on my character. (Participant E)

The participants highlight societal expectations regarding the behavior of a "good girl", revealing the added challenges faced by pregnant adolescents living with HIV. The intersection of pregnancy and HIV status intensifies judgment, resulting in ostracization from the community, even though some families may be more accepting.

There are certain expectations about how a 'good girl' should behave. Being pregnant is challenging enough, but being pregnant with HIV brings a whole new level of judgment. Some families are more accepting, but the community at large often ostracizes us. (Participant F)

The community's perception of HIV as a death sentence compounds the challenges faced by pregnant adolescents living with HIV. The dual burden of being both an adolescent with HIV and pregnant is perceived as a double offense, leading

to social distancing and avoidance. The resulting isolation is emphasized as being as hurtful as the illness itself, reflecting the emotional toll of stigma.

Our community sees HIV as a death sentence, and when you're an adolescent with HIV and pregnant, it is like you've committed a double offense. They distance themselves, avoid me, and that isolation is very hurtful. (Participant A)

Theme 3: Healthcare System Challenges

The participants' narratives illustrate their experiences within healthcare settings, revealing insights into their interactions, the support services they encounter, and the overarching influence of the healthcare system on their journey. These stories encapsulate the initial encounters of pregnant adolescents within healthcare settings, providing a clear portrayal of the immediate impact of the healthcare system in shaping perceptions and attitudes.

One participant shared her experience, reflecting on the subtle but discernible stares and whispers at the clinic. She keenly sensed being labeled.

At the clinic the stares and whispers were subtle, but I sensed them. It is like they already labeled me – not just as a pregnant teen but as a burden because of my HIV status. (Participant G)

Another participant shed light on the challenges arising from the open discussions of their cases by healthcare providers. This candid discourse, sometimes carried out within earshot of others, engendered a sense of vulnerability and reluctance to seek help or disclose one's HIV status.

Sometimes, the healthcare providers discuss our cases openly, and you can't help but think, who else is listening? It makes you reluctant to seek help. (Participant B)

The participants' perspectives emphasize the need for confidentiality and sensitivity within healthcare settings to foster an environment conducive to the well-being and trust of pregnant adolescents living with HIV.

Theme 4: Psychosocial Impact of Stigma

The firsthand accounts of these young mothers-to-be unveil a poignant narrative, illustrating how stigma indelibly etches its mark on their mental health, self-esteem, and overarching psychosocial well-being. These narratives explicitly exemplify the burdens these adolescents bear, showcasing the profound impact of societal judgment on their lives.

One participant encapsulates this struggle, expressing,

It is like carrying two burdens - the weight of being HIV-positive and the heaviness of how people look at me. My mind is always racing, thinking about what others say, and it is hard to find peace. (Participant H)

This sentiment reveals the constant mental turmoil these adolescents endure as they grapple with the dual challenges of their HIV-positive status and the societal stigma attached to it.

Another participant articulates the corrosive impact of stigma on her sense of self-worth, stating,

sometimes I doubt myself, my worth. I question if I deserve to be happy or have a healthy baby. It is like society has already decided I'm a failure because of my status. (Participant C)

This expression captures the complex interplay between the burden of an HIV-positive status and the additional weight of societal perceptions. The constant mental strain and the pursuit of peace become elusive under the persistent scrutiny and judgment.

A different perspective emerged with one participant stating,

I feel lonely, I'm not close to my friends and family, and it feels like I'm in a completely different world. This is impacting everything - my relationships, my dreams, everything. (Participant K)

This narrative highlights the isolating consequences of stigma, extending beyond the individual to impact their relationships and aspirations.

Theme 5: Resilience and Coping Mechanisms

Through the narratives shared by the participants, a profound understanding emerged, weaving a rich tapestry of resilience that highlighted essential threads of strength, determination, and adaptability. The following quotes explicitly illustrate the nuanced ways in which these participants coped with and transcended HIV-related stigma:

my family and friends provided the strength I needed to face each day. They became my shield against stigma and discrimination. (Participant L)

This highlights the crucial role of families and social support as a foundation, enabling individuals to confront and overcome the adversities of stigma.

