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International Journal of Medical Science and Dental Health (ISSN: 2454-4191)
Volume 11, Issue 05, May 2025,
Doi https://doi.org/10.55640/ijmsdh-11-05-04

Phenomenological Study of HIV Patients' Experiences of Care, Support and Treatment in Banda Aceh City

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Received: 13 May 2025, **accepted:** 17 May 2025, **Published Date:** 22 May 2025

ABSTRACT

HIV is a chronic disease that affects not only physical health but also causes profound psychosocial stress. The Care, Support, and Treatment (CST) services are a comprehensive strategy provided to improve the quality of life of people living with HIV (PLHIV). However, the success of CST programs largely depends on how PLHIV perceive and experience these services in their daily lives. This study aims to deeply explore the lived experiences of people living with HIV in accessing CST services in Banda Aceh, focusing on their care experiences, forms of social and emotional support, and the dynamics they face in obtaining treatment. This study employed a qualitative approach with a phenomenological method. Six informants—including active PLHIV, outreach workers, CST officers, and health department staff—were selected purposively. Data were collected through in-depth interviews and observation, then analyzed thematically with the aid of NVivo 12 software to uncover the subjective meanings of their experiences. Three main themes emerged. First, the experience of receiving CST services revealed a sense of satisfaction with medical care, although some technical and emotional challenges were still present. Second, social and emotional support from family, healthcare providers, and community groups played a crucial role in strengthening psychological resilience. Third, in the treatment process, informants encountered challenges such as limited access, therapy side effects, and concerns about stigma, yet they demonstrated strong commitment to treatment adherence. This study emphasizes the need for a more humane, empathetic, and holistic approach to CST services. Sustainable social support, effective communication, and assurance of confidentiality are key elements in improving the quality of life of people living with HIV.

KEYWORDS: HIV, Lived Experiences, Care, Support, Treatment, Phenomenology.

INTRODUCTION

Human Immunodeficiency Virus (HIV) remains one of the most complex global health challenges of the 21st century. By the end of 2023, an estimated 39.9 million people were living with HIV worldwide, with 1.3 million new infections and 630,000 AIDS-related deaths recorded in the same year. Although significant progress has been made, such as a 39% reduction in new infections and 51% in deaths since 2010, disparities in access to services persist, particularly in low-middle-income countries (Patel et al., 2020).

Southeast Asia, including Indonesia, contributes 6.7 million HIV cases, placing this region as the third epicenter after Sub-Saharan Africa (Adriansyah & Firdausi, 2018).

Indonesia is one of the countries with the highest number of HIV/AIDS cases in the world. This causes HIV to remain a public health burden in Indonesia (Ayubbana et al., 2022). The first HIV case was discovered in Indonesia in April 1987. Within 10 years since it was first discovered, at the end of 1996 the number of positive HIV cases reached 381 and 154 AIDS cases (Balatif, 2020).

The increase in cases in Aceh Province also continues to increase as seen from the Aceh Health Service Report (2022), where HIV cases in 2021 were 155 cases and increased to 210 cases in 2022. The highest HIV cases in Aceh, namely, Banda Aceh City ranked first with 88 cases, followed by Langsa City with 67 cases (Aceh Health Service, 2023).

Banda Aceh City also experienced a rapid increase in HIV cases, in 2020 reaching 5 cases, increasing drastically in 2021 to 84 cases, 2022 to 88 cases and in 2023 there were 140 cases, while in 2024 there were 131 cases. With a total of 504 cases throughout 2008-2024. (Banda Aceh City Health Office, 2024).

Based on the report that there are: Sexually Transmitted Disease Sufferers (1 case), Heterosexual (89 cases), Resti Couples (27 cases), Bisexual (1 case), Transvestites (2 cases), Female Sex Workers (0 cases), Men Having Sex with Men (184 cases), Sex workers (5 cases), Injecting Drug Users (2 cases), TB Patients (7 people), Perinatal (3 cases), Blood Transfusion (2 cases), Sex Worker Clients (13 cases) and the last is No factors (22 cases). It can be concluded that the report illustrates that the highest HIV cases in Banda Aceh City are among Men Having Sex with Men (MSM). (Banda Aceh City Health Office, 2023).

