Stigma-Related Lived Experiences of Families Caring for Children with HIV in Indonesia: A Phenomenological Study

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Abstract: Human immunodef iciency virus (HIV)-related stigma remains a significant concern in Indonesia, where misconceptions about transmission, moral judgment, and concerns about family reputation may expose children living with HIV and their families to rejection, concealment, and social exclusion. This descriptive phenomenological study aimed to gain a deeper understanding of the lived experiences of parents and primary caregivers caring for children living with HIV in the context of stigma. Seventeen parents and primary caregivers were purposively recruited from three Indonesian regions: Lampung Province, Semarang in Central Java Province, and the Special Region of Yogyakarta. Data were collected through in-depth, semi-structured interviews and analyzed using Colaizzi's seven-step phenomenological method.

Three themes and seven subthemes emerged: anticipating negative judgment from others, concealing the child's HIV status to avoid discrimination, and withdrawing from social engagement and restricting interaction; these findings demonstrate that caregivers actively protected children through secrecy and restricted social exposure, although these strategies increased emotional burden, constrained communication, and reduced opportunities for social support. Nurses can apply these findings by providing confidential, family-centered, and stigma-sensitive assessments; therapeutic communication; psychosocial counseling; individualized disclosure support; referral to peer and community resources; and culturally responsive HIV education that strengthens family confidence and promotes safe social participation.

Keywords: Caregivers, Family, HIV infections, Indonesia, Nursing, Phenomenology, Social stigma

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Introduction

Human immunodeficiency virus (HIV) remains a significant global public health issue, particularly among children.[1] Advances in antiretroviral therapy have transformed HIV into a manageable chronic condition. However, children living with HIV still require lifelong treatment, continuous health monitoring, and sustained psychosocial support.[2] Parents, guardians, and other family members assume primary responsibility

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for treatment adherence, daily care, emotional support, and management of the child's health needs.[3] These long-term caregiving responsibilities may create substantial emotional, social, and practical demands for the entire family.[4]

HIV-related stigma creates an additional burden that distinguishes pediatric HIV caregiving from many other chronic care experiences.[5] Negative labels, moral judgments, misconceptions about transmission, and fear of rejection may affect not only children living with HIV but also the families who care for them.[6] The impacts of stigma on families include persistent fear, shame, parenting stress, emotional distress, anticipated blame, and concern that the child may experience rejection, exclusion, or discrimination.[6,7] Stigma may also influence caregiving practices by encouraging families to conceal the child's HIV status, restrict disclosure to trusted individuals, avoid seeking support, withdraw from community activities, and limit the child's interactions with peers and the wider social environment.[8,9] Although these responses are often intended to protect the child, they may reduce social support, disrupt family communication and caregiving routines, increase caregivers' psychological burden, and restrict the child's opportunities for social development, participation, and a sense of belonging.[10,11]

Indonesian socio-cultural values related to family reputation, social harmony, privacy, and collective identity may intensify the effects of HIV-related stigma.[12] Disclosure of a child's HIV status may be perceived as bringing shame to the entire family, which can encourage secrecy, discourage open communication, and prevent families from seeking psychosocial or community support.[7,13] This cultural context may discourage open communication and help-seeking behaviors, thereby increasing the likelihood of secrecy and social withdrawal among families.[14] Existing research often overlooks the nuanced ways in which stigma influences family dynamics, caregiving practices, and social interactions in everyday life.[4] Furthermore, the voices of caregivers who are directly responsible for the child's well-being are frequently underrepresented in the literature.[15]

The perspectives of parents and primary caregivers who directly manage the child's daily care remain underrepresented in the literature. This knowledge gap limits the development of culturally sensitive and family-centered support for families affected by pediatric HIV. Therefore, this descriptive phenomenological study aimed to explore the lived experiences of families caring for children living with HIV in the context of stigma in Indonesia.

Review of Literature and Conceptual Framework

Stigma Theory provides a relevant theoretical basis for understanding the social challenges faced by families caring for children living with HIV. Goffman defines stigma as an attribute that discredits a person or group and reduces their full social acceptance within society.[16] Society constructs stigma through negative labels, stereotypes, and discriminatory attitudes toward certain conditions, including HIV.[4] HIV carries strong social meanings in many settings because people often associate it with fear, shame, and moral judgment. This theory explains how social perceptions can shape the experiences of children with HIV and the families who care for them.[17,18]

Stigma Theory also explains the process through which families experience social pressure in everyday life.[16] Community members may attach negative meanings to HIV, and community members may judge not only the infected child but also the family. Families often face fear of rejection, exclusion, or blame because society may view HIV as a deviant condition.[19,20] Caregivers may then change their communication, social behavior, and protective decisions in response to this perceived stigma.[11] This theoretical perspective is important because it helps researchers understand how external social values influence family caregiving experiences.[21]