Connecting with peers who shared similar experiences was like finding a safe haven. We became each other's confidants, allies in the fight against discrimination. (Participant F)

The transformative power of peer relationships in turning stigma into shared strength is remarkable. The solidarity within these groups emerged as an empowering force, countering the isolation typically associated with stigma.

Understanding my own worth became a powerful armor against the discrimination I faced. (Participant I)

This internal resilience empowered participants to redefine the trajectory of their lives, asserting their identity beyond the limitations imposed by their HIV-positive status, and actively challenging the prevailing stereotypes that contribute to the perpetuation of stigma.

Discussion

The study explored HIV-related stigma among pregnant adolescents living with HIV in southwestern Uganda, recognizing the amplified impact of the HIV epidemic on adolescents in Sub-Saharan Africa. Our aim was to comprehensively explore and grasp HIV-related stigma among this demographic, framed within conceptual frameworks such as the Social Ecological Model and the Health Belief Model. Through our research, we uncovered five primary themes: Experiences of double stigma, Social and cultural influences shaping stigma, challenges within the healthcare system, psychosocial impacts of stigma, and resilience and coping mechanisms. While similar studies have explored HIV-related stigma among various populations,³¹ our focus specifically on HIV-positive pregnant adolescents provides a unique perspective. By concentrating on this vulnerable group, we not only shed light on their experiences but also offer insights into potential interventions and support systems tailored to their needs. This targeted approach contributes to the broader discourse on addressing HIV-related stigma in Sub-Saharan Africa.

The findings of the study shed light on the pervasive experiences of double stigma among pregnant adolescents living with HIV in western Uganda. Double stigma, characterized by the intersection of societal prejudices related to both HIV status and teenage pregnancy, creates a particularly challenging environment for these young women. This aligns with previous research emphasizing the intersectionality of stigma and its heightened impact on marginalized groups.³² This aligns with previous research emphasizing the intersectionality of stigma and its heightened impact on marginalized groups.³³ Studies on HIV-related stigma and adolescent pregnancy support our findings, emphasizing the need for targeted interventions that recognize and address the unique challenges faced by individuals navigating multiple stigmatized identities.³³ The disappointment expressed regarding anticipated community support is in agreement with studies highlighting the gap between expectations and reality in the face of stigma.³⁴ The transformative nature of the double stigma, as described by participants, call for the urgent need for implementing tailored interventions to support the mental health and well-being of pregnant adolescents living with HIV in this context. The transformative nature of the double stigma, as described by participants, calls for the urgent need for implementing tailored interventions to support the mental health and well-being of pregnant adolescents living with HIV in this context.

Applying the SEM¹⁴ to our findings reveals the multilayered nature of HIV-related stigma experienced by pregnant adolescents. At the individual level, participants described internalized stigma and feelings of shame associated with their HIV status and pregnancy, reflecting intrapersonal factors. Interpersonally, societal prejudices and community attitudes

towards HIV and adolescent pregnancy perpetuated stigma, indicating the influence of interpersonal relationships and community norms. Studies on HIV stigma corroborate these results, emphasizing the detrimental effects of open discussions on individuals' willingness to engage with healthcare services.^{21,35} Furthermore, systemic challenges within the healthcare system, such as breaches of confidentiality and inadequate support services, underscored the impact of institutional factors on stigma experiences. By examining stigma through the lens of the SEM, we gain a holistic understanding of its interplay across multiple levels of influence, guiding the development of interventions that target each level to effectively mitigate stigma.

Similarly, the HBM,¹⁵ offers valuable insights into the cognitive and perceptual factors shaping pregnant adolescents' responses to HIV-related stigma. Our findings reflect how participants' perceptions of susceptibility to stigma, severity of its consequences, and perceived benefits of coping mechanisms influence their experiences and behaviors. For instance, the perceived severity of stigma, exacerbated by cultural beliefs associating HIV with moral judgment, influenced participants' decisions to disclose their HIV status and seek healthcare services. The study's findings resonate with previous research emphasizing the impact of cultural beliefs and societal expectations on individuals with HIV, particularly women and adolescents.²¹ By integrating the Health Belief Model, we can identify key determinants of stigma-related behaviors and tailor interventions to address cognitive barriers and enhance coping strategies.