To prevent further spread and a very significant increase, institutional, systematic, comprehensive, participatory and continuous handling is needed. In accordance with the regulation of the Minister of Health of the Republic of Indonesia Number 21 of 2013 concerning the handling of Human Immunodeficiency Virus and Acquired Immuno Deficiency Syndrome. One of them is by establishing HIV Services or commonly called Care, Support and Treatment Services (PDP). The purpose of establishing this PDP service is to improve services so that all people with HIV get standard services and easier and faster access. The more people infected with HIV, the more efforts are needed for therapy, care and treatment. The increase in cases has an impact on the need for services. The establishment of PDP is expected to contribute to achieving the target of eliminating HIV by 2030, namely ending AIDS in 2030, which is marked by the achievement of three zeros, namely zero new infections, zero deaths due to HIV, and zero stigma or discrimination (Nugroho & Wibowo, 2023).In supporting the program, there are 23 PDPs in the city of Banda Aceh, consisting of 11 PDPs in Community Health Centers and 12 PDPs in government/private hospitals. The report on the number of screenings and positive results obtained for each PDP, namely: PKM Baiturrahman (screened 428, positive 3), PKM Banda Raya (screened 117, positive 0), PKM Batoh (screened 151, positive 9), PKM Jaya Baru (screened 87, positive 0), PKM Jeulingke (screened 72, positive 0), PKM Kopelma (screened 192, positive 10), PKM Kuta Alam (screened 173, positive 4), PKM Lampaseh Kota (screened 124, positive 0), PKM Lampulo (screened 86, positive 0), PKM Meuraxa (screened 583, positive 6), PKM Ulee Kareng (screened 144, positive 3) RS Bhayangkara Level IV Banda Aceh (screened 71, positive 3), RS Cempaka (screened 426, positive 1), Harapan Bunda Hospital (screened 1229, positive 1), Aceh Mental Hospital (screened 37, positive 1), USK Teaching Hospital (screened 121, positive 4), Pertamedika Umi Rosnati Hospital (screened 238, positive 7), Tgk. Fakinah Hospital (screened 475, positive 0), Iskandar Muda Class II Hospital (screened 45, positive 9), Cempaka Az-Zahra Women's and Children's Hospital (screened 817, positive 0), Aceh Provincial Women's and Children's Hospital (screened 294, positive 0), dr. Zainoel Abidin Regional Hospital (screened 1813, positive 49), Meuraxa Regional Hospital (screened 793, positive 21) (Banda Aceh City Health Office, 2024).

Seeing the health center as the first access point for the community, researchers conducted an initial survey so that we can draw the data results into 3 main groups where PKM Meuraxa has the highest number of screenings, PKM Kopelma has the highest number of positive results, while PKM Bandara Raya has the lowest number of screenings and positive results but is active in conducting screening for activities related to HIV.

Previous studies have shown that HIV-positive people's experiences of PDP services vary widely depending on socio-cultural contexts (Mulqueeny & Taylor, 2022). In Banda Aceh, strong religious and social norm factors can influence people's perceptions of health services. However, previous studies have focused more on clinical and epidemiological aspects, while the subjective experiences of HIV-positive people have not been widely explored (Sukmawati et al., 2021).

Currently, there is a lack of qualitative research that reveals the perspectives of people with HIV on PDP programs. In fact, an in-depth understanding of the experiences of people with HIV can help identify specific challenges in service delivery (Şenyürek et al., 2021). The phenomenological approach was chosen because it is able to reveal the meaning of individual life experiences, which is very relevant in the health sector (Vuletić & Kern, 2020)

MATERIALS AND METHOD

This type of research uses a qualitative design where researchers try to find out how HIV sufferers experience PDP in the city of Banda Aceh. The study approach used in this qualitative research is descriptive phenomenology.

