

## Self-Disclosure of Adolescents with HIV/AIDS at the Lentera Foundation in Surakarta

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### ABSTRACT

This study engagement aimed to understand the self-disclosure experiences of adolescents living with HIV/AIDS at Yayasan Lentera Surakarta and to strengthen community-based psychosocial support. The program was conducted from May to July 2025 through group discussions and in-depth interviews with 10 adolescent participants, using a phenomenological method. The materials were delivered through dialogic and reflective approaches to encourage openness. Findings revealed that disclosure is highly personal, influenced by past trauma, social support, and self-acceptance. A safe environment like Lentera fosters adolescents' confidence to disclose their status. These results have important implications for developing empathetic and contextual disclosure support interventions.

## **INTRODUCTION**

Adolescents living with HIV/AIDS in Indonesia face multidimensional challenges that extend beyond physical health to complex psychological and social issues. While most adolescents are engaged in identity formation and building healthy social relationships, those with HIV carry an additional burden—living with a health status that is highly stigmatized. One of the greatest challenges they encounter is the process of self-disclosure, or revealing their HIV status to others. In practice, this is not merely a personal decision, but a struggle for social acceptance and self-worth.

The process of self-disclosure is intricately tied to adolescent psychological development. During this stage, adolescents are highly dependent on peer acceptance and sensitive to rejection. Their desire to feel “normal” and be part of a group often clashes with the reality that disclosing their HIV status may lead to social exclusion. Here lies the dilemma: the need to be honest and receive support versus the desire to remain accepted by hiding their health identity.

Yayasan Lentera Surakarta presents itself as a compelling and relevant setting for exploring this issue. As the only institution in Indonesia that provides long-term care for children and adolescents with HIV from an early age, it offers a uniquely supportive and inclusive environment. Within this safe space, adolescents can explore their identity without fear of being judged. However, their lives do not revolve solely within the walls of the foundation—they must also face the outside world, which may not be as understanding or accepting.

Thus, a critical question arises: how do adolescents with HIV navigate the process of disclosure outside the safe zone of the foundation? This question forms the foundation of the need to understand their subjective experiences directly, rather than through the assumptions of caregivers or health professionals. Self-disclosure becomes a pivotal point that can affect mental health, social relationships, and the overall quality of life.

Previous research has shown that factors such as social support, self-acceptance, and past disclosure experiences greatly influence the decision to be open. Adolescents who experience a supportive environment and positive disclosure outcomes tend to be more confident in sharing their HIV status with close individuals. On the other hand, those who have faced rejection, breached confidentiality, or verbal abuse tend to withdraw and remain silent.

In a study by Nöstlinger et al. (2015), it was found that a sense of safety and strong interpersonal relationships significantly increased the likelihood of healthy disclosure. Conversely, in the research by Madiba and Mokgatle (2016), adolescents perceived disclosure as dangerous due to high levels of stigma and public ignorance about HIV. Silence, for them, became a survival strategy.

Self-Determination Theory (SDT) by Deci and Ryan (2000) offers a valuable framework for understanding disclosure motivation. Disclosure can be autonomously motivated—originating from personal values and internal will—or controlled, driven by social pressure. In the context of Yayasan Lentera, there is significant potential to foster autonomous motivation, as the community nurtures self-acceptance and promotes values of honesty and empathy.

Unfortunately, there is still a lack of in-depth studies in Indonesia exploring how adolescents with HIV experience disclosure. Most interventions rely on normative assumptions or moral imperatives and often fail to reflect the actual psychosocial realities that adolescents face. Therefore, a phenomenological approach is particularly relevant to uncover the deeper meanings of disclosure from the adolescents' own perspectives.

Phenomenology focuses on the lived experiences of the subject without imposing external interpretations. Using this approach, researchers can listen to and capture the personal narratives of adolescents about how they grapple with identity and disclosure decisions in daily life. The question is not simply whether they disclose, but why and how they navigate the process.

Yayasan Lentera also serves as a rich social laboratory, being a unique and stigma-free community. Within the foundation, adolescents are able to speak openly and honestly. This highlights that openness is strongly influenced by the social context—meaning that disclosure is not solely about individual bravery, but also about the quality of the environment that either enables or inhibits it.

Findings from this study are expected to contribute to the theoretical development of self-disclosure in the Indonesian context. Cultural collectivism, social norms, and family values heavily shape how adolescents handle personal information. Insights from Yayasan Lentera can be used as a foundation for building more contextually relevant theories.