The findings of the study show a recurrent theme regarding the psychosocial impact of stigma. The accounts of these young mothers-to-be expose the profound toll on their mental health, self-esteem, and overall psychosocial well-being. The narratives exemplify the dual burdens these adolescents face, describing the constant mental turmoil of navigating both the weight of being HIV-positive and the heaviness of societal judgment. Interestingly, participants mention the isolating consequences of stigma, signifying its impact on relationships and aspirations. These findings resonate with existing literature that highlights the detrimental psychosocial effects of HIV-related stigma, aligning with studies³³ emphasizing the need for comprehensive support systems to address the mental well-being of individuals living with HIV.³⁶ Our findings emphasize the importance of fostering a supportive environment to mitigate the profound impact of stigma on the lives of this vulnerable population.

The results in our study show a significant theme of resilience and coping mechanisms in the face of HIV-related stigma which aligns with previous studies.³⁷ Participants shared stories highlighting the pivotal role of families, peers and social support in providing a protective shield against stigma, emphasizing the importance of external networks as a foundation for overcoming adversities. The findings align with previous studies emphasizing the significance of social support in mitigating HIV-related stigma.³⁸ Moreover, the transformative power of peer relationships in turning stigma into shared strength resonates with existing literature on the positive impact of peer support.³⁹ The participants' emphasis on internal resilience, acknowledging one's worth as a potent armor against discrimination, adds a dimension to existing research on empowering individuals to challenge prevailing stereotypes. His result suggests the importance of fostering supportive social environments and promoting self-empowerment to enhance the well-being of pregnant adolescents living with HIV, ultimately contributing to the broader efforts of destigmatizing HIV.

Strengths and Limitations of the Study

The study offers a thorough exploration of the challenges faced by pregnant adolescents living with HIV, showing the intersectionality of stigma, cultural dynamics, healthcare obstacles, and psychosocial repercussions. By focusing on the high HIV burden in western Uganda, the findings gain contextual relevance, underscoring the imperative for tailored interventions. However, limitations include the relatively small sample size of 28 participants, potentially constraining the generalizability of results. Geographical centrality on Mbarara may hinder capturing diverse experiences, and potential recall bias underscores the need for a longitudinal approach to enhance data accuracy.

Practical Implications

The findings in this study underscore the complex interplay between stigma, healthcare provision, and patient well-being for pregnant adolescents living with HIV. Double stigma exacerbates the challenges they face, compounded by societal prejudices and healthcare system shortcomings. Policies must prioritize robust confidentiality protocols, ensuring trust and patient-provider confidentiality are upheld. Practical solutions involve implementing comprehensive training for

healthcare professionals on confidentiality practices, strengthening legal protections for patient information, and fostering supportive environments that empower women to access care without fear of discrimination. By addressing these issues, healthcare systems can better serve pregnant adolescents living with HIV, safeguarding their rights and improving health outcomes.

Conclusion

The study uncovers a pervasive double stigma for pregnant adolescents living with HIV in southwestern Uganda, driven by societal biases against both HIV status and teenage pregnancy. Cultural influences worsen discrimination by associating HIV with immoral behavior. Healthcare system challenges, like confidentiality concerns, emphasize the necessity of supportive healthcare environments. The profound psychosocial impact on mental health and self-esteem is evident. Despite these challenges, the study emphasizes resilience and coping mechanisms, underlining the importance of external support and internal strength. Urgent targeted interventions are needed to address the intersectionality of stigma, cultural influences, healthcare issues, and psychosocial well-being for the betterment of this vulnerable population.

Data Sharing Statement

The raw data for this article is available from the principal investigator (amirkabs2017@gmail.com) upon reasonable request.

Acknowledgment

We would like to express our gratitude to the participants who took part in the study.

Funding

None of the authors received funding for this study.

Disclosure

No competing financial conflict exists.

