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ORIGINAL RESEARCH

Experiences of People Living with HIV and Tuberculosis amid Fear, Guilt, and Silence: A Qualitative Study

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Abstract

Background: People living with HIV–TB (PLHIV–TB) continue to experience persistent stigma, fear, guilt, and silence that shape their psychosocial wellbeing and social interactions. HIV–TB represents a double burden that intensifies stigma and moral judgment, particularly within sociocultural and religious contexts. However, the lived experiences of PLHIV–TB in Indonesia remain insufficiently explored, despite the country's unique cultural and religious dynamics. Understanding these contextualized experiences is essential for strengthening holistic, culturally responsive, and stigma-sensitive HIV–TB care.

Purpose: This study aimed to explore experiences of PLHIV-TB amid fear, guilt, and silence within the Indonesian sociocultural context.

Methods: A descriptive phenomenological design was employed, with 20 PLHIV-TB purposively selected from Lampung, Palembang, Depok, and Yogyakarta between January and June 2025. Data were collected through in-depth, semi-structured interviews lasting 45–70 minutes and analyzed using NVivo software with Colaizzi's method. Trustworthiness was ensured through member checking, peer debriefing, and reflexivity.

Results: Six themes captured the essence of participants' experiences: (1) living under constant fear of exposure, (2) choosing silence as protection, (3) bearing the weight of guilt and moral judgment, (4) loneliness amid social disconnection, (5) struggling with faith and moral reconciliation, and (6) searching for meaning and self-acceptance. Participants' narratives revealed a transformation from concealment and shame toward spiritual reconciliation and dignity through emotional and faith-based resilience.

Conclusion: The lived experiences of people living with HIV–TB in Indonesia are shaped by intertwined dynamics of fear, guilt, and silence within a context of pervasive stigma. At the same time, some individuals demonstrate adaptive processes that reflect a complex journey from suffering to meaning-making and self-acceptance. These findings underscore the need for stigma-sensitive, psychosocial, and spiritually informed interventions to support holistic HIV–TB care.

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1. Introduction

People living with HIV and tuberculosis (PLHIV–TB) represent one of the most vulnerable populations affected by infectious disease coinfection worldwide. People living with HIV (PLHIV) face a 15–22 times higher risk of developing active tuberculosis, which remains the leading cause of HIV-related mortality globally (World Health Organization, 2025). PLHIV-TB may experience a compounded psychosocial burden due to overlapping stigma (Reis et al., 2026). The presence of tuberculosis can intensify fears of contagion, increase visible illness-related stigma, and reinforce moral judgment, which may shape disclosure decisions, social interactions, and coping strategies differently compared with people living with HIV alone (Magidson et al., 2025). These contextual differences highlight the importance of specifically exploring the lived experiences of PLHIV–TB to better inform holistic and stigma-sensitive care (Salnikova et al., 2025).

HIV prevalence remains a major public health concern and is compounded by social and moral stigma within a religiously conservative society (Jocelyn et al., 2024; Sujianto et al., 2025). Tuberculosis imposes a substantial psychological burden due to its visible symptoms, contagious nature, and prolonged treatment regimens (Danso-Appiah et al., 2025). PLHIV frequently conceal their health status to avoid discrimination and rejection from family and community members. Pervasive self-stigma driven by societal misconceptions and discriminatory practices impedes timely healthcare-seeking and effective disease management, particularly in settings characterized by social and structural barriers (Asrina et al., 2023). HIV-related stigma manifests through avoidance of contact, differential treatment, labeling, and internalized stigma (Amirudin et al., 2025). Coinfection with tuberculosis amplifies these stigmatizing experiences and produces profound psychological distress, including feelings of guilt, injustice, anger, and suicidal ideation, which complicate treatment adherence and overall well-being (Hook et al., 2021; Mwita & Mkenda, 2025).

Indonesia's sociocultural context, where religion, morality, and family honor intersect, often deepens the sense of guilt and moral conflict experienced by PLHIV, particularly among those co-infected with TB (Fuady et al., 2025). This intersection creates a complex environment where individuals navigate not only the medical implications of their conditions but also profound moral and social judgments that influence their emotional well-being and engagement with healthcare services (Embleton et al., 2023). The path from secrecy to acceptance, and from guilt to redemption, remains underexplored within the HIV-TB literature. A phenomenological approach offers a way to understand these experiences as lived realities, revealing how individuals interpret fear, stigma, and silence in relation to their identity, spirituality, and social world. Ultimately, this research seeks to provide a deeper understanding of the internal worlds of coinfected individuals, illuminating the profound psychosocial burdens that transcend clinical symptoms and treatment regimens (Hook et al., 2021; Mwita & Mkenda, 2025).