Practically, this study can guide the development of more empathetic and experience-based disclosure support protocols. Intervention strategies should not focus solely on how quickly adolescents disclose but rather on how to build psychological readiness, facilitate reflection, and create safe spaces that respect the adolescents' autonomy.

Furthermore, the data from this study can serve as strong advocacy material to create more inclusive social environments for adolescents living with HIV. Schools, healthcare systems, and communities need to be educated on the importance of respecting disclosure decisions as a personal right, not a moral obligation.

From a social perspective, adolescents who successfully disclose their HIV status in healthy ways demonstrate psychological resilience. They have often undergone processes of self-acceptance, identity reinforcement, and emotional regulation. This study seeks to identify the components that foster such resilience and how the environment plays a role in nurturing it.

This study aligns with the national agenda on HIV/AIDS prevention, which now emphasizes not only medical intervention but also individual empowerment and community-based support. Approaches grounded in adolescents' real-life experiences are more likely to succeed because they reflect their actual needs and lived realities. By directly involving adolescent voices, intervention programs become more relevant and contextual. This is crucial to developing strategies that are not only technical but also human-centered. Effective social support must begin with an understanding of adolescents' subjective experiences.

Using a phenomenological approach, data is collected through in-depth interviews and analyzed thematically. This process allows researchers to capture subtle meanings embedded in adolescents' narratives. Each story is treated as a reflection of a broader social reality, often overlooked by quantitative methods. Phenomenology opens the door to understanding what adolescents feel and think in a more authentic way. Thus, this approach provides a depth of analysis not attainable through numerical data alone.

This approach also creates space for adolescents to reinterpret their own life experiences. In many cases, the interview process offers therapeutic value, as participants finally have the opportunity to tell their stories to someone who listens without judgment. This moment becomes important not only as part of the research process but also as an emotionally healing experience. It shows that research can have a positive psychological impact. This ethical and emotional value is a unique strength of the qualitative method.

By deeply exploring personal narratives, this study can uncover new dimensions of self-disclosure that are rarely captured in conventional surveys. These include feelings of courage, irrational fears, or inner conflicts between loyalty to family and personal freedom. These dimensions are important because they often shape adolescents' willingness to disclose but remain hidden from typical assessments. Narratives like these offer a more honest and complex picture compared to closed-ended responses. The findings can help shape more sensitive and empathetic intervention approaches.

Ultimately, this research aims not only to produce academic knowledge but also to help build a more human-centered and empathetic approach to adolescent HIV support. The voices of adolescents captured in this study are expected to serve as a foundation for more inclusive, just, and compassionate social change for people living with HIV in Indonesia. The findings emphasize the importance of hearing directly from those affected. When their voices are used as the basis for policy, interventions become more impactful and sustainable. This research serves as a reminder that significant change often begins with the courage to listen to those who are seldom heard.

## **THEORETICAL REVIEW**

This study employs the phenomenological approach as its main theoretical and methodological framework. Phenomenology originates from the ideas of Edmund Husserl, who emphasized the importance of understanding reality as it is experienced by the subject themselves. In this context, phenomenology is used to deeply explore the subjective experiences of adolescents in disclosing their HIV status, without excessive interference or interpretation from the researcher's perspective. This approach allows for a rich understanding of the social, emotional, and psychological contexts surrounding the phenomenon of self-disclosure, as experienced by adolescents as a meaningful life process (Creswell, 2013).

The foundational theory for this research is the self-disclosure theory, first introduced by Sidney Jourard. This theory explains that self-disclosure is the act of revealing sensitive personal information to others, typically done to build

trust, intimacy, and social identity. Disclosure is a gradual and selective process, heavily influenced by interpersonal relationships and an individual's perception of the safety and risk associated with sharing such information (Derlega et al., 1993). In the context of adolescents living with HIV/AIDS, disclosure is not merely a social act, but a psychologically charged decision-making process shaped by fears of stigma and the desire for acceptance.

To further enrich the understanding of disclosure motivation, this study also incorporates the Self-Determination Theory (SDT) developed by Deci and Ryan (2000). SDT posits that human behavior is driven by three basic psychological needs: autonomy, competence, and relatedness. Disclosure that is autonomously motivated—based on personal values and inner will—leads to more positive psychological outcomes compared to disclosure driven by external pressure or social obligation. In this study, it was found that adolescents' motivations for disclosure varied widely—from fear-based amotivation, to socially compelled (controlled motivation), and finally to healthier, self-driven (autonomous) disclosure.

