

## Original Research Article

# EXPERIENCES OF PEOPLE LIVING WITH HIV/ AIDS IN SURVIVING LIFE

Bagas Biyanzah Drajad Pamukhti<sup>1\*</sup>, Meira Erawati<sup>1</sup>, Muflihatul Muniroh<sup>2</sup>, Nur Setiawati Dewi<sup>1</sup>

<sup>1</sup> Master of Nursing Study Program, Faculty of Medicine, Universitas Diponegoro, Semarang, Indonesia

<sup>2</sup> Medical Study Program, Faculty of Medicine Universitas Diponegoro, Semarang, Indonesia

### \*Correspondence:

#### Bagas Biyanzah Drajad Pamukhti

Master of Nursing Study Program, Faculty of Medicine, Universitas Diponegoro, Semarang, Indonesia  
Jl. Prof. Soedarto, Tembalang, Kec. Tembalang, Kota Semarang, Jawa Tengah 50275

Email: [bagas.biyanzah@gmail.com](mailto:bagas.biyanzah@gmail.com)

### Article Info:

Received: July 29, 2021

Revised: November 19, 2021

Accepted: December 26, 2021

### DOI:

<https://doi.org/10.36720/nhjk.v10i2.293>

### Abstract

**Background:** Fear of contracting HIV in the community causes discrimination and stigma to people living with HIV/AIDS (PLWHA) because people still consider HIV/AIDS taboo. Many of the sufferers struggle to reveal their HIV status to others, but they get negative results such as rejection, stigmatization and even discrimination which can be a high psychological burden. Stigma and discrimination against PLWHA are the main obstacles to achieving a good quality of life.

**Objectives:** This study is intended to explore the in-depth experiences of people living with HIV/AIDS in surviving life.

**Methods:** This research is a phenomenological case study. The sample in this study amounted to three people who were recruited from Healthy Loving Care Foundation Semarang City. The sample was determined using a purposive sampling technique according to the inclusion criteria, that is age 20 and 50 years, diagnosed with HIV/AIDS, conscious, cooperative, not experiencing cognitive, hearing and speech disorders, willing to participate in the study by signing the informed consent. The data was collected by in-depth online interviews and then recorded in transcripts and analyzed using Amedeo Giorgi's data analysis technique.

**Results:** This study showed that participants experience adversity due to HIV/AIDS but the participants get out of their slump by accepting their illness, taking treatment, finding a support system and becoming a positive people. The participants also in living their lives keep their illness a secret to survive so as not to experience bad stigma or discrimination. The results of this study reveal one main theme, Experiences of People living with HIV in Surviving life.

**Conclusion:** This study found the support received by participants and the response of participants to their condition as an effort to survive their lives.

**Keywords:** Experience, PLWHA, survival, living life.

## INTRODUCTION

Human immuno-deficiency virus (HIV) in Indonesia reported by the Ministry of Health in

2018 is as many as 640,443 people, 47% of people living with HIV/AIDS (PLWHA) and the highest percentage in the 25-49- and 20-24-

year age groups. The province with the highest number of HIV sufferers is DKI Jakarta with 55,099 people, followed by East Java with 43,399 people, West Java with 31,293 people, Papua with 30,699 people and Central Java with 24,757 people (Kemenkes RI, 2018).

The HIV virus pandemic, which has spread throughout the world, has not only affected physical health, but mental health and well-being as well (Limalvin, Putri, & Sari, 2020). HIV is a virus that until now has not found a vaccine to prevent transmission and cure, that ultimately brings about fear in society. Fear of contracting HIV causes discrimination and stigma for people living with HIV/AIDS (PLWHA) because people still consider HIV/AIDS taboo (Sen, Nguyen, Kim, & Aguilar, 2017).

Society still considers HIV/AIDS taboo because sufferers relate to homosexual behavior, drug use, and promiscuity, especially in Asian society which results in a lack of public understanding of HIV/AIDS (Yu, Chan, & Zhang, 2016). Many of the sufferers struggle to reveal their HIV status to others but get negative results such as rejection, stigmatization and even discrimination which can be a high psychological burden (Qiao et al., 2015). In addition, PLWHA may also experience pressure to marry, produce offspring and continue the family line but are afraid to reveal their status to their partners because of the stigma about people living with HIV (Qiao et al., 2015).

Research shows that there is a symbolic stigma, instrumental stigma, and a stigma of decency or social punishment in society. Symbolic stigma is a bad perception of PLWHA. Instrumental stigma is the fear of being infected if their children play with PLWHA children, the fear of being infected when shaking hands, and the fear of buying food sold by people with HIV/AIDS. The stigma of decency/social punishment is judging or blaming the sexual behavior of PLWHA (Puspita, Hayati, & Fuadah, 2017).

