

# The Perspective of the Acehnese Community in Indonesia toward HIV/AIDS

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## ABSTRACT

**Background:** HIV/AIDS has garnered public attention due to the challenges in its effective control, with its prevalence continuing to rise until 2019. Despite its global impact, public awareness of this disease remains limited. The perspective of the community on People Living with HIV/AIDS (PLWHA) in the Aceh region offers unique insights, indicating existing issues in the community environment. However, a comprehensive understanding of these issues is still lacking. This study aims to explore the challenges related to the Acehnese people's perspective towards PLWHA.

**Method:** A qualitative ethnographic design was employed, focusing on the subjective approach to understanding the perspectives of the Acehnese Community. In-depth interviews were conducted with 8 participants. The researcher served as a human instrument, directly involved in collecting and interpreting the data. Data were analyzed descriptively using iterative coding and thematic categorization.

**Result:** The study identified three themes related to the perspective of the community on People Living with HIV/AIDS (PLWHA): (1) Community Knowledge regarding HIV/AIDS and PLWHA, (2) Experiences of the Acehnese Community with HIV/AIDS and PLWHA and (3) Community Values towards HIV/AIDS and PLWHA. Individuals with knowledge about HIV/AIDS can provide proper care for PLWHA patients, fostering an understanding of transmission dynamics. Society exhibits positive attitudes towards PLWHA when exposed to sufficient information. Conversely, negative perceptions arise when society attributes the disease to certain behaviors or considers it as a curse, leading to non-acceptance and ostracism. The perspectives imposed on PLWHA significantly influence their perception of the surrounding community. Community knowledge is crucial in shaping these perspectives, particularly from individuals with experience caring for PLWHA. Society holds both positive and negative values concerning HIV/AIDS and PLWHA.

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## INTRODUCTION

Individuals facing health issues in Aceh Besar District are often stigmatized by the community, even for their own biological children. This leads to expulsion and ostracism from their family environment. One example is a child who was diagnosed with HIV/AIDS and was insulted and expelled from their family. In the Acehnese dictionary, the term "budok" refers to leprosy and carries a strong negative connotation, often associated with disdain and exclusion.(1) Budok disease is incurable, and those affected should be isolated. Parents warn children to stay away from them to avoid getting infected.

Formerly known as leprosy, Budok disease, also called elephantiasis, was prevalent in Aceh Besar Regency, leading to the isolation of affected individuals. The disease is now associated with HIV/AIDS. Aceh

Province is a unique region granted special authority to regulate and manage the government and local community interests based on the 1945 Constitution of the Republic of Indonesia. This has led to special regulations, including penalties such as flogging for violators of Sharia law. The penalty serves as a deterrent for individuals violating Sharia rules related to illicit closeness, adultery, gambling, and other actions that are not in accordance with the Sharia regulations.(2)

The occurrence of HIV/AIDS cases in Aceh Province has drawn significant attention from the Aceh government. In 2009, there were 40 reported cases of HIV/AIDS. However, by 2017, the incidence rate had surged to 408 cases, with an additional 111 cases reported in a year.(3) HIV/AIDS cases are increasing significantly in several areas of Aceh province. This

could lead to negative perceptions from communities with strong cultural ties. In 2018, there were 640,000 diagnosed cases of HIV in Indonesia. The current incidence rate is 1 per 1,000 people, with a yearly increase of 0.17%. Deaths from HIV/AIDS-related diseases have increased by 60% since 2010.(3) HIV/AIDS has garnered public attention due to its uncontrolled prevalence, with rates continuing to increase until 2019. Global information dissemination about the disease remains limited, contributing to a lack of understanding regarding transmission and prevention. This insufficient exposure fosters fear of interacting with those affected by HIV/AIDS, which in turn perpetuates societal stigma towards individuals or groups impacted by the disease.(4)

People Living with HIV/AIDS, commonly referred to as PLWHA in Aceh society, continue to be associated with negative perceptions. These opposing perspectives persist even within healthcare facilities and among healthcare professionals providing health services.(5) The issue leads to discrimination against PLWHA in healthcare services and preventive treatments.(6) The government has attempted to address these negative perceptions by empowering the community through communication, information, and education, enhancing religious understanding, and strengthening family resilience through religious values and prevailing cultural norms.(2) Cases of PLWHA in several regions give rise to stigma. For example, in Saudi Arabia, the stigma surrounding PLWHA is attributed to a culture that firmly adheres to religious values and the belief that HIV is a divine punishment.(7) Research articles from various cultures consistently highlight stigma towards PLWHA, indicating widespread occurrences within specific communities tied to distinct cultural groups. In Australia, the stigma against PLWHA is rooted in cultural values shaped by the fear of HIV infection, driven by concerns about its rapid and unrestricted transmission.(8) In Brazil, the stigma places PLWHA in a specific stratum within the community due to actions that contradict cultural values, leading them to be perceived as part of a marginalized group.(9)

Every group develops unique perspectives through communication among its members. These perspectives shape how group members interpret their experiences, with judgments influenced by the definition of situations as positive or negative. According to Becker, these perspectives affect individual views on community issues and contribute to cultural dynamics.(10) Transcultural nurses play a critical role in bridging the gap between public and professional nursing care. They focus on the comparative analysis of culture and subculture, addressing beliefs about health, illness,

and societal values. The aim is to apply nursing knowledge to provide culturally sensitive care for specific groups. Acting as advocates, these nurses employ a health promotion approach, serving as role models while effectively assessing perspectives on individuals living with HIV/AIDS.

