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RESILIENCE OF PEOPLE LIVING WITH HIV IN INDONESIA: CONSTRAINTS AND CHALLENGES

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ABSTRACT

Objective: People living with HIV/AIDS (PLHIV) experience psychosocial problems during their treatment process. In such circumstances, resilience in PLHIV is a crucial factor in improving their medication adherence and quality of life. This study aims to explore resilience in PLHIV. **Methods:** A qualitative study with a phenomenological approach was employed to explore resilience in Indonesian PLHIV. In-depth interviews were conducted with twelve PLHIV who were selected purposively based on certain inclusion criteria. All participants were registered in the outpatient clinic of top referral hospitals in Surabaya in April 2023. The data were analyzed using a thematic analysis. **Results:** The majority of PLHIV who participated in this study were women and had been married. Most participants had been diagnosed with HIV and had been on treatment for two years. Four themes were identified from the data: self-acceptance, spiritual satisfaction, personal competence, and hopefulness. **Conclusion:** The findings indicated that PLHIV accepted their current condition despite the challenges they faced due to stigma and rejection. They stated that acceptance led to physical, psychological, and social satisfaction. The findings of this study serve provide insight for nurses in maintaining resilience in PLHIV.
Keywords: Resilience; Self-Acceptance; HIV/AIDS; PLHIV

INTRODUCTION

The incidence of human immunodeficiency virus infection (HIV) is a serious global issue, despite the implementation of numerous control initiatives. There were over 1.3 million new infections in 2022, translating to 3,500 new infections each day. It is estimated that 39 million individuals have been infected with HIV, making the overall prevalence of HIV, approximately 0.7%, substantial (Joint United Nations Programme on HIV/AIDS, 2023). In the South-East Asia Region (SEAR), Indonesia has the second-highest number of people (both men and women) living with HIV (PLWH). From 5846 in 2004 to 242 point 699 in 2017 the rate has considerably increased annually (Efendi et al., 2020). HIV primarily affects people who are at the highest level of their productivity. In addition to having an effect on an individual's health, HIV also hinders the development and prosperity of families, communities and entire nations. Challenges include a significant number of undiagnosed cases, limited access to antiretroviral therapy (ARV), gaps in clinical care for those with advanced disease, and stigmatization (Aghaie et al., 2021; Sikkema et al., 2015)

HIV infection can be accelerated by psychological stress through behavioral and physiological/immune pathways such as reduced treatment adherence (Webb et al., 2018). People living with HIV experience mental and social distress as a result of stigma or complications from the disease (i. e. anxiety despair etc.) and protective factors like social support resilience and self-efficacy may enable them to get past these obstacles (Zhang et al., 2018). A fundamental idea in positive psychology resilience is associated with constructive adaptation and efficient coping in the face of adversity. HIV-positive

individuals must be resilient because they are exposed to a variety of stressors including the effects of HIV stigma related to HIV mental illness interpersonal violence unstable housing poverty and stressors that may be more prevalent in women than in men due to child-bearing responsibilities gender-related stigma and sex discrimination (Dale et al., 2015). The HIV literature discusses resilience as a protective factor that mitigates the link between stress and mental health in people living with HIV (PLWH) (Dulin et al., 2018). Resilience has also been associated with positive health benefits, including viral suppression, treatment adherence, and quality of life (QoL), both physical and mental (Fumaz et al., 2019; Hernansaiz-Garrido & Alonso-Tapia, 2017; Logie et al., 2018; Rubtsova et al., 2017).

Resources related to resilience are needed to change behaviors and result in better health which could help PLHIV overcome the negative effects of their challenges (Rivera-Picón et al., 2022). Insufficient coping mechanisms and self-discipline may hinder the process of PLHIV developing resilience (Weidner et al., 2016). PLHIV who exhibit higher resilience are generally less affected by adverse stressors associated with their challenging circumstances (Costa-Cordella et al., 2022; Ridgeway et al., 2018). Increased resilience is strongly correlated with lower rates of depression in people living with HIV (McGowan et al., 2018). Research on the experiences of people living with HIV in building resilience in Indonesia is still scarce. Examining the strategies and experiences employed by PLHIV to build resilience is helpful because it sheds light on the kind of care and support that medical professionals should offer. Individuals with resilience can develop adaptive coping mechanisms become more resilient and successfully adjust to perceived stressors (Dow et al., 2018). It is anticipated that knowledge of resilience will aid in selecting the best tactics and initiatives for managing HIV/AIDS especially when it comes to enhancing patient quality of life and medication adherence (Tansey et al., 2017). As resilience can have a positive impact on individual health behaviors and a significant long-term impact on quality of life it is imperative to investigate its role in enhancing adherence (Misutarno et al., 2022). For this reason, the purpose of this study was to explore resilience in PLHIV.

