

Conference Paper

Exploring Physical Problems among Postpartum Women with Hiv/AIDS in West Java, Indonesia: A Qualitative Study

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Abstract

Indonesia is experiencing the fastest HIV/AIDS cases development in Asia, especially with regards to mother to child transmission levels. Postpartum women with HIV may suffer from a lot of physical problems due to the immune system disruption. Many of them have high risk for opportunistic infection such as tuberculosis, chronic diarrhea, and meningitis. Few studies have been conducted into these physical problems, especially in a low income country whereas the access to HIV drugs is still limited. This study aims to explore the physical problems among postpartum women with HIV/AIDS in West Java, Indonesia. This study used a qualitative design with a phenomenology approach. The semi-structured interview was used to collect information from women of between 24 and 38 years old, with a child with a maximum age of 12 months, and various other inclusion criteria. Purposive sampling was applied to select the participants. Colaizzi's method was used to analyze the data. Six participants agreed to join in this study. We found three themes concerning the major physical problems experienced by postpartum women with HIV/AIDS: 1) physical response toward disease prognosis; 2) body weight changes, and 3) the side effects of HIV drugs. The most common physical symptoms were exhaustion, fever, headache, low back and joint pain, nausea, and weight change. Physical symptoms management design and implemented in health care services should provided for HIV/AIDS patients.

Keywords: HIV/AIDS, Physical, Problems, Postpartum women, qualitative study

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1. Introduction

Indonesia is recognized as the fastest HIV/AIDS cases development in Asia, especially among heterosexual groups [1]. According to the data reported by Indonesian Ministry of Health, since 1987, the cumulative cases of HIV/AIDS was 26,483, and 5,056 died. The centers for disease control and prevention (CDC) reported that in 2014, the new HIV cases were 21,031 cases with the highest distribution was among people at the age of 25-49 years (73.7%) [2]. The proportion of women being infected with HIV was increased

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every year. In 2015, more than 34% of women were HIV positive, which is believed that there are many women infected with HIV but underreported. The increasing prevalence of women infected with HIV might due to changes in the transmission trend. In the beginning, the majority of HIV risk factors was injecting drug use and nowadays change to the heterosexual groups, especially among housewives or other sexual partners. It was reported that a total housewives being infected with HIV were 3,092 cases in 2014.

West Java province is one of the highest with prevalence of HIV/AIDS in Indonesia. According to the data from the Health Service of West Java Province in 2013, about 29% of people with HIV/AIDS were women. Within three months, there were 92 housewives reported diagnosed with HIV in West Java. According to the data from HIV/AIDS referral hospital in West Java, in the past two years, more than 85 women joined the provider-initiated HIV testing and counselling. Of 85 women, 25 of them having children with three were positively diagnosed with HIV. As many of women being infected by HIV and getting pregnant. They have faced more complex problems especially during postpartum. They are required to make a lot of adjustment dealing with HIV infection and mothers' role. During the postpartum period, they may suffer from a lot of physical problems due to the HIV disease progression, changing hemodynamic after pregnancy, and side effects of HIV drugs. Many of them reported having an opportunistic infection such as tuberculosis, chronic diarrhea, and meningitis [3]. As a result, postpartum women with HIV/AIDS often experienced with some treatment related to oxygenation, electrolyte fluid, nutrients and problems due to the decreased of consciousness. Physical problems can be caused by the persistent vaginal vulva candidiasis which is not resonant with the therapy, cervical dysplasia, pelvic inflammatory disease with tubal and ovarian abscesses [4]. Therefore, the research question of this study "what is physical problems among postpartum women with HIV/AIDS".

2. Methods and Equipment

This study conducted a phenomenological approach to explore various physical problems among postpartum women with HIV/AIDS from the perspective of Sundanese culture. Patients diagnosed with HIV/AIDS, women age 24 to 38 years old, having a child with age maximum at 12 months old, Moeslem, Sundanese were considered as eligible criteria. Approval of human subjects for safety sought from the admission to hospital's Institutional Review Board. The patient selection was performed by the researcher at the maternity outpatient department in one of the referah hospital in West Java province, Indonesia. The researcher set up an adequate setting for the interview.