The Aceh community's perspective on PLWHA has raised concerns for the author, reflecting an ongoing issue in the community. The complexity of the root causes suggests an incomplete understanding of the situation. To address this, the author advocates for a more comprehensive study of the Acehnese community's viewpoint on PLWHA. Using Leininger's model theory, an ethnographic approach is proposed to delve into the Acehnese community's background. This approach aims to facilitate a deeper understanding of prevailing beliefs and values and to illustrate their perspective on PLWHA. The research objective is to uncover the challenges related to the Acehnese community's perspective on People Living with HIV/AIDS (PLWHA).

## **METHOD**

### **Research design**

This research is a qualitative study designed to reveal the perspective of the Acehnese community towards people living with HIV/AIDS (PLWHA). The study employs a qualitative ethnographic design, focusing on the Acehnese community's perspective through a subjective approach. This approach seeks to depict how the Acehnese community interprets PLWHA in Aceh Province and to understand how participants hear, see, feel, decide, and evaluate occurrences involving PLWHA in Aceh.

### **Setting and samples**

The subjects in this study are prominent figures in the Aceh community, recognized for their credibility among the people and the government, and considered to have expertise in the situation and conditions relevant to the research theme. The subjects include key informants (village head, representatives from the Aceh cultural office, Aceh history experts, health center workers) and supporting informants (community members and traditional leaders). Participants were selected through purposive sampling, with the researcher determining the sample criteria beforehand.

### **Measurement and data collection**

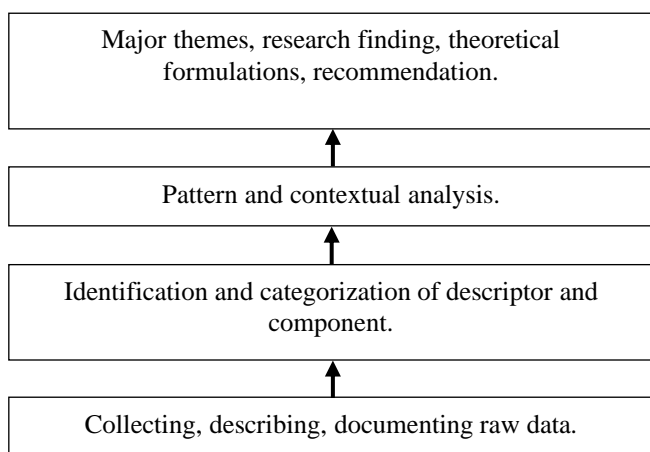
The instrument used in this research is a human instrument (the researcher) directly involved and serves dual roles and functions as the main tool in the study. Since the researcher is a beginner with limited proficiency in conducting interviews, in-depth interviews were

conducted to explore common key topics and understand the meanings expressed by participants.

The main question posed during the interviews was: "As a member of the Acehnese community, what is your perspective on individuals with HIV/AIDS?" This question was designed to encourage participants to provide information as broadly as possible, reflecting their personal views as members of the Aceh community, particularly if they had family members affected by HIV/AIDS. If participants were unable to provide comprehensive information, the researcher followed up with additional questions developed from the participants' main statements. These follow-up questions were crafted to ensure the interviews reached a saturation point, thoroughly exploring the participants' perspectives.

### Data analysis

The data analysis focuses on evolving data by repeatedly reading field notes and transcriptions of the acquired data. The ethnographic study aims to describe events and developments observed in the field, enabling interpretation and comparison in alignment with the research objectives.



**Figure 1.** Data analysis

The data analysis commences with a thorough examination of detailed raw data, including transcribed interviews, on-site observations, participatory experiences, and notes. Data is coded and categorized in the second phase based on interview questions. The third stage involves scrutinizing the data for recurring patterns and achieving idea saturation to understand individuals' values, beliefs, and practices in their environmental context. The author analyzes and interprets the data in the final phase, confirming the main themes, caregiving actions, and decisions. While face-to-face follow-up interviews are preferred, telephone calls or emails are used during the

pandemic to clarify interpretations, meanings, and findings.

### Trustworthiness/rigor

Ensuring trustworthiness in qualitative research involves critical elements, such as validity and reliability.(11) Trust is established by accurately representing participants' experiences. Four criteria—credibility, dependability, confirmability, and transferability—are employed to assess the validity of the data.(12)

### Ethical considerations.

Approval for ethical considerations was obtained from the Ethics Committee at Universitas Padjadjaran under reference number 268/UN6.KEP/EC/2023. The researchers elucidated the research objectives throughout the recruitment and interview processes. Participants provided written consent, and verbal consent was additionally obtained via WhatsApp before the interviews were conducted.

## RESULT AND DISCUSSION

### Participant Characteristics

Eight individuals participated in this research. The first participant is a 43-year-old male civil servant employed at the Aceh Provincial Health Office. The second participant is a 44-year-old male a civil servant. The third participant is a 65-year-old academician who works as an educator. The fourth participant is a 30-year-old male religious leader. The fifth participant is a 30-year-old female healthcare professional at the Regional General Hospital of Aceh Province. The sixth participant is a 30-year-old male representing the youth of Aceh and serving as a member of the village election committee. The seventh participant is a 30-year-old male serving as a Tuhapeut (village official). The eighth participant is a 30-year-old female healthcare professional at the Aceh Province Regional General Hospital .