Family Systems Theory provides another strong foundation for this study because the theory views the family as an integrated, interdependent system.[21] Friedman explains that each family member affects and is affected by the condition of other family members. A health problem in one member does not remain an individual issue; but it influences roles, relationships, communication, and coping patterns within the whole family.[21] A child's HIV diagnosis may therefore alter family routines, caregiving responsibilities, emotional interactions, and decision-making processes.[4] This theory supports the idea that caregiving must be understood as a family response rather than as an individual action only.[21]

Family Systems Theory explains how families adapt to internal and external stressors. Families perform essential functions such as affective support, socialization, health care, and role allocation in response to illness.[21] The presence of a chronic condition such as HIV may require the family to reorganize these functions in order to maintain stability and protect the child.[4] Family members may strengthen emotional bonds, redefine caregiving roles, and adjust interaction patterns to manage long-term care demands.[17] This theory is appropriate because it emphasizes that the family acts as the main context in which caregiving, protection, and adaptation occur.[21]

The conceptual framework of this study integrates Stigma Theory and Family Systems Theory into one coherent explanation. Stigma theory positions HIV-related stigma as the external social force that shapes negative labels, social judgment, and discriminatory attitudes toward the child and family.[8,22] Family as an interconnected system that responds to that external pressure through role adjustment, caregiving, emotional support, and adaptation.[21] The framework assumes that stigma from the social environment influences the family system, and the family system then organizes its internal responses to protect and care for the child with HIV.[23] Together, these two theories provide a clear conceptual basis for examining family caregiving in the context of pediatric HIV.

A descriptive phenomenological approach was selected because the study sought to understand and describe the meanings and essential structure of families' everyday experiences of caring for children living with HIV. Descriptive phenomenology allowed the researchers to remain close to participants' descriptions while identifying common meanings across their experiences. Colaizzi's method was selected because it provides a systematic and transparent process for analyzing phenomenological data through repeated reading of transcripts, extraction of significant statements, formulation of meanings, development of theme clusters, construction of an exhaustive description, identification of the fundamental structure of the phenomenon, and validation of the findings with participants.[24] This structured process was consistent with the study's purpose of describing the shared essence of family caregiving experiences while minimizing the imposition of predetermined interpretations.

Study Question

"What are the lived experiences of families caring for children living with HIV in the context of stigma in Indonesia?"

Methods

Study Design: This study employed a descriptive phenomenological design to explore the lived experiences of families caring for children living with HIV in Indonesia. A phenomenological design was appropriate because the study sought to understand how family caregivers perceived, experienced, and gave meaning to their everyday caregiving responsibilities.[25] Descriptive phenomenology enabled the researchers to remain close to participants' accounts and identify the common meanings and essential structure of their caregiving experiences across different family and

socio-cultural contexts. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) in reporting this study.[26]

Sample and Setting: The study was conducted in three regions in Indonesia: Lampung Province, Semarang (Central Java), and Yogyakarta Special Region. These settings were selected to capture diverse socio-cultural and healthcare contexts where children living with HIV receive care through healthcare facilities and community-based support systems. The research settings included both healthcare environments, such as HIV clinics and community health centers, and community contexts where families interact with neighbors, extended family members, and social networks. These environments provided a comprehensive context for understanding how stigma is experienced and managed by caregivers in their daily lives.

Participants were recruited using purposive sampling based on their ability to provide rich and meaningful insights into the phenomenon under study. Inclusion criteria required participants to 1) be a parent or primary caregiver of a child diagnosed with HIV, (2) have been actively involved in the child's care for at least one year, (3) reside in Lampung, Semarang, or Yogyakarta, and (4) be willing and able to communicate their experiences verbally.

Access to participants in Lampung, Semarang, and Yogyakarta was approved by the respective community health centers (Puskesmas). The healthcare professional responsible for the HIV program at each community health center acted as the local gatekeeper and assisted the researchers in identifying potentially eligible family caregivers. The HIV program coordinators provided initial information about the study to eligible caregivers and facilitated contact with those who expressed an interest in participating. Recruitment continued until data saturation was achieved, indicating that no new themes or significant insights emerged from subsequent interviews.

Ethical Consideration: Ethical approval for this study was obtained from the Health Research Ethics Committee of Universitas Aisyah Pringsewu, Indonesia (Ref. No. 921/UAP.OT/KEP/EC/2025). Participation in the study was voluntary, and written informed consent was obtained from all participants prior to data collection. Participants were informed of their right to withdraw from the study at any time without any consequences. Measures were taken to ensure confidentiality, anonymity, and psychological safety throughout the research process. Pseudonyms were used to protect participants' identities.

