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Adapting to HIV: The Paradoxes of Autonomy and Vulnerability Among Young People Living with HIV in Tororo District, Eastern Uganda - A Qualitative Study

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Background: HIV is a significant public health issue in Uganda, particularly among young people (15–24 years), with an estimated 150,000 living with the virus. This study examines the paradoxes of autonomy and vulnerability experienced by young people living with HIV (YPLHIV) in Tororo District, Uganda. It explores how stigma, social support, and healthcare systems shape their experiences, influencing both their autonomy and vulnerability.

Methods: This qualitative study in Tororo District explored the autonomy and vulnerability of young people living with HIV, using 18 in-depth interviews and 3 focus group discussions to examine personal, social, and healthcare influences.

Results: Findings reveal how stigma, social isolation, and dependence on family support impact autonomy. Participants highlighted the importance of peer support, healthcare empowerment, and resilience in managing HIV. While struggling with medication adherence and gendered expectations, many expressed a desire for independence while acknowledging the critical role of support systems in maintaining their well-being.

Conclusions and Recommendations: This study explores the tension between autonomy and vulnerability among young people living with HIV in Uganda, emphasizing the roles of stigma, social support, and healthcare providers. Recommendations include stigma reduction, peer support integration, and family involvement in care.

Keywords: HIV, autonomy, vulnerability, stigma, young people, peer support, social support

Introduction

Human Immunodeficiency Virus (HIV) remains one of the most pressing public health challenges in sub-Saharan Africa, with young people being disproportionately affected. In Uganda, an estimated 150,000 young people (aged 15–24) are living with HIV.[1] As one of the epicenters of the HIV epidemic, Uganda continues to face substantial health and social burdens associated with the disease. The experiences of young people living with HIV (YPLHIV) are especially complex, as they are navigating the challenges of managing a chronic, stigmatized condition while transitioning into adulthood. In particular, issues surrounding autonomy and vulnerability form a paradoxical dynamic that affects how these individuals understand and engage with their health, social networks, and daily lives.

Autonomy, the ability to make independent decisions about one's life, is a cornerstone of psychosocial well-being, particularly for young people as they transition to adulthood.[2] However, for YPLHIV, the assertion of autonomy is often complicated by the vulnerabilities associated with living with a chronic illness, particularly a stigmatized condition such as HIV. The need for independence and self-sufficiency may be in direct tension with the ongoing need for external support in managing their health, maintaining social relationships, and adhering to treatment regimens. The balance

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between autonomy and vulnerability has become a central theme in the literature on chronic illness management, and it is critical to understand how this dynamic plays out among YPLHIV in Uganda.

A key factor influencing autonomy among YPLHIV is stigma. HIV-related stigma has been shown to significantly affect the mental and emotional health of young people, limiting their social participation, increasing isolation, and exacerbating feelings of vulnerability.[3] Studies in sub-Saharan Africa have demonstrated that HIV stigma is often internalized by individuals, leading them to conceal their status, avoid social interactions, and sometimes disengage from necessary healthcare services.[4] These experiences of stigmatization are not only associated with a loss of autonomy but also with a decline in overall well-being.[5] This raises important questions about the ways in which stigma constrains young people's ability to assert their autonomy, particularly in a societal context where disclosure of HIV status may result in severe social consequences.

At the same time, vulnerability is an intrinsic aspect of living with HIV, particularly for YPLHIV who are at an increased risk for physical and emotional complications. Vulnerability, in this context, is not only a result of the disease itself but also the external forces that shape an individual's experience of living with HIV, including social networks, family dynamics, and healthcare environments.[6] Young people often rely on family and peer support to help navigate the complexities of living with HIV. However, the nature and extent of this support vary widely and can both empower and limit their ability to assert autonomy.[7] For example, while family support can provide emotional resilience and practical assistance, it can also reinforce dependence and reduce opportunities for independence, particularly if families maintain control over health decisions.

Healthcare providers also play a significant role in shaping the autonomy and vulnerability of YPLHIV. The quality of healthcare services, including the attitudes and behaviors of healthcare providers, influences how young people experience autonomy in their care. Empowering healthcare providers who encourage shared decision-making and treat YPLHIV with dignity have been shown to enhance both treatment adherence and self-management.[8] Conversely, providers who are perceived as judgmental or dismissive may contribute to increased vulnerability, exacerbating feelings of shame and fear, which further complicate efforts to manage their HIV status.[9]

While much of the existing literature has explored autonomy and vulnerability among YPLHIV in general, there is a dearth of research that specifically examines these dynamics within the Ugandan context, particularly among young people in rural areas. This gap is particularly evident in Tororo District, a region in Eastern Uganda, where the intersections of cultural attitudes, healthcare access, and socio-economic factors are likely to influence the experiences of young people living with HIV in unique ways. This study aims to address this gap by exploring how young people in Tororo District navigate the paradoxes of autonomy and vulnerability in the context of HIV.

