

Original Research Article

Experiences of people with HIV/AIDS (PLWHA) at the critical condition due to AIDS

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ABSTRACT

Background: PLWHA who suffered critical condition and being treated in intensive care the majority (84%) due to *Pneumocystis carinii pneumonia*, 47% experienced respiratory failure, sepsis, 12% and 11% neurologic disease. The death rate PLHIV patients treated in intensive reaches 83%. Of all patients passing through a critical phase, 27% survived for 1 year, 18% survive the second year, 13% survived 3 years and 11% last more than four years. They have the experience that need to be explored in a comprehensive manner to provide support to people living with HIV else.

Methods: This research was conducted through qualitative research with phenomenological approach that focuses on the depth of the process through in-depth interviews on 10 participants. Participants in this study were HIV-positive people who visit the Polyclinic Teratai Hasan Sadikin Hospital in Bandung. Recruitment of participants was done by purposive sampling with criteria for inclusion namely 1) PLHIV been treated in hospital with critical conditions, 2) Ability to communicate with tray, 3) People who say they remember past experiences related to the care in critical condition.

Results: The data were analysed to identify themes about the experiences of people living with HIV during critical condition. The results found six themes namely: 1) experiencing emotional response, 2) striving to overcome the feelings and the impact of illness, 3) closer to God, 4) undergoing their destiny as People Living with HIV/AIDS (PLWHA), 5) received support and prayers of people around, and 6) has a hope of a cure.

Conclusions: PLWHA treated in a critical condition experience threat of death from opportunistic infections and had the psychological burden of disease due to the stigma of HIV/AIDS. This makes them slumped physically and psychologically, thus they felt helpless. The recommendation from the results of this research is that communities, families and health workers should provide a support system to people living with HIV in order to increase life expectancy due to a collapsed condition and hopelessness.

Keywords: Critical condition, Experiences, PLWHA

INTRODUCTION

In the last decade, HIV cases continue to increase and spread throughout the world, including Asia and Indonesia.¹ According to Ditjen Pemberantasan Penyakit Menular and Penyehatan Lingkungan (PPM and PL) (Directorate General of Communicable Disease Control

and Environmental Health), Department of Health of the Republic of Indonesia, the cumulative cases of AIDS in Indonesia on 2009 reached 18,442 people and on 2010 reached 21,770 with 1,206 new cases.² From these data, West Java ranks second in the number of cases in 2009 reached 3,233 people and 588 people died (18.19%) and in 2010 reached 3,710 people and 663 people died (17%).

The escalation number of people living with HIV/AIDS (PLWHA) in West Java is caused by the high practice of injecting drugs. From 3,710 cases, 2,695 (72.6%) cases of PLWHA was the consequence of numerous needle/syringe sharing behaviours to drug users.²

Most of the PLWHA make HIV/AIDS a traumatic experience throughout their life. It corresponds to the double burden faced by PLWHA which are a physical illness such as immunity decreasing and psychosocial stressors due to the bad stigma from society.³

Some research shows the majority of PLWHA are experiencing stress and depression when first diagnosed with HIV.⁴ Research in Iran showed that those who were diagnosed with HIV respond to fear of exposure status and the devastating impact of HIV.⁵ Research in Argentina describes that people living with HIV/AIDS most of them possessed rejection or introversion and silence respond.⁶

The insufficient efforts of treating PLWHA harmed some people who got lack access to health services. Partial PLWHA falls in critical condition due to opportunistic infections such as pneumonia, prolonged diarrhea, and loss of consciousness. Patients who experience oxygen insufficiency, loss of fluids and electrolytes as well as disturbance of consciousness are serious threats to their lives as well,⁷ thus it requires intensive care with close supervision and multidisciplinary approach of health professions.⁸

The PLWHA treated in intensive care unit mostly (84%) are caused by experiencing *pneumocystis carinii pneumonia*,⁹ respiratory failure 47%, sepsis 12% and neurologic disease 11%.¹⁰ During treatment in intensive care, the patient received various types of services/actions that most (87%) received mechanical ventilation assistance and 78% keep getting antiretroviral medicine.¹¹

PLWHA's experiences when hospitalized in critical condition were strongly influenced by the failure to adapt the disease, environment, and stress due to a deadly threat.¹² PLWHA's experiences are also associated with the health workers' interaction with the patients. Some research indicates bad attitudes of nurses in caring AIDS patients. Research in Nigeria shows that nurses often avoid contact with patients and rarely provide health education.¹³ The same conditions occurred in Uganda, Brazil, and Bosnia, most nurses fear of contact with people with AIDS and give less health education on the reasons of limited facilities/equipment.¹⁴

