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EXPERIENCES OF PEOPLE LIVING WITH HIV IN OBTAINING HEALTH INFORMATION : A PHENOMENOLOGICAL STUDY

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ABSTRACT	Keywords
People living with HIV (PLHIV) face a complex adaptation process after receiving an HIV diagnosis, particularly in understanding the disease and initiating antiretroviral therapy (ART). Health information plays a critical role in shaping self-acceptance, decision-making, and treatment adherence. This study aimed to explore the experiences of PLHIV in obtaining and interpreting health information.This study employed a descriptive qualitative design with a phenomenological approach. Twelve participants were purposively selected and were active members of a peer support group at Yayasan Pontianak Plus. Data were collected through semi-structured in-depth interviews and observations. Data analysis was conducted using the Colaizzi method.The findings revealed that PLHIV obtain health information from various sources, including non-governmental organizations, peer communities, religious communities, books, social media, and healthcare professionals. Non-governmental organizations and peer communities emerged as the most dominant and meaningful sources because they provide both health education and emotional support. Healthcare professionals were also considered trusted sources of information, particularly regarding antiretroviral therapy. However, differences in participants' experiences with the initial side effects of ART influenced how they interpreted the information they received.In conclusion, the experience of obtaining health information among PLHIV is multidimensional and shaped by interactions with multiple information sources. Collaborative and patient-centered educational approaches are needed to support treatment adherence and improve the quality of life of PLHIV.	***Phenomenology, HIV, Health information, People living with HIV (PLHIV)***

INTRODUCTION

Human Immunodeficiency Virus (HIV) remains a global health challenge with long-term effects on the physical, psychological, social, and spiritual well-being of people living with HIV (PLHIV).

After diagnosis, PLHIV navigate a complex adaptation process that involves understanding their condition, accepting personal life changes, and deciding on antiretroviral therapy (ART). Health information plays a crucial role in this process by shaping their understanding, attitudes, and behaviors toward the disease and treatment (WHO, 2022).

PLHIV obtain health information from diverse sources, including healthcare professionals, community support such as peer groups and non-governmental organizations (NGOs), and digital media. These sources can enhance knowledge, foster self-acceptance, and promote engagement with health services. However, access to and interpretation of this information vary widely due to differences in educational background, health literacy, personal experiences, and socio-cultural factors (UNAIDS, 2021). Some PLHIV benefit from strong emotional support in communities, while others face conflicting or unverified content, especially on social media.

Healthcare professionals particularly nurses and counsellors play a strategic role in providing accurate details on ART, side effects, and adherence importance. Yet, PLHIV subjective experiences often diverge from medical explanations. Many who feel healthy beforehand encounter early side effects, leading to confusion, anxiety, or doubts about received information. This can erode trust in health services and affect therapy continuation decisions (Kemenkes RI, 2020). Meanwhile, easy digital media access both enriches and complicates interpretation, as online content often mixes personal anecdotes with unverified claims (WHO, 2019).

Prior studies have identified PLHIV health information sources and emphasized community and professional roles. However, these remain mostly descriptive, focusing on source identification or knowledge levels. In-depth qualitative evidence is limited on how PLHIV interpret, negotiate, and integrate information into daily lives especially in Indonesia's context of stigma, family values, and religious norms. This meaning-making process critically influences condition acceptance, treatment comprehension, and ART adherence decisions.

This gap matters because, despite identified sources, few studies critically examine how interpretive differences affect adaptation and ART adherence in Indonesia. Without deeper insight into these experiences, PLHIV education and support strategies may lack sensitivity to real needs.

This study uses a phenomenological approach to explore PLHIV lived experiences in sourcing and interpreting health information. It examines their understanding of sources, subjective evaluation and interpretation processes, and effects on self-acceptance and treatment choices. Such insights can inform more effective, context-specific education and support in Indonesia.