Data Collection: Data were collected between August and December 2025 using in-depth, face-to-face interviews guided by a semi-structured interview guide. The research team developed the interview guide based on the research question, literature on family caregiving for children living with HIV, and the study's conceptual framework. The guide included open-ended questions such as: *"Can you describe your experience of caring for a child living with HIV?"; "How has your child's condition affected your family's daily life?"; "How do family members and other people respond to your child's condition?"; "What challenges have you experienced while providing care?";* and *"How have you and your family responded to these challenges?"* Probing questions were used to explore participants' responses in greater depth.

The interview guide was pilot-tested through interviews with individuals who were not included in the final study sample. The pilot interviews were used to assess the clarity, relevance, sequence, and sensitivity of the questions. The research team reviewed the pilot interview process and refined the wording and order of several questions to improve comprehension and encourage detailed descriptions of participants' experiences. The interviews were conducted in private and comfortable settings, including participants' homes. Each interview lasted approximately 45 to 75 minutes. All interviews were audio-recorded with the participants' permission and subsequently transcribed verbatim.

The interviews were conducted by the first author, a male nursing lecturer with a doctoral degree in nursing and substantial experience in qualitative research, particularly in conducting in-depth interviews and interpreting lived experiences in health-related contexts. A second researcher, who was an experienced qualitative researcher and interviewer, assisted during data collection by conducting non-participant observation and documenting field notes. The observations focused on participants' nonverbal expressions, emotional responses, tone of voice, pauses, changes in facial expression, and relevant contextual conditions during the interviews. These observational notes were used to complement the audio-recorded interview data and support interpretation of the participants' accounts.

Before the interviews began, participants were informed about the identity and professional background of the primary researcher, including his role as a nursing academic and the purpose of the study, so that they understood the researcher's interest in exploring the experiences of families caring for children living with HIV. The researchers acknowledged the importance of reflexivity in qualitative inquiry. Throughout the study, the research team maintained reflexive journals to critically examine their assumptions, professional backgrounds, prior experiences in qualitative research, and potential influence on data collection, participant interaction, and interpretation of findings.

Data Analysis: Data were analyzed manually using Colaizzi's seven-step phenomenological approach.[24] First, the researchers read each transcript repeatedly to achieve familiarity with the participants' accounts. Second, significant statements directly related to families' caregiving experiences were extracted. Third, the researchers formulated meanings from each significant statement while remaining close to the participants' intended meanings. Fourth, the formulated meanings were organized into clusters of subthemes and themes by identifying similarities, differences, and recurring patterns across participants' accounts. Fifth, the theme clusters were integrated into an exhaustive description of the phenomenon. Sixth, the exhaustive description was condensed into a fundamental structure representing the essential meaning of the participants' experiences. Seventh, the exhaustive description and fundamental structure were presented to participants during member checking to determine whether the interpretation accurately reflected their experiences. Examples illustrating the progression from participants' statements to formulated meanings, subthemes, and themes are presented in **Table 1**.

Table 1. Example of Colaizzi's data analysis for the subtheme "Anticipating blame and moral labeling from the community" within the theme "Fear of negative judgment from others"

Excerpts of transcribed interview contents: "What challenges have you experienced while providing care?"	Read repeatedly and identify significant statements	Formulate meanings	Cluster themes	Develop an exhaustive description	Produce the fundamental structure	Seek verification of the fundamental structure
P1: "I often feel that people in my community will eventually blame us for my child's condition, as if this illness reflects a moral failure on our part. Even without direct comments, the fear of	**P1:** "People in my community will eventually blame us for my child's condition" and "the fear of being judged and labeled negatively is always present."	**Code 1:** Anticipation of community blame. **Code 2:** HIV perceived as a moral failure.	**Subtheme:** Anticipating blame and moral labeling from the community.	Participants described persistent concern that community members would associate their child's HIV	Anticipated community judgment created a persistent fear that caregivers and their	The exhaustive description and fundamental structure were returned to selected participants for verification. Participants

Table 1. Example of Colaizzi's data analysis for the subtheme "Anticipating blame and moral labeling from the community" within the theme "Fear of negative judgment from others" (Cont.)

Excerpts of transcribed interview contents: "What challenges have you experienced while providing care?"	Read repeatedly and identify significant statements	Formulate meanings	Cluster themes	Develop an exhaustive description	Produce the fundamental structure	Seek verification of the fundamental structure
being judged and labeled negatively is always present in my mind." **P3:** "In our neighborhood, HIV is still strongly associated with something shameful, so I constantly worry that if people find out, they will label our family as irresponsible or immoral without trying to understand our situation." **P7:** "I feel that society tends to judge quickly without knowing the full story, and that makes me afraid that we will be seen as bad parents who failed to protect our child."	**P3:** "They will label our family as irresponsible or immoral." **P7:** "We will be seen as bad parents who failed to protect our child."	**Code 3:** Fear of being labeled irresponsible or immoral. **Code 4:** Fear of being perceived as inadequate parents.	**Theme:** Anticipating Negative Judgment from Others.	diagnosis with parental irresponsibility, immorality, or failure. The anticipation of blame occurred even when participants had not directly experienced discriminatory comments. HIV-related social meanings caused caregivers to remain alert to possible judgment and influenced how they viewed their position within the community.	families would be morally blamed and socially devalued because of the child's HIV diagnosis.	were asked whether the interpretation accurately represented their experiences of anticipated blame and moral judgment. The participants confirmed that the interpretation reflected their experiences, and no substantive revisions were required.