The experience of PLWHA at the critical time is based on a poor prognosis. The death rate of people with HIV/AIDS treated in intensive care reaches 83%.¹⁵ In the United States, the death rate of AIDS patients hospitalized in the intensive care unit (ICU) reached 50%-60%.¹⁶ Of all patients passing through a critical phase, 27% survived for 1 year, 18% survive for 2 years,

13% survive for 3 years and 11% survived for more than 4 years.¹⁰ Based on these descriptions, the researchers formulate the problem as follows: "How was PLWHA's experience at the moment through a critical condition in hospital as a result of AIDS?" This research aims to reveal and understand the experience of PLWHA at the time of being hospitalized in critical condition. With qualitative methods, researchers expect to be able to explore and excavate the experience of PLWHA in critical condition with the threat of death due to multi-organ failure, psychosocial, and spiritual problems

METHODS

This is a study involving the experience of PLWHA when hospitalized in critical condition. This study focuses on the meanings and significances based on the presence of a physical, psychological, social and spiritual response that occurs in a critical condition. This research used a qualitative method with a phenomenological approach which focuses on the depth of the process by using various natural methods.

The participants in this study were HIV-positive people who visited Teratai Polyclinic at Hasan Sadikin Hospital in Bandung. The recruitment of participants was conducted by purposive sampling which participant selection was based on the judgments made by the researcher. The inclusion criteria include: 1) PLWHA have been hospitalized due of a critical condition, 2) Being able to communicate with the Indonesian, 3) Patients who say they remember past experiences related to the care in critical condition.

The techniques used in collecting the data was semi-structured with in-depth interviews. The interview started with open questions about the experiences of being treated in a critical condition. Further questions were questions to clarify the statement of participants. The follow-up questions are also aimed to clarify and focus the answers of the participants so that researchers get an overview of the themes that might arise. The follow-up questions involved the changes they experienced, techniques of dealing with the alteration, the difficulties they encountered, the meaning of health status that is being experienced, and the support they have obtained. The interview was terminated after there was found no new information from participants. Before ending the interview, the researcher conducted termination by re-evaluating and clarifying any meaningful phrase of participants to avoid confusion. Technical analysis of data includes pre-analysis and interpretation. Researchers use thematic analysis to identify themes that emerged from transcripts according to the interviews.

RESULTS

The research was conducted to ten participants with the majority of men as many as 8 people and 2 women with an average age of 31.5 years. The educational

background can be varying from 2 people of Diploma 3, 6 people of high school, and 2 people of junior high. The occupations of participants were 5 vendors, 2 drivers, 2 internet cafe employee and civil servants 1. The marital status of the participants was 9 people have married and one person was unmarried. For more details on this section can be seen in Table 1.

Table 1: Baseline characteristics of PLWHA in Bandung Indonesia.

Characteristics	Values
Male	8
Female	2
Sex ratio (male: female)	4:1
Age (mean±SD)	31.5 years
High school	6
Diploma 3	2
Junior high	2
Married	9
Unmarried	1
Vendors	5
Drivers	2
Internet cafe employee	2
Civil servants	1

The participants were treated and suffered a critical condition with 6 people were diagnosed pulmonary tuberculosis, 3 people were diagnosed cerebral toxoplasma infection and one person suffered bronchitis with tuberculosis. For more details on this section can be seen in Figure 1.

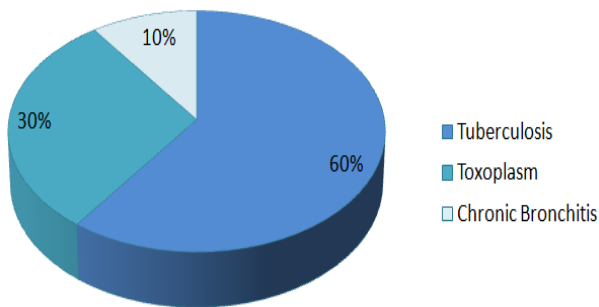


Figure 1: PLWHA diagnosis in critical condition.

The participants were treated and suffered a critical condition with clinical profile is show in Table 2.

Table 2: Clinical profile of participants.

Symptoms	Values
Coughs	5
Diarrhea	4
Shortness of breath	4
Unconscious	3
Convulsions	1
Chest Paint	1

Based on a thematic analysis obtained the following themes 1) At the moment of being hospitalized in critical condition PLWHA experiencing an emotional response, 2) Living a life destined as people living with HIV and AIDS, 3) Getting closer to God, 4) Struggling to cope with feelings and the impact of the disease, 5) Prayers and support from people around, 6) The Hope to recover.