This qualitative study seeks to explore the lived experiences of young people living with HIV in Tororo District, Uganda, and to examine how they negotiate the tensions between asserting their autonomy and managing the vulnerability associated with their HIV status. Using in-depth interviews and focus group discussions, this study will investigate how stigma, social support networks, healthcare systems, and personal agency shape the autonomy and vulnerability of YPLHIV in this region. The term "autonomy" refers to the capacity of individuals to make independent decisions and act in ways that align with their own values and desires, while "vulnerability" denotes the susceptibility to harm, exploitation, or dependency, often arising from factors beyond an individual's control. Within the context of young people living with HIV, these concepts intersect in complex ways. On one hand, the desire for autonomy is crucial for self-expression, independence, and empowerment, enabling individuals to navigate their personal and social identities. On the other hand, the vulnerability associated with living with HIV—ranging from health-related challenges to social stigma—can limit one's ability to exercise full autonomy. This tension creates a paradox, where the pursuit of autonomy may simultaneously expose individuals to heightened vulnerability. The study seeks to explore how young people living with HIV experience and navigate this paradox, shedding light on the interplay between their agency and the risks they face, ultimately providing a deeper understanding of how these dynamics shape their lives. The findings of this study will contribute to a deeper understanding of the psychosocial challenges faced by YPLHIV in Uganda and inform interventions aimed at improving the quality of care, promoting resilience, and fostering greater autonomy among this vulnerable population.

Methodology

Study Setting and Participants

This study was conducted in Tororo District, Eastern Uganda, to explore the paradoxes of autonomy and vulnerability among young people living with HIV (YPLHIV). Tororo District, with its mix of rural and urban areas, provides a relevant context to examine the intersection of health challenges, social influences, and individual experiences among YPLHIV. The study involved 18 participants, purposively selected from the local population of young people aged 10 to 24 years. This sample included 10 females and 8 males, ensuring gender balance in the representation of experiences. Participants were drawn from diverse backgrounds, encompassing a range of social, cultural, and healthcare-related experiences, offering a comprehensive understanding of the challenges and perceptions of YPLHIV. The sample size was deemed sufficient based on saturation theory in qualitative research, which posits that data collection should continue until no new themes or patterns emerge. In this case, the research team found that after 18 interviews and 3 focus group discussions (FGDs), the themes were sufficiently represented, and no additional insights emerged. The sample size also aligns with qualitative research standards for an in-depth exploration of the issues. The study included three FGDs, each with 6 to 7 participants, allowing for a deeper exploration of individual experiences, group dynamics, and shared insights. This combination of individual interviews and group discussions provided a well-rounded approach to understanding the complexities faced by YPLHIV in the district.

Study Design

This study employed a qualitative research design, which is particularly suited for exploring complex and sensitive issues such as autonomy, vulnerability, and the lived experiences of young people living with HIV. A combination of in-depth interviews and focused group discussions (FGDs) was used as the primary data collection methods. In-depth interviews allowed for detailed exploration of personal experiences, while the FGDs provided opportunities for participants to discuss and reflect on common themes in a group setting. The research design was chosen to capture a wide range of perspectives and to allow the participants to express their views in their own words, both individually and collectively.

Eligibility Criteria

Eligible participants for this study were young people aged 10 to 24 years who were living with HIV. To ensure ethical standards, participants were required to provide explicit informed consent (or assent, with parental consent for those under 18). Participants needed to be willing to share their personal experiences related to living with HIV. The inclusion criteria were designed to ensure diversity in gender, age, and HIV-related experiences. The recruitment process involved outreach through HIV support networks, healthcare facilities, and community organizations. Exclusion criteria applied to individuals who, due to severe cognitive impairments or other conditions, were unable to meaningfully engage in interviews or focus group discussions (FGDs). Ethical considerations followed the principles outlined in the Declaration of Helsinki, ensuring participant confidentiality, voluntary participation, and the right to withdraw at any time without consequence. All procedures were approved by the relevant ethical review boards to protect the rights and welfare of participants.

Data Collection

Data collection was conducted through semi-structured in-depth interviews and focused group discussions. The in-depth interviews provided a space for participants to share their experiences of living with HIV, their perceptions of autonomy and vulnerability, and the social, cultural, and healthcare-related factors that influence their coping mechanisms. These interviews were conducted by trained researchers with experience in qualitative research, HIV-related issues, and the social dynamics of the local community. The interviews were facilitated in the local languages (Luganda, Ateso, and Adhola) and translated where necessary, ensuring that the researchers could establish rapport and foster a comfortable environment for participants. The FGDs were also conducted in local languages, allowing participants to discuss common experiences and share insights in a group setting, further enhancing the depth of the data.

The semi-structured interview and FGD guides were designed to allow for flexibility, addressing the key research questions while also enabling emergent themes to be explored. The guides included open-ended questions and prompts to facilitate in-depth discussions about the participants' experiences of living with HIV, their sense of autonomy and vulnerability, and the factors that influence their coping strategies.

All interviews and FGDs were audio-recorded with participants' consent, transcribed verbatim, and stored securely to ensure confidentiality. The transcripts were translated as needed, and the research team reviewed them to ensure accuracy. The data were analyzed using NVIVO version 14 software to assist with organizing and coding the data.