Quantitative studies have linked stigma to treatment outcomes but have not captured the lived emotional and moral experiences of fear, guilt, and silence among PLHIV-TB (Hojilla et al., 2021; Prizeman et al., 2023). Therefore, a phenomenological approach is essential to explore these subjective experiences in depth. Few studies in Indonesia have adopted a phenomenological lens to examine these issues. For example, Fauk et al. (2021) found that social and moral perceptions of HIV within families and communities in Yogyakarta and Belu contributed to persistent discrimination and isolation. Similarly, other research highlights how the stigma surrounding tuberculosis, viewed as a highly contagious illness, leads to social withdrawal and feelings of powerlessness among those affected (Nasir et al., 2024). Existing studies have primarily emphasized social processes and external stigma, with limited attention to the lived experiences of fear, guilt, and silence as intertwined internal and moral struggles among PLHIV–TB. This gap underscores the need for qualitative inquiry to understand how individuals experience, interpret, and navigate these challenges in their everyday lives. Therefore, this study aimed to explore the experiences of PLHIV-TB in Indonesia amid fear, guilt, and silence.

2. Methods

2.1. Research design

This study employed a descriptive qualitative phenomenological approach to explore the experiences of individuals diagnosed with HIV, including those co-infected with tuberculosis, employing in-depth interviews to gather rich, descriptive data. This approach is particularly suitable for investigating complex human experiences such as fear, guilt, and silence, which are often deeply personal and culturally mediated.

2.2. Setting and samples

This study was conducted in four urban HIV-TB service settings in Indonesia, including Lampung, Palembang, Depok, and Yogyakarta, between January and June 2025. These sites were selected to reflect variations in sociocultural, religious, and healthcare contexts. Lampung and Palembang represent mixed urban and semi-rural populations in Sumatra, while Depok and Yogyakarta represent urban Java, characterized by diverse socioeconomic and religious backgrounds. A total of 20 participants were recruited across the sites, including 3 from Lampung, 4 from Palembang, 6 from Depok, and 7 from Yogyakarta. The selection of these areas was also informed by the national burden of HIV–TB coinfection, with approximately 17.136 reported cases nationwide (Ministry of Health, Republic of Indonesia, 2025), highlighting the relevance of exploring lived experiences across diverse Indonesian contexts. Participants were recruited purposively in collaboration with HIV–TB program coordinators at the community healthcare centers *(Puskesmas),* who assisted in identifying individuals who met the inclusion criteria and ensured voluntary participation and confidentiality.

Twenty participants were purposively selected using criterion-based sampling. Inclusion criteria were: (a) aged ≥18 years, (b) diagnosed with HIV and co-infected with TB for at least six months, (c) aware of their HIV status, (d) able to communicate in Bahasa Indonesia, and (e) willing to provide informed consent. Both men and women were included, with varying marital statuses, socioeconomic backgrounds, and duration of diagnosis, to ensure depth, variation, and richness of lived experiences. Participants who were acutely ill or psychologically unstable were excluded. Recruitment was facilitated through HIV clinics and peer support groups. Data saturation was considered achieved when additional interviews no longer generated new meanings, experiential nuances, or thematic insights, and when the emerging structure of lived experiences became stable through ongoing iterative analysis.

2.3. Measurement and data collection

A semi-structured interview guide was formulated based on prior studies addressing HIV-TB stigma and lived experiences. Data were gathered through in-depth, face-to-face semi-structured interviews conducted in private counseling rooms at participating clinics in multiple regions. The first author, a nursing lecturer specializing in HIV patient care, served as the primary interviewer and has extensive experience in qualitative research, including participation in numerous training programs and workshops in qualitative methodologies. The same interview guide was used to ensure consistency across sites while allowing flexibility to probe context-specific experiences. Interviews lasted approximately 45–70 minutes and were audio-recorded with participants' consent. Data collection and preliminary analysis were conducted concurrently across study sites and continued in each region until data saturation was reached in all regions, indicated by the absence of new themes, meanings, or experiential variations, thereby ensuring depth and consistency of lived experiences across participants. The interview questions were formulated as open-ended prompts and are presented in Table 1.

Table 1. Interview guidelines

No	Questions for the Participants
1	Can you describe your personal experience and emotional reactions when you first learned of your diagnosis of HIV with tuberculosis?
2	How have you experienced and managed feelings of fear, such as fear of rejection, moral judgment, or concerns about others discovering your health status?
3	Have you ever experienced feelings of guilt, regret, or moral or spiritual conflict related to your illness, and how did you make sense of those feelings?
4	How have your relationships with family members, friends, and the broader community changed since your diagnosis?
5	In what ways has this experience affected your faith, spirituality, or relationship with God, and how have you sought meaning or inner peace?
6	What strategies have you used to cope, adapt, and eventually accept your condition while continuing your daily life and undergoing treatment?

All sessions were audio-recorded with a digital recorder and supplemented with field notes to capture nonverbal expressions and contextual observations. Interviews were conducted in Bahasa Indonesia to facilitate participants' expression of their experiences and minimize potential language barriers. The interview transcripts were subsequently translated into English by IA and MAA, and back-translation procedures were applied to ensure semantic equivalence, accuracy, and preservation of contextual meaning during analysis. Field notes were expanded immediately after each session to preserve context and emotional tone.

2.4. Data analysis

Data were analyzed using Colaizzi's seven-step phenomenological method (Colaizzi, 1978; Vignato et al., 2022), which includes: (a) reading all participants' descriptions to acquire a sense of their experiences; (b) extracting significant statements related to the phenomenon; (c) formulating meanings from each statement; (d) clustering formulated meanings into themes; (e) integrating the findings into an exhaustive description of the phenomenon; (f) identifying the fundamental structure of the experience; and (g) returning to participants for validation and clarification of findings (member checking). Member checking was conducted by returning summary findings and preliminary themes to selected participants who agreed to follow-up contact. Participants were invited to review, validate, and clarify the interpretations, and their feedback was incorporated to refine the final themes.