MATERIALS AND METHODS

Research design

A qualitative study with a phenomenological approach was employed to explore the experiences of PLHIV in achieving resilience to improve medication adherence and quality of life.

Setting and samples

This study was conducted on PLHIV in Surabaya City, Indonesia in April 2023. The participants who met the criteria for data saturation (Gentles et al., 2015) in this study were 12 PLHIV, namely living in Surabaya city, being diagnosed with HIV through various modes of transmission for a minimum of one year, between the ages of 21 and 35 years, and currently undergoing ARV treatment. All PLHIV in this study were registered in type A hospitals in Surabaya. The sample was selected using the purposive sampling method.

Measurement and data collection

An in-depth interview guide was developed based on the research objectives, which consisted of several questions aimed at eliciting comprehensive and detailed responses from the participants. The research questions were formulated based on several concepts and previous research (Fang et al., 2015; Fitryasari et al., 2021; Guo et al., 2022). In this study, supporting tools such as a voice recorder (from a smartphone application), papers, and writing instruments were used to record the interview findings. The in-depth interview activity was conducted in a private setting to ensure the confidentiality of the data and lasted between 30 and 45 minutes. Each participant was interviewed once. All interviews were conducted with the authors facing the participant, maintaining a distance of approximately one meter, and separated by a table. The recording device was placed approximately 50 cm from the participant, with the microphone directed toward the participant. The interview with each participant was concluded when all the necessary information related to the research objectives had been obtained. Subsequently, the contract with the participant was terminated. The in-depth interviews were recorded audibly, transcribed word-for-word, and confirmed for accuracy through authors re-listening to the recordings. Additionally, all authors collectively analyzed, assessed, and deliberated on each interview and transcript. Participants were anonymized and designated with codes ranging from P1 to P12.

Data analysis and Trustworthiness/rigor

The collected data were immediately analyzed using the Colaizzi's method, which consists of the seven steps as described by Colaizzi (1979) in (Polit & Beck, 2010). The analysis results were derived from qualitative variables in this study, utilizing keywords, categories, themes, and subthemes. The principal investigators performed internal member checking on the thematic outcomes from the in-depth interviews, focusing on ensuring the reliability of the study (Gunawan, 2015). Additionally, the findings underwent scrutiny by experienced researchers to minimize personal bias and uphold data quality through comparison and contrast. Furthermore, all methodological decisions and issues were meticulously documented, and an audit trail was meticulously compiled over a span of about four weeks.

Ethics Statement

This study received ethical approval from the Research Ethics Committee of the Faculty of Nursing, Universitas Airlangga, Indonesia on April 3, 2023, with a certificate number 2813-KEPK. Several ethical principles applied in this study were anonymity, confidentiality, beneficence, justice, and veracity.

RESULTS AND DISCUSSION

The interviews were conducted with 12 PLHIV in Surabaya, East Java. The identities of the PLHIV were anonymized using codes.

Table 1 Demographic characteristics of the PLHIV (n = 12)

Code	Gender	Age (year)	Education	Marital status	Duration of illness (year)	ARV consumption (year)	Occupation
P1	Female	29	Senior high school	Married	2	2	Housewife
P2	Female	32	Junior high school	Divorced	2	2	Self-employed
P3	Female	29	Senior high school	Married	2	2	Self-employed
P4	Male	30	Senior high school	Single	4	4	Unemployed
P5	Female	27	Junior high school	Married	2	2	Housewife
P6	Female	29	Senior high school	Married	2	2	Housewife
P7	Male	35	Senior high school	Married	5	5	Househusband
P8	Female	29	Junior high school	Divorced	2	2	Self-employed
P9	Female	28	Junior high school	Single	2	2	Civil servant
P10	Female	28	Senior high school	Married	2	2	Self-employed
P11	Male	30	Junior high school	Single	2	2	Driver
P12	Male	32	Junior high school	Married	3	3	Security

Table 1 shows that the majority of PLHIV participating in this study were females, with the youngest participant being 27 years old and the oldest being 35 years old. The highest educational background among the 12 PLHIV was senior high school, and the most common marital status was married. The duration of HIV diagnosis and ARV treatment was identical. The majority of PLHIV in this study were self-employed, while others were predominantly housewives. The themes derived from the interview results are as follows:



Figure 1 Themes identified related to adult PLHIV

Theme 1: Self-acceptance

Two sub-themes were identified in the self-acceptance of PLHIV, namely acceptance of destiny and perception of illness.