### Thematic Analysis

Thematic analysis was employed in this study to identify, analyze, and report themes from the collected data. This method is widely used in qualitative nursing research to detect patterns or extract key themes.(13) The research findings revealed the perspectives of the Aceh community towards PLWHA in Aceh, categorized into three main themes. The identified themes in this research are based on determinant factors influencing the Aceh community's perspective on PLWHA. These themes include 1) Community Knowledge regarding HIV/AIDS and PLWHA, categorized into two sub-themes: a)

Community with Knowledge about HIV/AIDS and PLWHA, b) Community without Knowledge about HIV/AIDS and PLWHA, 2) Experiences of the Acehese Community with HIV/AIDS and PLWHA, 3) Community Values towards HIV/AIDS and PLWHA, further divided into two sub-themes: a) Positive Values of the Aceh Community towards HIV/AIDS and PLWHA, b) Negative Values of the Aceh Community towards HIV/AIDS and PLWHA.

### **Theme 1: Community Knowledge regarding HIV/AIDS and PLWHA**

Community perspectives on HIV/AIDS and PLWHA are significantly influenced by the information available. Participant expressions highlight this theme, emphasizing their understanding of HIV/AIDS, including its transmission mechanisms and groups at risk. The findings within this theme are categorized into two sub-themes based on participants' expressions, specifically focusing on their levels of knowledge about HIV/AIDS and PLWHA.

#### **Community with Knowledge about HIV/AIDS and PLWHA**

This sub-theme emerged from participants' statements indicating that certain community members possess a good level of knowledge about HIV/AIDS and PLWHA. Several factors contribute to this understanding, including education, exposure to information, and personal or professional experiences. These insights are reflected in the expressions of the first, third, fifth, and eighth participants, as follows:

*“Daily, I work as a manager for HIV/AIDS prevention programs in Aceh. The distribution of People Living with HIV/AIDS (PLWHA) in Aceh is almost similar to other regions in Indonesia. However, the prevalence is slightly lower in Aceh compared to North Sumatra, Java, and Papua. However, cases of HIV/AIDS in Aceh are not uncommon; it is not something new. The first case of HIV/AIDS in Aceh was identified in 2005 in the Bireun Regency.” (P1)*

*“HIV is no longer unfamiliar in our society, especially among those around us. In the academic world, we frequently discuss issues related to HIV/AIDS that often occur in the community.” (P3)*

*“I, as a nurse in the operating room of the Regional General Hospital in the Province of Aceh, have cared for patients with HIV/AIDS, even though there are rare cases of people living with HIV/AIDS (PLWHA). Nevertheless, I have attended to 1-2 individuals in the past.” (P5)*

*“If in hospitals, I never meet [them], but for example, I did work at the community health center (Puskesmas), there were incidents in remote areas in Nagan Raya Regency.” (P8)*

The participants have knowledge and experience in caring for PLWHA, which has helped them understand the transmission methods. This knowledge has also contributed to preventive efforts by stakeholders, as expressed by some participants.

*“We are making efforts to control them, including promoting a clean and healthy lifestyle together and avoiding risky sexual behaviors. Moreover, if they engage in risky behaviors, we hope they dare to take risks and get tested.” (P1)*

*“That is why we provide education, for example, through the children we educate here. During community service programs, when there is something like that, we assign them to areas where they can provide education about HIV.” (P3)*

*“Maybe my colleagues, be more cautious in your actions towards patients because we might not know if these patients have a history of HIV or not. As we mentioned earlier, it might not have been detected when entering a room, so the completeness of Personal Protective Equipment (PPE) for procedures should be used as best as possible.” (P5)*

*“If in the room, I mean, this hospital, for HIV patients, they have a separate room, yes, a particular space. However, regarding taking care of them, our vigilance is higher regarding implementation. And as for discrimination, maybe not. We focus more on patients with high infectious and high-risk infections or something like that. So, for protocols, we are more meticulous like that.” (P8)*

The preventive attitudes expressed by the participants above, such as promoting clean and healthy living within the community, conducting educational outreach in villages, and emphasizing caution in medical procedures (e.g., the use of Personal Protective Equipment [PPE]), highlight a proactive approach to prevention. Furthermore, these preventive attitudes are also reflected in the general public, particularly among those with higher levels of education, better access to accurate information, and sufficient knowledge about HIV/AIDS and PLWHA. This perspective is evident in the responses provided by the sixth and seventh participants, as follows:

*“I, as a young person, believe that there should be at least some education, be it in schools or elsewhere, to introduce the fact that HIV is like this.” (P6)*

*“The breakthroughs that the government has implemented, as I mentioned earlier, such as premarital counseling, may already be applied throughout Indonesia as standard socialization. This should continue to be promoted, not only within the community but also within the school environment, as sex education should not be considered taboo in society; there must be a separate understanding.” (P7)*

Based on the participants' expressions, it is suggested that education on preventing HIV/AIDS should be introduced to underage children, with a focus on understanding the reproductive system. Additionally, there is a need for public awareness campaigns about HIV/AIDS and PLWHA to improve general knowledge

#### **Community without Knowledge about HIV/AIDS and PLWHA**

On the other hand, the interview results reveal that some communities still lack awareness and understanding of HIV/AIDS and PLWHA. This was expressed by the second and fourth participants, as follows:

*“The HIV disease is considered a disgrace; as a cultural enthusiast, I have never been aware of it. Even if there is data from the government, it might be released for what purpose—perhaps for research with an orientation towards health education, or it could be for research.” (P2)*

*“Regarding HIV/AIDS, lately, I personally, both through social media and in person, rarely hear about this disease, even though it has been circulating for several years on social media. As far as I know, I do not have much information about HIV/AIDS, especially since I have never personally encountered someone with it.” (P4)*

*“Concerning HIV/AIDS or people with HIV/AIDS symptoms, I may have read or heard about it, but I have never interacted with such individuals. They tend to keep things secretive, so I have not had the chance to engage with them.” (P6)*

*“Yes, I have heard about and am aware of HIV/AIDS, but I do not know much because I have never seen it directly.” (P7)*

From several expressions of the participants above, it is evident that there are communities in Aceh with a less-than-adequate level of understanding and knowledge regarding HIV/AIDS and PLWHA. Information dissemination and education through social media and health education are crucial for the community to comprehend HIV/AIDS and PLWHA.