Transcripts were coded manually, and themes were developed inductively. Two researchers (AW and US) independently analyzed transcripts, and differences in interpretation were discussed until consensus was reached. NVivo 14 software supported data organization and coding consistency.

2.5. Trustworthiness/rigor

This phenomenological study established rigor and quality by systematically applying the four criteria of trustworthiness: credibility, dependability, confirmability, and transferability (Ahmed, 2024). Credibility was enhanced through sustained, iterative engagement with the data rather than by interview duration alone, including in-depth interviews, repeated immersion during transcription and analysis, member checking, peer debriefing with qualitative research experts, and ongoing reflexive discussions within the research team. Dependability was ensured by maintaining a detailed audit trail documenting recruitment, data collection, transcription, translation, coding, and theme development. Confirmability was established through bracketing, reflexive memo writing, researcher triangulation, and grounding all interpretations in participants' verbatim quotations. Transferability was supported by providing thick descriptions of the study context, participant characteristics, and sociocultural settings. These methodological strategies ensured that the findings were credible, transparent, and firmly grounded in participants' experiences.

2.6. Ethical consideration

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Nursing, Universitas Indonesia (No. 025/UN2.F12.D1.5.4/ETIK/2025). Written informed consent was obtained from all participants prior to data collection. Participants were assured of anonymity, voluntary participation, and the right to withdraw at any time without consequences. Codes were used to protect identity. All audio recordings and transcripts were stored securely in password-protected files accessible only to the research team.

3. Results

3.1. Participant demographic profile

A total of 20 participants were involved in this study, comprising 11 males and 9 females aged between 26 and 45 years. Most participants were married and had completed senior high school education. They represented diverse occupations, including private employees, laborers, housewives, students, volunteers, and civil servants. All Participants (20) were diagnosed with HIV with TB co-infection, with an average duration of diagnosis of 5.2 ± 2.7 years. Detailed demographic characteristics of the participants are presented in Table 2.

3.2. Themes and sub-themes

The phenomenological analysis identified six overarching themes that describe the lived experiences of fear, guilt, and silence among PLHIV with TB co-infection in Indonesia. A comprehensive description of each theme, supported by participants' narratives. The themes and sub-themes of this study are described in Table 3.

3.2.1. Theme 1: Living under constant fear of exposure

Many participants experienced persistent fear of exposure as a central psychological burden in their daily lives. This overarching fear manifested primarily in concerns about social rejection following disclosure and anxieties about contagion, stigma, and moral judgment.

Table 2. Characteristics of the participants

Participant	Gender	Age (years)	Marital Status	Occupation	Years since Diagnosis	Education Level
P1	Male	34	Married	Private employee	3	Senior high school
P2	Female	30	Single	Unemployed	3	Junior high school
P3	Male	41	Married	Self-employed	5	Senior high school
P4	Female	28	Married	Housewife	4	Senior high school
P5	Male	38	Single	Labourer	6	Elementary school
P6	Female	27	Single	Student	2	Bachelor's degree
P7	Male	33	Married	Driver	4	Senior high school
P8	Female	36	Widow	Seller	4	Junior high school
P9	Male	29	Single	Freelancer	3	Bachelor's degree
P10	Male	42	Married	Farmer	7	Elementary school
P11	Female	32	Married	Housewife	3	Senior high school
P12	Male	39	Divorced	Technician	8	Senior high school
P13	Female	29	Single	Student	3	Bachelor's degree
P14	Male	42	Married	Civil servant	8	Bachelor's degree
P15	Female	32	Married	Seller	6	Senior high school
P16	Male	37	Single	Security guard	4	Senior high school
P17	Female	28	Single	NGO volunteer	5	Bachelor's degree
P18	Male	40	Married	Fisherman	7	Elementary school
P19	Female	35	Married	Housewife	6	Senior high school
P20	Male	37	Divorced	Teacher	8	Bachelor's degree

Notes. NGO: Non-Government Organization

Most participants perceived disclosure as a potential trigger for social exclusion, which encouraged secrecy, selective disclosure, and cautious social interaction. Several participants simultaneously worried about being perceived as infectious or morally judged, which reinforced self-monitoring behaviors and avoidance of situations that might reveal their diagnosis. This theme was constructed from two interconnected sub-themes: fear of exposure and rejection, and fear of contagion and moral judgment.