Stigma cannot be separated from the values and norms that exist in society. People

think that people living with HIV/AIDS (PLWHA) are people who carry infectious diseases, so people think they have to keep their distance. People also assume that people affected by HIV are people with promiscuity, users of illegal drugs and have deviated from socio-cultural and religious values and norms that apply in society (Kemenkes RI, 2012; Maharani, 2017; Pessin, 2017).

Public belief that people living with HIV/AIDS (PLWHA) is a bad labe is still common. The view of people with HIV/AIDS who are identical as bad people such as female sex workers, drug users and so on makes it difficult for sufferers to get support from family, peers, community, and health services. Bad labeling causes discrimination against people living with HIV/AIDS (PLWHA) in daily life as distancing themselves, not allowing certain contacts and sharing property such as not allowing sufferers to use the same toilet. Many people living with HIV/AIDS feel stressed and helpless in their lives because bad labels for both their behavior and their lives have been rooted in the culture or norms that exist in society (Ahmed et al., 2018; Woodgate et al., 2017).

Stigma and discrimination against people living with HIV/AIDS (PLWHA) are the main barriers to achieving a good health-related quality of life. Stigma is also a factor that causes people living with HIV/AIDS (PLWHA) more often to cover themselves up, keep secret and hide their illness from society, family, and their partners (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Fear of discrimination and stigmatization of themselves is the cause of PLWHA mainly closing themselves to the environment and health services, this makes it difficult to overcome the development of AIDS in the world (Rueda et al., 2016).

Fear of stigma and discrimination causes people living with HIV to choose to keep their disease status secret. This phenomenon affects physical, mental health and well-being. Therefore, qualitative research on the experience of PLWHA in surviving life needs to be studied more deeply. It aims to gain a deep

understanding of PLWHA in surviving their lives.

## **METHODS**

### *Study Design*

The research design used in this research is a phenomenological case study. Case studies focus on a particular situation, group of people, event, program or phenomenon. Phenomenology is a science that emphasizes the view of thinking and focuses on human subjective experiences (Moleong, 2014). A phenomenological case study is a research design that seeks to understand a case or the essence of a complex human experience and the underlying structure of a phenomenon experienced (Merriam, 2009; Merriam & Tisdell, 2016). Case study research can be combined with other research designs such as ethnography and phenomenology, this is because it has a relationship with the essence of one's experience related to a phenomenon. Case studies allow researchers to observe and analyze data at a much smaller and more in-depth level (Merriam, 2009).

### *Setting*

Data retrieval is carried out on May 30 2020 which is carried out online through the WhatsApp application. Online interviews of three participants with HIV were conducted at their homes. The researcher asked the participants during the interview process to prepare a place so that the interview process could run smoothly. Researchers asked the Healthy Loving Care Foundation - in bahasa indonesia it is called Yayasan Sehat Peduli Kasih (PEKA) - Semarang City to select participants according to the research criteria. PEKA is an institution that is engaged in the issue of HIV and AIDS by providing support to PLWHA and peer support groups, so that they understand the participants according to the inclusion criteria of the study. The researcher then got the participant's contact person for online interviews due to the COVID 19 pandemic. The researcher then introduced and

explained the purpose and time contract, then the three participants were willing to be interviewed on May 30, 2020. The next stage was to validate interview transcripts to the three participants for three times periodically where each validation, the researcher conducts interviews again to complete the required data.

### *Research Subject*

Data collection in this study uses purposive sampling technique. Participants involved in this study have met the inclusion and exclusion criteria that have been set. The involvement of a number of participants is based on data saturation, in the sense that when the data is saturated and no new information is obtained, the number of participants is not increased (Sugiyono, 2018, 2019). Participants in this study amounted to three participants.

Participants were recruited from Non-Governmental Organizations (NGOs) Sehat Peduli Kasih Foundation (PEKA) Semarang City. The criteria of participants was between the ages of 20 and 50 years, diagnosed with HIV/AIDS, composmentis awareness, cooperative, not experiencing cognitive, hearing and speech disorders, willing to participate in the study by signing an informed consent.

### *Instruments*

The first data collection process, the researcher documents the literature, articles and related research results and then makes interview guidelines. Before conducting the interview, the researcher explained the informed consent, after the participants agreed to be the research sample, the researcher asked several questions to fill in the demographic data. The researcher conducted an in-depth interview using a cell phone as a voice recorder, then the researcher wrote down the results of the interview into an interview transcript for analysis so as to determine the research topic. The duration of the interviews varied between 20-40 minutes according to the time agreed upon by the researcher and the participants and was conducted twice for each participant. The

questions given to participants related to the experience of PLWHA in surviving life.