Purposive sampling was applied to select a six participants. After met with participants who match with the criteria then the researcher introduced herself and provided the necessary information. The participants have ensured that the data remained confidential and anonymous. Finally, the researcher scheduled an interview after having obtained their willingness to participate and signed written consent forms. The interviews started as semi-structured interviews and continue to use exploratory questions. Each interview lasted between 45 and 60 minutes. The interviews were conducted using an MP3 player (Creative model) with the consent of the participants. The participants informed about the probability of another meeting to complete and clarify the interviews at the end of each interview. Even though the participants agreed, only one case requires a second interview. The following question was used to direct the process of the interview.

The data analysis was used in using Colaizzi technique, who advocated a descriptive approach enquiry involved a process of validating the finding the structure of phenomenon with participant. There are seven steps to ensure the completion of the analysis. First, in order to acquire general feeling for experience, their statement will be read and reread (step 1). Then, the important step is extracting significant statement to generate information pertaining directly to phenomenon studies (step 2) and formulating meaning will be written in scientific language to illuminate various context of phenomenon (step 3). Next step was categorizing into cluster of themes and validating with original text (step 4). After that, the finding will integrated into comprehensive description of the desired phenomenon (step 5), and this description will be returned to the participants to validate finding (step 6). The last step was incorporating any changes based on the informants' feedback (step 7). In this study, for validity and reliability data, criteria was used [5].

Believability of the study ensured through the researcher's long-term engagement in collecting and analyzing the data, and use of the revisions and reviews that conducted by the research associates and participants. To provide the transferability of the study, the research fully explained and the context and stages of the study fully described to the subjects by the researcher.

3. Results

3.1. Physical response toward disease prognosis

The most common symptoms reported were fever and joint pain complained by the 3th and 6th participants, as stated, "... if in the day I will not feel..., but when the night comes I feel fever..., fever in the night..., but no fever in the day...I also feel pain in here (pointing to her legs and hands),..., it's not comfortable... (p.3, p.6). They also complained dizziness as expressed by participants numbered 3 and 6. The statement is as follows: "... dizzy..., so my head feels so heavy.... (p.3, p.5). It also stated by participant number 1 and 2, the statement as following "... I feel dizzy sometimes..., if I feel dizzy again it means I'm not feeling well... (p.1, p.4).

Furthermore, they also complaint of a long period of a cough as reported from the second participant. The statement as follows: "... just like coughing..., usually I'm coughing just two days..., but now I have it six days..., but seldom..., now I almost get a cough three times in a year... (p.2). The second participant also expressed low back pain and easily for getting tired as stated "... sure I feel it... I feel joints pain on my waist..., I feel fatigue... (2) and decreased of endurance "... it turns out my body endurance is indeed decreased..., indeed..., very low endurance..., it was heavily raining..., directly I had a headache... (p.2). The other participant (number 3) explained tiredness and weakness. The statement as follows: "... since delivering a baby..., I feel that I am easy getting sick when at work..., so if I feel tired means it is very tired..., I feel weak..., continuously weak..., before delivering I don't feel these symptoms... (p.3). The last physical response toward disease prognosis was swelling and bluish bruises on the lower extremities as reported by the third participants. The statement as follows: "... if I walk from home to work place..., now I get sick directly..., having swell..., bluish bruises... on my legs..., if I walk too far... (p.3)

3.2. Weight changes

There was a weight loss before and after being diagnosed with HIV/AIDS. It was related to problems of nutritional intake as complained by the sixth participants. The participant revelation as follows: "... I've lost 17kg already., do not want to eat..., I lost my appetite..., just want to sleep, just a deep sleep... (p.6). The presence of weight decreased in postpartum mother with HIV/AIDS is experienced by the participants numbered 3, as follows: "... if you see the other woman after having babies is getting fat..., well not with me..., I'm skinny..., used to be at 42kg little bit chubby..., but now I'm only 38Kg..., so skinny..., others think of me that I am too skinny... (p.3).

A postpartum participant with HIV / AIDS who haven't got the weight changes are experienced by participants numbered 1 and 2. It's accordingly expressed below: "... until now, I have no big difference in weight..., as usual..., seems that everything is healthy... (p.1).

