

The Impact of Shocking Diagnoses and Limited Support: A Qualitative Study in HIV Patients

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ABSTRACT

An HIV diagnosis often leads to significant psychological distress, including social stigma and emotional impact, which affect family support. This situation can trigger self-harm behaviors as maladaptive coping mechanisms. This study aims to explore the emotional experiences of individuals diagnosed with HIV, as well as the impact of limited family support on their psychological well-being and the coping mechanisms they employ. The research adopts a descriptive qualitative approach with a case study design. Data were collected through in-depth interviews with five HIV/AIDS participants at Yayasan Sehat Peduli Kasih, Banyumas. Data analysis was conducted inductively to identify key themes, such as the lack of family support and self-harm behaviors. The study found that family support varied significantly among participants. Some received emotional and practical support from family members, while others faced stigma and rejection. Self-harm behaviors, such as self-injury, were carried out by participants as a response to the emotional pressure of an HIV diagnosis and the lack of family support. Emotional distress following an HIV diagnosis is often exacerbated by insufficient family support, leading to self-harming behaviors. Concrete and collaborative efforts are required to establish and strengthen family support through targeted health education, counseling, and peer-group initiatives. Furthermore, stigma reduction programs at both family and community levels are essential to foster acceptance, enhance psychological resilience, and improve treatment adherence among people living with HIV/AIDS.

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1. INTRODUCTION

An HIV diagnosis often triggers severe psychological impacts, such as stigma, social isolation, and emotional distress, especially when not accompanied by family support. This can encourage self-harm as a form of maladaptive coping behavior. HIV is a disease that attacks the immune system and, if left untreated, can develop into AIDS, a condition that weakens the body against various infections and cancers. Besides physical threats, people with HIV/AIDS also face social stigma that can trigger stress, depression, and self-harming thoughts. In Indonesia, the period from January to June 2022 recorded 22,331 HIV cases out of over 2 million people tested,

with 18,479 of them receiving ARV therapy. In Central Java, 2,931 people living with HIV were recorded, and 2,155 have undergone ARV treatment (Liyanovitasari & Setyoningrum, 2024).

Self-harm is a complex phenomenon influenced by many factors, including illnesses like HIV. People living with HIV often face significant psychosocial challenges, including stigma, social isolation, and mental health disorders such as depression and anxiety. Self-harm is itself a maladaptive coping process where individuals use physical pain to cope with perceived psychological distress, and the impact of self-harm can be very pervasive and affect social relationships. In this context, self-harming behavior often appears as a response to emotional pressure experienced by individuals, including those with HIV (Cahyaningrum et al., 2024).

Family support plays an important role in the recovery and treatment process for people with HIV/AIDS (PLWHA). Families that provide emotional and practical support can help reduce stress and improve the quality of life for people living with HIV. Research shows that strong social support can reduce feelings of loneliness and anxiety and improve adherence. Therefore, it is important to understand the relationship between HIV, family support, and self-harm. Effective family support not only helps people living with HIV feel more accepted and supported, but also serves as a deterrent to self-harm. Therefore, comprehensively addressing these challenges requires a holistic approach that includes recognizing the importance of HIV education and psychological support from family (Julianto et al., 2024).

People with HIV/AIDS (PLWHA) are more vulnerable to psychological and social problems. Family support plays a very important role in the mental health status of HIV/AIDS patients. According to research, the majority of respondents with mental disorders (50.4%) received high levels of support from their families. However, the proportion of respondents who received no or little support from their families reached (28%). This highlights how vulnerable people with HIV/AIDS are to reduced motivation due to the loss of support from their smallest and closest community group, namely their own families (S. Putri et al., 2022).

2. RESEARCH METHOD

This study utilized a qualitative descriptive design with a case study approach to understand the lived experiences of PLWHA (People Living with HIV/AIDS). The research was conducted at Yayasan Sehat Peduli Kasih, Banyumas, and involved five participants selected through purposive sampling. Inclusion criteria included individuals aged 18 or older, diagnosed with HIV, and having experienced a lack of family support.

Data were collected through in-depth semi-structured interviews. Each interview lasted approximately 45-60 minutes and was audio-recorded with participants' consent. Interviews focused on emotional responses post-diagnosis, perceived support systems, and experiences of self-harm. Data analysis employed inductive thematic analysis, allowing themes to emerge directly from the data without imposing pre-existing theories.

3. RESULT AND DISCUSSION

This study found that complex emotional experiences after HIV diagnosis, including confusion and fear, and the lack of family support are major stressors for people with HIV/AIDS, leading to self-harm as a form of maladaptive coping. Family support varied significantly among participants. Some received emotional and practical support from family members, while others faced stigma and rejection. Self-harm behaviors, such as self-injury, were performed by participants in response to the emotional stress of an HIV diagnosis and a lack of family support. Based on the thematic analysis of interviews with five participants, three main themes were identified that represent their emotional experiences and coping behaviors after receiving an HIV diagnosis and facing a lack of family support:

3.1 Emotional Diagnostic Experience

The experience of HIV diagnosis refers to the process by which someone experiences symptoms leading to HIV infection, visits a doctor, and ultimately receives a formal diagnosis from a healthcare provider. This process often involves complex emotional responses such as confusion, fear, and ultimately acceptance of the health condition. HIV diagnosis often follows a series of non-specific symptoms that can be mistaken for other health conditions. According to the interview findings, two categories emerged: participants who experienced sadness and participants who exhibited indifference upon receiving an HIV diagnosis.

