

Original Research

The Symptom Experience and Management in People with HIV Who Underwent Antiretroviral Therapy During the Covid-19 Pandemic in Bali, Indonesia

Nyoman Agus Jagat Raya^{1*}, Ni Kadek Ayu Suarningsih²

^{1,2}Medical Surgical Nursing Division, Nursing Department, Faculty of Medicine, Udayana University

***Corresponding author:**

Nyoman Agus Jagat Raya

Medical Surgical Nursing Division, Nursing Department, Faculty of Medicine, Udayana University, Bali

Jalan PB Sudirman, Denpasar, Bali, Indonesia, Ph: +62-361-222510

Email: jagatraya91@unud.ac.id

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ABSTRACT

Antiretroviral (ARV) therapy does not only provide some benefits but also has side effects that cause symptoms experienced by people with HIV (PWH). Strategies for effective symptom management were needed, especially during the COVID-19 pandemic. The purpose of this study was to explore the symptom experience and management strategies in PWH during the COVID-19 pandemic. A qualitative phenomenology design was used. A cross-sectional with purposive and snowball sampling techniques was used from July to October 2021. Eight participants joined an in-depth interview based on the criteria of the participants, such as people who were infected with HIV, 18 years or older, on ARV therapy, and willing to sign the informed consent. Thematic analysis was used after data saturation was reached. Three themes were found in this study; 1) The symptoms of ARV side effects, which included physical and psychological symptoms that appeared in PWH; 2) The symptom management of ARV side effects, which described the history of hospitalization, pharmacological and non-pharmacological management; 3) The symptom condition during the COVID-19 pandemic. The symptom experience of ARV side effects required strategies to manage the appearance of the symptoms, especially those amid the COVID-19 pandemic. This study could become fundamental evidence to consider in providing nursing care to PWH and supporting the symptom management model among PWH further.

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Introduction

HIV infection and AIDS cases have become a worldwide concern approximately 40 years after the first incidence in 1981. According to the Joint United Nations Programme on HIV and AIDS (UNAIDS), 1.7 million new infections of HIV were diagnosed worldwide in 2019, with 690,000 people dying from AIDS (UNAIDS, 2020). Meanwhile, the number of HIV infections in Indonesia continues to rise year after year, peaking in 2019 with 50,282 cases, with Bali ranking seventh among the top ten most HIV cases, with 2,283 instances (Pusat Data dan Informasi Kesehatan Kemenkes RI, 2020). This rise in instances corresponds to people with HIV (PWH) having more access to antiretroviral (ARV) therapy. In mid-2020, UNAIDS (2020) estimated that 26 million HIV-infected people were receiving ARV therapy.

ARVs help PWH improve their quality of life by limiting HIV transmission to others, slowing virus growth, reducing viral load increases, and enhancing their health status (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2018). ARVs, on the other hand, might cause PWH side effects. Long-term ARV usage can have harmful physical, psychological, and social consequences (Chen, et al., 2013). According to data, more than 80% of PWHs experience at least one worsening symptom after starting an antiretroviral therapy (ART) regimen (Edelman, Gordon, Barradas, & Justice, 2012). Pain, weight loss, exhaustion, sadness, and sleeping difficulty are some symptoms that develop after a year of using ARVs (Wakeham et al., 2018). Symptom management becomes important for PWH.

Due to the frequent number of COVID-19 cases, the symptom management process during the COVID-19 pandemic poses its own set of problems and impediments for PWH. The elderly, smokers, and people with comorbidities that potentially aggravate their health and cause death were the most common people who died of COVID-19 (Siagian, 2020). Due to immunity issues, PWH is one of the populations sensitive to COVID-19. A reduction in CD4 cells, an increase in viral load, and non-adherence to taking ART all enhance the possibility of developing COVID-19 (Mirzaei, McFarland, Karamouzian, &

Sharifi, 2020). Because this phenomenon has the potential to cause symptoms in PWH, a symptom management strategy was required during the COVID-19 pandemic. Symptom management aims to reduce symptom frequency, minimize symptom aggravation, and alleviate symptom-related distress (Humphreys et al., 2014). According to Modeste & Majeke (2014), PWH with symptom complaints used various tactics, including meditation, alternative treatment, seeking medical care, changing their eating habits, and taking medication. This method was implemented before the COVID-19 pandemic. Thus further research on the impact of ARV treatment on symptom management during the COVID-19 pandemic is still required.