This research was conducted in the city of Banda Aceh at 3 PDP services (Support and treatment care) that meet inclusive criteria, namely:Meuraxa Health Center,Kopelma Darussalam Community Health Center AndBanda Raya Health Center.This research was conducted on 3 PDPs in Banda Aceh City, from February to March 2025. Selection of Informants;HIV sufferers (main informant) based on being registered on a PDP that meets the criteria, understands the service, has been in the PDP service for at least 6 months. Outreach (supporting informants/triangulation) Selected from PDP information, most active in the work area, Officers responsible for PDP (supporting informants/triangulation). Selected based on active PDP data and are officers who are active in PDP activitiesAndPDP Program Manager (supporting informant/triangulation).

The data collection tools used in this study consisted of interview guidelines and field notes. Research from the interview results obtained into qualitative data analysis software (NVIVO 12).

RESULTS

Participant characteristics are an important aspect used to understand the social, psychological, and professional context of the informants who contributed to this study. In qualitative research, understanding the background of participants greatly contributes to interpreting interview results, as well as identifying the relationship between subjective experiences of participants and the health care system being analyzed.

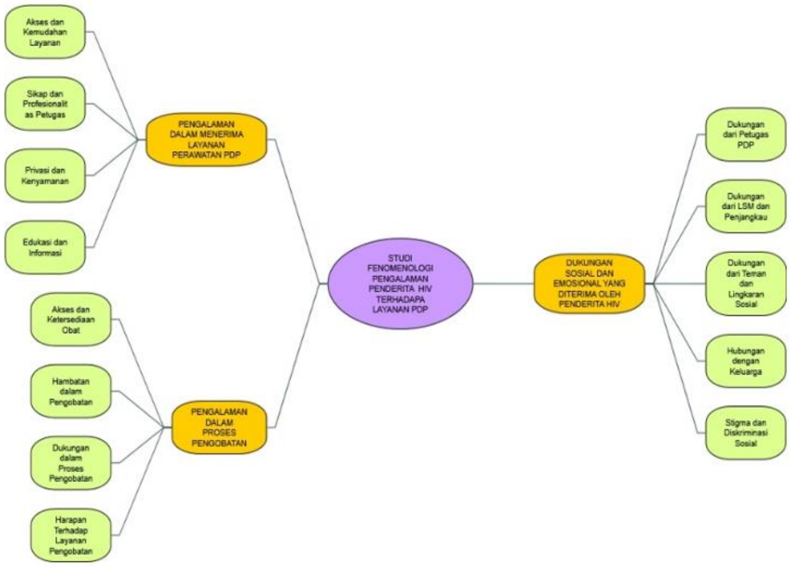
Table 1. Demographic Characteristics of Participants

No	Participant Code	Age	Gender	Last education	Marital status	Work	Religion	Domicile
1	P1	19	Man	MAN	Bachelor	Student	Islam	Copelma
2	P2	22	Man	SENIOR HIGH SCHOOL	Bachelor	Student	Islam	Copelma
3	P3	32	Man	S1	Bachelor	Contract employees	Islam	Ulee Lheue
4	Penjang-you (PJ)	36	Man	D1	Bachelor	Outreach (NGO)	Islam	Lambugop
5	Officer (T)	47	Man	S1	Marry	PDP Officer	Islam	Ulee Lheue
6	Health Office (D)	42	Woman	S1	Marry	Health Office Staff (P2P)	Islam	Cold

Based on the table above, it can be identified thatThe majority of participants in this study were male (83.3%), reflecting the dominance of a key group in the HIV population, namely young men. The ages of participants ranged from 19 to 47 years, indicating the involvement of the productive age group in this study. This age group tends to be socially and economically active, but is also more vulnerable to the spread of HIV due to behavioral risk factors and limited information.

The education level of the participants was quite diverse, ranging from graduates of MAN, SMA, to S1. The majority of participants (50%) had a higher education background (S1), which shows that understanding of HIV issues does not always depend on the level of education. This is important because even though they have a higher education, stigma and obstacles to accessing services are still experienced by participants.