#### **Theme 2: Experiences of the Aceh Community with HIV/AIDS and PLWHA**

This theme is based on the expressions of participants who have firsthand experience with PLWHA and are knowledgeable about HIV/AIDS. Experience serves as a form of deeper understanding of PLWHA and HIV/AIDS, as articulated by the first, third, and fifth participants, as follows:

*“Almost 80% of HIV/AIDS patients in Aceh are males, with the majority engaging in high-risk sexual behavior, particularly men who have sex with men. Some cases occur within Islamic boarding schools (day), within the institution itself, or involve individuals we have interviewed or approached. In the case of sex with men, when they trust us and feel close, they open up about their information.” (P1)*

*“There was a case of a newlywed couple where the husband was discovered to be HIV-positive, and the wife was unaware. Only three months into their marriage, the husband experienced symptoms such as diarrhea, nausea, and vomiting. He was then referred to the hospital, where examinations revealed that he had HIV.” (P3)*

*“In my experience as a nurse at the Regional General Hospital of Aceh Province, when a patient is diagnosed with HIV/AIDS, we immediately monitor and provide specialized care.” (P5)*

*“In a health center, there was an incident in remote areas of Nagan Raya Regency where a family, unaware of the husband's HIV status, continued with regular prenatal check-ups. It was later discovered that the woman was HIV-positive. We investigated further, suspecting the transmission might be linked to her husband. In the area where I live, many outsiders, such as those from Sumatra, frequently visit Aceh.” (P8)*

Based on the statement that there are several cases of HIV/AIDS in Aceh Province, with almost 80% of them being cases of Male-to-Male Sexual Transmission, there are also instances involving married couples. Additionally, specialized care is provided by healthcare professionals for PLWHA treated at the hospital.

Furthermore, PLWHA cases are also managed at a community health center in one of the remote villages in Aceh, with healthcare professionals from the hospital overseeing the care. Most of those with experience are stakeholders who have either cared for or accompanied PLWHA patients. With their valuable experience and knowledge, these stakeholders are able to effectively describe the incidents they have encountered. Moreover, the first participant expressed that support and care for PLWHA have already been developed in Aceh Province.

*“Moreover, now, treatment, care, and support for patients with HIV/AIDS is available at the PDP clinic (Treatment Support Care) – so there are already many PDP clinics in Aceh, a total of 48 PDP clinics in Aceh.” (P1)*

Based on the participants' expressions above, such as those who are directly involved with PLWHA—including healthcare professionals, academics, and practitioners actively engaged in preventing and managing HIV/AIDS cases in Aceh—there has been growing support for PLWHA in terms of prevention, treatment, and care.

### **Theme 3: Community Values towards HIV/AIDS and PLWHA**

This theme emerges from the values expressed by participants regarding HIV/AIDS, which lead to ideas generated by participants about HIV/AIDS and PLWHA. These ideas influence the actions of participants regarding their perspectives on PLWHA. Within this theme, there are two supporting sub-themes: positive values towards HIV/AIDS and PLWHA, and negative values towards HIV/AIDS and PLWHA.

#### **Positive Values of the Aceh Community towards HIV/AIDS and PLWHA**

This sub-theme is motivated by the expressions of some participants who consider HIV/AIDS and PLWHA to be topics that are not taboo in society. These values reflect the attitudes and behaviors of the community towards PLWHA. In the past, there was a disease referred to as "budoek," which in the Acehnese language signifies a "curse." However, the participants' expressions regarding HIV/AIDS or PLWHA cannot be linked to the "budoek" disease. As expressed by the first participant, the third participant, and the fifth participant:

*“HIV is different from the term "budoek" disease; for people with HIV (PLWHA), there is no quarantine or grouping like the "budoek" disease. Now, the cases in Aceh involve individuals within their own families.” (P1)*

*“In my opinion, "budoek" is related to leprosy, and leprosy has no connection with HIV because HIV results from unclear human relationships. In contrast, leprosy and kusta are caused by a virus that infects a person, leading to the conditions of leprosy or kusta.” (P3)*

*“I've heard about it before, even before I worked as a nurse. So, the disease, as people commonly say, those who have "budoek" disease were even isolated because they believed it could be contagious. However, HIV/AIDS is different from "budoek" disease because it is not as easily transmitted; for example, mere skin contact does not lead to transmission. It spreads through the bodily fluids of the patient.” (P5)*

Based on the interview results, it can be concluded that there is a positive perception of the community towards PLWHA. This positivity is attributed to sufficient exposure to information, leading to sound knowledge and experiences regarding HIV/AIDS and PLWHA. Additionally, participants believe that the term "budoek" is unrelated to PLWHA, as it refers to a disease from the past. Furthermore, participants expressed the view that individuals with HIV/AIDS and PLWHA should receive strong social support from the community and should not face negative stigma or discrimination. The first, third, fifth, sixth, and seventh participants share this sentiment.

