

Original Article

People living with HIV experience in dealing with HIV/AIDS symptoms

Rahmi Muthia^{1*} | Fitri Mailani¹ | Dally Rahman¹ | Emil Huriani¹ | Khatijah Lim Abdullah²

¹ Faculty of Nursing,
Universitas Andalas, Padang
25163, Indonesia

² Department of Nursing
School of Medical and Life
Sciences Sunway University
47500 Bandar Sunway PJ

***contact**

rahmimuthia@nrs.unand.ac.id

Received : 06/07/2021

Revised : 12/07/2021

Accepted : 16/07/2021

Online : 23/07/2021

Published : 31/08/2021

Abstract

Aims : This study aimed to explore the PLWH live experience in dealing with HIV / AIDS symptoms.

Design : This study applied qualitative method.

Methodos : This study used descriptive explorative to explore the HIV symptoms experiences of PLWH in Padang West Sumatera, Indonesia. We conducted an unstructured interview among purposively sample PLWH. Inclusion criteria for participation were being male or female PLWH, residing in Padang, and age over 18 years. Data saturation was reached after the completion of 9 interviews. Content analysis was used to analyze and interpret qualitative data.

Results : The following themes emerged from the data: (a) face troublesome symptoms, (b) health literacy in HIV care, and (c) make efforts to heal.

Conclusions : PLWH experience HIV symptoms, continue to adapt and learn. The information about HIV symptoms experiences can facilitate caregiver to plan nursing care, identify education needs to help PLWH dealing with symptoms of HIV. This research can be the basis for conducting further research on how to manage the symptoms of HIV.

KEYWORDS : HIV, symptom experience, symptom management

INTRODUCTION

HIV / AIDS continues to be a global health problem since its inception until now. At the end of 2019, approximately 38 million people were living with HIV / AIDS. There is currently no treatment to cure HIV, however, 62% of people living with HIV are receiving antiretroviral therapy (ART). This prevention strategy is quite effective in preventing opportunistic infections, controlling the virus, and preventing HIV transmission, as evidenced by a 39% reduction in new HIV infections, and the likelihood of lives being saved due to ART. (1).

Although HIV management is statistically effective in reducing morbidity and mortality, several studies examining the results of HIV / AIDS management in terms of quality of life have found that the quality of life for PLWH is still low (2); (3); (3). The quality of life for



PLWH is built internally by physical and mental conditions, and externally from social conditions and sources of support (4). From the physical condition, the symptoms of HIV / AIDS are one of the causes of the low quality of life in PLWHA (5).

The incidence of HIV / AIDS symptoms in PLWHA is high. According to research by Wilson et al. Symptom disorders occur in about 71% -85% of PLWHA. Reportedly, 96.9% of HIV / AIDS patients reported experiencing at least 1 symptom a year, 31% of them had severe symptoms, 8% of patients complained of 10 or more symptoms, and more than 80% of respondents stated that their symptoms were disturbing (6).

The symptoms of HIV infection are very complex and varied. The incidence of HIV / AIDS symptoms depends on the stage of infection (7). The incidence of HIV / AIDS symptoms is associated with progressive disease and clinical conditions (8). In addition, the symptoms of HIV / AIDS that occur are influenced by the length of time they have had HIV, the ART regimen, the CD4 condition, the opportunistic infections experienced, the side effects of ART that are felt, and the psychological conditions of PLWHA (4). So the experience of HIV / AIDS symptoms is very subjective. However, according to experience, HIV / AIDS symptoms are often not identified by health care providers, are rarely reported by patients, and are not treated (8). Moreover, there are no official guidelines to help PLHIV in the management of HIV / AIDS symptoms. The purpose of this study was to explore the PLWH live experience in dealing with HIV / AIDS symptoms.

METHODS

Design

Study design was a qualitative research, using explorative descriptive research methods to explore the HIV symptoms experiences of PLWH in Padang West Sumatera, Indonesia.. Explorative descriptive research aims to describe the state of a phenomenon, explore extensively about the causes or things that influence the occurrence of something, that is not intended to test certain hypotheses but only describes what is a situation.