METHOD

This study adopted a descriptive qualitative design with a phenomenological approach to deeply examine the everyday lived experiences of people living with HIV (PLHIV). Participants were recruited via purposive sampling according to defined inclusion criteria: HIV-diagnosed adults aged 18–60 years, actively involved in peer support groups at Yayasan Pontianak Plus (across Pontianak City, Singkawang City, and Kubu Raya Regency), capable of clear communication, and consenting to participate. Exclusions encompassed those with unstable health, receiving inpatient care, or unable to engage fully in interviews. 12 participants were ultimately enrolled, with sample size guided by data adequacy until saturation occurred no further novel themes surfaced.

Data were gathered through in-person, in depth semi structured interviews supplemented by real-time observations, conducted by three nursing master's-level researchers. The interview protocol, vetted by HIV nursing and qualitative research specialists for alignment with study aims, supported sessions lasting 45–60 minutes at the foundation site to safeguard participant comfort and confidentiality. Proceedings were audio-recorded (with permission), transcribed verbatim in Indonesian, and augmented by field notes detailing contextual elements and nonverbal cues.

Analysis followed Colaizzi's method: exhaustive review of transcripts and notes for holistic insight; extraction of key statements tied to PLHIV experiences; derivation of meanings from those statements; grouping into categories, subthemes, and linked themes; and synthesis into an exhaustive experiential narrative. Three researchers jointly coded and interpreted data to bolster interpretive rigor.

Rigor was upheld via targeted strategies. Credibility drew on member checking, verifying findings directly with participants. Dependability relied on a detailed audit trail spanning data gathering to analysis. Confirmability stemmed from researcher reflexivity and multi-analyst involvement. Transferability benefited from methodological triangulation of interviews, observations, and field notes.

Ethical clearance came from the Tanjungpura University Faculty of Medicine Ethics Committee (29 May 2024; No. 6186/UN22.9/PG/2024). Participants received full briefings on aims, methods, and rights including voluntary withdrawal prior to providing written informed consent. Data confidentiality was maintained through anonymized coding and secure storage.

RESULTS

This study involved 12 participants with diverse characteristics, including age, gender, risk factors for HIV transmission, duration of illness, occupation, and educational background. All participants were receiving antiretroviral therapy (ART).

Table 1. Characteristic of Participants

Participants	Age	Sex	Risk Factor of Transmission	Duration of illness	Occupation	Level of Education
P1	47	Male	IV Drug User	18 years	Salesman	High School
P2	44	Male	IV Drug User	20 years	Administration	High School
P3	37	Male	IV Drug User	15 years	Seller	High School
P4	38	Male	Sexual Intercourse	3 years	Teacher	Bachelor
p5	39	Fema	Sexual	14 years	Housewife	Hi

		le	Intercourse			gh School
p6	32	Male	IV Drug User	16 years	private sector employee	Bachelor
P7	30	Female	Sexual Intercourse	6 years	Housewife	Bachelor
P8	28	Male	Sexual Intercourse	5 years	private sector employee	Bachelor
P9	34	Male	Sexual Intercourse	2 years	Teacher	Bachelor
P10	54	Female	Sexual Intercourse	14 years	private sector employee	Junior High School
P11	23	Male	Sexual Intercourse	3 years	private sector employee	Diploma
P12	24	Male	Sexual Intercourse	6 years	Singer	High School

Table 1 presents the characteristics of the 12 participants, consisting of nine males and three females aged between 23 and 54 years. Participants had diverse educational and occupational backgrounds, ranging from junior high school graduates to bachelor's degree holders. The reported risk factors for HIV transmission included injection drug use and sexual contact.

Data analysis generated one overarching theme: sources of health information accessed by people living with HIV (PLHIV). This theme comprised several subthemes that illustrate how participants obtained and interpreted health information within their daily lives.

Theme 1: Community-Based Sources of Information

Non-Governmental Organizations (NGOs)

Most participants identified non-governmental organizations (NGOs) as an important source of health information. These organizations not only provide education regarding HIV but also offer assistance and emotional support. One participant stated:

"Information from the Pontianak Plus Foundation" (P3).