The researcher conducted the validity of the data by asking all interviewees to review the complete description of the written interview transcript to confirm that the transcript accurately and reflected the essence of the experience experienced directly. The researcher involved three researchers, authors 2, 3 and 4 in reviewing data, documents and in-depth discussions about determining categories and analyzing data. Credibility is also enhanced by including many quotes from participant conversations that are included in the research results. Researchers compile research reports clearly and systematically so that readers can find out whether or not there is bias in applying the results of this research in different places.

#### *Data Analysis*

The transcript was then analyzed using the Amedeo Giorgi method, the steps taken were the researcher read the entire description (transcript) to develop a phenomenological attitude or enter into the participant's life situation, the researcher found the meanings in the transcript and put a mark on each meaning, the researcher filtering from meanings that are not relevant to the research question, the meaning units are then reformulated by the researcher using language as close as possible to the participant's language which is then transformed into psychological language, then the researcher synthesizes and integrates psychological themes that have been studied. found and described as the main themes or core experiences of participants (Kahija, 2017).

#### *Ethical Consideration*

This research was conducted by applying the ethical principles contained in the Declaration of Helsinki to ensure the fulfillment of the rights of participants. The willingness of participants to be involved in this study was legalized with an informed consent form that was filled out and signed by the participants voluntarily. This research has obtained permission from the Healthy Loving

Care Foundation (PEKA) Semarang City as evidenced by a permit letter with letter number 92/YSPEKA/II/X/2021.

## **RESULTS**

The results of interviews conducted with three participants admitted that they contracted HIV from risky behavior through sexual intercourse. When first diagnosed, participants generally feel down and seek immediate treatment. Participants feel changes in themselves in the form of physical, cognitive which causes them to take better care of their health. After being diagnosed with HIV, participants prefer to keep their status as a person living with HIV a secret in the community and family. This is done because they think they will be discriminated against and stigmatized if their status as people with HIV is revealed. The stigma attached to HIV sufferers as a disgrace is that someone with bad behavior in the environment around where they live is the background for them to keep their identity as PLWHA a secret. Some participants also experienced direct stigmatization from health workers and the community which caused them to choose to keep their status secret. The form of support from family and closest friends motivates them to try to become positive individuals, which is useful for others, one of which is by providing education about HIV prevention, transmission, and treatment which is expected to eliminate the stigma that exists in society against PLWHA, which is the hope of every participant.

This study reveals the experiences of people with HIV/AIDS and finds one theme, namely, the experiences of people living with HIV/AIDS in surviving life.

#### *Case*

##### *Participant 1*

The first participant is a 26-year-old male with a high school education, diagnosed with HIV since June 2015 and has been receiving regular treatment. The first-time participants were diagnosed with HIV, they felt disbelief and believed that death was getting closer.

Participants got stigma from health workers at the hospital when they first found out that they had HIV which caused them trauma and the background behind them to keep their disease status a secret because they believed that society would stigmatize and discriminate against them.

#### *Participant 2*

The second participant is a 40-year-old woman with a senior high school education, diagnosed with HIV since 2018 and has been undergoing treatment regularly while keeping her disease status secret. Participants believe that if the status of their illness is known to their surroundings, they will be alienated from their family and society. The participant is currently pregnant and refuses all visits to the puskesmas to carry out a pregnancy check so that his disease status is not known to others.

#### *Participant 3*

The third participant is a 25-year-old man with a college education, diagnosed with HIV since 2014 and has been receiving regular treatment. Participants had opened up their disease status to other people who were eventually shunned and made him more insecure in establishing relationships with other people.

#### *Phenomenological Structure*

*Theme: Surviving a life as PLWHA*

*Subtheme: Adversity*

The responses from the experience of knowing that they were diagnosed with HIV for the first time in the three participants showed a downturn. Participants expressed feelings of sadness, confusion, disappointment, shock, stress, and feeling that death was imminent. This is present in the expression of P1.

“....confused, sad, crying, all I think about is just die, die, die, die, die, die, and die....” (P1 : Line 63-64)

A downturn is also reflected in P2 who explains that he has mixed feelings.

“...wow, stressed, devastated, felt that life would not last long, disappointed, all mixed together” (P2 : Line 55-56)

Even though the participants experienced a slump, the participants expressed that they felt they had to get treatment immediately by asking for treatment as soon as possible so that the disease would get treatment before it got worse.

“...At that time I was thinking how to make treatment, how I ask for treatment as soon as possible...” (P3 : Line 55-56)

#### *Subtheme: Feeling self-change*

After participants were diagnosed with HIV/AIDS and became a PLWHA, all participants felt physical, cognitive, and emotional changes. and more concerned about their own health.

