Discriminatory Behavior among People Living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome against Adherence to Antiretroviral Treatment

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Abstract

BACKGROUND: Globally, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) is a serious health issue, as the number of sufferers increases from year to year. As there are many HIV/AIDS cases, antiretroviral treatment (ART) regimens’ success is determined by the high adherence of people living with HIV/AIDS (PLWHA) undergoing a treatment regimen. PLWHA adherence in undergoing ART regimens can be influenced by discriminatory behavior toward them.

AIM: This study aims to identify discriminatory behavior in PLWHA toward adherence to ART in Yogyakarta.

METHODS: This research used a qualitative method with a phenomenology approach. The collection of data was carried out through interviews and observation. Participants totaling seven people were determined by purposive sampling. The data validity employed source triangulation and checked the data back to the participants. Analysis of data was by comparing among categories, marking, and describing descriptively.

RESULTS: The results showed that PLWHA got discriminatory behavior around them during ARV treatment, which came from the attitude of health workers and unpleasant experiences from the environment, but this discriminatory behavior did not affect PLWHA adherence to ART treatment.

CONCLUSION: Discriminatory behavior from health workers and the environment around PLWHA did not affect PLWHA adherence during ARV treatment.

Introduction

The acquired immune deficiency syndrome (AIDS) is a global health epidemic caused by the human immunodeficiency virus (HIV) [1]. It is estimated that the world’s population suffering from HIV/AIDS is around 36.7 million people [2]. Indonesia’s total number of HIV/AIDS cases in 2018 was around 640,443 people [3]. The transmission of HIV/AIDS has spread over widely to all provinces in Indonesia, one of which is the province of Yogyakarta. Yogyakarta province was ranked 9th concerning the HIV/AIDS problem [4]. For treatment, people living with HIV/AIDS (PLWHA) receive antiretroviral treatment (ART). ART has been an essential part of PLWHA’s HIV/AIDS prevention efforts to reduce disease burden and increase life expectancy [5].

Many studies have shown that the percentage of patients remaining in care after ART initiation was low [6]. The most frequent cause for treatment failure is non-adherence to ART [7]. There is an association between discrimination and adherence to ART [8]. PLHWA’s stigma and prejudice affect PLWHA in initiating ARV therapy and adhering to ARV therapy due to the sense of inferiority felt after discriminatory behavior [9]. One of the community foundations in Yogyakarta engaged in the health sector, primarily related to HIV/AIDS issues, is the Victory Plus foundation. Based on a preliminary survey at the Yogyakarta Victory Plus Foundation, it was found that 3908 people living with HIV underwent ARV treatment, and 583 people living with HIV adhered to treatment. Based on this incident, the researchers were interested in examining the disclosure of HIV/AIDS status to PLHIV adherence to ARV treatment.

Methods

This study used qualitative methods with a phenomenological approach. This research was conducted in February–April 2019. In this study, the participant inclusion criteria were PLWHA who were obedient and never missed the current ARV treatment, and were willing to be research informants, and could

communicate verbally. The total number of respondents in this study was seven people because the data had reached data saturation when they were in the 7th participant. Data retrieval was done by in-depth interviews and unstructured observation. The focus of observation would develop during the interview. The data’s validity was carried out using source triangulation, namely, toward representatives of participant families, peer support, and VCT (Voluntary Counselling Test) service doctors at the community health center and rechecking data with participants. Data analysis was performed by comparing one category with the other, marking in each unit, and describing descriptively the essence of the phenomenon been obtained. The study was conducted at the Victory Plus Yogyakarta foundation. This research has passed the ethical test by the Faculty of Medical and Health Sciences, Universitas Muhammadiyah Yogyakarta ethics committee with ethics number 029/EP-FKIK-UMY/I/2019.

Results

Characteristics of participants (Table 1)

The first participant was a woman, aged 37 years when taking data, had married status, had one child, and lived with husband and child. The participant’s job was a private employee. The participant has been diagnosed with HIV/AIDS Stage 3 since 2017 and has been undergoing first-line ARV treatment from 2017 to the present.

The second participant was a woman and 42 years old when data were taken. The participant’s status was married, but her husband died in 2015. She had two children and lived with parents and children. She worked as a peer supporter at the Victory Plus Foundation. The participant has been diagnosed with HIV/AIDS Stage 2 since 2008, and the first child has been diagnosed with HIV/AIDS Stage 4 since 2008, while the second child was negative. Participants underwent first-line ARV treatment from approximately 2010 to the present.

The third participant was a man and aged 38 years when collecting data. He had married status but divorced already, had children, but the children were negative and lived alone. He has been diagnosed with HIV/AIDS Stage 3 status since 2014 and has been undergoing first-line ARV treatment since 2014. The participant’s job was a private employee.

The fourth participant was a woman and aged 48 years at the time of data collecting, had married status, had three children, and lived with her children. The participant has been diagnosed with HIV/AIDS Stage 2 since 2009 and started her first-line ARV therapy regimen in 2010. The participant’s job was peer support at the Victory Plus Foundation.

The fifth participant was a 30-year-old man when taking data, not married, and lived alone. Participants were diagnosed with stage 4 HIV/AIDS in 2014 and started first-line ARV therapy in 2014. The work of the participants is peer support at the Victory Plus Foundation.

The sixth participant was a 52-year-old man when data taken, had the status of being married, and had children, but now lived alone. The participant was diagnosed with Stage 4 HIV/AIDS in 2009 and started first-line ARV treatment from 2011 until now. The occupation of the participants was peer support at the Victory Plus Foundation.