Sub-theme 1.1: Acceptance of destiny

The participants expressed their ability to accept their diagnosis of HIV and maintain a positive outlook on their current condition. They also mentioned their capability to maintain good relationships with others despite the challenges they face as PLHIV.

"*...So, I have to think positively again, I have to support myself. Maybe, no matter what, it's God who gives the trials. So maybe from that experience, I feel that whatever it is, God gives the best, whether it's this illness or something else. Maybe this is a reminder for me.*" **(P2)**

Other PLHIV expressed that they chose to live their lives more happily because life and death were predetermined by God, and it was their duty to live their lives to the fullest.

"*Because whatever happens in the world, we have to accept it. Whether it's illness or anything else, it has to be accepted. Once it's accepted, then we strive, right?"* **(P9)**

The participants continued living their lives as usual, similar to before they were diagnosed with the illness. They expressed that they had accepted their condition wholeheartedly and felt happier in living their current lives.

Sub-theme 1.2: Perception of illness

Some participants demonstrated a sufficient understanding and knowledge about HIV. They acknowledged that the disease affected the immune system, and that the medication they took could improve their condition and enhance their quality of life.

"...Finally, I feel like, oh, so not everything is as bad as it seems with this disease." **(P6)**

Other participants had limited knowledge about HIV, perceiving the disease to only exist abroad and not in Indonesia.

"*Because what I used to think was just from watching TV news, I thought the disease was only abroad, really. In my mind, it only existed abroad because I never saw it.*" **(P7)**

It is crucial to provide PLHIV with education about HIV, including its causes, management, and the risks associated with non-adherence to medication. Such education can help prevent the increased occurrence of opportunistic infections in PLHIV.

Theme 2: Spiritual satisfaction

Two sub-themes were identified in the spiritual satisfaction of PLHIV, namely optimism in life, and engaging in prayer and good deeds. This theme relates to the ability of PLHIV to persevere due to their belief in God and destiny.

Sub-theme 2.1: Optimism in life

The participants expressed that they approached life with optimism due to the support they received from their families and loved ones.

"I have to be optimistic; I have to be healthy for the sake of my children. I want to see my children succeed." **(P8)**

The majority of PLHIV in this study were single parents. Their children were the main factor that sustained their optimism in life.

Sub-theme 2.2: Engaging in prayer and good deeds

The participants expressed that after being diagnosed with HIV, their frequency of worship increased and they felt closer to God. They stated that worship brought them peace and gratitude for their lives. In addition to performing obligatory prayers such as salah, some participants also mentioned that they regularly engaged in additional acts of worship such as reading the Quran and reciting dhikr.

"*Yeah, that... praying. Every day. Reading the Quran. I read a few pages every day to stay calm*" **(P9)**

"But I still hold a tasbih (prayer beads) and engage in istighfar (seeking forgiveness) ..." **(P10)**

Engaging in worship activities was seen as a way to find inner peace and tranquility. Approaching the Almighty God was considered helpful in accepting their condition and reducing depression and denial regarding their illness.

Theme 3: Personal competence

Two sub-themes were identified in the personal competence of PLHIV, namely self-ability and productivity. This aspect relates to the individual perception of their capability to achieve goals despite setbacks or failures.

Sub-theme 3.1: Self-ability

This aspect pertains to composed action. Individuals who exhibit composure tend to approach challenges with careful consideration. They demonstrate the ability to manage stress effectively and maintain concentration on their objectives amid pressure or difficulties.

"I usually don't go directly to the health center first; I mean I will take medication at home first. If I don't get better, then I go to the health center." **(P12)**

The personal capabilities of PLHIV included the ability to manage the side effects of medications, optimize immune system function, and adhere to treatment schedules.

Sub-theme 3.2: Productivity

The personal capabilities of PLHIV were manifested in their daily lives through entrepreneurship, such as opening a catering business, selling cakes, and other small-scale ventures.

"...and I also have my own business. Catering." **(P2)**

"I run a small food stall." **(P10)**

The majority of PLHIV worked as entrepreneurs to increase their family's income. The choice to become an entrepreneur was also motivated by the desire to distract themselves from the stress and sadness caused by their illness in a more productive way.

Theme 4: Hopefulness

Two sub-themes were identified in the hopefulness of PLHIV, namely disclosure status and social relationships.

Sub-theme 4.1: Status disclosure

The status of PLHIV was typically shared with their closest and trusted individuals such as family, friends, and partners.

"My family knows, and my biological sibling knows. Yes, my biological sibling knows. It's just to be prepared, you know, in case something happens to me someday, so that my family is aware." **(P6)**

Disclosing their status to family and partners served as a precautionary measure in case their condition worsened and they needed immediate assistance. Furthermore, disclosing their status to potential partners allowed PLHIV to assess whether their partners were willing to accept them as they were.