Participants felt a change in their body weight which increased after contracting HIV compared to when they were healthy.

“....the change is, in the past i might have been thin, but now i'm fat...” (P1 : Line 58-59)

In addition, participants feel more often forget and often feel dizzy.

"Yes, I often forget, keep getting dizzy" (P2 : Line 68)

However, after the participants became PLWHA status, participants became more aware of maintaining their health.

“.what is it.. just be more aware of health ” (P3 : Line 59)

“.....really take care, especially take care of myself ....” (P3 : Line 116)

“.... So I'm more aware of my own body, especially my health ...” (P3 : Line 124)

#### *Sub-theme: Persisting in secrecy*

The commitment of the three participants to hide and keep their status secret from their families and society stems from fear and concern about stigma and discrimination that



might occur if their disease status is known. This is as expressed by P1 below.

“Yes, I don't open my status to the public” (P1 : Line 89)

The commitment to keep his illness status secret from his family and community is also evident from P2's expression.

“...but sorry, my family, the community, no one knows until now ...”(P2 : Line 56-58)

One of the efforts made by participants to maintain the confidentiality of the disease so that it is not known by the surrounding environment is by refusing visits from public-health workers who will check pregnancy, as stated by P2.

“...when I was pregnant, the public-health center wanted to visit me, but i stopped them immediately. I didn't want to” (P2 : Line 60-61)

The reluctance of all participants to be open about their status as PLWHA is due to the belief that society considers HIV/AIDS to be a disgrace and something bad.

“...the people didn't want it, from the past until now people still think the same” (P1 : Line 98)

“ ... that's a disgrace, it's ugly, it's his fault and so on blablabla ...” (P1 : Line 134)

In addition, participants believe that if their disease status is known by their families and communities, they will definitely get social isolation or worse, participants will be expelled from their homes. Even though the participants felt that they could not live alone without the help of others.

“... I am sure that you will be removed from your family, villagers, you will be bullied, you will definitely be removed and become a topic of conversation. Our family is close, even the smallest things will know that” (P2 : Line 77-80)

“... the thought is that he is disgusted and should not be allowed to live in this

village, he feels that he is clean, pretends to be clean and everything ...”(P2: Line 141-144)

“... they all don't want to know me and I feel that I will live alone, I feel that I can't live without the help of others” (P2 : Line 164-166)

Some participants themselves have experienced stigma and discrimination as well as published status that makes participants feel traumatized and insecure so that they prefer to keep their status secret.

“...the nurse herself even asked a lot of why did you get hit? You're still young, so who are you with?... it makes you drop ...” (P1 : Line 43-51)

“...At that time I wanted to open my mouth, I was wrong to open it to someone, finally he stayed away, then finally the status had been everywhere ...”(P3 :Line 77-78)

“...maybe if you meet the wrong person you will be more insecure ...” (P3 : Line 124-127)

The existence of negative public stigma about PLWHA as a disgrace and discrimination experienced as PLWHA makes participants feel concerned, participants hope that people's perspective and understanding regarding HIV/AIDS will change. so that there is no negative stigma against PLWHA in the future.

“...I was concerned about people in the past, just as now They blamed the illness, after all, those are her own problem. Honestly, I'm more open to students and schoolchildren so that maybe 20 years from now when they become parents and they understand about this kind of disease and feel no worries about it, there is no other stigma, that is my hope...”(P1 : Line 201-212)

“I hope their perspective sees me that my development is healthy like other normal people regardless of my illness ...” (P2: Line 216-218)

“..people talk about HIV like people talk about cancer or other diseases ...”(P3 : Line 156-164)

*Subtheme: Feeling the psychological burden*

Stigma, discrimination and fear caused a negative impact on the if their status is published. The impact they feel is emotional pressure in the form of trauma to stigma, being insecure, feeling oppressed (persecuted), and not succeeding in having a good household.

“.....I have a burden like that, I also just found out what HIV disease is, I also have not received it but there I have been cornered ...” (P1 : Line 43-51)

“..I feel down I feel mistreated, I don't feel managed to have a good household and my husband ran away to someone else and was more comfortable with other people ...”(P2 : Line 101-107)

*Sub-theme: Trying to be a positive person*

Despite the participants' commitment in facing stigma and discrimination in the form of keeping their disease status secret from the community. Participants also try to become more positive individuals in their behavior by establishing relationships, sharing with others, pouring out their hearts so that they can support each other and be more open to their families.