Data Management and Analysis

The data from both the in-depth interviews and focus group discussions (FGDs) were analyzed using thematic analysis. The analysis process was conducted independently by two researchers to ensure rigor and credibility. The research team began by conducting multiple readings of the transcripts to familiarize themselves with the data and gain a deep understanding of participants' experiences. A codebook was developed to categorize recurring themes and subthemes related to autonomy, vulnerability, and the social, cultural, and healthcare-related factors that influence young people living with HIV (YPLHIV). The coding process was iterative, allowing for continuous refinement and adjustment of codes as new insights emerged. Descriptive analysis was employed to provide a comprehensive account of participants' experiences, with direct quotes from the interviews and FGDs used to support the findings.

Data Trustworthiness

To ensure the trustworthiness and credibility of the qualitative data, several strategies were employed throughout the data collection and analysis process. First, triangulation was utilized by integrating data from multiple sources, including in-depth interviews and focus group discussions. This allowed for a more comprehensive understanding of the research phenomena and helped to validate the consistency of the findings across different participant groups. Second, we implemented a code-recode strategy during data analysis. The primary researcher conducted the initial coding of transcripts and then repeated the coding process after a two-week interval. The consistency between the two coding sessions was compared, and discrepancies were discussed and resolved to enhance the reliability of the coding framework. Third, peer debriefing was conducted with an independent qualitative researcher who reviewed the codes, themes, and interpretations. This process provided an external check on the analytical procedures and helped mitigate potential researcher bias. Collectively, these measures contributed to enhancing the rigor, credibility, and trustworthiness of the study findings.

Reflexivity

Throughout the research process, the research team maintained a reflexive stance, acknowledging their own positionality and potential biases. The team recognized that the sensitive nature of the study required careful consideration of power dynamics, both in terms of the researcher-participant relationship and the broader social context of HIV in Tororo District. The researchers were mindful of how these dynamics could shape the interpretation of the data and actively worked to create a respectful and open environment for participants to share their experiences. The team's reflection on their own perspectives allowed for a more nuanced interpretation of the findings, ensuring that the voices of YPLHIV were heard authentically and with sensitivity to their context.

Results

This qualitative study sought to examine the paradoxical nature of autonomy and vulnerability as experienced by young people living with HIV in Tororo District, Eastern Uganda. The research was designed to capture the nuances of how these individuals navigate their lives, balancing the desire for independence with the challenges posed by their HIV status.

The primary research question addressed was how young people aged 10 to 24 years, living with HIV, perceive and manage their autonomy and vulnerability. Additionally, the study sought to understand how social, cultural, and healthcare-related factors influence their experiences and coping mechanisms.

The findings from the study are organized into primary and secondary themes, each of which provides insight into the complex intersection between autonomy and vulnerability for young people living with HIV as shown in Table 1 below.

Table 1 Showing the Primary Themes, Secondary Themes and Quotations

Primary Theme	**Secondary Theme**	**Quotations**
The Struggle for Autonomy Amidst Stigma	*Stigma and Social Restrictions*	"Sometimes, I feel like I'm being held back by my HIV status. I want to go out with my friends and do normal things, but when I think about it, I know people might judge me if they find out, so I stay home more. I don't feel free." (Female, IDI, 19 years)
	Isolation and Withdrawal	"I don't talk to many people about my HIV status because I know they'll treat me differently. Even my friends, they don't understand. Sometimes I just wish I could be like everyone else, but I can't." (Male, FGD2, 18)
	Parental Control and Dependency	"My parents support me a lot, but I feel like I'm still not completely independent. They are always checking if I've taken my medication. It's like I am still a child." (Female, IDI, 17 years)
	Resilience and Agency	"Having HIV doesn't mean I'm not in control of my life. I've learned to manage it, but it's not always easy. I've faced a lot of challenges, but I refuse to let HIV define me." (Male, FGD 3)
	Peer Pressure and Health Responsibility	"Sometimes my friends ask me to do things that I know could affect my health, like drinking or going out all night. I feel torn between being part of the group and protecting my health. It's hard to say no." (Female, IDI, 19 years)
Adapting to HIV: The Need for Support Systems	*Dependence on Family Support*	"Without my family and friends, I would have lost hope a long time ago. They remind me that I'm not alone. They make sure I take my medication every day. I think I can live on my own someday, but for now, I still need their help." (Male, FGD 1, 22 years)
	Hope and Emotional Support	"When I was first diagnosed, I thought my life was over. But my family was there for me every step of the way. They reminded me that I could still achieve my dreams. Without them, I don't know where I would be." (Female, 20 years, IDI)
	Peer Support and Shared Experiences	"It helps to talk to someone who understands exactly what you're going through. In my support group, we share our struggles, but we also give each other strength. I don't feel so alone anymore." (Male, 23 years, FGD3)
	Empowering Healthcare Providers	"The doctors don't treat me like I'm weak. They treat me with respect and show me that I have control over my life. When I go for my check-ups, I feel like I'm in charge of my health." (Female, 18 years, IDI)
	Fear of Losing Support	"I'm scared that if I ever lose my family's support, I won't be able to handle living with HIV. I need them to remind me to take my pills and check in on me. I don't think I could do this alone." (Male, 19 years, FGD 3)
	Desire for Future Independence	"My parents make sure I follow my treatment plan, but I know that one day I'll be able to do it on my own. For now, I need them, but I can't wait to be able to handle things by myself." (Male, 21years, FGD 2)
	Emotional Support and Stability	"Sometimes, it's not about the medication or the doctors. It's about having someone to talk to, someone who tells you that everything will be okay. My friends and family do that for me." (Female, 19 years, IDI)

(*Continued*)

Table 1 (Continued).