DISCUSSION

At the moment of being hospitalized in critical condition PLWHA experiencing an emotional response.

PLWHA’s critical condition might impart additional serious burdens and bring them closer to the mortality threat. According to the five stage model of death and dying by Kubler-Ross (1969), that the stages of emotional adjustment associated with mourning in every individual who felt the loss can be denial, anger, bargaining, depression and acceptance.¹⁷ The process of grieving in PLWHA is the loss of lives due to being diagnosed with diseases that have no hope for a cure or live.¹⁸ The emotional responses experienced by people living with HIV include angry and shocked, ashamed and embarrassed if others knew their status, anxiety and stress, despair and immediately wanted to die, accepting and surrender to the disease. The anger as a stressor often makes them unstable and cannot control their own selves. The rage PLWHA felt arose when they were contemplating the reality and realise the cause of the illness is their selves. One of the participants revealed, “There is anger against my own self, I sometimes get angry, crying” (P8). Other participants expressing angry with others “I was angry at that time, then I scold the nurse” (P1). The rage experienced by PLWHA can be accompanied by a rejection of the conditions they felt. One of the participants said, “I feel worried and stressed out, sir, startled too, I can’t accept this” (P9).

In this phase, PLWHA tried to preserve the loss they felt and might act aggressively more than usual. This was one of the coping mechanism to cover up feelings of disappointment and a manifestation of anxiety due to the loss they have to face. This was also supported by research, that severe stress has the consequence of the various responses of the body such as unusual thoughts, anger, fear, rebel and escaping the reality.¹⁸

PLWHA which are treated in a critical condition shows the anxiety and fear of the mortality threat. The anxiety experienced by PLWHA are also accompanied by feelings and uncertain thoughts, as expressed by participants 3, “I often feel inferior, sir, I cannot calm my mind, after being told of having this kind of disease, they said it cannot be cured. I’m just thinking how I continue my life”. Anxiety and stress felt by PLWHA are associated with the worsening impact of AIDS, as expressed by participants 8 “at that time, I was worried, feared of not getting cured and have no future anymore”. At the time of being depressed, PLWHA tend to be

helpless to change the situation at hand, so they tried to get the convenience with the help of others (seeking social support).

A stigma given by society to PLWHA are making them more depressed and isolated, especially they fear of disclosing their statuses mainly related to work, as expressed by participants 3, "I actually feel embarrassed with my co-worker". Fright is also because they know that AIDS is the result of bad behaviour, especially related to sexual behaviour and drug abuse, as expressed by the participants 1, "embarrassed as hell, the disease's been labelled by society as 'negong', I feel ashamed and insecure, sir, if it is possible, do not let others know if I get this kind of disease".

The fearful feeling of exposing status is a coping, but also a pressure for them.¹⁹ Prolonged psychological stress causes PLWHA increasingly isolated and less open to other people so that it falls on depression and approximately 50%-60% of adults living with HIV suffered from chronic depression.²⁰

The expression of depression in PLWHA shows their powerlessness facing severe conditions. One participant said, "that time I was mostly quiet, so lazy, not having any passions to do anything" (P4). The results of this research are supported by Brown's invention (2001), that the complaints expressed by the participants show that depression can be demonstrated by the silent reaction that leads to rejection.

Long-drawn depression can cause PLWHA became discouraged by their desire to end their life. As expressed by the participants 8, "I often cry, I used to want to die because my illness is hard to be healed". "It seems I want to die already, I give up, maybe it's time I ... It seems like my life is useless, though I'm still young" (P2). Some researchers reported that higher levels of depression symptoms of PLWHA due to the rapid development of AIDS and deficient immune owned by people living with HIV/AIDS.¹⁸ The Depression felt by PLWHA in a critical situation is the impact of the inability to deal with more severe stress.²¹

Living a life destined as people living with HIV and AIDS.

Most of the participants revealed that the disease that they have now is a fate. As expressed by participants 3, "perhaps this is a destiny that I have to live, I don't know how to turn back time, so yes we just accept it". The phrase is based on the belief that God created all things, and it's already set (destiny). Fate as a sign of the power of God that must be believed and it has happened so it must be endured and faced. As happened in Syria, that HIV/AIDS is set as God providence. This assumption is to redeem the PLWHA from discrimination struggled by a doctor, that PLWHA are not criminals, but a patient who needs medical assistance.²²

Most of the participants revealed that the disease was a punishment for his actions. This was expressed by participants 6, "the disease is the result of my actions that I once did, so I should accept it." "Maybe this is the sins that I have ever done before, yes ... like a punishment" (P10). PLWHA consider AIDS as a punishment from God because the patient had unmarried sexual intercourse and they regretted it and ask for forgiveness for the strength. One participant said, "we don't need to blame others, we do that so we should bear the sins, but God is a forgiver, which is important for us to repent, pray, Allah will forgive". Spiritual strength possessed by the participants, help them accepted the fact what they have gone through was a test from the Creator.