These three theories complement and enrich one another in framing the understanding of the phenomenon under study. Phenomenology provides the space to understand disclosure as a deeply personal and emotional experience; self-disclosure theory explains the process, timing, and rationale behind individuals' decisions to open up; while Self-Determination Theory clarifies the psychological motivations behind disclosure decisions. The integration of these theories is also consistent with field findings, where disclosure is often influenced by past experiences, emotional readiness, and the presence (or absence) of supportive social contexts.

Thus, these theories serve not only as a conceptual framework for designing and conducting the research, but also offer practical insights for developing empathetic and gradual disclosure support strategies for adolescents living with HIV. As demonstrated in this study, building such approaches requires a nuanced understanding of individual motivations, emotional experiences, and adolescents' perceptions of their social world. These theories prove highly relevant in grasping the complexity of disclosure in a holistic and contextual manner.

## **IMPLEMENTATION AND METHODS**

This research was conducted at Yayasan Lentera Surakarta, an institution that specifically supports children and adolescents living with HIV/AIDS. Located in Surakarta City, Central Java, the foundation has been active since 2012. It provides protection, social rehabilitation, and psychosocial support for children and youth affected by HIV. Its inclusive and supportive environment makes it an ideal location for exploring the subjective experiences of adolescents regarding self-disclosure. With its open and empathetic community character, adolescents feel safe enough to reflect on their life experiences.

The research was carried out from May to July 2025. The stages included initial coordination with foundation management, participant selection, in-depth interviews, and the process of transcription and data analysis. Initial

coordination was essential to build trust between the researcher and the foundation, including the youth mentors. The researcher ensured that all ethical procedures were followed, including approval from an ethics board and consent from the foundation and youth mentors. These preparations aimed to ensure the research was conducted ethically, safely, and with the well-being of participants in mind.

Participants in this study were adolescents aged 13 to 18 who lived at or were actively engaged with Yayasan Lentera. Specific inclusion criteria were applied: participants had to be aware of their HIV status, willing to participate, and able to verbally share their experiences. Ten adolescents were selected purposively to reflect diversity in background. Factors such as age, gender, length of stay at the foundation, and disclosure experience were considered. The goal was to ensure that the findings would represent a broad and meaningful spectrum of experiences.

This study used a qualitative method with a phenomenological approach. This approach aimed to understand the meaning of disclosure experiences from the adolescents' own perspectives. Phenomenology allows the researcher to enter the participants' subjective world without judging or interfering with the meanings they construct. The main focus was to explore the essence of their experiences and understand how adolescents interpret disclosure as part of their life journey. Therefore, this method was deemed most appropriate for the research objectives.

Data collection was carried out through semi-structured in-depth interviews. Each adolescent was interviewed individually in a quiet and comfortable room within the foundation. Each interview lasted approximately 45 to 60 minutes. All interviews were recorded with participants' consent, and the researcher also took field notes. These notes were useful for capturing non-verbal expressions and emotional nuances that might not be evident in audio recordings.

Interview material covered several key topics designed to thoroughly explore the disclosure experience. Some core questions included how the adolescents first learned of their HIV status and what emotions they experienced afterward. Other questions addressed whether they had disclosed their status to others, such as friends, teachers, or partners. The researcher also explored their social responses, emotional reflections after disclosure, and their hopes or fears about the future. All questions were open-ended and flexible to allow participants' narratives to develop naturally.

The data were analyzed using phenomenological thematic analysis. The first stage involved reading the full transcripts to understand the general context. The next step was open coding to identify recurring significant statements. These codes were grouped into categories that reflected specific themes. From there, main themes were constructed to capture the essence of the adolescents' disclosure experiences.

To maintain the credibility of the data, triangulation was applied. Preliminary findings were discussed with youth mentors at the foundation to gather insights from those who knew the participants closely. Additionally,

member checking was conducted with participants who agreed to verify whether the interpretations aligned with their intended meaning. The researcher also practiced critical reflection regularly to maintain objectivity and sensitivity to participants' emotional dynamics. These strategies were important for minimizing bias and preserving the integrity of the data.

The entire research process was carried out with great attention to ethics, participant comfort, and psychological safety. The interviews were not only data collection tools, but also became expressive spaces that, in some cases, allowed participants to feel relief after sharing. This shows that research can be a meaningful reflective experience for participants. A non-judgmental and empathetic atmosphere was key to successfully eliciting their narratives. Thus, the method not only produced high-quality data but also provided emotional benefits to the adolescents involved.

Through this approach, the study aims to provide a comprehensive picture of how adolescents with HIV at Yayasan Lentera construct meaning around their identity. It also offers insight into how disclosure is experienced within a supportive community context. The findings are not only academically important but also useful for improving field-based mentoring practices. The research affirms the importance of safe spaces and empathetic methods in supporting adolescents living with HIV. It is hoped that these findings can serve as a reference for other institutions in developing more humane and context-sensitive programs.