In Indonesia, particularly during the COVID-19 pandemic, research on symptom experience and symptom management of the impact of ARV therapy on PWH has not been widely studied. During the COVID-19 pandemic in Indonesia, Karjadi et al. (2021) performed a study on the knowledge, attitudes, and behavior of PWH, but did not particularly address symptoms or symptom management behavior. Previous research has exclusively focused on symptom management in cardiovascular, neurologic, and cancer patients (Voss, 2013). As a result, this study aims to explore PWH's symptom experience and management strategies during the COVID-19 pandemic in Indonesia, particularly in Bali. This research is planned to give a fundamental overview for planning nursing interventions for HIV-infected patients in symptom management while on lifetime ART, particularly during the COVID-19 pandemic.

Method

This study uses a qualitative phenomenological approach. A cross-sectional design using purposive and snowball sampling techniques was conducted to collect participants from July to October 2021 in Bali, Indonesia. The inclusion criteria for the participants involved in this study were people who already knew their HIV status, were 18 years or older, were undergoing ARV therapy, and were willing to sign an informed consent. The exclusion criteria were HIV persons who were pregnant.

The data collection procedure began with coordinating the research plan with Denpasar AIDS Commission and the PWH companion team. Participants were selected based on the inclusion criteria and asked about their willingness to communicate further with the researcher. The researchers and participants communicated to determine the time for the in-depth interview through the Zoom or Webex application due to the rules of implementing restrictions on community activities and health protocols during the COVID-19 pandemic. The researchers asked about the participant's willingness to be interviewed and recorded one by one, as evidenced by the informed consent. The interview lasted 30-45 minutes for each participant.

The researchers employed a semi-structured interview guide that included field notes. The results of many kinds of literature related to the research topic were used to review the interview guide. The first question was, "Do you have symptoms after taking ARV during the Covid-19 pandemic?", then continued the main question was, "Could you describe your symptom experience after taking ARV?" and "How do you manage your symptom?". After the verbatim process had been completed, thematic analysis was utilized to compile the study results. After identifying the right code for each statement or answer from the interview, sub-categories, categories, and, eventually, the research theme was determined. To assure the accuracy and validity of research data, the credibility, transferability, and confirmability processes were used.

The Research Ethics Commission of the Faculty of Medicine, Udayana University issued a declaration of ethical feasibility (Number: 1782/UN.14.2.2.VII.14/LT/2021) for this study, which took into consideration the participants' rights to autonomy, justice, confidentiality, and the benefits of research. Participants read the informed consent on the first page of the Google form and then choose "agree" if they want to proceed with the study's in-depth interview process.

Results and Discussion

Five male participants dominated the group of eight, with all participants between

the ages of 29 and 47. Three heterosexual, two bisexual, and three homosexual participants made up the sexual orientation of the participants. There were four Hindus and four Muslims among the participants. The previous education was dominated by three participants at the senior high school level, three at the bachelor's degree level, and two at the junior high school level. All of the participants were employed in the private sector. Table 1 shows the participants' most recent antiretroviral therapy.