This statement indicates that community organizations serve as accessible sources of information for PLHIV, particularly following their diagnosis.

Another participant explained:

*"Her name is ***… and it turns out that's where I received treatment and was educated. Then, right after that, I tested positive for HIV" (P4).*

This account illustrates the role of NGOs in providing initial understanding regarding HIV and available treatment options.

However, participants' experiences were not always entirely positive:

*"Oh, sis ****, they told me it was okay—they said there was a cure, and that I'd get better. But actually, I was healthy before… but after I started taking the ARV, I immediately felt terrible—I got sick" (P5).*

This statement suggests that physical experiences after initiating therapy may influence how participants interpret previously received information regarding antiretroviral therapy.

Several participants also mentioned educational activities organized by community groups:

"It's from that community, you know. Back then, we used to have meetings—sometimes we were invited by the KPA, sometimes to Muslim events or educational sessions" (P6).

Community meetings provided opportunities for PLHIV to obtain information while also sharing experiences with others who have similar conditions.

Another participant stated:

"I often participate in activities with my friends at the Pontianak Plus Foundation" (P12).

Participation in community activities also strengthens social networks that help participants understand and cope with their illness.

Theme 2: Spiritual and Educational Sources

Religious Community

One participant reported that religious activities also served as a source of information and support:

"Sometimes I'm invited to Muslim events and given educational sessions" (P6).

Religious gatherings not only provide health-related information but also offer spiritual support that helps participants cope with their health condition.

Books

In addition to community sources, some participants obtained information through reading materials:

"According to the book, in the very beginning, there used to be a meeting every month" (P10).

Books and educational materials helped participants gain a more structured understanding of HIV, particularly during the early stages after diagnosis.

Theme 3: Digital Information Sources

Social Media

Social media also emerged as a source of information used by participants to seek additional knowledge regarding HIV and its treatment.

"Since I like reading, I often read articles on all kinds of topics. I saw on Instagram what the consequences of stopping the medication were like back then, so I know the risks" (P11).

The use of social media allows participants to access information easily, although the information often originates from various sources with differing levels of reliability.

Theme 4: Healthcare providers

Healthcare providers, particularly nurses and counselors, also served as an important source of health information for the participants.

*"Yes, I've been reaching out on my own, and I've also asked for help from **** and the counselor to get some information—like counseling for my family" (P5).*

This quote illustrates that healthcare providers played a role in providing counseling and assisting participants and their families in understanding the HIV condition.

"It was initially recommended by a nurse" (P7).

For some participants, healthcare providers served as the primary source of information regarding HIV treatment and care.

DISCUSSION

This study shows that the experiences of people living with HIV in accessing health information are influenced by various factors, including social background, experiences of living with the disease, and interactions with various information sources. Variations in age, gender, transmission risk factors, and duration of living with HIV indicate that the process of seeking and interpreting health information does not occur in a uniform context, but rather evolves through each participant's individual experiences.

Research findings confirm that community organizations and NGOs play a crucial role as sources of health information for people living with HIV. For many participants, NGOs serve as the first place to receive education following diagnosis, as well as a safe space to share experiences with others facing similar circumstances. This community-based support helps reduce fear following diagnosis and strengthens PLHIV's engagement with health services (UNAIDS, 2021). Beyond providing information, the presence of a community also offers emotional support that helps individuals cope with life changes resulting from a chronic illness. Previous research findings indicate that PLHIV actively involved in community support groups experience a range of emotional responses from denial to acceptance following diagnosis. Support from peer communities and family is a key factor in facilitating the process of self-acceptance and building hope for the future. However, persistent stigma within society and the healthcare system often acts as a barrier; therefore, collaboration between healthcare workers, NGOs, and peer communities is essential to create a more supportive environment (Fradianto et al., 2025).