Primary Theme	**Secondary Theme**	**Quotations**
Challenges of Medication Adherence and Autonomy	*Medication as a Constant Reminder*	"I hate having to take my pills every day. It's like a constant reminder that I'm sick. But I know if I don't, I could get worse. I just want to forget sometimes, like other people my age." (Female, IDI, 15 years)
	Struggle with Medication Control	"I feel like the pills control me more than I control them. Every time I have to take them; I think about how my life isn't my own. If I don't take them, my health will get worse, but I want to be in charge of my own life." (Male, 23 years, FGD3)
	Fear of Stigma and Concealing Medication	"Sometimes I don't take my medicine because I don't want anyone to see me with the pills. I feel like people will judge me if they know I'm HIV positive. It's easier when I can just be like everyone else." (Female, 19 years, IDI)
	Impact of Medication on Social Life	"I want to go out and be like my friends, but I can't because I have to take my medicine. It feels like I have to plan my whole day around it, and sometimes I just want to forget about it and live my life." (Male, 21years, FGD 2)
	Reluctance to Accept HIV Status	"I hate the pills. I hate the fact that I need them to stay alive. I want to be strong and healthy without needing anything. But I know if I don't take them, I'll get sick, so I just do it." (Male, 21 years, IDI)
Gender Dynamics and Autonomy	*Gendered Expectations and Caregiving*	"As a girl, you are expected to care for others. I want to take care of myself first, but sometimes I feel like I can't. My family expects me to look after my younger siblings, and I have to make sure they're safe from HIV too." (Female, FGD1, 17 years)
The Role of Peer Influence in Shaping Autonomy	*Peer Pressure and Health Conflict*	"My friends don't understand what it means to live with HIV. Sometimes they encourage me to drink or go out and party, but I know that's not good for my health. It's hard to say no, but I have to be strong." (Male, IDI, 20 years)
Resilience and Coping Strategies	*Acceptance and Empowerment*	"I have learned to accept my HIV status, and it doesn't control me anymore. I'm still in charge of my life. I choose how I live and who I let into my life." (Female, FGD 2, 24 years)
The Impact of Community Engagement	*Support Groups and Shared Strength*	"Being part of a support group helps me to be open about my HIV status. It makes me feel like I'm not alone. I'm part of something bigger, and that gives me strength to face each day." (Male, IDI, 18 years)
The Role of Healthcare Providers in Promoting Autonomy	*Healthcare Empowerment and Control. Note that healthcare empowerment refers to self-efficacy in healthcare decision-making, with a focus on participant's ability to manage their own healthcare, improve access to services, and the role of provider support.*	"My doctor talks to me like I am in control of my life. He tells me I can live a full life if I stick to my treatment. That makes me feel like I have choices, not just one path." (Female, IDI, 21 years)

The Struggle for Autonomy Amidst Stigma

A major finding of the study was the tension young people felt between asserting their autonomy and dealing with the societal stigma associated with HIV. This theme emerged from several interviews and focus groups with participants who described how their HIV status affected their independence in both private and public settings. One participant stated

> Sometimes, I feel like I'm being held back by my HIV status. I want to go out with my friends and do normal things, but when I think about it, I know people might judge me if they find out, so I stay home more. I don't feel free. (Female, IDI, 19 years)

This quotation highlights the impact of stigma on the participant's autonomy. The internalized fear of judgment restricts her from fully exercising her independence, even in social settings. Despite her desire for normalcy, the perceived social restrictions shape her actions, leading to withdrawal from activities that would otherwise foster a sense of independence.

> I don't talk to many people about my HIV status because I know they'll treat me differently. Even my friends, they don't understand. Sometimes I just wish I could be like everyone else, but I can't. (Male, FGD2, 18)

This participant's statement highlights how stigma impacts their sense of belonging and autonomy. The fear of judgment leads to isolation, which restricts their ability to fully engage in social activities and exercise independence.

> My parents support me a lot, but I feel like I'm still not completely independent. They are always checking if I've taken my medication. It's like I am still a child.(Female, IDI, 17 years)

Here, the participant reflects on the balance between the care provided by their family and their desire for independence. The quote exemplifies how familial care, while supportive, can sometimes feel like a barrier to autonomy for young people.