## RESULTS AND DISCUSSION

This research was conducted through a series of in-depth interviews with ten adolescents residing at Yayasan Lentera Surakarta. All participants were aware of their HIV status and ranged in age from 13 to 18 years old. The interviews were conducted individually, using a semi-structured approach and lasted approximately 45–60 minutes per participant. A phenomenological method was employed to explore the adolescents' subjective experiences in navigating the process of self-disclosure. This approach allowed for a deep understanding of how each participant interpreted and lived through the decision to reveal or conceal their HIV status.

During the interviews, the researcher began each session with a reflective question about how participants first discovered their HIV status. This was followed by deeper questions about whether they had ever disclosed their status, and to whom – such as friends, partners, teachers, or others in their environment. Some participants showed a high level of emotional openness, while others were more reserved and needed more time to share. The interviews were conducted in a safe and nonjudgmental atmosphere to allow the participants to speak freely. Creating this safe space was essential to capturing honest and meaningful responses.

Thematic analysis of the interview transcripts revealed five main themes that illustrated the dynamics of self-disclosure among adolescents: (1) Self-Acceptance as a Prerequisite for Disclosure, (2) Fear of Social Stigma, (3) Limited Disclosure within Safe Environments, (4) The Role of Emotional Support from

the Foundation, and (5) Hopes for a More Open Future. These five themes appeared consistently across most participants, although the context and narrative varied. Each theme represented a different dimension of how disclosure is experienced and interpreted. This confirmed that self-disclosure is not a simple act, but a complex process influenced by emotional, psychological, and social factors. The following table summarizes the key findings from these categories.

Table 1. Self-Disclosure Experiences of HIV Adolescents at the Lentera Foundation

No	Category	Data Findings
1	Self-Acceptance	Disclosure begins after the adolescent feels at peace with his or her HIV status.
2	Fear of stigma	Fear of social rejection is a major barrier to disclosure.
3	Limited disclosure in a secure environment	Disclosure is only made to trusted people such as fellow residents.
4	The role of the Foundation in providing a sense of security	The foundation's mentors and environment help teenagers build courage.
5	Hope for a more open life	Teenagers hope that one day they can be more open without fear of discrimination.

Most participants stated that they only began considering disclosure after reaching a level of self-acceptance and understanding that HIV was not the end of their future. The process of accepting their condition was not immediate; several reported needing years to fully come to terms with being different from most of their peers. This aligns with Gillard & Roark's (2012) study, which suggested that the motivation to disclose often emerges after an individual has developed a stable self-concept. For adolescents, reaching this point of acceptance is deeply personal and often shaped by their environment. Without a sense of inner peace, disclosure remained an emotionally risky act.

Despite this, fear of stigma and discrimination remained the most common reason participants chose not to disclose to outsiders. Their stories reflected a strong concern about being treated differently, excluded, or even expelled from school or their community. These findings are consistent with studies in Eastern and Southern Africa, which also identified fear of social stigma as a major barrier to disclosure (Madiba & Mokgatle, 2016; Nöstlinger et al., 2015). This fear was not imagined but based on real and observed instances of discrimination. For many participants, silence felt safer than risking judgment or rejection.

Nonetheless, all participants expressed feeling safe enough to disclose within the environment of the foundation. Disclosure to fellow residents, mentors, or volunteers at the foundation felt safe because they were surrounded by people who understood and did not judge them. Several described Lentera as

their “second family” – a place where they were accepted exactly as they were. This underscores the importance of safe spaces for gradual and controlled disclosure. Similar findings were reported in Kitetele et al. (2022), which emphasized the role of peer-based environments in easing the disclosure process.

Support from the foundation—including psychosocial counseling and routine activities that foster a sense of belonging—was crucial in helping adolescents reach self-acceptance and navigate disclosure decisions. Some participants noted that group discussions and peer support sessions made them feel stronger and less alone. These activities provided not only knowledge, but also emotional reinforcement. The findings align with Dlamini & Mtshali (2024), who emphasized the critical role of emotional support from community structures in encouraging healthy and safe disclosure. Emotional safety was found to be as important as physical safety in enabling disclosure.

Many adolescents expressed hope that one day they would be able to live more openly without fear of stigma. They understood that disclosure does not have to be universal but wanted the ability to choose when and to whom they could be open. This desire highlights that, although disclosure is a personal choice, there is a broader aspiration for honesty and psychological freedom. For these adolescents, disclosure is not merely about communication – it is also about reclaiming dignity and strengthening identity. Therefore, the success of disclosure interventions should not be measured by how many adolescents have disclosed, but by how much agency and self-control they feel over their own identities.