*“So, the essence is that with trust, we assure them that we won't disclose their status, and if they are positive, they will be given access to treatment so that we can be friends in dealing with HIV/AIDS.” (P1)*

*“Ideally, we shouldn't isolate them too much but rather provide guidance, directing them towards a more positive outlook, especially for those affected by HIV.” (P3)*

*“For nurses and the community, if there is a patient with HIV/AIDS, there's no need to ostracize them, no need to distance ourselves. We can be friends and not discriminate against them anymore.” (P5)*

*“However, even if we base our relationships or friendships on that person, it's normal because we shouldn't discriminate against someone, even though their limitations or this situation is a test from Allah.” (P6)*

*“Of course, we will respond like that, meaning we will maintain social relationships as usual, not considering it a societal problem.” (P7)*

The participants' expressions above indicate that society should no longer practice stigma and discrimination. PLWHA should receive support from the community, including expressions of friendship such as care and empathy from the participants towards PLWHA. Furthermore, the support provided by the participants to PLWHA is expressed through positive actions, as stated by the second, fourth, and seventh participants, namely:

*"If someone is already infected, as you mentioned, repent to Allah and return to the right path. We must sincerely hope for healing with the immense help of Allah. We seek assistance from Allah, as there is no help from others."* (P2)

*"If one is afflicted with this disease, try seeking forgiveness (istighfar) and engage in charity. The Prophet once said to treat the sick around us by giving charity. Hopefully, through abundant charity and seeking forgiveness, Allah will accept our repentance and lift the disease, placing us among those Allah is pleased with."* (P4)

*"Even if we are judged as individuals infected with this disease, and even though people may make us scapegoats, let's think positively. Let's continue positively impacting others and offering new hope, even if it means inspiring others."* (P7)

Participants expressed ideas in the form of hopes through the spiritual values of religion. They also encouraged PLWHA to accept their fate with qualities such as patience, sincerity, and acceptance. Additionally, there were expressions of hope from stakeholders towards PLWHA, as conveyed by the first, second, and third participants, who stated that:

*"As part of the healthcare team, we hope this case becomes more controlled, so one of the control efforts is to promote clean and healthy living."* (P1)

*"Yes, we hope to reduce it so that no one else gets affected by HIV. As I mentioned earlier, the only way is always to conduct education in villages in the districts and, if possible, extend it to other districts, even if they need to become more familiar with it in the villages."* (P3)

*"For example, we hope that programs like HIV and leprosy will be available in health centers. Screening should be more precise from the grassroots level because it becomes more about treatment than screening once it reaches the hospital. In the Emergency Department, there*

*is no longer HIV screening. So, the hope is that screening is improved, especially at the village level."* (P8)

The form of hope expressed is through encouraging awareness and ongoing education about HIV/AIDS to the community and other stakeholders who may have limited exposure to information, both directly and through social media. This is achieved through counseling and socialization carried out by active and knowledgeable younger generations about HIV/AIDS. Additionally, healthcare professionals promote a clean and healthy lifestyle within the community as a preventive measure against HIV/AIDS. The same effort extends to PLWHA and primary healthcare services, aiming to enhance screening for patients visiting health centers to enable early detection of HIV/AIDS. Participants also emphasized that screening should be conducted as early as possible, with one of the government programs being pre-marital HIV screening, as mentioned by the eighth participant.

*"The breakthroughs that the government has already implemented, such as pre-marital counseling, may have been applied throughout Indonesia as a socialization norm that is continuously promoted."* (P7)

*"For example, it is like, before getting married, it is a good idea for prospective couples to check their HIV status. It seems like it has just started, right? Previously, it was not a common practice, so now they check it first."* (P8)

### **Negative Values of the Aceh Community towards HIV/AIDS and PLWHA.**

This sub-theme is influenced by the community's perception of HIV/AIDS and PLWHA in Aceh, where the disease is referred to as "budoek" in Acehnese language, as expressed by the second and fourth participants:

*"The HIV disease for Acehnese people themselves and in our daily lives is a curse that cannot be advised anymore, personally within the family. Every Acehnese indeed believes it is a cursed disease."* (P2)

*"I imagine a disease like AIDS is very, very taboo in society when the terms HIV/AIDS, leprosy, or leprosy, which are terrifying diseases, are heard. It can be said that HIV/AIDS is a humiliating or cursed disease. When people hear these terms, they gossip with neighbors or whisper with their relatives."* (P4)

Based on the expressions of the two participants above, it can be inferred that this "budug" disease is

considered similar to HIV/AIDS in today's context. "Budug" is perceived as a curse within the Acehese community. The Acehese people have been familiar with this disease since ancient times, as expressed by the second and fourth participants:

*"Yes, budug is a form of karma that takes the shape of calamity. I will give it to you, who have inflicted so much suffering, to experience suffering. So, this is retribution that we never expected. Someone's ingratitude is because of a disease that occurs in their body due to cause and effect. Now, let us replace the word budug with something more global like HIV, using this language. That is also the same model, the same concept for us, especially for Muslims and particularly for Acehese people; indeed, this is considered a curse and calamity."* (P2)

*"In Aceh, there is a disease or a term for a disease known as "tauen." As far as I remember, there is also a term for the disease called "budoek." It could be something like HIV categorized as a disease like taken, or it could be called the. I often hear about the disease Budoek; it is like a term for someone who has HIV; it can be said to be Budoek. Some say that the budoek disease is similar to leprosy or Hansen's, which is difficult to cure."* (P4).