Table 3. Themes and sub-themes of participants' experiences

Themes	Sub-themes
1. Living under constant fear of exposure	1.1 Fear of exposure and rejection 1.2 Fear of contagion and moral judgment
2. Choosing silence as protection	2.1 Silence as a shield against social stigma 2.2 Silence as emotional self-preservation
3. Bearing the weight of guilt and moral judgment	3.1 Guilt for transmitting illness to others 3.2 Moral and religious self-punishment
4. Loneliness amid social disconnection	4.1 Isolation within family and community 4.2 Social exclusion after illness disclosure
5. Struggling with faith and moral reconciliation	5.1 Spiritual questioning and surrender 5.2 Reframing suffering as divine purpose
6. Searching for meaning and self-acceptance	6.1 Rediscovering self-worth through recovery 6.2 Helping others as healing transformation

3.2.1.1. Sub-theme 1: Fear of exposure and rejection

Participants perceived potential rejection as a direct consequence of disclosing their HIV-TB status. Most participants limited disclosure to trusted individuals and maintained secrecy in broader social environments to preserve social acceptance, and some anticipated stigma even without actual disclosure, which increased emotional caution and reduced social openness, as described by Participant 7:

> *Every time I start coughing, I panic. My neighbors know I had TB before, and they start connecting the dots. Once they suspect HIV, everything changes. They stop greeting you, and they treat you like a walking danger. It's not just fear of death, it's fear of being seen as dirty.* (P7)

Participant 3 echoed this fear, explaining how self-protection required geographical and emotional distance:

> *I don't use the same clinic twice. I travel to another city to get my medicine because someone might recognize me from the TB ward. People gossip easily here; one word can destroy your whole life.* (P3)

These accounts reveal a form of anticipatory stigma, in which surveillance and gossip dictate even mundane activities such as coughing, visiting clinics, or collecting medicine. Fear operates as a disciplinary force that shapes how participants inhabit public space.

3.2.1.2.Sub-theme 2: Fear of contagion and moral judgment

Participants perceived strong societal associations between HIV-TB, contagion risk, and moral judgment. Most participants expressed concern about being labeled infectious or morally responsible for their illness. Several participants responded by concealing treatment practices, limiting physical interaction, and avoiding potentially exposing situations, as stated by Participant 12:

> *After I was diagnosed, I stopped sleeping in the same room as my wife. She still doesn't know about the HIV, but she knows about the TB. When I cough at night, she covers her face with the blanket. I can feel the distance between us growing with every cough.* (P12)

Participant 5 similarly described transforming ordinary domestic spaces into zones of silence and caution:

> *Sometimes I think the fear of being discovered is worse than the disease itself. I hide my TB medicine in a coffee can so my brother won't see it. I live in a small house, and secrets are heavy in small spaces.* (P5)

Both sub-themes reveal how fear becomes embodied, etched into gestures, routines, and silences. The participants' bodies serve as constant reminders of risk: morally condemned by HIV, biologically feared because of TB.

3.2.2.Theme 2: Choosing silence as protection

Participants adopted silence as a deliberate protective strategy to manage stigma associated with HIV–TB coinfection. This protective silence manifested in efforts to shield themselves from anticipated social stigma and to preserve emotional stability. Most participants chose non-disclosure to avoid potential discrimination, social distancing, or negative labeling within their communities. Several participants simultaneously used silence to regulate emotional stress and maintain psychological balance in the face of ongoing stigma concerns. This theme is composed of two complementary sub-themes: silence as a shield against social stigma and silence as a form of emotional self-preservation.

3.2.2.1.Sub-theme 1: Silence as a shield against social stigma

Participants used silence as a strategy to protect themselves from anticipated social stigma related to HIV–TB coinfection. Most participants limited disclosure of their health status to a small circle of trusted individuals to reduce the risk of discrimination or social exclusion. Several participants avoided discussing their illness in broader social contexts to maintain social acceptance and avoid negative labeling. A few participants reported modifying their daily interactions to minimize opportunities for unintended disclosure. These strategies allowed participants to maintain social stability while navigating stigmatizing social environments, as described by Participant 9:

> *After my TB treatment, I stopped talking about it. The last time I opened up, a friend told others that I had 'the disease from sinners.' Since then, I've learned that silence is safer than honesty.* (P9)

Participant 18 similarly portrayed silence as camouflage in everyday interactions:

> *People notice when you cough too much. Once, a coworker asked if I had TB again, and I just laughed and said it was allergies. They don't need to know that I'm still taking ARV. In silence, I can still be normal—at least for a while.* (P18)

For these participants, silence was not ignorance but intelligence—a form of social adaptation to moral hostility.

3.2.2.2. Sub-theme 2: Silence as emotional self-preservation

Participants used silence as a means of protecting their emotional well-being while living with HIV–TB coinfection. Most participants avoided discussing their diagnosis to prevent emotional distress, anxiety, or repeated stigma experiences. Several participants described silence as a coping mechanism that helped them maintain psychological balance and focus on treatment adherence. A few participants reported that controlled disclosure reduced emotional exhaustion and supported their sense of personal resilience. These experiences indicated that silence functioned not only as social protection but also as a form of emotional self-preservation in managing chronic illness stigma, as expressed by Participant 2:

> *My family knows I had tuberculosis, but not HIV. They think TB is curable, but HIV is a curse. I can't tell them both; it would destroy me. So, I keep quiet, take my medicine, and act strong.* (P2)

Participant 14 experienced similar withdrawal after moralizing encounters with healthcare workers:

> *When I was in the hospital for TB, the nurse said, 'This is your punishment; God is teaching you something.' After that, I never told any health worker about my HIV. They don't see us as patients; they see us as lessons.* (P14)

Through these voices, silence emerges as a form of inner containment, a way to manage despair when empathy is absent.