Table 1. Recent antiretroviral therapy

Participant (age)	Recent Antiretroviral Therapy
P1 (31 years)	Tenofovir Disoproxil Fumarate (300 mg)/ Lamivudine (300 mg)/ Efavirenz (Telura(600 mg)
P2 (30 years)	Nevirapine (200 mg); Lamivudine (150 mg) dan Zidovudine (300 mg)
P3 (29 years)	(Edurant rilpivirine) Dolutegravir (50 mg)/ Tenofovir Disoproxil Fumarate (300 mg)/ Lamivudine (300 mg)
P4 (47 years)	Nevirapine (200 mg)/ Lamivudine (150 mg)/ Zidovudine (300 mg)
P5 (31 years)	Tenofovir Disoproxil Fumarate (300 mg)/ Lamivudine (150 mg)/ Lopinavir (200 mg) Ritonavir (50 mg)
P6 (42 years)	Tenofovir Disoproxil Fumarate (300 mg)/ Nevirapine (200 mg)/ Lamivudine (150 mg)
P7 (42 years)	Lamivudine (150 mg)/ Tenofovir Disoproxil Fumarate (300 mg)/ Aluvia (Lopinavir 200mg/Ritonavir 50mg)
P8 (33 years)	Efaviren 600 mg/ Lamivudine 150mg/ Zidovudine 300 mg

Three themes emerged from the study. The first theme, symptom experience as a result of ARV therapy, is divided into physical and psychological symptoms. The second theme, symptom management of ARV therapy side effects, divides into three categories: hospital care, pharmaceutical, non-pharmacological, and hospital care. The condition of symptoms during the COVID-19 epidemic is the third theme.

Symptom experience of ARV therapy effects

This theme outlines participants' symptoms after they had begun taking ARVs and until they had changed their ARV therapy line. Some PWHs who started taking ARVs for the first time would have medication interactions for various reasons, one of which was an adverse drug reaction (ADR), which created disruptions and necessitated ARV evaluation (Menezes de Padua, Braga, & Mendicino, 2017). Another study found that ARV-related side effects were significantly linked to non-adherence to ARV therapy (Fonsah, et al., 2017). According to Meintjes et al. (2017), the initial initiation of PWH recommended for the first-time taking ARV was a regimen of nucleoside reverse transcriptase inhibitor (NRTI) drugs such as tenofovir (TDF), emtricitabine (FTC)/lamivudine (3TC), and efavirenz (EFV). It follows the participant's statement:

"So, the drug contains tenofovir, Lamivudine, and Efaviren" (P1)

However, several participants had symptomatic reactions to one of the ingredients advised as the first line of ARV therapy, necessitating a review of their usage for the next stage of therapy.

"Efaviren, and there is one more, I think there are four. Anyway, there is Efaviren. I'm allergic to Efaviren." (P3)

The participants in this study reported experiencing two types of symptoms due to the side effects of ARV therapy: physical and psychological symptoms. Headache, fever, rash, nausea, hair loss, mouth sores, weight loss, decreased appetite, joint and waist pain, dry skin, dark pigmented skin, weariness, itching, and diarrhea were among the physical symptoms identified by the researchers. One of the participants revealed the following statement:

"If the rash appeared all over the body, at first we felt like our body was warm, then it felt like it was hot, then bumps appeared like a mosquito had bitten us, then more bumps appeared, it is like we have skin inflammation." (P2)

PWHs who had just started ARV therapy reported muscle and joint pain,

itching, changes in skin texture and color, weariness, decreased appetite, diarrhea, nausea, vomiting, constipation, sweating, hair loss, dry mouth, and swelling of the hands and feet, according to Wakeham et al. (2018). Physical symptoms vary from person to person and could be impacted by the CD4 and PWH virus load when commencing antiretroviral therapy (Meintjes, et al., 2017).

In this study, not only physical but also psychological symptoms were observed. The inability to focus, insomnia, depression, hallucinations, stress, low self-confidence, and fear were all mentioned by participants.

"I just switched drugs yesterday, like that (hallucinations) yesterday. I used the blue one daily; it is a different manufacturer, then switched to the white tenofovir yesterday. It was like that for two days; if I'm not mistaken, it was like flying (hallucinating) but not really, it was just a transition. It's like my head was buzzing." (P5)

Due to several factors such as pressure to adhere to antiretroviral therapy for life, changing conditions from acute to chronic, and thinking about future conditions as PWH; ARV therapy had a clinical relation to an increase in the psychological burden of PWH with the emergence of feelings of sadness, worry, lack of concentration, fear, depression, and dislike of oneself (Quatremère, et al., 2017; Wakeham, et al., 2018). Nurses emphasized more research on the timing of symptoms and exacerbating variables, both physical and psychological, before identifying appropriate outcomes and nursing interventions for PWH.