Here is an explanation of the categories above:

a) Participants who experienced sadness and a lack of acceptance.

Partisipan 3 (P3): Yeah... Initially, that's how it was, sad for sure, but well, it is what it is

Partisipan 5 (P5): ee.. it's like not accepting it, yes, it's sad

Following their diagnoses, participants 3 and 5 evidently displayed astonishment and despair. It took them some time to come to terms with this fact.

b) Participants who feel neutral.

Partisipan 1 (P1): I didn't feel anything, it was just normal because I get sick often, so I thought it was just a regular illness

Partisipan 2 (P2): It's okay, because a friend of mine had it before too. I know it can be treated, so I'm not worried

Partisipan 4 (P4): Initially, I was confused, but I just went with it. The important thing was that I took my medication

3.2 Family support for people with HIV/AIDS

Family support varied; some participants received instrumental and emotional support, but most experienced a lack of support, even rejection or indifference from close family members.

Here is an explanation of the categories above:

a) Individuals lacking familial support

Partisipan 2 (P2): I'm just doing my own thing, sir. If you say I'm supported, well, there's nothing. Especially since I'm a widow, and I keep getting asked what's wrong with me by my family and children, but I just stay patient

Partisipan 3 (P3): My brother said this is my own fault, so I can't expect much from them

Partisipan 5 (P5): It's just that, my parents have been indifferent from the start. Luckily, he doesn't know either. They haven't liked me from the beginning

b) Participants supported by family

Partisipan 1 (P1): Most of my older sister, well, you know yourself, my husband doesn't care about me anymore. Luckily, my sister is always there to take me to get my medication

Partisipan 4 (P4): Being close to my mom, even just talking to her sometimes can make negative thoughts disappear

Family support is particularly evident in the form of instrumental support, such as providing medication, but also through emotional support from siblings. However, some participants reported experiencing stigma and rejection, which negatively impacted their mental health.

Based on interviews with 5 participants, the family support received by the participants varied. The family members who provided support or were aware of the participants' illness were very limited. In 1 participant, only the closest person provided support, ranging from emotional to instrumental support. However, some participants reported a lack of support from their partners or the stigma they faced. It can be concluded that family support was very limited from the immediate family, with no support from participants 1 to 5, as some were unaware of the participants' illness.

3.3 Self-harm among HIV/AIDS participants as a stress-reduction strategy

Every respondent to the study stated that they had self-harmed as a result of extreme stress. These acts are frequently performed to manage or communicate psychological suffering that is hard to articulate, not to end life.

Here is an explanation of the categories above:

Partisipan 1 (P1): If I feel like everything I'm going through is too heavy, I sometimes even like to bang my head against the wall

Partisipan 2 (P2): I like to hit my body to keep myself from getting too stressed

Partisipan 3 (P3): Yes, when I feel like I've given up, sometimes I like to cut my thighs

Partisipan 4 (P4): There was a time I wanted to run myself into a tree just to get it over with

Partisipan 5 (P5): I've pinched myself so hard that my skin bruised

All participants reported experiences of self-harm behaviors due to emotional distress. For example, frequently banging their head against the wall, hitting themselves, cutting their thighs, running into trees, and pinching themselves to distract from emotional pain.

Respondent stated during the discussion that they believe experiencing physical pain is preferable to living with guilt and the desire to hurt oneself all the time. This statement illustrates how people view physical pain as a short-term diversion from their emotional suffering. This suggests that self-harm is a coping mechanism for psychological distress. Researchers were able to verify the accuracy of the information that participants submitted. After applying the triangulation technique to volunteers, two researchers concluded that "yes, that's probably stress too." It was discovered that the information provided by participant 2 aligned with their behavior.

4. CONCLUSION

Based on the results of data analysis and discussion, the following conclusions can be drawn:

- 1) Individuals diagnosed with HIV experience various emotional responses such as sadness, fear, confusion, and gradual acceptance. These emotional reactions reflect the psychological impact of receiving an HIV diagnosis.
- 2) Limited family support, often influenced by stigma and rejection, intensifies psychological distress and increases the risk of maladaptive coping behaviors, including self-harm. Conversely, emotional and instrumental support from family members helps reduce stress, foster acceptance, and encourage treatment adherence.
- 3) Coping mechanisms among participants vary, with some resorting to self-harming behaviors to manage emotional pain, while others rely on family or internal resilience as positive coping strategies.
- 4) Concrete and operational efforts are needed to strengthen family support and reduce stigma toward people living with HIV/AIDS (PLWHA). These efforts include:
 - a) offering family-centered education to increase knowledge about HIV and its treatment;
 - b) putting in place peer-group and counseling programs to enable families to provide both practical and emotional support.
 - c) supporting neighborhood-based efforts to lessen stigma in order to cultivate compassion, tolerance, and a caring atmosphere.

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