References

1. United Nations International Children's Emergency Fund. *HIV and AIDS in Adolescents*. United Nations International Children's Emergency Fund; 2022.
2. Pannetier J, Lelièvre E, Le Cœur S. HIV-related stigma experiences: understanding gender disparities in Thailand. *AIDS Care*. 2016;28:170–178. doi:10.1080/09540121.2015.1096888
3. Florom-Smith AL, De Santis JP. Exploring the concept of HIV-related stigma. In: *Nursing Forum*. Vol. 47. Wiley Online Library; 2012:153–165.
4. Goffman E. 5 Stigma; (2003).
5. Hlahane MS. *HIV-Stigma Reduction and Responsible Disclosure Management in a Primary Health Care Setting*. North-West University; 2018.
6. Jolle J, Kabunga A, Okello TO, et al. HIV-related stigma experiences and coping strategies among pregnant women in rural Uganda: a qualitative descriptive study. *PLoS One*. 2022;17:e0272931. doi:10.1371/journal.pone.0272931
7. Nabunya P, Namuwonge F. HIV-related shame, stigma and the mental health functioning of adolescents living with HIV: findings from a pilot study in Uganda. *Child Psychiatry Hum Dev*. 2022;2022:1–8.
8. Brittain K, Gomba Y, Noholoza S, et al. HIV-related stigma, disclosure and social support: experiences among young pregnant and postpartum women living with HIV in South Africa. *AIDS Care*. 2023;35:399–405. doi:10.1080/09540121.2022.2121957
9. Paudel V, Baral KP. Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: a review of literature. *Reprod Health*. 2015;12:1–9. doi:10.1186/s12978-015-0032-9
10. Salters K, Loutfy M, De Pokomandy A, et al. Pregnancy incidence and intention after HIV diagnosis among women living with HIV in Canada. *PLoS One*. 2017;12:e0180524.
11. Phonphithak S, Hiransuthikul N, Sherer PP, Bureechai S. A qualitative study of the stigmatization and coping mechanisms among pregnant teenagers living with HIV in Thailand. *J Heal Res*. 2022;36:1141–1148. doi:10.1108/JHR-02-2021-0121
12. Treves-Kagan S, Steward WT, Ntswane L, et al. Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. *BMC Public Health*. 2015;16:1–13. doi:10.1186/s12889-016-2753-2
13. Plesons M, Cole CB, Hainsworth G, et al. Forward, together: a collaborative path to comprehensive adolescent sexual and reproductive health and rights in our time. *J Adolesc Heal*. 2019;65:S51–S62. doi:10.1016/j.jadohealth.2019.09.009
14. Larios SE. *Using the Social Ecological Model to Understand the Contextual Factors Associated with HIV Risk in Commercial Sex Workers at High Risk for Contracting HIV*. University of California, San Diego and San Diego State University; 2007.
15. Champion VL, Skinner CS. The health belief model. *Heal Behav Heal Educ Theory Res Pract*. 2008;4:45–65.
16. Pottinger AM, Boyne AS, Passard NN. Stigma and depression in adolescent mothers—how do types of households influence the mothers' mental well-being? *J Child Fam Stud*. 2023;32:3389–3400. doi:10.1007/s10826-023-02630-z