Getting closer to God

Most of the participants revealed when treated, they handed over all circumstances to the Lord by praying, begging for strength and forgiveness. Prayer that's already done by PLWHA in critical condition is spontaneous when they enter the treatment rooms, as expressed by participant 1, "I immediately pray for healing, O God, ... I want to live again". They also pray begging for strength as expressed by the participants 8, "I often pray, if I cannot be healed just take my breath away. If God still allows me to be healed, I wish I'll be given the strength, yes... up until now my condition is bearable". Pray is purposely to obtain forgiveness, reaching spiritual experiences and find the meaning in life. The concept of praying undertaken by PLWHA allowed to integrate into the life of their spiritual.²⁰

Struggling to cope with feelings and the impact of the disease

Conflict feeling felt by PLWHA related to its responsibilities towards the family, especially their presence of their children. As expressed by participant 1, "just fight the feeling, I really love my children, but I decided not to see them before I recovered." Death threats often arise causing a cognitive response shown with a chaotic mind.²¹

Conflict feeling felt by PLWHA are also affected by anxiety about the disease, as expressed by the participants 3, "only my mind can't calm because I was told that a disease like this can't be healed, I just think about how I continue my life". Conflict feeling is very haunted by AIDS prognosis which is close to death as expressed by the participants 4, "sometimes my mother also has bad thoughts, perhaps a lifetime (going to be short)".

Prayers and support from people around.

PLWHA who are in a desperation need support in order to come up again. Most of the participants revealed that they have family support, hospital worker, close friends and religious leaders. As expressed by participants 6, "my wife and children encouragements, prayers from my wife

and my family feel like one of the medicines, despite being surrender to the fate, family support is very important". The family member who is expected to assist during the treatment of PLWHA in a critical condition is the closest person which is wife. As expressed by the participants 10 "during the treatment I was strengthened by my wife and family, she was always waiting for me".

Family involvement is very important to diminish the stigma experienced by PLWHA in a critical condition, because the family is the one most understand the emotional state of the patient, understand the needs and provide comfort.²³ In addition to the family, hospital personnel, especially nurses have an important role in restoring the confidence of the PLWHA. Most participants said that the support of hospital workers felt so helpful to raise their life motivations. As expressed by participants 7, "the current hospital workers are better, sir, Previously the PLWHA were treated in rooms like caves, but now it is being treated like at home so, often they give explanations and patti me". The implementation of effective nursing management, nurses understand the needs of PLWHA, providing excellent service and improving treatment adherence program.²⁰

Family support and health care workers have not been enough to raise the motivation of PLWHA who are treated in a critical condition. Multi-actor approach is also needed by PLWHA who are in chronic depression level.²⁴ The support of close friends is also considered important by PLWHA who are treated in a critical condition. This was expressed by participants 6, "the support of the closest people, friends". One of the participants said that the help of priest through prayer also felt greatly helpful to boost their self-confidence, as expressed by the participants 3, "having this disease is a disgrace, sir, and the confidence can be raised by a priest... like Ustad".

The hope to recover

The support which has been obtained from the various parties, making the critical PLWHA have a high motivation to recover. One of the participants said, "although I am powerless ... I want to recover as well, I want to recover so I could walk again, I remember my family" (P2). Motivation arising within the PLWHA is also because they are aware that AIDS would infect more if their condition becomes weak. This realization raises their efforts to improve the body's defences through reviving their confidence. This was expressed by participants 7, "I will fight, if we are in despair, we cannot heal, sir, I want to recover, and it is pointless if we give up".

PLWHA who have high motivation are also followed with the hope for recovery. Hope can give you the strength to live in difficult times. Hope gives a consequence for the emergence of desire, pleasure, and life. According to Kylma, hope indicates that someone

has recognized the possibility to build something new. Hope can also give confidence that they will live worthily in the future.³

CONCLUSION

Double burden faced by PLWHA causes them to feel disturbed psychologically, such as angry and shocked, embarrassed and inferior to others, worry and stress against the harmful effects of the disease, feeling desperate and wanted to die, accept and surrender to existing conditions. They have to accept the fate to live their life as PLWHA and have always struggled against bad feeling due to death threats.

Pressure and powerlessness as PLWHA in critical condition, they need support from various parties such as family, health workers, close friends and religious leaders to reduce the burden of both physical and psychological. The support they get effectively revive their shattered and dampened hopes due to AIDS..

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