Based on the expressions of participants, it is believed that HIV/AIDS is a result of one's actions. The community perceives the disease as a consequence of harmful behavior, making HIV/AIDS a curse and karma for those affected. Consequently, society refuses to accept and ostracizes them, as expressed by the second and fourth participants, who stated:

*"They were instructed to seek treatment and quarantined first. At least they have been confined, truly repentant, genuinely praying, and regretting all actions that have violated both state and religious laws."* (P2)

*"Feeling isolated, being alone, confined to home because going out would be extremely embarrassing. They could be considered cursed or labeled as 'budok' (leprosy) by others. This becomes a topic of discussion in the community to the extent that not only going out of the house but even staying inside becomes a subject of gossip."* (P4)

Based on the participant's expression above, it is mentioned that HIV/AIDS and PLWHA are considered cursed acts that should be isolated from society and treated through quarantine or isolation from the community. This negative perception is also reflected in the opinion of the third participant, stating:

*"Some in the community even call medical professionals to their homes for HIV treatment because, according to Acehese people, this is a shameful act within the family. So, for individuals in the community facing HIV or, if known by others, they will be ostracised. Why? Because HIV is contagious, and they are afraid to be isolated elsewhere because sometimes they do not disclose that they are experiencing HIV."* (P2)

Based on the participant's expression, the family of individuals with HIV/AIDS also harbors a fear of society discovering that one of their family members has HIV/AIDS, leading them to seek treatment discreetly.

### **Community Knowledge regarding HIV/AIDS and PLWHA**

The results of this research provide an overview of the community's knowledge about HIV/AIDS and PLWHA. Knowledge is derived from awareness, which develops after an individual perceives a specific object. Perception involves the use of human senses, including sight, hearing, smell, taste, and touch. The higher the level of knowledge and understanding within the community regarding HIV/AIDS and PLWHA, the less likely irrational fears will trigger negative perspectives towards PLWHA.(14) The findings suggest that most participants who possess adequate knowledge of HIV/AIDS demonstrate a good understanding and positive attitudes towards PLWHA without fostering negative values. Participants display a proper understanding of HIV/AIDS, its modes of transmission, and prevention methods. A strong knowledge foundation about HIV/AIDS encourages participants to recognize the importance of preventing transmission to others. This suggests that as the community's knowledge of HIV/AIDS increases, their responses toward PLWHA tend to be more positive.(15)

The research also revealed that HIV/AIDS and PLWHA are no longer considered taboo subjects in society and are being discussed openly among professionals. Education levels correlate with the depth of knowledge, and those with higher education tend to have a more positive outlook on PLWHA, which, in turn, impacts community attitudes. Individuals with higher education are more likely to absorb information that influences health behaviors, such as HIV/AIDS-related information. Consequently, those with lower education levels are more prone to stigmatize PLWHA compared to individuals with advanced education.(16) The study further found that individuals with sufficient HIV/AIDS knowledge and awareness of PLWHA exhibit preventive attitudes toward the disease. Preventive behavior includes both active and passive responses to illness and disease.(17) The expressions of participants suggest that positive preventive



behavior can be fostered within the community, such as through socialization, promoting healthy living, and healthcare professionals conducting thorough screenings for patients entering healthcare facilities. These findings align with research that highlights how individuals with knowledge and a positive attitude play a significant role in the community's efforts to prevent the transmission of HIV/AIDS.

The subsequent findings of this research indicate that some communities have a low level of knowledge about HIV/AIDS, leading to negative attitudes toward PLWHA. Participants view HIV/AIDS as a stigma, which creates a negative impression within society. Additionally, social media plays a crucial role in providing information about HIV/AIDS to participants. It is important to enhance knowledge about HIV/AIDS as a form of self-protection and to cultivate a proper understanding of PLWHA. Insufficient knowledge can lead to misguided precautionary attitudes. This suggests that a lack of knowledge about HIV/AIDS contributes to increased stigma and discrimination against PLWHA.(18)

Knowledge is a key factor in determining attitudes and behaviors toward PLWHA. The Indonesian Demographic and Health Survey highlights that education levels and media exposure significantly influence an individual's knowledge and attitude. Therefore, there is a need to enhance knowledge through education and media exposure to reduce rejection and negative attitudes toward PLWHA. However, knowing alone is not enough to shape one's attitude or actions; it requires support from an individual's understanding and the ability to apply this knowledge in real-life situations.(19)

Another key finding of this study is that information about HIV/AIDS and PLWHA can be effectively disseminated through socialization and education, particularly in remote villages. This approach aims to provide sufficient insight and knowledge about HIV/AIDS and PLWHA. Comprehensive education, whether through counseling or awareness campaigns, is crucial for eliminating stigma and discrimination, and for enhancing public understanding of HIV/AIDS.(20)

### **Experiences of the Acehese Community with HIV/AIDS and PLWHA**

The findings of this research also suggest that the community's experiences with HIV/AIDS and PLWHA significantly influence their perspectives on PLWHA. Experience is understood as something encountered, lived through, or felt, whether recently or in the past. It can also be defined as episodic memory, which refers to the recollection of events experienced by an individual at a specific time and place, serving as a reference for autobiographical memory.(21) Every individual has a

different experience, even when observing the same object. This variation is influenced by factors such as the individual's level of knowledge and education, background, and the specific context in which the experience occurs. Factors like age, education level, socioeconomic background, culture, physical environment, occupation, personality, and life experiences also shape one's perception and understanding.(17)

The findings of this study reveal that personal experiences serve as a deeper source of knowledge regarding PLWHA and the disease itself. Participants who have encountered and cared for PLWHA patients perceive HIV/AIDS as a common issue rather than a recent development in Aceh. The first cases were identified as early as 2005, and currently, there are 48 Treatment Support Care clinics spread across the Aceh province.