“.....because I became like this I finally know people at the Health Service and several doctors, so we exchange knowledge ...” (P3 : Line 73-74)

“...I can take care of myself and my husband,” (P2 : Line 146-147)

“...it's a relief to be able toso there's no burden at all. At least I can pour my heart out to someone...support each other” (P1 : Line 114 - 120)”

“.. I dare to open up my status to my family after that, i can do treatment” (P1 : Line 127)

In addition to positive behavior, participants also always try to think positively by reducing their own emotions, keeping their

shame a secret so that they can feel calmer, less emotional, express emotions positively, and become role models in the family.

“.. overcoming the stigma actually eases one's own emotions, so that the sadness that has happened does not drag on ...” (P1 : Line 160-163)

“...I have always been positive even though sometimes other people don't ...” (R3 : Line 101-104)

“.. calmer, so not emotional ...”(P1 : Line 165-167)

“..express positively like eating, keep walking, you will get tired then sleep, then forget it the next day ...” (P3 : Line 137-139)

“I have to set a good example, from all my treatment from all my words ...”(P2 : Line 154-157)

Participants in dealing with life try to surrender everything to Allah, accept the situation, try to become a better person, be useful to others and the environment.

“...it's just lillahita'ala, it's also God who regulates it, so let's just accept the situation ...”(P1 : Line 179-186)

“I want to become a better person again, useful for the same friends, too, can be useful for students as well and perhaps children of school children ...” (P1 : 201-212)

“may be undergoing everything is better, healthier ...”(P3 : Line 156)

*Sub-theme: Finding support in surviving life*

Support system for people living with HIV who are stigmatized and discriminated against must be given motivation and encouragement to get through all of this well. The support of the closest family, peers and health workers can be a supporting factor in the success of the process of self-acceptance and treatment both in biopsychosocio and cultural.

P1 and P2 explained that nurses and members of peer support groups have quite a lot of roles in being a support system, they provide support in adjusting to their illness. This

support motivates participants to get back excited about life.

“...my peers at the hospital who know me actually make my spirit healthy, my spirit is to live a righteous life and eliminate negative thoughts ...” (P2 : Line 97-100)

“...actually my friends, the first is peer support member, the second is from nurses who really care about us, so they are very helpful ...”(P1: Line 170-171)

“ she is a nurse. To be able to live this life is because the spirit from Ms W, there is Ms. W, there is Ms. B. there is a mother, she is the same age as me, because from the smallest things I am always open...”(P2 : 199-202)

In addition to nurses and peer support group, participants received support from close friends and family.

“close friends with family ...”(P3 : Line 142)

“..that was the first time my friend knew he was positive thinking, meaning he could be healthy ...”(P1 : Line 93-94)

## DISCUSSION

This study explores the experiences of PLWHA in surviving life using a case study research design. This study found the theme of surviving life in people with HIV/AIDS which consists of six sub-themes, those are adversity, feeling self-change, surviving in secrecy, feeling psychological burden, trying to be a positive person, and a support system.

This study found results where all participants contracted HIV through risky sexual intercourse. HIV transmission is through bodily fluids that can be infected with other people through several ways including sexual intercourse, blood transfusions, sharing needles, and from mother to child (Basavarajaiah & Murthy, 2020; Kliegman et al., 2020).

The participants were tested for HIV for the first time because they got several symptoms of the disease which they eventually found out to be HIV positive. The first response

to know that they had HIV in the three participants experienced a slump and immediately sought treatment. The adversity experienced by participants in the form of feelings of sadness, confusion, disappointment, hit, stress, and feeling that death is getting closer. Research shows that people diagnosed with HIV tend to experience psychological problems such as stress, anxiety, and depression because they feel that death is very close (Radzniwan et al., 2016). Another study that is in line with this condition is a study which states that people with HIV/AIDS have a psychological burden from stress to depression which if not handled properly can lead to the idea of committing suicide (Wang et al., 2018; Yang et al., 2018).

People living with HIV/AIDS not only experience psychological stress but can feel self-change in the form of physical and cognitive changes as well. Changes in physical form experienced by participants were changes in body weight, while the cognitive changes found in participants were memory loss and headaches. This study also found results that participants became aware to maintain their health and maintain a healthy lifestyle. The decrease in the CD4 count as the immune system to prevent various diseases causes the entry of various diseases that can cause disease and affect changes in the body. Research shows that a decrease in CD4 count <200 /dL significantly increases the risk of serious diseases such as hepatitis, tetanus and so on in HIV patients (Erlandson & Karris, 2019). The most effective therapy to maintain CD4 is currently antiretroviral treatment (ART) (Hayes, 2020). ART therapy does not eradicate the virus and cure the patient but to suppress the virus for a long time and turn the disease course into a chronic process (Bhatt, Jindal, Sk, Malik, & Sangwan, 2014; Cunha et al., 2016). ). PLWHA requires lifelong treatment using ART, one of the obstacles to controlling HIV/AIDS is the stigma of discrimination (Rueda et al., 2016).