3.2.3.Theme 3: Bearing the weight of guilt and moral judgment

Many participants experienced a persistent sense of guilt and moral burden while living with HIV–TB coinfection. This burden manifested primarily through feelings of responsibility for potentially transmitting the illness to others and through internalized moral or religious self-judgment. Most participants associated their diagnosis with personal responsibility or perceived moral consequences, which shaped their emotional responses and self-perceptions. Several participants described ongoing psychological tension as they negotiated feelings of guilt alongside efforts to maintain self-worth and social identity. This theme was constructed from two interrelated sub-themes: guilt for transmitting illness to others and moral and religious self-punishment.

3.2.3.1.Sub-theme 1: Guilt for transmitting illness to others

Participants expressed guilt related to the possibility of transmitting HIV–TB coinfection to partners, family members, or close contacts. Most participants perceived themselves as potential sources of risk to others, even when preventive measures were in place. Several participants reported heightened vigilance in daily interactions to prevent transmission and to reduce feelings of responsibility. Sub-theme reveals the deep remorse felt by participants who feared that their illness had endangered loved ones, as described by Participant 1:

> *When my little daughter started coughing, I couldn't breathe from guilt. I thought maybe she caught it from me. Even after the doctor said it was just a cold, I still feel condemned every time she coughs. How can a mother live knowing she might harm her child?* (P1)

Participant 16 shared a similar experience of moral injury:

> *My wife never blamed me, but I blame myself every day. She took care of me when I was coughing blood, and later, she also tested positive. I feel like I destroyed her life. I keep praying, hoping that God will forgive what I have done.* (P16)

Their narratives show how contagion became moralized, with transmission interpreted as sin rather than accident. The fusion of infection and guilt intensified self-punishment and eroded self-esteem.

3.2.3.2. Sub-theme 2: Moral and religious self-punishment

Participants interpreted their HIV–TB diagnosis within moral or religious frameworks that emphasized personal accountability. Most participants associated their illness with perceived moral consequences, spiritual reflection, or self-evaluation of past behaviors. Some participants described engaging in religious or spiritual practices as coping mechanisms to manage guilt and seek emotional reconciliation, and a few reported experiences of self-blame or internalized stigma shaped by societal moral narratives. Sub-theme shows how participants internalized religious narratives of punishment, interpreting HIV–TB as divine retribution, as stated by Participant 10:

> *I believe this disease is a test, but sometimes I think it's God's punishment. Before I got sick, I drank, and I ignored my prayers. Now, every cough feels like a reminder from heaven to repent.* (P10)

Participant 20 also described equating sickness with spiritual debt:

> *I used to be active in church, but after my diagnosis, I stopped attending. I felt unworthy to sing in the choir. I kept asking God, 'Why me?' until I realized maybe I am being purified through pain.* (P20)

These testimonies illustrate how spiritual frameworks, though comforting, can reinforce self-blame. Participants oscillated between guilt and grace, between punishment and purification.

3.2.4.Theme 4: Loneliness amid social disconnection

Participants experienced profound loneliness as a consequence of disrupted social relationships following HIV–TB diagnosis. This sense of loneliness emerged both from reduced interaction within family and community settings and from perceived or actual social exclusion after illness disclosure. Most participants described diminished social connectedness due to stigma concerns, secrecy, or altered interpersonal dynamics. Several participants reported emotional distancing from others even in the absence of explicit rejection, which intensified feelings of isolation. This theme was developed from two complementary sub-themes: isolation within family and community, and social exclusion after illness disclosure.

3.2.4.1.Sub-theme 1: Isolation within family and community

Many participants reported experiencing social isolation within family and community contexts after their HIV–TB diagnosis. Most participants limited their interaction with others due to fear of stigma, misunderstanding, or unintended disclosure. A few participants described voluntary withdrawal from social activities as a strategy to avoid potential stigma or emotional discomfort. This sub-theme describes the silent distance that grew even inside participants' own homes, as stated by Participant 8:

> *After I came home from TB treatment, my children stopped hugging me. My husband told them to stay away 'until I'm really cured.' I eat alone now, not because they hate me, but because they are scared. That fear hurts more than the disease.* (P8)

Participant 4 echoed the same emotional exile:

> *My family built a small corner for me in the back room. They said it's for my rest, but I know it's because of the cough. Every sound I make feels like a sin that scares them. Sometimes I cry quietly so they won't hear.* (P4)

These accounts reveal that isolation was rarely forced; it was negotiated through love mixed with fear, a paradoxical care that excludes.

3.2.4.2. Sub-theme 2: Social exclusion after illness disclosure

Participants described experiences of social exclusion following disclosure of their HIV–TB status. Most participants perceived changes in social attitudes, communication patterns, or relational closeness after others became aware of their diagnosis. Several participants reported reduced social participation or changes in how they were treated by peers, colleagues, or community members. A few participants experienced explicit rejection or distancing behaviors that intensified emotional distress. This sub-theme highlights the community's reaction once participants' conditions became known, as narrated by Participant 11:

> *When the neighborhood found out I had TB and HIV, people stopped coming to our stall. Some even told their children not to buy food from us. They think the disease can stick to money. I lost customers, but what hurts most is losing my friends.* (P11)

Participant 13 described a similar social vacuum:

> *I used to join village meetings, but after they learned about my illness, they stopped calling my name. I still go sometimes, but I sit at the back, pretending not to care. Being there yet unseen—it's worse than being absent.* (P13)

The intersection of moral and contagion stigma transforms ordinary social life into a field of avoidance.