17. Rao D, Elshafei A, Nguyen M, et al. A systematic review of multi-level stigma interventions: state of the science and future directions. *BMC Med.* 2019;17:1–11. doi:10.1186/s12916-018-1244-y
18. Stephenson R. Community factors shaping HIV-related stigma among young people in three African countries. *AIDS Care.* 2009;21:403–410. doi:10.1080/09540120802290365
19. Mwalabu G, Evans C, Redsell S. Factors influencing the experience of sexual and reproductive healthcare for female adolescents with perinatally-acquired HIV: a qualitative case study. *BMC Women's Health.* 2017;17:1–13. doi:10.1186/s12905-017-0485-9
20. Erasmus MO, Knight L, Dutton J. Barriers to accessing maternal health care amongst pregnant adolescents in South Africa: a qualitative study. *Int J Public Health.* 2020;65:469–476. doi:10.1007/s00038-020-01374-7
21. Miyingo C, Mpayenda T, Nyole R, et al. HIV treatment and care of adolescents: perspectives of adolescents on community-based models in northern Uganda. *HIV/AIDS-Research Palliat Care.* 2023;Volume 15:105–114. doi:10.2147/HIV.S405393
22. Phonphithak S, Hiransuthikul N, Sherer PP, Bureechai S. A qualitative study of the stigmatization and coping mechanisms among pregnant teenagers living with HIV in Thailand. *J Heal Res.* 2021;2021:1.
23. Kimera E, Vindevogel S, Reynaert D, et al. Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: a photovoice study. *PLoS One.* 2020;15:e0232359. doi:10.1371/journal.pone.0232359
24. Toska E, Roberts KJ, Cluver L, Sherr L, Laurenzi C. Adolescent mothers affected by HIV and their children: understanding and meeting their needs in our HIV response and global commitments. *Coalit Child Affect.* 2019;2019:1.
25. Akankunda S, Nambi Najjuma J, Tayebwa S, et al. The role of mass media campaigns in improving adherence to antiretroviral therapy among adolescents living with HIV in Southwestern Uganda. *HIV/AIDS-Research Palliat Care.* 2022;14:397–407. doi:10.2147/HIV.S375789
26. Creswell JW. *A Concise Introduction to Mixed Methods Research.* SAGE publications; 2021.
27. Clandinin DJ, Rosiek J, Clandinin D. Mapping a Landscape of Narrative Inquiry: borderland Spaces and Tensions. In: Jean Clandinin D, editor. *Handbook of Narrative Inquiry: Mapping a Methodology.* Thousand Oaks, CA: Sage; 2007:35–75.
28. Bowling A. *Research Methods in Health: Investigating Health and Health Services.* McGraw-hill education (UK); 2014.
29. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77–101. doi:10.1191/1478088706qp0630a
30. Crawley FP, Hoet JJ. Ethics and law: the declaration of Helsinki under discussion. *Appl Clin Trials.* 1998;7:1.
31. Armoon B, Higgs P, Fleury M-J, et al. Socio-demographic, clinical and service use determinants associated with HIV related stigma among people living with HIV/AIDS: a systematic review and meta-analysis. *BMC Health Serv Res.* 2021;21:1–20. doi:10.1186/s12913-021-06980-6
32. Rutenberg N, Kaufman CE, Macintyre K, Brown L, Karim AM. Pregnant or positive: adolescent childbearing and HIV risk in South Africa; 2002.
33. Hill LM, Maman S, Groves AK, Moodley D. Social support among HIV-positive and HIV-negative adolescents in Umlazi, South Africa: changes in family and partner relationships during pregnancy and the postpartum period. *BMC Pregnancy Childbirth.* 2015;15:1–9. doi:10.1186/s12884-015-0542-z
34. Toska E, Laurenzi CA, Roberts KJ, Cluver L, Sherr L. Adolescent mothers affected by HIV and their children: a scoping review of evidence and experiences from sub-Saharan Africa. *Glob Public Health.* 2020;15:1655–1673. doi:10.1080/17441692.2020.1775867
35. Atuhaire L, Shumba CS, Nyasulu PS. “My condition is my secret”: perspectives of HIV positive female sex workers on differentiated service delivery models in Kampala Uganda. *BMC Health Serv Res.* 2022;22:1–13. doi:10.1186/s12913-022-07561-x
36. Rooks-Peck CR, Adegbite AH, Wichser ME, et al. Mental health and retention in HIV care: a systematic review and meta-analysis. *Heal Psychol.* 2018;37:574. doi:10.1037/hea0000606
37. Adams C, Kiruki M, Karuga R, et al. “Your status cannot hinder you”: the importance of resilience among adolescents engaged in HIV care in Kenya. *BMC Public Health.* 2022;22:1–13. doi:10.1186/s12889-022-13677-w
38. Reif S, Wilson E, McAllaster C, Pence B, Cooper H. The relationship between social support and experienced and internalized HIV-related stigma among people living with HIV in the Deep South. *Stigma Heal.* 2021;6:363. doi:10.1037/sah0000271
39. Keyes SE, Clarke CL, Wilkinson H, et al. “We’re all thrown in the same boat ”: a qualitative analysis of peer support in dementia care. *Dementia.* 2016;15:560–577. doi:10.1177/1471301214529575

HIV/AIDS - Research and Palliative Care

Dovepress

Publish your work in this journal

HIV/AIDS - Research and Palliative Care is an international, peer-reviewed open-access journal focusing on advances in research in HIV, its clinical progression and management options including antiviral treatment, palliative care and public healthcare policies to control viral spread. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/hiv-aids—research-and-palliative-care-journal>