Data Trustworthiness: The rigor and trustworthiness of the study were evaluated using credibility, dependability, confirmability, and transferability.[27] Credibility was enhanced through in-depth interviews, comparison of the interview data with observational field notes, member checking of the preliminary findings, and the return of interview transcripts to participants for comment and correction. These strategies helped ensure that the findings accurately represented the participants' intended meanings and experiences. Dependability was supported by maintaining an audit trail that documented the data collection procedures, methodological decisions, analytical processes, and development of themes. Peer debriefing with co-researchers and qualitative research experts was also conducted to examine the consistency of the analytical process. Confirmability was strengthened through reflexive journaling, peer debriefing, and the use of participants' quotations to demonstrate that the interpretations were grounded in the data rather than the researchers' assumptions. Transferability was addressed by providing detailed descriptions of the participants, research settings, sociocultural context, and research procedures, enabling readers to assess the applicability of the findings to other settings and populations

Findings

A total of 17 participants, consisting of parents and primary caregivers of children living with HIV, were recruited in this study. The informants were drawn from three regions in Indonesia, namely Lampung, Semarang, and Yogyakarta. The majority of the caregivers were mothers, although fathers and extended family members such as grandparents were also involved in the caregiving process. The informants varied in terms of age, educational background, occupation, marital status, and duration of caregiving.

Caring for children living with HIV required long-term commitment, emotional resilience, and continuous adaptation. Most informants had been providing care for several years, reflecting the chronic nature of HIV and the ongoing responsibilities associated with treatment adherence, health monitoring, and psychosocial support. The detailed profile of the informants is presented in **Table 2**.

Table 2. Informant profile

Informant	Age (years)	Sex	Occupation	Education level	Marital status	Duration of care (years)	Relationship with child
P1	34	Female	Housewife	Secondary school	Married	6	Mother
P2	29	Female	Street vendor	Primary school	Married	4	Mother
P3	40	Male	Driver	Secondary school	Married	7	Father
P4	58	Female	Unemployed	Primary school	Widowed	8	Grandmother
P5	36	Female	Small trader	Secondary school	Married	5	Mother
P6	31	Female	Factory worker	Diploma	Married	3	Mother
P7	42	Male	Construction worker	Secondary school	Married	9	Father
P8	28	Female	Housewife	Secondary school	Married	2	Mother
P9	45	Female	Domestic worker	Secondary school	Married	6	Aunt
P10	33	Female	Private Employee	Bachelor's degree	Married	5	Mother
P11	37	Female	Small trader	Secondary school	Married	7	Mother
P12	61	Male	Retired	Primary school	Married	10	Grandfather
P13	30	Female	Housewife	Secondary school	Married	4	Mother
P14	35	Female	Tailor	Diploma	Married	6	Mother
P15	39	Male	Farmer	Secondary school	Married	8	Father
P16	32	Female	Shop assistant	Secondary school	Married	3	Mother
P17	41	Female	Housewife	Primary school	Married	11	Mother

Table 3 shows the final themes and subthemes identified from the data analysis. Three major themes and seven subthemes emerged from the lived experiences of the 17 informants, described below. Each theme is supported by several subthemes and representative quotations, reflecting the depth and variation of the caregivers' experiences.

Table 3. Themes and subthemes

Theme	Subtheme
Theme 1: Anticipating Negative Judgment from Others	Anticipating blame and moral labeling from the community
	Worry about the child being judged because of the diagnosis
Theme 2: Concealing the Child's HIV Status to Avoid Discrimination	Deliberate secrecy about the child's diagnosis
	Limiting disclosure to trusted family members only
	Avoiding conversations that may reveal the child's condition
Theme 3: Withdrawing from Social Engagement and Restricting Interaction	Avoiding participation in community activities
	Restricting the child's interaction with peers and the wider environment

Theme 1: Anticipating Negative Judgment from Others

This theme refers to the emotional burden experienced by parents due to the anticipation of negative judgments from others regarding their child's HIV diagnosis. Participants described persistent concerns about being blamed, morally stigmatized, and socially devalued by the community. These fears extended not only to themselves as parents but also to their children, whom they believed might be unfairly judged, rejected, or treated differently because of the diagnosis. This theme comprises two sub-themes:

Sub-theme 1.1: Anticipating blame and moral labeling from the community

This sub-theme highlights parents' fears of being blamed and morally judged by the wider community because of their child's condition. Participants expressed concern that HIV was often associated with shame, irresponsibility, and moral failure, leading them to worry that others would negatively label their family even without understanding the full circumstances. As participants P1, P3, and P7 stated:

> *"I often feel that people in my community will eventually blame us for my child's condition, as if this illness reflects a moral failure on our part. Even without direct comments, the fear of being judged and labeled negatively is always present in my mind."* (P1)

> *"In our neighborhood, HIV is still strongly associated with something shameful, so I constantly worry that if people find out, they will label our family as irresponsible or immoral without trying to understand our situation."* (P3)

> *"I feel that society tends to judge quickly without knowing the full story, and that makes me afraid that we will be seen as bad parents who failed to protect our child."* (P7)

These statements illustrate that the fear of stigma is not only related to actual discrimination but also to anticipated social condemnation. Parents perceived that their child's HIV diagnosis could trigger blame and moral labeling toward the family, creating anxiety and caution in their interactions with others. This suggests that stigma functions as a strong social pressure that influences how parents interpret their place within the community.

Sub-theme 1.2: Worry about the child being judged because of the diagnosis

This sub-theme describes parents' deep concern that their children would be unfairly judged, rejected, or treated differently because of their HIV diagnosis. Participants emphasized that their worries were centered on the child's innocence and vulnerability, particularly in future social settings such as school and peer relationships. This is reflected in the statements of participants P2, P6, and P17:

> *"My biggest concern is my child, because I am afraid that other people will judge them unfairly and treat them differently, even though they are innocent and do not fully understand their condition."* (P2)

> *"I always think about my child's future, especially when they start school, because I am worried that other children or even parents might treat them differently if they know about the diagnosis."* (P6)

> *"I worry that my child will grow up feeling isolated or rejected if society continues to attach negative meanings to HIV without proper understanding."* (P17)

These reflections show that parents' fears were strongly focused on the child's future social acceptance and emotional wellbeing. The diagnosis was viewed not only as a health condition but also as a source of possible rejection that could affect

the child's relationships, identity, and sense of belonging. This indicates that anticipated stigma is experienced by parents as a threat to their child's social development and quality of life.

Theme 2: Concealing the Child's HIV Status to Avoid Discrimination

This theme refers to parents' efforts to protect their child from stigma and discriminatory treatment by concealing the child's HIV status. Participants described secrecy as a deliberate and protective strategy aimed at preventing negative social reactions, rejection, and misunderstanding from others. This concealment was reflected in selective disclosure, restricted communication, and careful management of everyday conversations. This theme comprises three sub-themes:

Sub-theme 2.1: Deliberate secrecy about the child's diagnosis

This sub-theme highlights parents' intentional efforts to keep their child's HIV diagnosis private in order to protect them from stigma and discriminatory treatment. Participants viewed secrecy as a necessary form of protection, even though it created emotional burdens and limited their ability to openly discuss their situation. As participants P8, P10, and P13 stated:

> *"We made a conscious decision to keep my child's HIV status completely private, because we believe that sharing it openly would only expose them to stigma and discrimination that they do not deserve."* (P8)

> *"Keeping this as a secret is not easy, but I feel it is necessary to protect my child from being treated differently by others who may not understand the condition properly."* (P10)

> *"We have agreed within the family that this information should not be shared outside, because once people know, we cannot control how they will react."* (P13)

These statements show that concealment was not merely an act of withholding information but a deliberate strategy to shield the child from anticipated stigma. Parents perceived disclosure as a potential source of harm, leading them to prioritize privacy over openness. This indicates that secrecy functioned as a protective mechanism within a social environment still shaped by fear, misunderstanding, and discrimination toward HIV.

Sub-theme 2.2: Limiting disclosure to trusted family members only

This sub-theme describes how parents selectively disclosed their child's diagnosis only to a very limited number of trusted family members. Participants emphasized that trust, emotional safety, and fear of further disclosure were central considerations in deciding whom to inform. This is reflected in the statements of participants P2, P6, and P14:

> *"I only shared my child's condition with one family member whom I truly trust, because I needed emotional support, but at the same time I was afraid of being judged or misunderstood."* (P2)

> *"Choosing who to trust is very difficult, because once the information is out, it cannot be taken back, and that risk makes me very careful."* (P6)

> *"I prefer to keep the circle very small, only those who really understand and support us without judgment."* (P14)

These reflections indicate that disclosure was carefully controlled and based on the perceived reliability and understanding of others. Parents needed emotional support, yet they remained cautious because disclosure carried the risk of stigma if the information spread beyond trusted individuals. This suggests that selective disclosure served as a balancing strategy between seeking support and protecting the child and family from social harm.