Sub-theme 4.2: Social relationships

The PLHIV reported that disclosing their status did not change in their social interactions and relationships, both with family and close friends.

"Nothing changed, really, nothing changed. My younger sibling and my immediate family still treat me the same as before." **(P2)**

Some PLHIV also explained that participating in peer support groups provided them with additional social support during their treatment journey.

"So, when I came there, wow, they greeted me warmly, 'Hi, Mrs. K, how are you doing?' It's like I'm special to them when they see me." **(P7)**

Social relationships were indicators of resilience. The ability to communicate and interact with others indicated that PLHIV could overcome the challenges associated with their diagnosis of HIV and mitigate social stigma by actively participating in social activities.

The results of the study indicated that resilience in PLHIV was formed through individual acceptance, particularly in psychological and spiritual aspects. Resilience helps individuals accept God's decisions regarding their illness more easily. In addition, acceptance strengthens personal competence, especially in medication adherence and daily activities. The findings of this study indicated that accepting one's condition was crucial for developing resilience as a form of positive coping mechanism for PLHIV. Belief in one's ability to self-manage HIV treatment is necessary to enhance their overall health, both physically and psychologically (Aregbesola & Adeoye, 2018). The conviction in self-management of HIV treatment significantly affects the psychological well-being of PLHIV (Han et al., 2021). These results align with research by Rzeszutek et al. (2016), underscoring the importance of cultivating optimal psychological conditions for effective HIV/AIDS treatment and care (Rzeszutek et al., 2016). The acceptance of illness and adherence to therapy among PLHIV are shaped by their perspectives, beliefs, mental health status, and social support networks.

Creating a supportive environment where individuals can gradually share their narratives is crucial for fostering self-acceptance and enhancing resilience among those living with HIV (Folayan et al., 2022). Reflecting on their HIV journey enables individuals to recognize pivotal moments where they perceive their illness as a catalyst for positive personal growth (Valente et al., 2022). According to Horter et al. (2017), individuals who accept their HIV status are more inclined to actively participate in healthcare and take

responsibility for self-management. Another aspect of resilience that forms in PLHIV is spiritual satisfaction. Spiritual beliefs serve as a source of strength for individuals facing the vulnerabilities associated with the illness (Pinho et al., 2017). A critical aspect is enhancing patients' understanding of their illness and shifting their mindset from seeking a cure to surrendering to God and fostering social connections (Kumboyono et al., 2018). Spiritual involvement plays a crucial role in the acceptance process as it provides positive effects, such as reducing depression, improving the quality of life, reducing fear of death, and cultivating a sense of purpose. Spiritual well-being involves a profound understanding of oneself, the social sphere, the environment, and the Creator. Therefore, spiritual well-being consistently correlates with the quality of life (Miners et al., 2014).

PLHIV who have achieved resilience after being diagnosed with HIV find it easier to attain optimal quality of life. One indicator of achieving quality of life is the courage to disclose their HIV status to others, especially family members and partners. The bravery in disclosing their status is also associated with improved adherence to ARV medication, undetectable viral loads, immune recovery, and improved clinical status (Fletcher et al., 2020; Wen et al., 2021). HIV status disclosure is encouraged among PLHIV to obtain ongoing social support. Therefore, participants who have disclosed their HIV status are more likely to have better social support, greater control over their health, and be better prepared to face the challenges associated with disclosing their HIV status at the household and community levels (Albright & Fair, 2018). At the individual level, health-related quality of life (HRQOL) encompasses the perception of physical and mental health, such as energy levels and mood, and their interrelationships, which include health risks, functional status, social support, and socioeconomic status (Fumaz et al., 2019). At the community level, HRQOL extends to encompass community-level resources, conditions, policies, and practices that influence the perceived health and functional well-being of populations (George et al., 2016). PLHIV have a chronic progressive disease that induces unique resilience mechanisms within the Indonesian society. Future healthcare and management of PLHIV should socially support and motivate these mechanisms to guide PLHIV towards a more comfortable and healthier lifestyle. Nurses can play a role as counselors and educators in assisting PLHIV in adapting to the challenges faced after being diagnosed with HIV/AIDS.

CONCLUSION

PLHIV have a chronic progressive disease that induces unique resilience mechanisms within Indonesian society. Future healthcare and management of PLHIV should socially support and motivate these mechanisms to guide PLHIV towards a more comfortable and healthy lifestyle. The role of nurses as counsellors and educators can assist PLHIV in adapting to the challenges faced after being diagnosed with HIV/AIDS.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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