Study Participant

Nine participants were purposively sample through community key informant. Inclusion criteria for participation were being male or female PLWH, aged 26-45, and residing in Padang.

Ethical Considerations

Researchers gave participants the freedom to determine participation as participants in this study, after obtaining information related to the research. Participants who were willing to take part in all data collection processes, the researchers provided informed



consent as written evidence of participants' willingness as informants in the study. Researchers have ensured that the activities carried out benefit the participants, free from physical, psychological and exploitation hazards. If during the interview process creates emotional reactions or psychological problems, then the interview be stopped. The researcher keeps the identity of the participant secret by not mentioning the name in the data attachment, but includes the code. The letter P means 'participants' so that P1, P2, P3 etc, mean first, second, etc.

Ethics approval to conduct this research was granted by health research ethics committee RSUP Dr. M Djamil Padang (reference: No 227/KEPK/2020).

Data Collection

From July to September 2020, we conducted an unstructured interview The potential participant was contacted by telephone, and informed verbal consent to participate was obtained after the aim of the study was explained. They were also informed that a face to face interview would be conducted and audiotaped.. Interviews lasting 30 to 60 minutes were conducted in the local language, Bahasa –Minang kabau language. We used a interview guide that content of main question and probing. Recruitment continued until data saturation was determined when no other new theme was elicited from the interviews.

Data Analysis

After interviews were transcribed, all personal identifying information was removed. Verbatim transcripts, observation notes, and socio-demographic forms provided the primary data for analysis. Descriptive statistics were used to describe the study sample's socio-demographic characteristics. Content analysis was used to analyze and interpret qualitative data. Three of the five investigators with qualitative research experience independently coded the data and meetings were arranged to discuss and compare the coding. The coding were read, analysed and discussed with the texts to identify the integrity of the transcribed texts. This results in the two researcher agreeing upon the themes.

RESULTS

Data saturation was reached after interviewing 9 participants, including 3 women and 6 men. Characteristic participants is reported in table 1. The following themes emerged from the data analysis: (a) Face troublesome symptoms, (b) Health Literacy in HIV Care, and (c) *Make efforts to heal*.

Participants' characteristics (N=9)

Variables		
Nationality		
	Indonesia	9
Gender		
	Female	3
	Male	6
Age		
	26-35	7
	36-45	2
Region		
	Islam	9
Marital Status		
	Single	4
	Married	4
	Widowed	1
Educational Level		
	Senior high school	5
	barcelor's degree	2
	graduate degree	2
Risk factor for HIV transmission		
	IV drug user activity	2
	homosexual activity	3
	heterosexual activity	2
	Bisexual activity	2
Time since first HIV diagnosis		
	≤3 years	2
	4-6 years	1
	7-9 years	4
	10 or more years	2
receiving ART		9

Face troublesome symptoms



This theme included the following three sub themes: “Physical symptoms”; “Psychologically symptoms”: “Symptoms due to infections.

Physical symptoms

The physical symptom was present in all participants. It encompassed the many and varied symptoms like fatigue, joint felt so sore, fever, stomach pain, diarrhea, weight decrease, thrush, hard to breathe, shortness of breath and insomnia, rashes, itchy, got a bad appetite, so slim and coughed. This is the statement from the participants:

“Every time I did a physical activity that needed more energy, I felt fatigued. In every fatigue condition, all of my joints felt so sore, my hand, my joint fell asleep, and after that, I always got a fever. I thought I always try to maintain my health I met my nutrition but I often got a fever. My stomach often felt painful, ill, and then I got diarrhea.”(1)

Psychologically symptoms

HIV diagnosis can affect psychological well-being. Out participant report *psychological effect and symptom burden* after having the diagnosis. This is the statement from the participants:

I felt like I did not have self-confidence anymore, I was easily crying. (4)

My emotion became unstable, became flighty like lunatic, easy to get angry and mad. (9)