Sub-theme 2.3: Avoiding conversations that may reveal the child's condition

This sub-theme highlights parents' efforts to avoid or redirect conversations that might expose their child's HIV status. Participants described being highly cautious during daily interactions, often giving vague answers or steering discussions away from sensitive topics to maintain privacy. As participants P1, P5, and P17 stated:

> *"Whenever someone asks about my child's health, I respond in a very general way, because I am afraid that giving too much detail might lead to more questions and possible suspicion."* (P1)

> *"I have learned how to redirect conversations so that people do not ask too deeply about my child's condition."* (P5)

> *"Even simple questions can make me anxious, because I am afraid they might lead to something more sensitive."* (P17)

These statements illustrate that concealment extended into everyday communication practices, requiring parents to constantly monitor their words and responses. Ordinary social interactions could become sources of anxiety because of the possibility that sensitive information might be unintentionally revealed. This shows that the effort to maintain secrecy was emotionally demanding and shaped how parents managed communication in their social environment.

Theme 3: Withdrawing from Social Engagement and Restricting Interaction

This theme refers to the tendency of parents to reduce social engagement and limit both their own and their child's interactions with others in order to avoid stigma and discrimination related to the child's HIV diagnosis. Participants described withdrawing from community life, restricting social exposure, and carefully controlling interactions as protective responses to fear of judgment and rejection. This theme comprises two sub-themes:

Sub-theme 3.1: Avoiding participation in community activities

This sub-theme highlights parents' tendency to withdraw from community activities after their child's diagnosis. Participants described reducing their involvement in social gatherings because of fear that questions, attention, or curiosity from others might eventually expose their child's condition. As participants P3, P10, and P12 stated:

> *"Before my child's diagnosis, I was quite active in community activities, but now I prefer to stay at home because I am afraid that people might ask questions that I cannot answer honestly."* (P3)

> *"Sometimes I miss being part of the community, but the fear of being exposed is stronger than my desire to socialize."* (P10)

> *"I feel that withdrawing from social life is the only way to avoid unwanted attention and possible judgment."* (P12)

These statements show that social withdrawal emerged as a protective response to anticipated stigma. Parents limited their participation in communal life not because they no longer valued social connection, but because involvement in public settings increased the risk of uncomfortable questions, exposure, and negative judgment. This suggests that fear of stigma contributed to a gradual isolation from community life and reduced parents' social participation.

Sub-theme 3.2: Restricting the child's interaction with peers and the wider environment

This sub-theme describes parents' efforts to limit their child's social interactions in order to protect them from rejection, unfair treatment, and possible discrimination. Participants expressed concern that

broader peer and community contact could increase the risk of their child being stigmatized if the diagnosis became known. This is reflected in the statements of participants P4, P9, and P17:

> *"I am very careful about my child's interactions with others, because I am afraid that if their condition becomes known, they might be rejected or treated unfairly by their peers."* (P4)

> *"Sometimes I feel guilty for limiting my child's social life, but I believe it is necessary to protect them from harm."* (P9)

> *"It is a difficult balance between letting my child live normally and protecting them from possible stigma and discrimination."* (P17)

These reflections indicate that parents viewed restricted social interaction as a form of protection, even though it created emotional conflict and concern about the child's normal development. Parents attempted to balance the child's need for socialization with the perceived need to prevent exposure to stigma. This shows that anticipated discrimination shaped not only parental behavior but also the child's opportunities for peer connection and broader social participation.

Discussion

This study used descriptive phenomenology to capture caregivers' first-person accounts of caring for children living with HIV, while Family Systems Theory provided a relational lens for interpreting how these individual experiences were embedded within family roles, communication patterns, caregiving decisions, and reciprocal adaptation.[21] The findings revealed three interconnected themes: anticipating negative judgment from others, concealing the child's HIV status to avoid discrimination, and withdrawing from social engagement and restricting interaction. Although phenomenology foregrounded the subjective meanings expressed by individual caregivers, Family Systems Theory clarified that the child's HIV diagnosis affected caregivers' emotional well-being, family communication, disclosure decisions, protective responsibilities, and social participation within an interdependent family system. The integration of these perspectives therefore preserved the depth of caregivers' lived experiences while explaining how the child's condition and stigma-related responses were organized and negotiated across the family system.