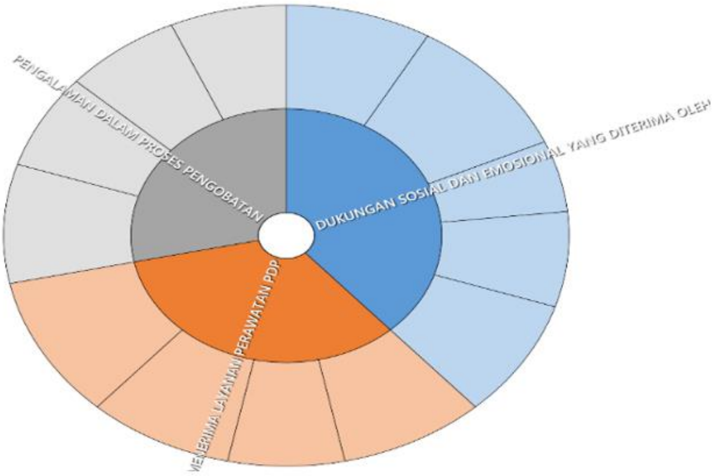
Most participants were single (66.7%), which may affect openness to family and social vulnerability to stigma. In addition, job variations show the representation of various roles in the PDP service system, ranging from service recipients (HIV sufferers), outreach workers, health service workers, to parties from the health office. Participants such as outreach workers and PDP workers have different views than service recipients. They understand the system from the inside, and provide insight into policy implementation, drug distribution constraints, and other technical obstacles. In contrast, service recipient participants highlight psychosocial obstacles, such as discrimination and service privacy.



Picture 1. Research Result Data Schema

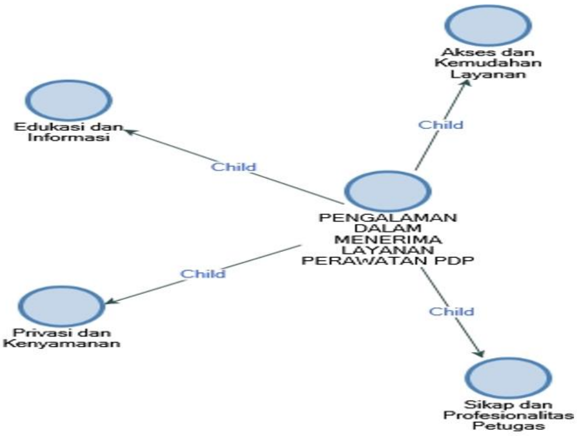
Based on the scheme above, several themes, sub-themes and categories were obtained which are interrelated with each other to provide an in-depth explanation regarding the patient's experience of care, support and treatment (PDP) services.

Then the researcher also presents the data from the radial hierarchical visualization results (Figure 4.2.2.2) which illustrates three main dimensions in the patient experience, namely social and emotional support received, experience in the treatment process, and receipt of PDP care services. Each dimension is further described into subcategories that reflect specific aspects of the patient's interaction with the health care system. The concentric circle shape emphasizes the equality between the three dimensions, indicating that none is more dominant, but rather complements each other in forming a complete understanding of the patient's journey. The use of different colors serves to emphasize the boundaries between dimensions and facilitate visual interpretation. Overall, this visualization not only presents data, but also shows the depth of meaning and complexity of the patient's experience qualitatively.



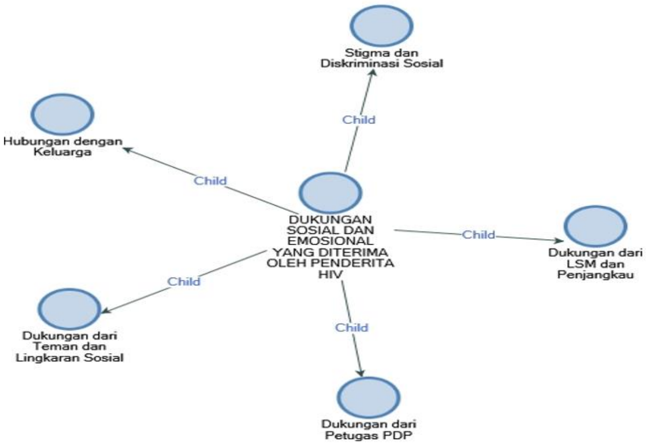
Picture 2. Hierarchical Visualization

This is a visualization of the thematic structure of the theme "Experience in Receiving PDP Care Services", which consists of four main subthemes: Access and Ease of Service, Education and Information, Privacy and Comfort, and Attitude and Professionalism of Officers (Figure 4.2.2.3). Each subtheme has a direct relationship as a child node of the parent theme, indicating that these four aspects are integral in describing the experience of HIV sufferers towards PDP. This visualization illustrates a systematic categorization structure and facilitates understanding of important dimensions in PDP care services according to the informant's perspective.