> Having HIV doesn't mean I'm not in control of my life. I've learned to manage it, but it's not always easy. I've faced a lot of challenges, but I refuse to let HIV define me.(Male, FGD 3, Male)

This quote demonstrates resilience in the face of adversity. The participant shows that while HIV presents challenges, it does not completely limit his autonomy. His response reflects the sense of agency that can coexist with the experience of vulnerability.

> Sometimes my friends ask me to do things that I know could affect my health, like drinking or going out all night. I feel torn between being part of the group and protecting my health. It's hard to say no.(Female, IDI, 19 years)

This quotation sheds light on the peer pressure that many young people face, especially regarding behaviors that could undermine their health. The tension between social inclusion and health responsibility further complicates their autonomy.

Adapting to HIV: The Need for Support Systems

Young people in study repeatedly mentioned the critical role of family, healthcare providers, and peer support networks in helping them adapt to living with HIV. This theme reflects the complexities of balancing autonomy with the recognition that their health and survival often depended on others. This was appreciated by the statement from one participant below

> Without my family and friends, I would have lost hope a long time ago. They remind me that I'm not alone. They make sure I take my medication every day. I think I can live on my own someday, but for now, I still need their help. (Male, FGD 1, 22 years)

This participant emphasizes the paradox of dependence and independence. While he recognizes his need for support in managing his HIV status, he also expresses a desire for eventual autonomy, suggesting that the journey toward independence is gradual and deeply intertwined with external support.

> When I was first diagnosed, I thought my life was over. But my family was there for me every step of the way. They reminded me that I could still achieve my dreams. Without them, I don't know where I would be.(Female, 20 years, IDI)

This participant expresses the deep emotional support and hope provided by her family. While she struggles with the challenges of HIV, the unwavering support from her family has been pivotal in maintaining her resilience and motivation to continue living with hope.

> It helps to talk to someone who understands exactly what you're going through. In my support group, we share our struggles, but we also give each other strength. I don't feel so alone anymore. (Male, 23 years, FGD3)

Peer support groups provide a sense of shared understanding and emotional safety, helping participants cope with the challenges of living with HIV. This quotation reflects how group solidarity plays a role in reducing isolation and fostering both autonomy and a sense of collective support.

> The doctors don't treat me like I'm weak. They treat me with respect and show me that I have control over my life. When I go for my check-ups, I feel like I'm in charge of my health. (Female, 18 years, IDI)

This quotation highlights the empowering role healthcare providers play in the lives of young people living with HIV. By treating them with respect and involving them in decisions about their health, healthcare professionals contribute to a greater sense of autonomy, which complements the support they receive.

> My parents make sure I follow my treatment plan, but I know that one day I'll be able to do it on my own. For now, I need them, but I can't wait to be able to handle things by myself. (Male, 21years, FGD 2)

This statement reflects the delicate balance between dependence and the desire for autonomy. While the participant acknowledges his current reliance on family support, he also expresses a strong desire for eventual independence, indicating that the journey to self-sufficiency is a gradual process.

> Sometimes, it's not about the medication or the doctors. It's about having someone to talk to, someone who tells you that everything will be okay. My friends and family do that for me. (Female, 19 years, IDI)

This participant underscores the importance of emotional support in managing HIV. Beyond the physical aspects of treatment, the emotional reassurance provided by loved ones plays a vital role in fostering a sense of stability and autonomy, particularly when dealing with the emotional burden of living with a chronic illness.

> I'm scared that if I ever lose my family's support, I won't be able to handle living with HIV. I need them to remind me to take my pills and check in on me. I don't think I could do this alone. (Male, 19 years, FGD 3)

This quotation reflects the vulnerability that comes with dependency on support systems. The participant expresses a fear of isolation, indicating that without the support of family and friends, managing HIV might feel overwhelming. It also highlights the emotional and practical importance of external support in maintaining their health.

> Being part of a peer group for people living with HIV has made me believe in myself more. They taught me that I'm not the only one going through this, and that I can still live a meaningful life. (Female, 22 years, FGD2)

This participant points to the transformative impact of peer networks in promoting self-efficacy. By connecting with others who share similar experiences, she gains confidence in her ability to navigate her HIV status, demonstrating the power of shared experiences in fostering autonomy.

Challenges of Medication Adherence and Autonomy

A recurring theme in the data was the tension between maintaining autonomy and adhering to the daily HIV treatment regimen. Many participants expressed a struggle to balance taking their medication regularly with the desire to live a normal, autonomous life without constant reminders of their illness. One female participant described the psychological burden of medication adherence:

> I hate having to take my pills every day. It's like a constant reminder that I'm sick. But I know if I don't, I could get worse. I just want to forget sometimes, like other people my age. (Female, IDI, 15 years)

This quote highlights the conflict between the need for medication and the desire for autonomy. The participant's feeling that the medication serves as a constant reminder of her illness interferes with her sense of independence and desire to live like her peers. Similarly, another male participant shared:

> I feel like the pills control me more than I control them. Every time I have to take them, I think about how my life isn't my own. If I don't take them, my health will get worse, but I want to be in charge of my own life. (Male, 23 years, FGD3)