The theory of stigma was started by Goffman (1963) which states that stigma to a



person is the giving of a marker / label of a character that has been tarnished in the context of social relations. Stigma in general is the prejudice of a person or society that provides a social label to separate a person or group with a bad stamp or view based on physical, behavioral, and social characteristics that are considered to deviate from the rules or norms that exist in society (Erving, 1963).

Participants committed to hiding and keeping their status secret from their families and communities stemmed from fear and concern about stigma and discrimination that might occur if their disease status was known. Participants limit social interaction to avoid publicizing their disease status. Some participants have also experienced stigma from health workers and the community that causes psychological impacts such as trauma, insecurity to start interacting with new people, feeling oppressed (persecuted), and not succeeding in having a good household so that they prefer to keep his status a secret. Research shows that stigma is also a major factor that causes people living with HIV/AIDS (PLWHA) to cover themselves up, keep secrets and hide their illness from society, family, and their partners (Stangl et al., 2013). Other research also mentions that social stigma experienced, including ostracism, social isolation, humiliation, judgment, and making fun of is the most dominant compared to other forms of stigma (Mohamed Boushab, Fall-Malick, Ould Cheikh Melaïnine, & Basco, 2017). Stigma and discrimination also affect all life activities of sufferers including accessing health services while they still have to live because they think about the future of their children (Sosodoro, Ahmad, Prabandari, & Hakimi, 2017).

Participants in this study tried to become more positive individuals in their behavior by establishing relationships with trusted people, sharing with others, pouring out their hearts and trying to close the family's disgrace so that they could reveal their status to their closest family. In addition to behaving in a positive manner, participants also always try to think positively

by reducing their own emotions, keeping the family's shame a secret so that they can feel calmer, less emotional, express emotions positively, and become a role model in the family. Research mentions group support including family and closest people, interpersonal therapy and getting peer support in the form of counseling and telling the problem to others which is the best treatment management for psychological distress experienced by PLWHA (Asrat, Schneider, Ambaw, & Lund, 2020).

The support system for people living with HIV who are stigmatized and discriminated against must be given motivation and encouragement to accept their life circumstances. The support of the closest family, peers, health workers and religious institutions can be a supporting factor in the success of the process of self-acceptance and treatment both in biopsychosocio and cultural (Tang & Chen, 2018). In this case, support from family members, peers and health workers is the biggest factor in the success of PLWHA in surviving and living their lives (Tang & Chen, 2018).

## **CONCLUSION**

Based on the results of the research and discussion that has been disclosed, the conclusion of this study is that the three participants can survive life as people with HIV by keeping their disease status secret and getting support from peers (people with the same disease), family and health workers. . This is because participants believe that they will get stigma and discrimination in the form of social isolation from family and society if their health status is published. In addition, some participants have also been stigmatized and shunned by others when they first revealed their status to others.

## **SUGGESTIONS**

Support (support system) from the closest people is a must in the treatment of people with HIV/AIDS, by providing education to the public about HIV disease and the importance of

support for PLWHA so that stigma and discrimination no longer appear in the community.

#### ACKNOWLEDGMENT

Thank you to our participants from Yayasan Sehat Peduli Kasih.

#### DECLARATION OF CONFLICTING INTEREST

We strictly certify that there is no conflict of interest between the authors of this article.

#### FUNDING

Researcher acknowledges that this research used the researcher's personal funds without interference from other parties.

#### AUTHOR CONTRIBUTION

**Bagas Biyanzah Drajad Pamukhti:** Collecting data, analyzing data, compiling research results, conducting discussions, compiling manuscripts.

**Meira Erawati:** Assisting in the interpretation of research results, directing more in-depth discussions regarding research results, directing the preparation of the manuscript.

**Muflihatul Muniroh:** Assisting in the interpretation of research results, directing more in-depth discussions regarding research results, directing the preparation of manuscripts.

**Nur Setiawati Dewi:** Assisting in the interpretation of research results, directing more in-depth discussions regarding research results, directing the preparation of manuscripts.