Symptom management of the effects of ARV therapy

Symptom management involves using a variety of measures to treat or control symptoms that emerge as a result of ARV therapy, either independently or by seeking medical help. The study's theme depicts participants receiving treatment in a hospital when symptoms arose due to ARV drug side effects and other medical problems, necessitating additional treatment in healthcare facilities.

"At the hospital, I was treated, at that time, I also had Tuberculosis and hepatitis, and I was

immediately treated, then I was treated for three months, the doctor said, 'Just change this medicine, you are not suitable for this type because you are allergic.' (P3)

ARV therapy dosing in HIV co-infected individuals necessitated specific care when starting ARV or evaluating ARV usage. The optimum time to start ARV therapy, drug interactions between ARVs and other co-infectious disease therapies, drug addictive toxicity between ARVs and other co-infectious medications, alternate ARV therapy in the event of ARV resistance, and immune conditions were all factors to consider, as shown by the CD4 count and viral load data (Panel on Antiretroviral Guideline for Adults and Adolescents, 2018).

Participants in this study also said that symptom relievers, such as itching relievers, anti-allergic, anti-nausea, pain relievers, and appetite-enhancing medicines, were used when symptoms emerged.

"In the end, I used anti-itch powder. It only lasted for a while; once that was done, later there would be another one, the red rash would appear again." (P6)

"I took a break first, after taking ARV in the morning, I was around noon, a gap of 2 to 3 hours, I took appetite medicine." (P7)

The majority of the pharmacological management done by participants in this study was focused on reducing physical symptoms caused by ARV medication. PWH who were experiencing symptom complaints would visit a clinic or a doctor for symptom relief medication (Modeste & Majeke, 2014). Information on how to assess and manage physical symptoms was needed by PWH to improve self-monitoring abilities (Zhu, et al., 2018), so that the integration of self-care services from PWH when reporting to health workers could be clearer and more accurate, especially in the evaluation of ARV therapy.

Another strategy for dealing with symptoms caused by ARV therapy was non-pharmacological management. Participants in this study reported that they used a variety of non-pharmacological symptom management strategies, including sleeping, watching TV, playing games, exercising, maintaining healthy eating and living behaviors, becoming social

media content creators, traveling, and using potions. Traditional herbs, a break from other activities, family support, being alone, prayer, music, yoga, and meditation were also mentioned as beneficial strategies to deal with the symptoms.

"So, for the itching, I took a shower using Sambiroto water which was still warm and at the same time, I drank warm Sambiroto water. It really helped reduce the nausea." (P4)

"Yes, getting closer to Him (God) and just pray." (P7)

"Do sports, I often do yoga, but if it's unbearable, I go to a physiotherapist. ... I also meditate." (P8)

PWH had used complementary therapies such as changing their diet, doing spiritual activities, exercising, and refusing negative coping to help patients minimize physical and psychological symptoms (Eller, et al., 2013; Modeste & Majeke, 2014; Quatremère, et al., 2017). In this study, non-pharmacological management addressed the participants' psychological symptoms while on ARV therapy. Several participants in this study mentioned praying and diverting the mind's attention to pleasant things. It was due to the strong impact of religions and cultures in Indonesia; hence incorporating God was seen to be more beneficial in alleviating PWH's psychological burden (Raya & Nilmanat, 2021). Assistance for PWH was a priority to help manage psychological symptoms while undergoing ARV therapy through continuous care nursing intervention (Menezes de Padua, Braga, & Mendicino, 2017).

Symptoms during the COVID-19 pandemic

The participants in this study presented an account of the symptom conditions that had occurred during the COVID-19 pandemic, which were similar to those that existed prior to the pandemic. Participants were still taking ARVs daily, adjusting to the COVID-19 health routine, and experiencing the same symptoms as before the COVID-19 pandemic. However, this study discovered a novel picture: participants believed that psychological symptoms were more severe during the COVID-19 pandemic,

despite symptom management remaining the same as before the pandemic.