This statement underscores the tension between the necessity of medication and the loss of control over one's life, reflecting the internal struggle between health maintenance and self-determination. The impact of stigma on medication adherence was also evident, as one participant expressed:

> Sometimes I don't take my medicine because I don't want anyone to see me with the pills. I feel like people will judge me if they know I'm HIV positive. It's easier when I can just be like everyone else. (Female, 19 years, IDI)

The fear of stigma directly influenced her medication adherence, illustrating how social judgment can undermine a young person's ability to manage their health. Conversely, the presence of social support was cited as an important factor in medication adherence. For instance, some participants noted that having supportive family members or peers who encouraged regular medication use made it easier to maintain their regimen and navigate the emotional challenges of living with HIV. In contrast, a lack of social support compounded the struggle to adhere to treatment. One male participant expressed:

> I want to go out and be like my friends, but I can't because I have to take my medicine. It feels like I have to plan my whole day around it, and sometimes I just want to forget about it and live my life. (Male, 21 years, FGD 2)

This quote highlights the social isolation and disruption to daily life caused by medication adherence. Overall, the results indicate that both stigma and social support significantly impact medication adherence, with stigma serving as a major barrier for many participants. The differential experiences of young men and women suggest that gender may influence how stigma is internalized and how social support systems are accessed, affecting their overall adherence to HIV treatment regimens.

Gender Dynamics and Autonomy

A significant theme that emerged from the data was the role of gender in shaping autonomy and vulnerability. Gendered expectations around sexuality, reproductive health, and caregiving roles were particularly influential in shaping the experiences of young people living with HIV. Female participants, in particular, described facing additional challenges due to societal pressures placed on them based on their gender. One female participant shared:

> As a girl, you are expected to care for others. I want to take care of myself first, but sometimes I feel like I can't. My family expects me to look after my younger siblings, and I have to make sure they're safe from HIV too. (Female, FGD1, 17 years)

This quotation illustrates how gendered expectations limit young women's autonomy. While the participant expresses a desire to prioritize her own health and well-being, she is simultaneously burdened by the expectation to fulfill caregiving responsibilities for her family. This dynamic complicates her ability to exercise autonomy over her own health. In contrast, male participants generally did not report similar caregiving burdens, though they still faced challenges related to societal norms of masculinity and sexuality. The gendered expectations placed on women, particularly the societal view that women should prioritize caregiving over self-care, shaped their autonomy in distinct ways. This theme demonstrates the intersectionality of gender and HIV status, where young women face compounded pressures that hinder their ability to exercise control over their lives and health, while young men's autonomy is shaped by different sets of societal expectations. This gender-specific analysis highlights how gendered norms shape vulnerability and autonomy in unique ways for young men and women.

The Role of Peer Influence in Shaping Autonomy

Peer relationships were frequently mentioned as both a source of support and a site of tension. Many young people reported that their friends provided emotional support, but they also struggled with the pressure to conform to group norms, which could include risky behaviors.

> My friends don't understand what it means to live with HIV. Sometimes they encourage me to drink or go out and party, but I know that's not good for my health. It's hard to say no, but I have to be strong. (Male, IDI, 20 years)

This quotation captures the conflict young people face in balancing their desire for social inclusion with the need to make health-conscious decisions. Peer pressure to engage in risky behavior clashes with the participant's health priorities, highlighting the complexities of maintaining autonomy in social contexts where understanding of HIV is limited.

Resilience and Coping Strategies

A secondary theme that emerged was the resilience exhibited by many young people living with HIV. Participants demonstrated a remarkable ability to adapt, find coping strategies, and maintain a sense of hope for the future. This resilience was closely tied to their sense of autonomy and personal agency.

> I have learned to accept my HIV status, and it doesn't control me anymore. I'm still in charge of my life. I choose how I live and who I let into my life. (Female, FGD 2, 24 years)

This participant's response reflects a sense of regained autonomy despite living with HIV. She speaks of a personal transformation from vulnerability to empowerment, suggesting that resilience plays a critical role in navigating the paradox of living with a chronic illness.

The Impact of Community Engagement

Several participants highlighted the importance of community-based HIV education and support groups in fostering both individual and collective autonomy. These groups provided a sense of belonging, safety, and mutual understanding, which were key to overcoming feelings of isolation and vulnerability.

> Being part of a support group helps me to be open about my HIV status. It makes me feel like I'm not alone. I'm part of something bigger, and that gives me strength to face each day. (Male, IDI, 18 years)

The participant's statement reflects the empowering effect of community engagement on individual autonomy. By participating in a support group, he gains the strength and validation needed to manage his HIV status more independently. This engagement creates a space where participants can express vulnerability without judgment, fostering a sense of empowerment.

The Role of Healthcare Providers in Promoting Autonomy

Healthcare providers were identified as key figures in helping young people balance their autonomy and vulnerability. The support provided by doctors, nurses, and counselors was seen as essential in building confidence in managing their health and making informed decisions about their treatment.