#### ORCID

**Bagas Biyanzah Drajad Pamukhti**  
<https://orcid.org/0000-0002-4871-2678>

**Meira Erawati**  
<https://orcid.org/0000-0003-2861-4293>

#### Muflihatul Muniroh

<https://orcid.org/0000-0003-0020-6722>

#### Nur Setiawati Dewi

<https://orcid.org/0000-0001-6425-5801>

#### REFERENCES

- Ahmed, S., Autrey, J., Katz, I. T., Fox, M. P., Rosen, S., Onoya, D., ... Bor, J. (2018). Why do people living with HIV not initiate treatment? A systematic review of qualitative evidence from low and middle-income countries. *Social Science and Medicine*, 213, 72–84. <https://doi.org/10.1016/j.socscimed.2018.05.048>
- Asrat, B., Schneider, M., Ambaw, F., & Lund, C. (2020). Effectiveness of psychological treatments for depressive symptoms among people living with HIV/AIDS in low- and middle-income countries: A systematic review and meta-analysis. *Journal of Affective Disorders*, 270(1), 174–187. <https://doi.org/10.1016/j.jad.2020.03.068>
- Basavarajaiah, D. M., & Murthy, B. N. (2020). *HIV Transmission Statistical Modelling*. Singapore: Springer. <https://doi.org/https://doi.org/10.1007/978-981-15-0151-7>
- Bhatt, B., Jindal, H., Sk, S., Malik, J. S., & Sangwan, K. (2014). Vaccination in HIV positive adults: Need to address. *Human Vaccines and Immunotherapeutics*, 10(10), 3011–3012. <https://doi.org/10.4161/21645515.2014.971645>
- Cunha, G. H. da, Galvão, M. T. G., Medeiros, C. M. de, Rocha, R. P., Lima, M. A. C., & Fechine, F. V. (2016). Vaccination status of people living with HIV/AIDS in outpatient care in Fortaleza, Ceará, Brazil. *Brazilian Journal of Infectious Diseases*, 20(5), 487–493. <https://doi.org/10.1016/j.bjid.2016.07.006>
- Erlandson, K. M., & Karris, M. Y. (2019). HIV and Aging Reconsidering the Approach to Management of Comorbidities. *Infectious*

- Disease Clinics of North America, 33(3), 769–786.  
<https://doi.org/10.1016/j.idc.2019.04.005>
- Erving, G. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliff: Prentice-Hall Inc.
- Hayes, E. V. (2020). Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome. In Nelson Textbook of Pediatrics, 2-Volume Set (21st ed.). Philadelphia: Elsevier Inc. <https://doi.org/10.1016/B978-0-323-52950-1.00302-3>
- Kahija, Y. La. (2017). *Penelitian Fenomenologis: Jalan Memahami Pengalaman Hidup* (G. Sudibyo, Ed.). Yogyakarta: PT Kanisius.
- Kemkes RI. (2012). *Buku pedoman penghapusan stigma dan diskriminasi bagi pengelola program, petugas layanan kesehatan dan kader*. Retrieved January 3, 2020, from <http://perpustakaan.kemkes.go.id/inlislite3/opac/detail-opac?id=7409>
- Kemkes RI. (2018). *Hari AIDS sedunia, momen STOP penularan HIV: saya berani, saya sehat*. Retrieved September 2, 2019, from <http://www.depkes.go.id/article/view/18120300001/hari-aids-sedunia-momen-stop-penularan-hiv-saya-berani-saya-sehat.html>
- Kliegman, R. M., Geme, J. W. S., Blum, N. J., Shah, S. S., Tasker, R. C., & Wilson, K. M. (2020). *Nelson Textbook of Pediatrics* (21st ed.). Philadelphia: Elsevier Inc. <https://doi.org/10.1016/B978-1-4377-0126-5.00056-2>
- Limalvin, N. P., Putri, W. C. W. S., & Sari, K. A. K. (2020). Gambaran dampak psikologis, sosial dan ekonomi pada ODHA di Yayasan Spirit Paramacitta Denpasar. *Directory of Open Access Journals*, 11(1), 81–91. <https://doi.org/10.15562/ism.v11i1.208>
- Maharani, F. (2017). *Faktor -Faktor Yang Berhubungan Dengan Stigma Terhadap Orang Dengan Hiv Dan Aids (Odha)*. *Journal Endurance*, 2(2), 158–167. <https://doi.org/10.22216/jen.v2i2.1300>
- Merriam, S. B. (2009). *Qualitative Research A Guide to Design and Implementation: Revised and Expanded from Qualitative Research and Case Study Applications in Education* (2nd ed.). San Francisco: Jossey-Bass A Wiley Brand.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative Research A Guide to Design and Implementation* (4th ed.). San Francisco: Jossey-Bass A Wiley Brand.
- Mohamed Boushab, B., Fall-Malick, F.-Z., Ould Cheikh Melainine, M. L., & Basco, L. K. (2017). Forms of Stigma and Discrimination in the Daily Lives of HIV-Positive Individuals in Mauritania. *The Open AIDS Journal*, 11(1), 12–17. <https://doi.org/10.2174/1874613601711010012>
- Moleong, L. J. (2014). *Metodologi Penelitian Kualitatif (Revisi)*. Bandung: PT Remaja Rosdakarya Offset.
- Pessin, A. (2017). *The Sociology of Howard S. Becker Theory with a Wide Horizon*. Chicago: The University of Chicago Press.
- Puspita, A., Hayati, F., & Fuadah, D. Z. (2017). Stigma Masyarakat Terhadap Orang Dengan Hiv Aids (Odha). *Jurnal Ilmu Kesehatan*, 8(2), 151–159.
- Qiao, S., Li, X., Zhou, Y., Shen, Z., Tang, Z., & Stanton, B. (2015). The role of enacted stigma in parental HIV disclosure among HIV-infected parents in China. *AIDS Care*, 27, 28–35. <https://doi.org/10.1080/09540121.2015.1034648>
- Radzniwan, R., Alyani, M., Aida, J., Khairani, O., Nik Jaafar, N. R., & Tohid, H. (2016). Psychological status and its clinical determinants among people living with HIV/AIDS (PLWHA) in Northern Peninsular Malaysia. *HIV and AIDS Review*, 15(4), 141–146. <https://doi.org/10.1016/j.hivar.2016.11.002>
- Rueda, S., Mitra, S., Chen, S., Gogolishvili, D.,