Picture 3. Project Map Visualization Theme 1 (one)

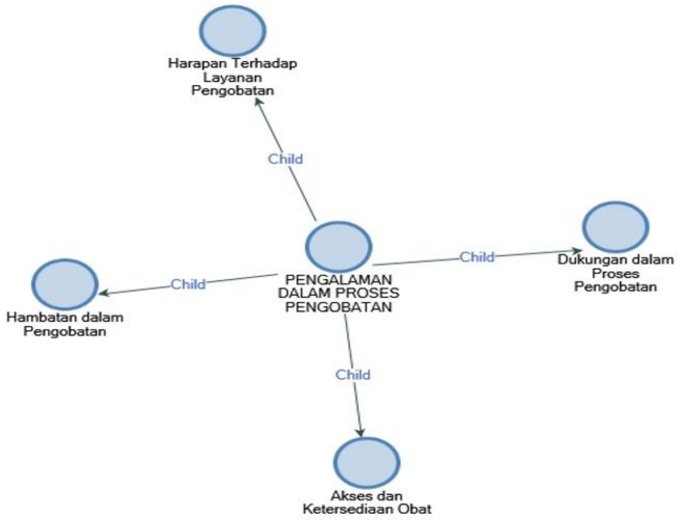
This theme reveals the dynamics of participants when accessing and undergoing PDP services. This theme describes the entry path to services, ease of accessing treatment, attitudes of officers, and the comfort of the service room. It was found that the response of health workers, system flexibility, and availability of information played an important role in forming positive perceptions of services. However, on the other hand, negative experiences also emerged such as discrimination from non-PDP health workers, as well as the impact of the Primary Service Integration (ILP) policy which was considered to interfere with the privacy and comfort of patients. The Primary Care Integration (PLC) policy, which aims to integrate HIV services into the general health care system, is considered to have a negative impact on the comfort and privacy of HIV sufferers. The loss of special consultation rooms and the involvement of general workers who have not been specifically trained in handling HIV create a sense of insecurity and increase the risk of stigma and discrimination. Although PLC upholds the principle of equal access, its implementation has not fully considered the psychosocial needs of HIV sufferers who require sensitive and confidential services. Therefore, the implementation of PLC needs to be evaluated contextually by considering the rights to confidentiality, comfort, and empathetic service, as emphasized in the human rights-based HIV service standards of WHO and UNAIDS.



Picture 4. Project Map Visualization Theme 2 (Two)

The figure above shows the structure of the theme "Social and Emotional Support Received by HIV Patients" which consists of six main subthemes as child nodes. These subthemes include Stigma and Social Discrimination, Relationships with Family, Support from Friends and Social Circles, Support from PDP Officers, and Support from NGOs and Outreach Workers. This visual shows that the experience of support does not only come from formal services, but also from broader social relations, including challenges that arise in the form of stigma. The interrelationships between these elements emphasize the complexity of the social-emotional conditions faced by HIV patients in everyday life.

This theme focuses on the support networks experienced by HIV sufferers during their treatment. This theme includes the form of support from PDP officers, the important role of NGOs and outreach workers, and social relationships with close friends and family. Support from officers and NGOs has proven to be very important because it helps maintain the continuity of treatment, provides education, and is a safe place to share. On the other hand, limitations in openness to family are an emotional challenge for sufferers, given the still strong stigma and fear of rejection. This theme emphasizes the importance of social support systems as a psychological and motivational foundation in HIV treatment.



Picture 1. Visualization of Project Map Theme 3 (Three)

This theme includes access to drugs, efficiency of the distribution system, and administrative challenges such as the activeness of BPJS and the existence of a drug deposit system. Positive experiences emerged from the ease of access to drugs through outreach and coordination with responsive officers. However, there were also obstacles such as long waiting times at the hospital, time constraints due to work, and confusion due to differences in policies between facilities. Participants also expressed the hope that treatment services would be more equitable and systematic, and prioritize an approach that respects the special needs of HIV sufferers.