The seventh participant was a 36-year-old man when data taken, not married, and lived alone. He has been diagnosed with HIV/AIDS since 2010 and started his first-line ARV therapy regimen from 2010 until now. The participant’s job was a private employee.

In this study, researchers found a theme related to the adherence of PLWHA in undergoing ART regimens, namely, discriminatory behavior against ARV treatment. Discriminatory behavior against ARV treatment included health workers’ attitudes during ARV treatment and unpleasant experiences from the environment during ARV treatment.

Attitudes of health workers during ARV treatment

Most participants received unfavorable treatment by health workers in health services during ARV treatment. It was supported by the following interview excerpts:

So once at Hospital X told me to take control and take medicine, “oh this is the ODHA, later
Unpleasant experiences from the environment during ARV treatment

In this study, most participants during the ARV treatment regimen experienced unpleasant experiences from the environment. It was supported by an excerpt from the interview results, as follows:

“I was told I could not work there anymore, yeah…” (participant 1)
“Surely, those mothers ask your child why, what kind of pain is that, and it makes me embarrassed and afraid to leave the house.” (participant 2)
“At that time, I was given two choices, I wanted to leave, or I opted out …” (participant 3)
“So, the drinks or food that I have touched they do not want to eat, sis…” (participant 4)
“Was also expelled from work …” (participant 5)
“There’s attitude is bad towards me …” (participant 6)

In this study, the experience of one participant who did not experience unpleasant things from the surrounding environment was also found. It was supported by the following interview results:

“As for the discrimination from the environment during treatment, it is not really that bad…” (participant 7)

In this study, participants experienced less pleasant experiences from the surrounding environment during treatment, namely, being dismissed from their jobs because they often had permission to take ARV drugs to health services. Based on the participants' experience, sometimes, people around them often asked why they often took drugs, what pain, and even when they knew the participants’ status, many chose to stay away and leave.

Discussion

In this study, adherence to PLWHA in undergoing ART regimens was influenced by discriminatory behavior from health workers and the environment. Discriminatory attitudes from health workers experienced by participants comprised queuing for drugs at the end, fear of contact with PLWHA, especially when giving action, less friendly in services, especially medical education, and so on. The attitudes of health workers toward PLHIV included fear of contact with HIV patients and not wanting to give intervention to HIV patients. In this study, there were also some participants who, during their ARV treatment, had never experienced discriminatory behavior from health workers.

Participants who either received discrimination or not from health workers in this study continued to...
follow a routine treatment regimen. It contrasts with research that stigmatizing attitudes and discrimination by health workers cause their fear for PLWHA to be late in accessing treatment or not wanting ARV treatment services [10]. The fear of the stigma faced by people using ARVs resulted in failure to stick to therapy so that patients preferred remote treatment services rather than near their homes, putting them at risk of irregularly taking ARVs. It was because they were afraid to be seen by friends and neighbors. Besides, this stigma made them hide their HIV status, so they did not want to tell others about their HIV status [9].

Factors that hinder treatment adherence are poor knowledge about treatment, lack of patient follow-up, dissatisfaction about the quality of ART services provided by health workers, lack of confidentiality among health workers in handling HIV patients, long waiting times in health facilities, and fear of health workers affected the infection from the patient [11].

Most participants had unpleasant experiences in the environment during their ARV therapy regimen. The experience encompassed work dismissal because the participants often asked permission from work to take ARV drugs at health services. The neighbors and neighborhood friends did not want to hang out with PLWHA, and they were afraid of being infected. This made the neighbors’ attitude were less friendly towards PLWHA. PLWHA stigmatized society and environment, such as being excluded, receiving a rejection from people in the PLWHA environment, and not being accepted in the workplace. PLHWA can be fear or be stigmatized by the public through acts of discrimination, abuse, or ostracism [10]. Stigma and discrimination against PLHWA could come from colleagues, friends, and society. PLHWA hid the HIV/AIDS status due to the stigma experienced. They were silent, sad, hopeless, anxious, and scared of revealing their HIV status, which could negatively impact their quality of life [12]. However, some participants did not experience discrimination in their surroundings.

In this study, it was also known that both participants who experienced unpleasant experiences from the environment and not continued to adhere to treatment and routinely undergo therapy regimens. It is different from previous research, which stated that discriminatory behavior significantly affected PLHWA adherence to treatment. HIV-related stigma may be taking a toll on HIV prevention, treatment, and the care of people living with HIV [13]. The stigma and discrimination that PLHWA has experienced affected PLHWA in starting ARV therapy and adherence to ARV therapy. It was due to the feeling of inferiority felt after getting discriminatory behavior. Social factors related to ARV adherence were fear of using health services when taking ARV drugs, fear of being seen interacting with health care workers providing HIV services, fear of stigma and discrimination from society, and fear of being embarrassed by the community if their HIV status was revealed [14].

On the other hand, factors that support PLHWA in taking ARV drugs are family and friends. Adherence to taking ARVs is strongly influenced by the support of the people closest to people living with HIV, especially wives. Various forms of family support in increasing ARV adherence are such as always reminding husbands every time they take medication and helping to prepare ARVs on time [15].

Conclusion

Discriminatory behavior from health workers and the environment around PLHWA did not affect PLHWA adherence during ARV treatment. Future researchers should look for other factors causing non-adherence of PLHWA to ARV therapy and how health workers and the community may minimize stigma and discrimination.

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