3.2.5. Theme 5: Struggling with faith and moral reconciliation

Participants experienced an ongoing struggle to reconcile their HIV–TB diagnosis with their spiritual beliefs and moral self-understanding. This struggle manifested through spiritual questioning as well as efforts to reinterpret illness within a broader religious or existential framework. Most participants engaged in reflection about faith, responsibility, and meaning. Several participants described a gradual movement from questioning toward acceptance or surrender, which supported emotional stability. This theme was derived from two connected sub-themes: spiritual questioning and surrender, and reframing suffering as divine purpose.

3.2.5.1. Sub-theme 1: Spiritual questioning and surrender

Participants questioned spiritual meaning and personal faith following their HIV–TB diagnosis. Most participants reflected on illness in relation to divine will, personal accountability, or existential uncertainty. Several participants reported emotional tension between questioning their circumstances and seeking spiritual reassurance, and a few described eventual surrender to perceived divine plans, which contributed to emotional relief and improved psychological adjustment. This sub-theme describes participants' inner battle between doubt and devotion, as explained by Participant 6:

> *When I was first diagnosed, I stopped praying. I thought God had abandoned me. Every pill I took felt like punishment for my sins. But one night, when my chest pain got worse, I cried and said, 'If You still want me to live, please give me strength.' That was the first time I felt peace again.* (P6)

Participant 13 voiced a similar struggle:

> *At church, people preach compassion, but when they learned about my illness, they avoided me. I felt betrayed by both people and God. Then I realized maybe my faith shouldn't depend on others. I started praying alone, quietly, and it helped me forgive.* (P13)

These quotations show that spiritual questioning served as a threshold toward surrender when human rejection forced participants to rediscover personal spirituality independent of social validation.

3.2.5.2. Sub-theme 2: Reframing suffering as divine purpose

Participants interpreted their illness as part of a broader divine purpose or spiritual journey. Most participants reframed suffering as an opportunity for personal growth, spiritual reflection, or moral development. Several participants described increased engagement in religious practices as part of their coping process, and a few reported strengthened faith and renewed meaning in life following acceptance of illness. This sub-theme describes the transformation from despair to acceptance, as stated by Participant 17:

> *I used to ask, 'Why me?' Now I tell myself, maybe God chose me to remind others to be careful. TB and HIV humbled me; they taught me to value life, to stop judging. Pain became my teacher.* (P17)

Here, illness becomes a moral pedagogy rather than punishment. By reframing their experience as part of divine purpose, participants re-established self-worth and spiritual equilibrium.

3.2.6. Theme 6: Searching for meaning and self-acceptance

Participants engaged in an ongoing process of searching for personal meaning and developing self-acceptance while living with HIV–TB coinfection. This process manifested through efforts to rebuild self-worth during recovery and through transformative experiences involving support for others with similar conditions. Most participants described gradual emotional adjustment as they integrated illness into their self-identity. This theme was composed of two complementary sub-themes: rediscovering self-worth through recovery and helping others as healing transformation.

3.2.6.1. Sub-theme 1: Rediscovering self-worth through recovery

Participants reported renewed self-worth as they experienced physical recovery, adherence to treatment, or improved health stability. Most participants associated recovery progress with increased confidence, self-efficacy, and emotional reassurance. Several participants described a shift from self-blame or stigma-related distress toward greater self-acceptance. This sub-theme highlights personal transformation following TB survival and the regaining of physical strength, as shared by Participant 15:

> *When I finished my TB medicine, I looked in the mirror and cried. I was thin, but alive. For the first time, I thanked God for my body. Before, I hated it because of the virus. Now I see it as proof that I fought and survived.* (P15)

Recovery became symbolic: the healed body replaced the shamed body, enabling a renewed sense of identity and agency.

3.2.6.2. Sub-theme 2: Helping others as healing transformation

Participants engaged in supportive roles for others living with HIV–TB coinfection as part of their coping process. Most participants perceived helping others as a meaningful activity that reinforced emotional healing and personal growth. Several participants reported increased empathy, social connectedness, and a renewed sense of purpose through peer support activities, and a few participants described these experiences as transformative moments that strengthened self-acceptance and life meaning. This sub-theme shows and reflects the shift from self-protection to altruism, as expressed by Participant 19:

> *I started visiting new patients at the clinic. I tell them, 'Don't hide as I did.' When they see me healthy, they believe they can live too. Every time I share my story, I feel lighter, like the disease no longer controls me.* (P19)

Through acts of sharing, participants reclaimed power over their narrative, transforming pain into empathy and silence into solidarity.

4. Discussion

This study aimed to explore how people living with HIV-TB cope amid fear, guilt, and silence. Six themes emerged: living under constant fear of exposure; choosing silence as protection; bearing the weight of guilt and moral judgment; loneliness amid social disconnection; struggling with faith and moral reconciliation; and searching for meaning and self-acceptance. Each theme is discussed in the following section.