Similar findings also emerged in the study by Senyurek et al. (2021) in Turkey, where participants reported discriminatory attitudes and a lack of confidentiality on the part of healthcare workers, leading many to feel isolated and struggle to access services. Therefore, closer collaboration between healthcare workers, NGOs, and peer groups is essential to create a more supportive environment for people living with HIV in Indonesia. The same pattern was observed in the study by Kumwenda et al. (2023) in Malawi, where internalized stigma drove self-isolation and reduced access to HIV services. Therefore, closer collaboration between healthcare workers, NGOs, and peer groups is essential to create a more supportive environment for people living with HIV in Indonesia.

However, the participants' experiences indicate that the information received is not always immediately interpreted as something positive. Some participants reported a decline in their physical condition after starting ARV therapy even though they had previously felt healthy. Such experiences can cause confusion and affect perceptions of the treatment being undergone. This situation highlights the importance of more comprehensive education regarding the initial side effects of ARVs and the body's adaptation process to therapy so that people living with HIV can understand the changes occurring without losing confidence in their treatment (WHO, 2022). In the context of healthcare services, healthcare providers need to possess adequate competencies in antiretroviral therapy (ART) management as well as effective communication skills to support treatment adherence (Rouleau et al., 2019).

In addition to community-based sources, this study also indicates that religious activities can serve as an alternative space for people living with HIV to access support and information. Involvement in religious communities provides a spiritual dimension that helps individuals make sense of their illness and strengthens their coping mechanisms. Spiritual support has been reported to contribute to improved psychological well-being and self-acceptance among individuals with chronic illnesses, including HIV (Koenig, 2012).

Other findings indicate that health information is also obtained through books and social media. Social media provides easy access to a wide range of information about HIV and treatment. However, the diversity of available information also carries the potential for misinformation. Information circulating on social media often stems from personal experiences or sources that are not always scientifically validated. This situation can lead to differing interpretations among people living with HIV and may cause confusion regarding appropriate treatment. Therefore, the ability to assess the credibility of information is a critical aspect of digital health literacy (WHO, 2019).

Healthcare providers continue to play a crucial role as a trusted source of information for participants. The therapeutic relationship between people living with HIV (PLHIV) and healthcare providers facilitates counseling, information clarification, and decision-making regarding treatment. Trust in healthcare providers is a factor that can strengthen adherence to antiretroviral (ARV) therapy and improve the quality of interactions within healthcare services (Ministry of Health of the Republic of Indonesia, 2020).

Overall, the findings of this study indicate that PLHIV's experiences in accessing health information are multidimensional and shaped through interactions with various information sources, including community, spiritual, digital, and professional sources. The phenomenological approach enabled this study to explore how PLHIV not only receive information but also interpret and adapt it to the life experiences they encounter. These results highlight the importance of a more integrated HIV education approach, involving the roles of the community and healthcare workers, as well as the targeted use of digital media, to ensure that the information received by PLHIV remains consistent and supports treatment adherence.

LIMITATIONS OF THE STUDY

This study involved key populations living with HIV, which presented a challenge for the researcher in engaging with people living with HIV. In this study, one participant was interviewed near a fairly crowded room, resulting in unclear communication during the first minute; however, the researcher immediately addressed this by moving the participant to a more conducive location, allowing the interview to proceed smoothly once again.

CONCLUSIONS

This study shows that people living with HIV obtain health information from various interconnected sources, particularly nongovernmental organizations (NGOs), peer groups, healthcare providers, and digital media. Among these sources, NGOs and peer groups play a crucial role as spaces for sharing experiences, providing education, and offering emotional support to help people living with HIV understand their condition and adhere to antiretroviral (ARV) therapy.

These findings underscore the importance of integrated HIV education strategies involving healthcare providers, NGOs, and peer communities to ensure that the information received by people living with HIV is more consistent, easier to understand, and supports treatment adherence.

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