> My doctor talks to me like I am in control of my life. He tells me I can live a full life if I stick to my treatment. That makes me feel like I have choices, not just one path. (Female, IDI, 21 years)

This quotation highlights how the healthcare provider's role in reinforcing the participant's sense of autonomy positively influences her outlook on life with HIV. The doctor's approach is not to impose control but to empower the participant by framing treatment as a choice rather than a mandate, thus promoting autonomy.

Discussion

In this study, we aimed to explore the paradoxical nature of autonomy and vulnerability among young people living with HIV in Tororo District, Eastern Uganda. Our findings provide valuable insights into the complex ways in which young people balance their desire for independence with the challenges of managing their HIV status. In particular, we identify the pivotal roles of stigma, family support, healthcare providers, and peer networks in shaping the autonomy and vulnerability of young individuals living with HIV. This study contributes to the growing body of literature on the psychosocial and healthcare-related experiences of young people with chronic illnesses, particularly HIV, in sub-Saharan Africa.

The results of our study suggest that young people living with HIV experience a significant tension between asserting their autonomy and navigating the vulnerability associated with their status. A key finding of our study was that stigma emerged as a substantial barrier to autonomy. Participants expressed feelings of isolation and withdrawal due to fears of judgment, particularly in social contexts. This is consistent with the work of,[10] who noted that stigma surrounding HIV is a major driver of social isolation and reduced quality of life among youth living with the virus. Additionally, our findings resonate with,[11] who similarly highlighted the challenges faced by young people in maintaining social relationships when dealing with the stigma of HIV.

Interestingly, our study also revealed a resilience in young people despite the stigma and vulnerability they face. This resilience was marked by the desire for independence and the ability to manage their health, which echoes the findings of,[5] who documented how youth with chronic conditions like HIV develop adaptive coping mechanisms to navigate their health challenges. Our results extend the work of[12] by showing that, despite feelings of vulnerability, many participants expressed a strong sense of agency, striving to live full lives beyond their diagnosis.

Moreover, our study highlights the complex relationship between dependency and autonomy in the context of HIV care. The need for ongoing familial and healthcare support was evident in many participant narratives. This aligns with findings from,[13] who discussed the importance of family and peer networks in fostering a sense of agency among young people living with chronic illnesses. While young people expressed the desire to gain full independence in managing their HIV, they simultaneously acknowledged the critical role of external support in their day-to-day survival and emotional well-being.

Our findings align with those of,[14] who emphasized the role of peer support networks in mitigating feelings of isolation and promoting health management among adolescents with HIV. The sense of belonging and empowerment expressed by participants in this study mirrors,[15] who demonstrated that peer groups provide not only emotional support but also practical advice on living with HIV. However, our results also contrast with,[16] who found that peer influence could sometimes lead to risky behaviors, such as non-adherence to medication, particularly when participants felt pressured to conform to social norms. This discrepancy may stem from differences in social contexts, with participants in our study indicating a higher level of resilience and agency despite peer pressure.

A key methodological strength of this study is the use of both in-depth interviews and focus group discussions, which allowed for a nuanced understanding of participants' experiences. This approach is consistent with,[17] who advocated for mixed-approaches to capture the complex psychosocial dimensions of living with chronic illness. In contrast to,[18] who primarily used quantitative measures, our qualitative approach provides richer insights into the emotional and psychological aspects of autonomy and vulnerability, highlighting the intersection of social, familial, and healthcare-related factors.

The findings of this study suggest that the tension between autonomy and vulnerability may be driven by several key mechanisms. First, stigma appears to be a central factor that inhibits autonomy. The fear of judgment from others, including peers and family, results in self-isolation and reluctance to disclose HIV status, which has been similarly documented by.[19] Stigma also influences medication adherence, as many young people reported hiding their medication or avoiding taking it in public to maintain social appearances, a phenomenon previously discussed by.[20]

Moreover, our study points to the role of social support in mitigating the vulnerability associated with HIV. Participants indicated that strong family and peer support systems were essential for both emotional and practical support. These findings are consistent with,[21] who proposed that emotional reassurance and guidance from family members and peers help young people cope with the complexities of living with HIV, thus fostering a sense of control over their lives. The role of healthcare providers in promoting autonomy was also evident, with participants expressing appreciation for being treated with respect and included in decisions about their health care, in line with the work of.[22]

The findings of this study have important implications for HIV care and policy. First, healthcare providers should be trained to foster a supportive and empowering environment for young people living with HIV, emphasizing respect, autonomy, and shared decision-making. As[23] argue, involving young people in their healthcare decisions enhances their sense of control and improves treatment adherence. Furthermore, HIV care programs should integrate peer support networks as part of their services, as these networks were identified as crucial in fostering a sense of belonging and empowerment among young people. Policy initiatives aimed at reducing HIV-related stigma in schools, communities, and healthcare settings are also needed to improve the social inclusion of young people living with HIV.

Reflexivity played a crucial role in the interpretation of the findings in this study. As researchers, we acknowledge that our personal biases, prior experiences, and positionality inevitably influenced how we analyzed and interpreted the data. Our understanding of the participants' lived experiences was shaped by our own perspectives, which include both our professional training and our social identities. By critically reflecting on these factors throughout the research process, we were able to ensure greater transparency and rigor in the analysis.