Stigma emerges as a central force shaping caregivers' experiences. The fear of negative judgment was not limited to direct discrimination but was also driven by anticipated stigma, in which caregivers expected blame because HIV was socially associated with morally disapproved behavior.[28,29] This pattern reflects courtesy or secondary stigma because the negative social mark attached to the child extended to parents and other family caregivers. Caregivers consequently felt evaluated in both their parenting roles and moral standing, which influenced their emotional well-being and patterns of social interaction.[19] The findings therefore support and extend Stigma Theory by showing that stigma operated through anticipated and culturally mediated judgment even when caregivers had not directly experienced overt discrimination.[30,31]

These experiences are inseparable from cultural and social contexts. In many Indonesian communities, values related to family reputation, social harmony, collective identity, privacy, and moral expectations strongly influence how HIV is interpreted and how affected families are judged.[12] Because HIV is often associated with socially disapproved behaviors, the child's diagnosis may be interpreted as reflecting parental irresponsibility or moral failure, thereby intensifying shame and fear among caregivers. Disclosure can consequently be perceived as a risk not only to the child's social acceptance but also to

the family's reputation and standing within the community.[6] As a result, stigma is embedded in broader cultural expectations that intensify anticipated blame, concealment, and social withdrawal rather than being experienced as an isolated event.[32] This underscores the need for interventions that address community narratives, moral judgments, and shared cultural beliefs rather than focusing solely on individual knowledge.[12]

Concealment of the child's HIV status reflects a deliberate and strategic response to these conditions.[8] Caregivers actively limited disclosure to trusted individuals and avoided conversations that could result in unintended exposure.[13] From the perspective of Family Systems Theory, these practices represented collective family decisions that reorganized communication patterns, privacy boundaries, and protective responsibilities within the family system.[21] The findings therefore extend Stigma Theory beyond individual identity management by demonstrating that stigma was managed collectively through family communication and caregiving decisions, while the continuous maintenance of secrecy created emotional and cognitive demands for caregivers.[33]

This strategy is commonly framed by caregivers as protection and responsibility rather than avoidance.[34] Safeguarding the child from discrimination, rejection, and exclusion becomes a priority, shaping decisions about openness and privacy. At the same time, a tension becomes apparent. While concealment may reduce immediate risks of stigma, it can restrict access to social support, limit opportunities for open communication, and constrain engagement with helpful resources.[13] Over time, these constraints may contribute to emotional fatigue among caregivers and influence the child's social development.[20] The coexistence of protection and restriction highlights a critical dynamic that merits attention in supportive care models.[35]

Social withdrawal and restricted interaction further illustrate how stigma and concealment reshape daily life. Many caregivers reduced their participation in community activities and carefully regulated their children's social contacts to prevent disclosure, rejection, and discrimination.[9] These actions reflected a family-level adaptation in which caregivers reorganized social relationships and restricted external interactions to create a safer and more controllable environment.[10] The findings therefore support and extend Family Systems Theory by demonstrating that HIV-related stigma can reshape family–community boundaries and reciprocally restrict the social participation of both caregivers and children.[4,33]

However, this adaptation carries consequences. Reduced interaction may lead to isolation, diminished emotional support, and fewer opportunities for children to develop social skills and relationships. Caregivers often describe a sense of loss in relation to previous levels of community involvement.[36] Short-term protection can therefore be accompanied by longer-term psychosocial challenges for both caregivers and children. Creating environments that enable safe participation without fear of judgment becomes an important goal for practice and policy.[28]

The findings also point to resilience and meaning-making in caregiving. Despite ongoing challenges, caregivers demonstrate commitment, flexibility, and a capacity to adapt. Their responses reflect agency in navigating complex social realities, including weighing risks, making strategic decisions, and sustaining family stability.[37] Viewing caregivers solely through a lens of vulnerability risks overlooking these strengths. A more balanced perspective recognizes both the burdens they carry and the capabilities they enact in response.[10]

This study contributes context-specific insights into caregiving in Indonesia, while also highlighting that research and practice involving families affected by HIV-related stigma carry ethical risks of inadvertent disclosure, deductive identification, emotional distress, and perceived coercion when access is facilitated through healthcare gatekeepers. Ethically responsive approaches should therefore preserve voluntary participation, separate recruitment support from consent decisions,

use private and safe communication procedures, minimize identifiable details in quotations and reports, secure recordings and transcripts, and allow participants to pause or withdraw without consequences

Limitations

The findings should be interpreted within the specific sociocultural contexts of Lampung, Semarang, and Yogyakarta. Descriptive phenomenology recognizes these local contexts as integral to participants' lived experiences rather than as methodological weaknesses. However, the meanings attached to social judgment, disclosure, family reputation, and interpersonal interaction may differ across cultural settings. Consequently, readers should consider the characteristics of the participants and study locations when assessing the transferability of the findings to other populations and cultural contexts.

Conclusions and Implications for Nursing Practice

This study concludes that parents and primary caregivers of children living with HIV experienced anticipated negative judgment, concealed the child's HIV status, and restricted social interaction as strategies to protect the child from stigma and discrimination. These findings suggest that nurses should routinely assess caregivers' fears of judgment, emotional burden, disclosure concerns, family communication, and social support, and apply confidential therapeutic communication, family-centered counseling, and individualized disclosure planning to help families make safe and informed caregiving decisions. Nurses should also facilitate referral to psychosocial and peer-support services, support safe social participation for children and caregivers, and collaborate with community health centers, schools, and community representatives to provide culturally appropriate HIV education and reduce misconceptions, moral judgment, and discriminatory responses.