"They (symptoms) are just the same." (P5)

"It is not burdensome from the clinical side (physical symptoms), but from the psychological side, it is." (P8)

"The health protocol should be more stringent, that's all." (P1)

"I do that (symptom management) by doing sport, then sunbathing, cleaning up, that's all and they already make me sweat." (P6)

Participants had adapted to ARV therapy and were able to manage their symptoms based on past experience, which explains why symptom experience and management were largely comparable before and after the COVID-19 pandemic. According to Roy's nursing theory, individuals can adapt to their surroundings since a coping mechanism serves as an intermediary between stimuli from individuals and adaptive reactions made by individuals (Callis, 2020). However, adaptive responses to psychological symptoms were still required to improve the management of the coping process because participants felt burdened during the COVID-19 pandemic. Karjadi et al. (2021) explained that PWHs in Indonesia were worried about contracting COVID-19, especially in the PWH group taking lopinavir/ritonavir (LVP/r).

During the COVID-19 pandemic, community activity restrictions influenced HIV health services, including challenges to ARV access, worries of running out of ARV stocks, and difficulties in finding peer support (Pantelic, et al., 2021). Furthermore, PWH was one of the comorbid groups at high risk of getting COVID-19, which could aggravate PWH conditions and increase the chance of death if humoral cells and T cells abnormalities were present, as well as a reduced immune response (Davies, 2020; Klatt, 2017; Mirzaei, McFarland, Karamouzian, & Sharifi, 2020). These phenomena raised participants' concerns so that the burden of psychological symptoms increased.

Several participants worked together to address these issues by applying health protocols, exercising, and seeking the morning sun. During the COVID-19 outbreak in

Indonesia, PWH continued to try to obtain and consume ARVs (Karjadi, et al., 2021). Wearing masks, washing hands, keeping distance, staying away from crowds, and getting vaccination were examples of how to adapt during the COVID-19 pandemic to decrease symptoms, particularly worry and stress (Siewe Fodjo et al., 2020). PWH counselors and assistants, such as nurses and other health workers, may offer accurate and clear information regarding the HIV-COVID-19 correlation so that PWH can grasp the information, reduce anxiety, and enhance self-care management during the COVID-19 pandemic.

Conclusion

Physical and psychological symptoms arose as a result of ARV therapy. Most of the participants frequently complained of rash, whereas hallucinations and difficulties concentrating were common psychological symptoms expressed by participants throughout ARV therapy. Physical symptoms occur when they first start taking ARVs and could be aggravated by other co-infectious conditions. Thus, nurses and health professionals in HIV health services must thoroughly examine, monitor, and review ARV therapy. Hospitalization was chosen when symptoms were considered to be worsening due to additional comorbidities or co-infections, as well as pharmacological and non-pharmacological management, both before and during the COVID-19 pandemic. The symptoms that arose during the COVID-19 pandemic were similar to those that were present before the pandemic, but there were worries that the psychological problems might be exacerbated. One of the managements to lessen concerns about contracting COVID-19 was to use health procedures. It was critical for nurses who accompanied PWH to provide clear and accurate HIV and COVID-19 information and education. This study provides a basic overview of the symptom experience and management of PWH undergoing ARV therapy during the COVID-19 pandemic so that further research for the development of HIV nursing interventions related to symptom management models is still needed.

Limitations of the study

There was no data on the length of ARV therapy or HIV infection. It may impact the occurrence and burden of symptoms. Because this study was conducted during a COVID-19 pandemic, in-depth interviews did not allow optimal monitoring of participants' nonverbal language in qualitative field notes. The researchers merely kept track of the participants' physical state during the interview based on displaying the Zoom and Webex programs. Furthermore, amid the COVID-19 pandemic, the researchers had trouble identifying participants, but it could be predicted using snowball sampling.

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Conflict of Interest

The researchers declare no conflicts of interest.

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