We made a conscious effort to approach the data with an awareness of our own assumptions and preconceptions, continuously questioning how our viewpoints might affect the interpretation of key themes such as autonomy, vulnerability, and the impact of stigma. For instance, as researchers, we were mindful of how gender dynamics and cultural context could influence participants' expressions of autonomy and vulnerability. Additionally, we remained open to challenging our interpretations and refining them in response to participants' nuanced narratives, particularly when considering how different factors—such as social support and stigma—shaped their experiences.

Reflexivity thus allowed for a more critical and balanced analysis of the findings, ensuring that the voices of the participants were foregrounded while simultaneously recognizing the role of the researchers in shaping the conclusions drawn from the data. This approach ultimately strengthened the trustworthiness and validity of the study, contributing to a more nuanced and comprehensive understanding of the challenges faced by young people living with HIV.

Study Strengths

The study's strengths lie in its robust qualitative methodological design, the relevance of its context, the diversity of its participants, and the reflexive approach to data interpretation. Together, these factors contribute to a deeper and more comprehensive understanding of the experiences of young people living with HIV in Tororo District, Uganda.

Limitations

Despite the valuable contributions of this study, several limitations must be acknowledged. First, the cross-sectional design limits our ability to draw conclusions about causality or the long-term trajectory of autonomy and vulnerability in young people living with HIV. Longitudinal studies, as suggested by,[24] would provide further insights into how autonomy and vulnerability evolve over time as individuals adjust to life with HIV. Additionally, the sample size of this study was relatively small, and our findings may not be generalizable to all young people living with HIV in Uganda or in other regions. Future studies with larger and more diverse samples are needed to explore the broader applicability of our findings.

Conclusion

This study provided valuable insights into the complex dynamics of autonomy and vulnerability among young people living with HIV in Tororo District, Eastern Uganda. While young people express a strong desire for independence, the barriers posed by stigma and social isolation often hinder their ability to fully assert their autonomy. The findings highlight the pivotal role of family, peer networks, and healthcare providers in navigating this tension, with social support emerging as a crucial factor in mitigating the vulnerability associated with HIV. Despite the challenges, many participants demonstrated resilience, actively managing their health and striving for agency in their daily lives. This research deepens our understanding of the psychosocial experiences of youth with HIV and calls for targeted interventions that address both the stigma surrounding HIV and the need for robust support systems to enhance the well-being of these young individuals.

Recommendation

To address the challenges young people living with HIV face, several recommendations are proposed. First, stigma reduction programs should be implemented in communities, schools, and healthcare settings to raise awareness, dispel myths, and foster social inclusion. Peer support networks are also crucial for enhancing a sense of belonging and empowerment, and should be integrated into HIV care programs, providing a space for shared experiences and mutual support. Healthcare providers must be trained to create a supportive, youth-centered environment that encourages shared decision-making and respects privacy, promoting autonomy and better health outcomes. Family involvement is also key;

educational initiatives can strengthen family support, improving disease management and emotional well-being. Future research should focus on longitudinal studies to track how autonomy and vulnerability evolve over time. Additionally, exploring the impact of socioeconomic factors, such as income and education, is essential for developing more tailored and effective interventions.

Abbreviations

HIV, Human Immunodeficiency Virus; YPLHIV, Young People Living with HIV; UNAIDS, Joint United Nations Programme on HIV/AIDS; ARVs, Antiretroviral Drugs; PHC, Primary Health Care; STI, Sexually Transmitted Infection; CD4, Cluster of Differentiation 4 (a protein marker on immune cells); HCT, HIV Counseling and Testing; CDC, Centers for Disease Control and Prevention; PEP, Post Exposure Prophylaxis; PrEP, Pre-Exposure Prophylaxis; SRH, Sexual and Reproductive Health; MCM, Medical Case Management; TASO,The AIDS Support Organization.

Data Sharing Statement

The data generated and analyzed during this study are available upon request from the corresponding author. The principal investigator is committed to ensuring transparency and accessibility of the research findings and will provide the data, including interview transcripts and coding information, subject to ethical considerations and confidentiality agreements. Requests for data access can be made by contacting the principal investigator directly.

Ethical Considerations

Ethical approval for this study was obtained from the Uganda National Council for Science and Technology (UNCST), as established by the Act of Parliament of the Republic of Uganda, under registration number HS4054ES. Ethical considerations followed the principles outlined in the Declaration of Helsinki, ensuring participant confidentiality, voluntary participation, and the right to withdraw from the study at any time without consequence. Informed consent was sought from all participants, who were fully briefed on the study's objectives, the voluntary nature of their participation, and the steps taken to ensure their confidentiality. Participants were made aware of their right to withdraw without any negative consequences. The study adhered to established ethical guidelines for qualitative research, ensuring the anonymity and privacy of participants' personal information. All data collected was securely stored, and access was restricted to authorized personnel only.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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