These findings demonstrate that self-disclosure among adolescents living with HIV is a multidimensional experience shaped by both intrapersonal and social factors. It is not a linear path, and readiness varies across individuals. The phenomenological approach proved essential in uncovering the meaning behind disclosure decisions and emotional responses. Each participant’s voice reflected a unique but interconnected story of fear, growth, and resilience. This reinforces the importance of listening deeply and designing interventions based on lived experience.

In conclusion, this study affirms that empathy, safe environments, and community-based empowerment are vital to supporting adolescents through the disclosure process. Providing adolescents with the tools, space, and emotional support they need can make disclosure less daunting and more empowering. This approach moves beyond compliance-based models and toward dignity-based models of care. By supporting adolescents where they are, rather than pushing them where they are not ready to go, practitioners and communities can become true allies. The experiences shared in this research offer valuable insights for improving care systems, reducing stigma, and honoring the voices of adolescents living with HIV.

## **CONCLUSION AND RECOMMENDATIONS**

Based on the findings of this study, the self-disclosure process among adolescents living with HIV/AIDS at Yayasan Lentera Surakarta is a complex, personal experience influenced by psychological dynamics and social context.

The five main themes identified—self-acceptance, fear of stigma, limited disclosure within safe environments, the emotional support role of the foundation, and hope for a more open future—indicate that disclosure is not merely a decision, but a psychosocial journey filled with emotional and social considerations. Adolescents who have accepted their HIV status are more likely to consider disclosure, but still do so selectively and only within environments they perceive as safe. Fear of stigma and discriminatory treatment remains the biggest barrier. Therefore, having a supportive and safe social context is a key factor in encouraging healthy disclosure.

Yayasan Lentera has proven to be a safe space that enables adolescents to learn, recognize, and share their identity more openly. Emotional support from staff and the presence of peers with similar experiences create an inclusive and empathetic atmosphere. Such a space helps build confidence and self-esteem while fostering healthy social relationships. In this context, disclosure is no longer a burden, but part of a natural process of self-acceptance. This shows that consistent social support plays a crucial role in developing adolescents' confidence to disclose their status.

These findings reinforce the idea that self-disclosure is not an end goal, but a long-term process that requires emotional awareness and continuous guidance. Disclosure should be understood as a form of social adaptation that involves readiness and sensitivity to its potential risks. A rushed or forced approach may lead to retraumatization for adolescents. Therefore, empathetic and gradual support is essential to create a safe space for emotional reflection. Yayasan Lentera serves as a best-practice model in this area by facilitating sustainable psychosocial development for adolescents.

As implementation recommendations, this study suggests five key steps to support healthy disclosure:

1. Strengthening disclosure support programs in foundation-based communities; foundations should continue to develop psychosocial approaches and individual counseling that encourage responsible and healthy disclosure.
2. Specialized training for mentors and social workers to help them understand disclosure dynamics from the adolescent's perspective, enabling them to provide empathetic support without forcing disclosure.
3. Developing structured group discussions and peer support systems, allowing adolescents to learn from peers who have experienced the disclosure process.
4. Increasing public education to reduce stigma and discrimination against people living with HIV, especially in schools and local communities, so that adolescents feel safer if they choose to open up in the future.
5. Implementing a gradual, readiness-based approach in all disclosure programs, ensuring the process aligns with each adolescent's emotional pace and preparedness.

With a deeper understanding of adolescents' disclosure experiences, future interventions can become more humane, contextual, and centered on the voices of the adolescents themselves. These voices – often marginalized – must serve as the foundation for building inclusive and empathetic policies. A properly supported disclosure process can help adolescents live more openly, improve mental well-being, and form stronger social relationships. This research emphasizes the importance of listening to adolescents' lived experiences, rather than imposing adult assumptions. In doing so, the courage to disclose can grow not from pressure, but from strength rooted in acceptance and sustained support.

### **FURTHER STUDY**

Building on these findings, further research is recommended to explore the long-term impact of supportive environments like the Lentera Foundation on the emotional resilience and social integration of adolescents living with HIV/AIDS. Future studies could adopt a longitudinal design to examine how self-disclosure evolves over time and in different social contexts, including school, family, and peer groups. Additionally, investigating the role of digital platforms and online peer support in facilitating safe disclosure may provide new insights into expanding support systems. Comparative studies across different cultural or institutional settings could also help identify best practices for fostering stigma-free environments that empower adolescents to navigate their self-disclosure journey more confidently.

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