Symptoms due to infections

Some participants had experience got some infection like *mouth fungus*, Sexually Transmitted Diseases (STD), *TB*, and *dermatitis*. Those infections are related to *somatic* symptom burden. This is the statement from the participants:

“At the end of 2017, my weight got decrease for about 20kg, it might be caused by mouth fungus that made my appetite had gotten worse, in the first, it was just in my mouth, my lips then spread to my tongue. (1)

I got skin allergies, all over my body got wound rashes, felt itchy, reddening, and got some small bump like variola. Then it had flaked off. For that, I went to get a consultation with a doctor and had been diagnosed with dermatitis. (6)

Health Literacy in HIV Care

This theme included the following four sub themes: “knowledge about HIV therapy”; knowledge about prevention ”; ” information about HIV management ”; and ” Empowerment the knowledge/information helps the patient to be independent ”

From the health care providers, peer groups and others, participants got information about the ARV for HIV therapy. So all participants consume ARV. This is the other statement from the participants about consuming the ARV:

I try to survive with ART. I shouldn't stop taking it. (3)

ARV medicines shouldn't be stopped to consume. (8)

Participants also found health literacy in HIC care about prevention care. This is the statement from the participants:

The consultant told me to avoid risky behavior. Even if the use of condoms is not 100% effective, it is the most effective way to do prevention. So we always use condoms. (6)

The doctor prompted me to take the medicine. It is better to prevent it before it is late. It is better to take the medicine now. (8)

participants also found health literacy in HIC care about how to care

This is the statement from the participants:

When we feel sick, we should get a treatment, If some symptom is relapsing, we should do self-correction to make it better in the future That's the only way to deal with it now. (6)

health literacy in HIC care also they got as a positive life learning

Look at me, Positive or not, I still can achieve what others can do too. So do you (2)

Although you are an PLWH, a sick person, but you can stand on your own, Do not demanding or troublesome for others even to your family. (3)

Make effort to heal

This theme included the following three categories: "I Took ARV"; "I try to avoid"; "I do a healthy lifestyle"

participants make the effort to heal with Took ARV

This is the statement from the participants:

I try to survive with this ART. I shouldn't stop taking it. (3)

I become afraid, so I took the medicine. (4)

participants make the effort to heal with try to avoid

This is the statement from the participants:

Diarrhea is triggered by food, like peanut sauce, etc. So, I try to avoid that kind of food and taking care of my eating habit. (6)

Whenever I get wet by rain, although it is just a little rain, I would instantly get collapsed. So, I choose to wait for the rain to stop rather than getting through the rain. (7)

participants make the effort to heal with *do a healthy lifestyle*

This is the statement from the participants:

I try to give good attention to my lifestyle. Change to be better: to eat meals regularly. In order to increase my body weight, I will eat fruits and vegetables. (5)

I try to manage a healthy lifestyle and avoiding stress. Our condition can become worse if we are stress, so I try to manage myself by not overthink my problems and let it flow. (6)

I still having sex. But now, I do it for just one person. And even if I am not detected anymore, I still use a condom while doing it. In addition to that, I will always pay attention to her cleanliness. Safety. At least, we try to take care of it and do it for ourselves. (7)

DISCUSSION

This study found that participants experienced symptoms in their life span. There are several types of symptoms that have been experienced by participants like fatigue, joint felt so sore, fever, stomach pain, diarrhea, weight decrease, thrush, hard to breathe, shortness of breath and insomnia, rashes, itchy, got a bad appetite, so slim and coughed. These symptoms reported as the most PLWH common symptoms (9).

There were recurrence reports in symptom timing from our participant's disease process. It was before they had the diagnostic tests, after they were diagnosed, when they first took ARV and the symptoms persisted even now especially when they were sick. According to Peterson & Bredow HIV as a chronic disease can have a trajectory based on the condition of the disease. Comorbidities that are experienced simultaneously with HIV infection and opportunistic infections experienced can also aggravate HIV symptoms ((10); (11); (12). In addition, previous studies have shown that several symptoms are side effects of ARV (13); (14). In other hand psychological symptoms were also reported by PLWH, stigma and worry are burdens of PLWH (9); (15).