Healthcare facilities for PLWHA, especially in Aceh, have expanded, providing better access to treatment and support. The availability of effective referrals to health facilities that offer Antiretroviral Therapy (ART)—along with care, treatment, and prevention services—is essential following an HIV diagnosis. Observational studies conducted on key populations, such as Female Sex Workers, Men who have Sex with Men, and Injecting Drug Users in four cities in Indonesia, show that the likelihood of initiating ART is higher when testing is conducted at a facility that also offers prevention, care, support, and treatment (PDP) services. This aligns with the responsibilities of primary healthcare units, which are tasked with providing comprehensive PDP services for TB-HIV patients, including counseling for HIV testing, preventive treatment for opportunistic infections, and other related services.

### **Community Values towards HIV/AIDS and PLWHA**

In the discussion of this research theme, two sub-themes were identified: positive societal values towards HIV/AIDS and PLWHA (People Living with HIV/AIDS), and negative societal values towards HIV/AIDS and PLWHA. Participants expressed positive values in the form of support and hope. These positive values were influenced by their knowledge and sufficient exposure to information about HIV/AIDS and PLWHA. Participants also tended to be more open towards PLWHA. Moreover, after learning about the infection history of PLWHA, personal empathy emerged as a deterrent to negative stigma, as not all infections resulted from actions that violated societal norms or religious rules.(22) The subsequent findings in this research reveal that ideas of hope, expressed by participants from various stakeholders, were shaped by religious values and the expectations placed on PLWHA. Spiritual values have a significantly positive impact on PLWHA. The findings also indicate a

significant correlation between the level of religious practice of HIV/AIDS patients and their well-being. Therefore, the religious values expressed by the stakeholders represent a form of positive support for PLWHA.(23)

Additionally, participants expressed support and hope for PLWHA, particularly emphasizing the importance of self-acceptance by those living with the disease. This suggests that the higher the social support from the community towards PLWHA, the lower the stigma experienced or perceived by PLWHA themselves.(24) The research findings clearly show that participants hope to control HIV/AIDS cases in Aceh, emphasizing the need for increased community outreach, especially among adolescents, to raise awareness about HIV/AIDS transmission and prevention. HIV/AIDS counseling activities primarily aim to enhance knowledge about prevention and the consequences of the disease. These sessions are designed to improve understanding and awareness among community members.(25) Furthermore, changes in knowledge about HIV/AIDS were observed in students after receiving educational counseling on the disease. The results indicate that counseling significantly influences students' knowledge and attitudes towards HIV/AIDS.(26)

The subsequent findings reveal that participants expressed a desire for improved early screening through primary healthcare services, such as community health centers (puskesmas), especially for patients presenting symptoms of HIV/AIDS. HIV screening is essential for self-detection or identifying health issues early. Participants suggested that early HIV/AIDS screening could be extended to prospective pre-marital partners. Mandating pre-marital HIV testing is considered one of the most effective measures to prevent HIV transmission, particularly within the family context. Knowing one's HIV status early allows for various efforts to prevent transmission. Prospective parents can reduce the risk of HIV transmission to their children by knowing their HIV status early. Early HIV diagnosis has the potential to reduce morbidity, mortality rates, and the spread of HIV. Therefore, mandating pre-marital HIV testing is seen as a practical and beneficial measure to protect families from HIV infection.(27)

The findings of this research highlight negative societal perceptions toward HIV/AIDS and people living with HIV/AIDS (PLWHA). Participants view HIV/AIDS as a "budoek" disease, a term that has existed in Acehnese culture for centuries. This disease is seen as a curse, a form of retribution, or karma, manifesting as a calamity. "Budoek" is believed to be an affliction that results from cause and effect, often interpreted as the consequence of deviating from religious principles or exceeding human

limits. As a result, participants perceive HIV/AIDS and PLWHA as a form of punishment, leading to societal rejection and ostracism. Discriminatory attitudes, stigmatization, and the marginalization of PLWHA are often fueled by social perceptions, moral judgments, and religious beliefs within the family and community. Many view HIV/AIDS as a cursed disease, justifying the expulsion of affected individuals from homes and their isolation from society. This stigma is comparable to the situation in Saudi Arabia, where the cultural and religious context also associates HIV with divine punishment.(7)

## **CONCLUSION**

The perspectives toward people living with HIV/AIDS (PLWHA) significantly influence how these individuals perceive their surrounding community. The level of community knowledge, especially from those with experience in caring for PLWHA, plays a crucial role in shaping these perspectives. Society holds both positive and negative values toward HIV/AIDS and PLWHA, with these values affecting how individuals with HIV/AIDS are viewed and treated.

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## **Conflict of Interest**

The authors declare no conflicts of interest.

## **REFERENCES**

1. Daud, B. and Durie, M. Kamus Basa Ach-Kamus Bahasa Aceh: Acehnese-Indonesian-English Thesaurus. Pacific Linguistics, The Australian National University, 1999.
2. DPR Aceh. Qanun Aceh Nomor 11 Tahun 2013 Tentang Kesejahteraan Sosial [Internet]. 2013. Available from: <https://aceh.bpk.go.id/wp-content/uploads/2014/08/Qanun-Aceh-Nomor-11-Tahun-2013-tentang-Kesejahteraan-Sosial1.pdf>
3. UNAIDS. Global HIV & AIDS statistics-fact sheet. Available from: <https://www.unaids.org/en/resources/fact-sheet>
4. Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, et al. HIV-related stigma among people with HIV and their families: A qualitative analysis. *AIDS Behav.* 2008;12(2):244–54.
5. Haryanti. Perception of People Living with HIV/AIDS on Social Stigma of HIV/AIDS in Sukoharjo District. *KesMas.* 2018;13(3).