DISCUSSION

Identifying the Experience of HIV Patients in Receiving PDP Care Services

The word cloud visualization shown in Figure 4.3.1.1, places the word “privacy” as the most dominant word that symbolically represents the primary needs of HIV sufferers in receiving health services. Other words that appear such as “friendly”, “space”, “guarded”, “easy”, and “accepting” reinforce the meaning that services that are considered good are not only about medical access, but also include protection of the patient’s identity and personal space. The dominance of the word “privacy” shows that emotional comfort and assurance of confidentiality are essential elements in the experience of HIV sufferers, especially in the early stages when they are adapting to new conditions and need a psychologically safe environment.

Words like “fast,” “connected,” and “website” also signal positive shifts in digital access and communication, supporting flexibility of services. This word cloud is not only a visual representation of word frequency, but also reflects the expectations and ideal experiences that people living with HIV want in receiving services that respect their dignity and holistic personal needs.

Exploring the Experiences of Social and Emotional Support Received by People Living with HIV

The Word Cloud visualization in the Figure above displays the words "discrimination" and "stigma" as dominant elements, reflecting the main realities experienced by HIV sufferers in the social context and health services. Other words such as "conveying", "privacy", "health center", and "consultation" show the dynamics of openness and the need for confidentiality in accessing services. This visualization shows that despite support from companions or officers, stigma and discrimination remain central challenges that affect the quality of life and psychology of sufferers.

Meanwhile, the Word tree in Figure 4. displays the word "stigma" as the root of various informant statements, illustrating that stigma is a widespread issue in the lives of HIV sufferers. Several quotes reflect the efforts of officers in building comfort and trust, while other quotes indicate rejection and prejudice from the community or general health workers. This visualization emphasizes that stigma is not only present in the form of labels, but also through social interactions and attitudes that influence the sufferer's daily-experiences.

Analyzing the Experience of HIV Patients in the Process of Obtaining Treatment

The results of the study show a wordcloud visualization of the word "treatment" that reflects various keywords that often appear in informants' narratives about their experiences during HIV therapy. The word "treatment" appears most dominantly, indicating the centrality of this issue in the discussion. Other words such as "process," "access," "discrimination," "health center," and "information" describe the complexity of the experience that includes technical, emotional, and social aspects. Terms such as "BPJS," "doctor," and "companion" also appear, reflecting the role of important actors in the service system. This wordcloud implies that treatment for HIV sufferers is not only related to drugs, but also to an ecosystem of services that support the healing process and self-acceptance.

CONCLUSION

This study shows that the experience of HIV sufferers in accessing and undergoing Care, Support, and Treatment (PDP) services in Banda Aceh is the result of a complex interaction between the structure of the health system, social support, and accompanying psychological factors.

1. In the first theme, it was found that ease of access to receiving care services has increased significantly thanks to simple procedures, the use of digital technology, and the involvement of outreach workers. These innovations provide a much-needed sense of security and efficiency, especially for patients who are accessing services for the first time. However, the Primary Care Integration (PLC) policy that eliminates special PDP rooms poses new challenges in the form of a loss of sense of security, disruption of privacy, and the potential for stigma to re-emerge in public service spaces.
2. In the second theme, social and emotional support was shown to play a very central role in maintaining psychological stability and increasing patient adherence to therapy. Service personnel and outreach workers were considered key actors in building relationships based on trust, empathy, and partisanship. In addition, support from close friends was able to create a "safe circle" amidst social isolation. However, relationships with family were still colored by fear, isolation, and stigma, indicating that the patient's immediate environment had not fully become a source of healthy emotional support.
3. In the third theme, it was found that the ARV drug distribution system has been running efficiently and flexibly, but there are still administrative obstacles such as long queues, inactive BPJS membership status, and drug deposit procedures that have not been well socialized. These obstacles can have an impact on the comfort and regularity of treatment, especially for patients who are in vulnerable social or economic conditions. The experience of obtaining good treatment is not only determined by the availability of drugs, but also by the extent to which the service system is able to adapt to the reality of the patient's life both technically, emotionally, and socially.

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