This study found that participants obtained information about HIV care from care giver and peer group. According to (16), information sources may come from Self-experience, Healthcare professional, Internet, Literature, Multiple Sources, Social Support, and TV ads



but (17) stated that care management for PLWH is doing what health workers recommend. Trust and Relationships Between Patients and Providers had An Essential effect in Health Literacy in HIV Care (18). So for PLWH, communicative officers are places to get information and support related to caring.

Peer support groups and support community was recommended to PLWH, they are people who are trusted and will help in any condition. Peer groups and NGOs have an important role to play in providing communication, information, and education (KIE) about HIV to PLWH (19). In addition, the support of NGOs and CSOs to adapt to diseases so as to improve coping that support in the form of emotional support, appreciation, material, information, and socialization provided to PLWH can accelerate psychological self-acceptance of positive HIV status.

HIV care appears based on hopes and efforts for a better life with regular ARV treatment. This theme was explained based on the Theory of Reasoned Action (TRA) theory which was coined by Ajzen in 1980. Healthy motivation, fear of worse conditions, and all information related to care became the reasons that led to the formation of behavior treatment. This study found the motivation of participants in taking treatment was a desire for health and efforts not to become severe. Participants take HIV treatment namely ARV and commit to their treatment. Same with other studi HIV self-management means living on antiretroviral therapy (ART) (20) This is consistent with the findings of research on patients with HIV in North America who adhere to ARV treatment that can successfully reduce the rate of circulation of viral infections in the body so that patients with HIV can improve the quality of life like other normal people (21).

Hope for a better life in the future is manifested in the concrete effort to a healthy life. This is also found in last research This is also found in last research hope become a coping mechanism that helped PLWH adapted on their new life (22). It make it make PLWH changing behavior like improved their diet behavior (23) and exercise (24). This effort is mostly done because of support, especially from close family, health workers, and peers (21).

CONCLUSION

The information obtained can facilitate caregiver to plan nursing care, decided education need to help PLWH dealing with symptoms of HIV. This research can be the basis for conducting further research on how to manage the symptom of HIV.

REFERENCE

1. Freudenreich O, Goforth HW, Cozza KL, Mimiaga MJ, Safren SA, Bachmann G, et al. Psychiatric treatment of persons with HIV/AIDS: An HIV-psychiatry consensus survey of current practices. *Psychosomatics*. 2010;51(6):480–8.