6. CDC. HIV among Gay, Bisexual, and Other Men Who Have Sex With Men (MSM). Atlanta: Center for Disease Control & Prevention; 2010. Available from: <https://www.cdc.gov/hiv/topics/msm/pdf/msm>
7. Omer T, Lovering S, Shomrani M Al. The lived experience of living with HIV/AIDS in the western region of Saudi Arabia. *Divers Equal Health Care*. 2014;11(4):215–24.
8. Herrmann S, McKinnon E, Hyland NB, Lalanne C, Mallal S, Nolan D, et al. HIV-related stigma and physical symptoms have a persistent influence on health-related quality of life in Australians with HIV infection. *Health Qual Life Outcomes*. 2013;11(1).
9. Ferraz D, Couto MT, Zucchi EM, Calazans GJ, dos Santos LA, Mathias A, et al. AIDS- and sexuality-related stigmas underlying the use of post-exposure prophylaxis for HIV in Brazil: findings from a multicentric study. *Sex Reprod Health Matters*. 2019;27(3).
10. Deddy. *Metodologi penelitian kualitatif*. Bandung: PT Remaja Rosda; 2013.
11. Speziale H. S, Carpenter D. R. *Qualitative research in nursing: advancing the humanistic imperative* (3rd ed.). Philadelphia : Lippincott Williams & Wilkins; 2003.
12. Priest HM. Essentials of nursing research: methods, appraisal, and utilization. *Nurse Researcher*. 2006;13:91–92.
13. Braun V, Clarke V. *Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology*. *Qual Res Psychol*. 2006;3(2):77–101.
14. Youssef L, Hallit S, Sacre H, Salameh P, Cherfan M, Akel M, et al. Knowledge, attitudes and practices towards people living with HIV/AIDS in Lebanon. *PLoS One*. 2021;16(3):e0249025.
15. Meganwati. Hubungan Tingkat Pengetahuan Dan Persepsi Dengan Stigma Masyarakat Terhadap Odhaberdasarkan Usia Dan Pendidikan Di Indonesia. *Nusantara Hasana Journal*. 2021;20(1).
16. Berek PAL, Bubu W. Hubungan Antara Umur, Jenis Kelamin, Pendidikan Dan Pekerjaan Dengan Stigmatisasi Terhadap Orang Dengan HIV/AIDS di RSUD Mgr. Gabrielmanek,Svd Atambua. *Jurnal Sahabat Keperawatan*. 2019;1(02):36–43.
17. Notoatmodjo. *Ilmu Perilaku Kesehatan*. Jakarta: Rineka Cipta; 2014.
18. Utami WN, Hutami MS, Hafidah F, Pristya TYR. Faktor-faktor yang Berpengaruh terhadap Stigma dan Diskriminasi kepada ODHA (Orang Dengan HIV/AIDS): Systematic Review. *Prosiding Forum Ilmiah Tahunan (FIT) IAKMI*. 2020;1(1):25–6.
19. Sri Wahyuni AS, Ronoatmodjo S. Hubungan Antara Pengetahuan HIV/AIDS dengan Sikap Penolakan Terhadap Orang Dengan HIV/AIDS (ODHA) Pada Masyarakat Indonesia (Analisis Lanjut Survei Demografi dan Kesehatan Indonesia 2012). *Jurnal Kesehatan Reproduksi*. 2017;8(1):41–52.
20. Asra E, Supriyatni N, Mansyur S. Stigma terhadap Orang dengan HIV dan AIDS (ODHA) pada Masyarakat di Kelurahan Kayu Merah Kota Ternate Tahun 2019. *Jurnal Biosainstek*. 2020;2(01):47–57.
21. Saparwati M, Sahar J, Mustikasari. Pengalaman kepala ruang dalam mengelola ruang rawat inap di RSUD ambarawa. *Prosiding Konferensi Nasional PPNI Jawa Tengah 2013* . 2013;1–5.
22. Pratiwi NK. Peduli HIV/AIDS: Eliminasi Stigma terhadap ODHA. *JCSE: Journal of Community Service and Empowerment*. 2021;2(2).
23. Andrianto MB. Praktik Keagamaan pada Penderita HIV/AIDS. *Jurnal Kesmas Aselepius*. 2021;3:34–40.
24. Erlina E, Mixrova S. Hubungan Dukungan Sosial dengan Stigma pada Orang dengan HIV/AIDS (Odha) di Kabupaten Purbalingga. *SENTRI: Jurnal Riset Ilmiah*. 2022;1(1):202–14.
25. Zakiyyah N, Triansari A, Uli L, Astuti DP. Penyuluhan HIV/AIDS untuk Meningkatkan Pengetahuan terhadap Pencegahan Penularan dan Akibatnya. *The 8th University Research Colloquium 2018*. 2018;184–8.
26. Eso A. Pengaruh Penyuluhan HIV/AIDS Terhadap Peningkatan Pengetahuandan Sikap Siswa Siswi Sekolah. *Jurnal Ilmiah Kesehatan*. 2019;2(13):88–96.
27. Fahrurrajib. *Wajib Skrining Tes Hiv Pra-Nikah sebagai Upaya Pencegahan Penularan HIV dalam Keluarga Keluarga [Internet]*. 2018; *The 3rd UGM Public Health Symposium*. Available from: <https://media.neliti.com/media/publications/260345-none-a242f49d.pdf>