4.1. Living under constant fear of exposure

This study demonstrates that people living with HIV–TB experience constant fear of exposure that profoundly shapes their daily lives, emotional states, and social interactions. Previous studies have similarly identified fear of disclosure as a central feature of living with HIV and tuberculosis, particularly in contexts where stigma, discrimination, and moral judgment remain pervasive (Jaimes et al., 2024). In line with these findings, perceived disclosure is a significant social risk, anticipating rejection, labeling, and deterioration of family and community relationships (Chen et al., 2026). However, unlike earlier research that often conceptualizes fear as a response to external stigma alone, this study reveals that fear becomes internalized and persistently regulates individuals' thoughts, behaviors, and emotional expressions.

Fear functions not merely as an emotional reaction but as an ongoing cognitive and moral process that prompts self-monitoring and avoidance strategies (Jaimes et al., 2024). In the Indonesian context, deeply embedded cultural and moral norms surrounding HIV and tuberculosis further intensify this fear by framing illness as a sign of moral failure or social deviance, a pattern also reported in previous qualitative studies (Fauk et al., 2021; Sujianto et al., 2025). Consequently, living under constant fear of exposure emerges as a foundational experience through which stigma is embodied and continuously reproduced in the lives of PLHIV–TB (Asrina et al., 2023). This fear can affect health behaviors, including treatment adherence, healthcare utilization, and willingness to engage in peer or community support due to concerns about unintended disclosure (Singh & Lata, 2026).

4.2. Choosing silence as protection

This study found that choosing silence is a primary protective strategy for people living with HIV–TB to shield themselves from stigma, discrimination, and social harm. Previous studies have consistently shown that non-disclosure is commonly adopted by people living with HIV and tuberculosis as a means of avoiding negative social consequences, particularly in highly stigmatizing environments (Ismail et al., 2021). In line with these findings, individuals deliberately conceal information about their illness to maintain social relationships and prevent moral judgment from family members and society (Takwi et al., 2025). Unlike prior research that often frames silence solely as a passive response to stigma, this study reveals it as an active, intentional coping mechanism rooted in self-preservation. Silence enables individuals to maintain emotional stability by minimizing exposure to judgment, blame, and social rejection (Ayala, 2022).

The tendency toward silence among Indonesian participants may reflect cultural values that emphasize social harmony, family honor, and the avoidance of public shame. Religious beliefs and moral norms may further shape this response, as HIV–TB is sometimes associated with moral judgment or spiritual accountability in certain sociocultural contexts (Syamsir et al., 2026).

However, this protective silence simultaneously limited opportunities for social support and reinforced feelings of isolation and emotional distance. Thus, choosing silence as protection emerged as a paradoxical strategy that safeguarded individuals from external stigma while deepening internal and relational disconnection in the lived experiences of people living with HIV–TB (Ayala, 2022; Sujianto et al., 2025).

4.3. Bearing the weight of guilt and moral judgment

This study revealed that people living with HIV–TB carried a profound burden of guilt and moral judgment that significantly shaped their emotional and psychological experiences. Previous studies have similarly reported that feelings of guilt and self-blame are common among people living with HIV and tuberculosis, often intensified by societal narratives that associate illness with personal wrongdoing or moral failure (Hook et al., 2021). Consistent with these findings, they internalized responsibility for their illness and expressed guilt related to the possibility of transmitting the disease to others (Tadesse et al., 2024). Unlike earlier research that frequently emphasizes external stigma, this study highlights how moral judgment becomes internalized and transformed into self-directed condemnation. Guilt in this context was deeply intertwined with religious and moral beliefs, leading individuals to perceive illness as a form of punishment or moral consequence (Mwita & Mkenda, 2025). Such internalized moral judgment intensified emotional suffering and reinforced negative self-perceptions, even in the absence of overt discrimination. Consequently, bearing the weight of guilt and moral judgment emerge as a central mechanism through which stigma is internalized and sustained in the lived experiences of people living with HIV–TB (Ayala, 2022; Jaimes et al., 2024). These complex psychosocial challenges highlight the importance of strengthening interprofessional collaboration to ensure integrated, stigma-sensitive, and patient-centered HIV–TB care (Akbar et al., 2025; Togari et al., 2026).

4.4. Theme 4: Loneliness amid social disconnection

This study identified loneliness as a pervasive psychosocial experience among people living with HIV–TB due to ongoing social disconnection. Previous qualitative studies have shown that stigma and fear of disclosure often prompt social withdrawal and weaken interpersonal relationships among individuals affected by HIV and tuberculosis (Brewer et al., 2026; Togari et al., 2026). Consistent with these findings, emotional isolation persists even when individuals remain physically present within family and community environments (Buyukcan-Tetik et al., 2026). However, unlike earlier research that primarily links loneliness to overt social exclusion after disclosure, loneliness also emerges in situations of non-disclosure and prolonged silence (Kokorelias et al., 2026). This pattern of restricted interaction reduces opportunities for emotional support, reinforces feelings of invisibility, and contributes to perceived social marginalization (Prizeman et al., 2023). Over time, this persistent loneliness influences participants' emotional well-being, coping behaviors, and sense of identity, thereby intensifying the psychosocial burden of living with HIV–TB (Ninnoni et al., 2023).