2. Feng MC, Feng JY, Yu CT, Chen LH, Yang PH, Shih CC, et al. Stress, needs, and quality of life of people living with human immunodeficiency virus/AIDS in Taiwan. *Kaohsiung J Med Sci.* 2015;31(9):485–92.
3. Giri S. Quality of life among people living with acquired immune deficiency syndrome receiving anti-retroviral therapy : a study from Nepal. 2013;277–82.
4. Nyamathi AM, Ekstrand M, Yadav K, Ramakrishna P, Heylen E, Carpenter C, et al. Quality of Life Among Women Living With HIV in Rural India. *J Assoc Nurses AIDS Care.* 2017;28(4):575–86.
5. Vyavaharkar M, Moneyham L, Murdaugh C, Tavakoli A. Factors associated with quality of life among rural women with HIV disease. *AIDS Behav.* 2012;16(2):295–303.
6. Wilson NL, Azuero A, Vance DE, Richman JS, Moneyham LD, Raper JL, et al. Identifying Symptom Patterns in People Living With HIV Disease. *J Assoc Nurses AIDS Care.* 2016;27(2):121–32.
7. Webel AR, Holzemer WL. Positive Self-Management Program for Women Living With HIV: A Descriptive Analysis. *J Assoc Nurses AIDS Care.* 2009;20(6):458–67.
8. Schnall R, Wantland D, Velez O, Cato K, Jia H. Feasibility testing of a web-based symptom self-management system for persons living with HIV. *J Assoc Nurses AIDS Care.* 2014;25(4):364–71.
9. Makoae LN, Seboni NM, Molosiwa K, Moleko M, Human S, Sukati NA, et al. The symptom experience of people living with HIV/AIDS in Southern Africa. *J Assoc Nurses AIDS Care.* 2005;16(3):22–32.
10. Mulhall AM, McCormack FX. A 25-year-old man with fatigue, dyspnea, and pulmonary cysts. *Ann Am Thorac Soc.* 2015;12(1):120–3.
11. Coughlin SS. Anxiety and depression: linkages with viral diseases. *Public Health Rev.* 2012;34(2):1–18.
12. Zuniga JA, Bose E, Park J, Lapiz-Bluhm MD, García AA. Diabetes Changes Symptoms Cluster Patterns in Persons Living With HIV. *J Assoc Nurses AIDS Care.* 2017;28(6):888–96.
13. Wantland DJ, Mullan JP, Holzemer WL, Portillo CJ, Bakken S, McGhee EM. Additive effects of numbness and muscle aches on fatigue occurrence in individuals with HIV/AIDS who are taking antiretroviral therapy. *J Pain Symptom Manage.* 2011;41(2):469–77.
14. Liu Z, Yang J, Liu H, Jin Y. Factors associated with fatigue in acquired immunodeficiency syndrome patients with antiretroviral drug adverse reactions: a retrospective study. *J Tradit Chinese Med.* 2013;33(3):316–21.
15. Bengtson AM, Pence BW, Crane HM, Christopoulos K, Fredericksen RJ, Gaynes BN, et al. Disparities in depressive symptoms and antidepressant treatment by gender and race/ethnicity among people living with HIV in the United States. *PLoS One.* 2016;11(8):1–16.
16. Cho H, Baik D, Beauchemin M, Schnall R. Understanding the predisposing , enabling , and reinforcing factors in influencing the use of a mobile-based HIV management app : A real-world usability evaluation. 2018;117(June):88–95.

17. Schultz ASH, Temple B, Gibbons C, Preston J, Ronson G. Listening to Those Who are Living With HIV and Tobacco Dependence and Exploring Their Health Care Context. *J Assoc Nurses AIDS Care*. 2014;25(1):46–59.
18. Dawson-rose C, Cuca YP, Webel AR, Sol SS, Rivero-m M, Eller LS, et al. Building Trust and Relationships Between Patients and Providers : An Essential Complement to Health Literacy in HIV Care. 2016;1–11.
19. Ibrahim K, Songwathana P, Boonyasopun U, Francis K. The HIV/AIDS epidemic in Indonesia: Does primary health care as a prevention and intervention strategy work? *Int J Nurs Pract*. 2010;16(2):87–91.
20. Wang K, Chen W, Zhang L, Bao M, Zhao H, Lu H. Facilitators of and barriers to HIV self-management : Perspectives of HIV-positive women in China ☆. *Appl Nurs Res*. 2016;32:91–7.
21. Crowley T, Merwe RNA Van Der, Skinner RND. Adolescent HIV Self-management : Lived. 2019;30(4):7–19.
22. Stroumpouki T, Perrett S, Kasdovasilis P, Papatheodorou P, Paparizos V, Stavropoulou A. “ A journey towards acceptance ” : The process of adapting to life with HIV in Greece . A Qualitative study. *Appl Nurs Res*. 2020;53(April 2019):151249.
23. Noh MS, Rueda S, Bekele T, Fenta H, Gardner S, Hamilton H, et al. Depressive symptoms, stress and resources among adult immigrants living with HIV. *J Immigr Minor Heal*. 2012;14(3):405–12.
24. Webel AR, Perazzo JD, Dawson-Rose C, Smith C, Nicholas PK, Rivero-Méndez M, et al. A multinational qualitative investigation of the perspectives and drivers of exercise and dietary behaviors in people living with HIV. *Appl Nurs Res*. 2017;37:13–8.