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Author Contributions

Conceptualization: US, IA
Methodology and study design: US, IA, MAA, ASM
Data acquisition, analysis, and interpretation: US, IA, MAA, FF
Investigation and data curation: US, IA, FF, GG
Validation: MAA, ASM, GG
Draft of the manuscript, revising the final draft, and final approval of the submitted version, accountability for all aspects of the work: US, IA, MAA

All authors reviewed and approved the final version of the manuscript and agreed to be accountable for all aspects of the work.

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The authors did not use generative AI or AI-assisted technologies in the writing or preparation of this manuscript.

Declaration Regarding Conflict of Interests

The authors declare that they have no competing interests.

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ประสบการณ์ชีวิตที่เกี่ยวข้องกับตราบาปทางสังคมของครอบครัวในการดูแลเด็กติดเชื้อเอชไอวีในประเทศอินโดนีเซีย : การศึกษาเชิงปรากฏการณ์วิทยา

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บทคัดย่อ: ตราบาปทางสังคมที่เกี่ยวข้องกับเชื้อไวรัสภูมิคุ้มกันบกพร่อง (เอชไอวี) ยังคงเป็นประเด็นความวิตกกังวลที่สำคัญในประเทศอินโดนีเซีย ซึ่งความเข้าใจผิดเกี่ยวกับการแพร่เชื้อ การตัดสินทางศีลธรรม และความกังวลเกี่ยวกับชื่อเสียงของครอบครัว อาจทำให้เด็กที่อยู่ร่วมกับเชื้อเอชไอวีและครอบครัว ต้องเผชิญกับการถูกปฏิเสธ การปกปิด และการถูกกีดกันทางสังคม การศึกษาเชิงปรากฏการณ์วิทยาแบบบรรยายครั้งนี้ มีวัตถุประสงค์เพื่อสร้างความเข้าใจอย่างลึกซึ้งเกี่ยวกับประสบการณ์ชีวิตของบิดา มารดา และผู้ดูแลหลัก ในการดูแลเด็กที่อยู่ร่วมกับเชื้อเอชไอวีภายใต้บริบทของตราบาปทางสังคม กลุ่มตัวอย่างเป็นบิดา มารดา และผู้ดูแลหลัก จำนวน 17 ราย ซึ่งได้รับการคัดเลือกแบบเฉพาะเจาะจงจาก 3 พื้นที่ในประเทศอินโดนีเซีย ได้แก่ จังหวัดลัมปุง เมืองเซมารังในจังหวัดชวากลาง และเขตปกครองพิเศษยอกยาการ์ตา เก็บรวบรวมข้อมูลผ่านการสัมภาษณ์เชิงลึกแบบกึ่งโครงสร้างและวิเคราะห์ข้อมูลด้วยวิธีการเชิงปรากฏการณ์วิทยา 7 ขั้นตอนของโคไลซซี

ผลการวิจัยพบ 3 ประเด็นหลัก และ 7 ประเด็นย่อย ได้แก่ การคาดการณ์ถึงการตัดสินเชิงลบจากผู้อื่น การปกปิดสถานะการติดเชื้อเอชไอวีของเด็กเพื่อหลีกเลี่ยงการเลือกปฏิบัติ การถอนตัวจากการมีส่วนร่วมทางสังคมและการจำกัดการปฏิสัมพันธ์ ข้อค้นพบเหล่านี้แสดงให้เห็นว่า ผู้ดูแลปกป้องเด็กอย่างจริงจังผ่านการเก็บรักษาความลับและการจำกัดการออกสู่สังคม แม้ว่ากลยุทธ์ดังกล่าวจะส่งผลเพิ่มภาระทางอารมณ์ ข้อจำกัดในการสื่อสาร และลดโอกาสในการได้รับความช่วยเหลือสนับสนุนทางสังคมก็ตาม พยาบาลสามารถนำข้อค้นพบเหล่านี้ไปประยุกต์ใช้โดยการให้บริการประเมินที่เป็นความลับ เน้นครอบครัวเป็นศูนย์กลาง และมีความไวต่อประเด็นตราบาปทางสังคม การสื่อสารเพื่อการบำบัด การให้คำปรึกษาทางจิตสังคม การสนับสนุนการเปิดเผยสถานะโรคที่เหมาะสมกับแต่ละบุคคล การส่งต่อแหล่งประโยชน์ในชุมชนและกลุ่มเพื่อนช่วยเพื่อน ตลอดจนการให้การศึกษาเรื่องเอชไอวีที่สอดคล้องกับบริบททางวัฒนธรรม เพื่อเสริมสร้างความมั่นใจของครอบครัวและส่งเสริมการมีส่วนร่วมทางสังคมได้อย่างปลอดภัย

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