4.5. Theme 5: Struggling with faith and moral reconciliation

This study identified spiritual struggle as a significant dimension of the lived experiences of people living with HIV–TB, particularly in relation to faith and moral reconciliation. Previous studies have shown that this disease often raises spiritual questions, especially in sociocultural contexts where illness is interpreted through moral or religious frameworks (Stafford et al., 2026; Syamsir et al., 2026). Consistent with these findings, participants in this study experienced spiritual conflict as they questioned divine justice, personal worth, and the meaning of their suffering. Unlike earlier research that primarily presents spirituality as a coping resource, this study reveals faith as a contested space characterized by doubt, guilt, and ongoing moral self-evaluation (Hutahaean et al., 2025). Participants struggled to reconcile their illness with religious teachings and frequently interpreted their condition as a test, punishment, or spiritual reminder (Hutahaean et al., 2025). Over time, some participants gradually moved toward spiritual surrender and reframed their illness as part of a broader divine purpose. This evolving spiritual negotiation shaped emotional adaptation, coping strategies, and identity reconstruction, highlighting struggling with faith and moral reconciliation as a dynamic process influencing meaning-making among people living with HIV–TB (Sujianto et al., 2025).

4.6. Theme 6: Searching for meaning and self-acceptance

This study identified searching for meaning and self-acceptance as a critical adaptive process in the lived experiences of people living with HIV–TB. Previous studies have reported that individuals with stigmatized illnesses often engage in meaning-making processes to cope with psychological distress and reconstruct a positive sense of self (Takwi et al., 2025). Consistent with these findings, participants in this study actively reinterpreted their illness experiences beyond fear, guilt, and silence. Unlike earlier research that primarily emphasizes coping as symptom management, this study highlights self-acceptance as a transformative process involving identity reconstruction, emotional healing, and renewed life orientation. This process of rediscovering self-worth may reflect an adaptive psychological response in which individuals reinterpret illness experiences through recovery, treatment adherence, and renewed social or spiritual engagement (Kokorelias et al., 2026). Engagement in helping others with similar conditions can also be understood as a meaning-making strategy that transforms personal suffering into a sense of purpose, contribution, and personal growth (Bellad et al., 2023). This process strengthens resilience, improves emotional well-being, and facilitates psychological integration (Stafford et al., 2026). Consequently, searching for meaning and self-acceptance function as a central mechanism for resilience, identity reconstruction, and long-term adaptation among people living with HIV–TB (Tan et al., 2025).

5. Implications and limitations

The findings of this study underscore the critical role of nurses in addressing the psychosocial and spiritual dimensions of care for people living with HIV–TB. Nurses are uniquely positioned to identify fear, guilt, and silence as hidden barriers to care and to create a safe, nonjudgmental environment that encourages trust and therapeutic communication. Integrating stigma-sensitive counseling, emotional support, and culturally responsive spiritual care into routine nursing practice may help reduce internalized stigma and social isolation. At the community level, nurses can play a key role in stigma reduction through health education and advocacy that challenge moralized narratives surrounding HIV-TB.

This study has several limitations that should be considered when interpreting the findings. The phenomenological design and qualitative approach limit the generalizability of the results to broader populations. Participants' experiences were shaped by specific cultural, religious, and social contexts in Indonesia, which may differ from other settings. The reliance on self-reported narratives may also be influenced by recall bias or social desirability. Despite these limitations, this study contributes important insights into the lived experiences of people living with HIV–TB by providing an in-depth understanding of how stigma, fear, silence, and spiritual negotiation shape psychosocial adaptation and identity reconstruction. The findings offer culturally grounded perspectives that may inform patient-centered care, psychosocial support interventions, and stigma-reduction strategies, particularly in sociocultural contexts similar to Indonesia's.

6. Conclusion

This study concludes that the lived experiences of people living with HIV–TB in Indonesia are profoundly shaped by the intertwined dynamics of fear, guilt, and silence within a context of pervasive stigma. Fear of exposure emerges as a foundational experience that influences disclosure decisions and constrains social interaction, while silence functions as both a protective strategy and a source of emotional isolation. Guilt and moral judgment are deeply internalized, often reinforced by cultural and religious narratives, intensifying psychological distress and self-stigmatization. These emotional burdens contribute to loneliness and social disconnection, even in the presence of family and community relationships. Future studies are needed to develop and evaluate stigma-sensitive, psychosocial, and spiritually informed interventions that support holistic care for people living with HIV–TB.

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Author contribution

IA: Conceptualization, Methodology, Formal analysis, Investigation, Project administration, and Writing-Original Draft. AW: Methodology, Validation, Investigation, Resources, Data Curation, and Writing - Original Draft. MAA: Methodology, Validation, Formal Analysis, Writing-Review & Editing, Visualization. US: Conceptualization, Supervision, Validation, and Writing-Review & Editing. AYN: Conceptualization, Supervision, Data Curation, and Writing-Review & Editing. All authors approved the final version of the manuscript.

Conflict of interest

The authors declare no conflict of interest related to this study.

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Declaration of Use of AI in Scientific Writing

The authors used Trinka to assist with grammar checking, language refinement, and improving the readability of the manuscript. No AI tools were used for content generation.

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