- Globerman, J., Chambers, L., ... Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*, 6(7), e011453. <https://doi.org/10.1136/bmjopen-2016-011453>
- Sen, S., Nguyen, H. D., Kim, S. Y., & Aguilar, J. (2017). HIV Knowledge, Risk Behavior, Stigma, and Their Impact on HIV Testing among Asian American and Pacific Islanders: A Review of Literature. *Social Work in Public Health*, 32(1), 11–29. <https://doi.org/10.1080/19371918.2016.1173612>
- Sosodoro, O., Ahmad, R. A., Prabandari, Y. S., & Hakimi, M. (2017). Internal Stigma of an HIV-Infected Housewife: a Phenomenological Study. *Jurnal Kesehatan Masyarakat*, 13(2), 158–168. <https://doi.org/10.15294/kemas.v13i2.9970>
- Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*, 16(2), 18734. <https://doi.org/10.7448/ias.16.3.18734>
- Sugiyono. (2018). *Metode Penelitian Kualitatif Untuk penelitian yang bersifat : eksploratif, enterpretif, interaktif dan konstruktif* (3rd ed.; S. Y. Suryandari, Ed.). Bandung: Alfabeta.
- Sugiyono. (2019). *Metode Penelitian Kuantitatif Kualitatif dan R&D* (2nd ed.; Sutopo, Ed.). Bandung: Alfabeta.
- Tang, K., & Chen, W. T. (2018). HIV and religion in HIV-infected Asians and their families: A qualitative study. *Applied Nursing Research*, 44, 18–24. <https://doi.org/10.1016/j.apnr.2018.09.003>
- Wang, W., Wang, Y., Xiao, C., Yao, X., Yang, Y., Yan, H., & Li, S. (2018). Psychological pathway to suicidal ideation among people living with HIV/AIDS in China: A structural equation model. *Psychiatry Research*, 260, 255–261. <https://doi.org/10.1016/j.psychres.2017.11.077>
- Woodgate, R. L., Zurba, M., Tennent, P., Cochrane, C., Payne, M., & Mignone, J. (2017). People try and label me as someone I'm not: The social ecology of Indigenous people living with HIV, stigma, and discrimination in Manitoba, Canada. *Social Science and Medicine*, 194(2), 17–24. <https://doi.org/10.1016/j.socscimed.2017.10.002>
- Yang, J. P., Simoni, J. M., Cheryan, S., Shiu, C. shi, Chen, W., Zhao, H., & Lu, H. (2018). The Development of a Brief Distress Reduction Intervention for Individuals Recently Diagnosed With HIV in China. *Cognitive and Behavioral Practice*, 25(2), 319–334. <https://doi.org/10.1016/j.cbpra.2017.08.002>
- Yu, N. X., Chan, C. L. W., & Zhang, J. (2016). Dyadic effects of stigma and discrimination on distress in Chinese HIV discordant couples. *AIDS Education and Prevention*, 28(4), 277–286. <https://doi.org/10.1521/aeap.2016.28.4.277>

**Cite this article as:** Pamukhti, B. B. D., et al. (2021). Experiences of people living with HIV/ AIDS in surviving life. *Nurse and Health: Jurnal Keperawatan*, 10 (2), 292-303. <https://doi.org/10.36720/nhjk.v10i2.293>