"... actually, my weight doesn't have a big influence..., it's only 47 kg since I was girl..., When I had my first marriage, it's 52 kg..., when I was pregnant, it's 55 kg..., after delivering a baby, it's 52 kg..., just keep it so... (p.2).

3.3. Side effects of antiretroviral (ARV) drugs

The most common symptoms related to HIV drugs' side effects were spotted reddish on the skin. It experienced by the fourth participants. It expressed as follows: "... when I took medicine...it was allergic..., from the first I took it..., my skin changed a bit red spot..., it is just like this (pointed to the reddish part in hand), *Alhamdulillah* (Islamic expression to expresses gratitude to Allah for his compassion and blessings) it's not much though, it was vague..., i also had small reddish spot on my back..., it felt odd..., I used seeing the flawless skin, but now it seems had a light swollen wound..., sort of.. (p.4). Other side effects were dizziness. It was experienced by the three participants. Those are stated as follow:"... the doctor said that it would be dizzy along the night..., 'just keep continuing', he said..., but further the headache became annoying..., I couldn't walk..., I felt like a drunk... (p.1). They also expressed that "... consuming the yellow, Efaviren, at 9 am, I will feel heavy dizziness..., every time if I had the meal I feel so dizzy... then I consumed the addition of CD4 at 9 pm But..., I thought that the feeling of being drunk..., I will feel dizzy when eating directly..., seem to be paralyzed, nothing I can do (p.4)."... better if I consumed efaviren at 9 pm, I could directly go to sleep...instead of not sleeping directly, I will be haunted in my sleep or act like a drunk..., or faint..." (p.6).

The side effects of ARV drugs also reported increased total cholesterol. The presence of increased cholesterol experienced by the first participants as stated below: "... consuming Tenofovir..., I have no complained..., only I had high cholesterol..., yes,....the risk is bigger..., because I have had a high cholesterol..., it's clearly high cholesterol..., but it hasn't been re-tested, I just wait for next month while waiting for the results of the cholesterol... (p.1). They also reported itching while taking antiretroviral drugs. The presence of itching responses experienced by participants stated as follow: "... it was itchy from the first time I had my ARV..., itchy mostly all over my body..., seems that I got a caterpillar on my skin, itchy..., I got no idea where is the exact itchy..., so I will scratch all over my body..., poor me got no idea the exact itchy... (p.4). The response of

antiretroviral medication is considered to be suitable and does not have any problems while taking antiretroviral drugs. It experienced by participants numbered 3, 5 and 6. Those stated as follows: "... as usual..., it's bitter a lot..., not really..., the spots disappear... (p.3) "... for me, I match in consuming the medicine *Alhamdulillah* ..., It is unchangeable..., if others change it..., due to the allergy..., or just..., appeared redish spot..., well not me, I match *Alhamdulillah*... (p.5) "... as long as taking duviral which equally with neviral..., I feel good after consuming those... (p.6).

4. Discussion

HIV/AIDS disease can spread widely and affects every organ. Based on the results of the interview, some participants revealed that since knowing themselves as HIV/AIDS-positive, the condition was decreasing and very high risk to get sick. Opportunistic infection that commonly reported was pneumonia, bronchitis, and pulmonary tuberculosis, fungal infections around the mouth, diarrhea, and nervous system disorders due to toxoplasma infection. Among postpartum women with HIV/AIDS, many of them had experienced critical condition and also hospitalized. The major complaints experienced in postpartum mothers with HIV/AIDS were feelings quickly tired and weak, fever, headache, lower back pain and joint pain, and nausea.

Feeling of tiredness and weakness are the most experienced by postpartum women with HIV/AIDS. It was supported by previous study conducted in all people living with HIV in Indonesia that fatigue is the most frequent symptoms (67%) [6]. Feeling of weakness can be affected by inadequate nutrition intake. According to FAO-WHO, most of people living with HIV/AIDS had nutrition deficiency, including vitamins and minerals [7]. The major reason of inadequate of nutritional intake due to loss appetite and impaired absorption of nutrients [8]. Nearly 87% of individuals with HIV/AIDS treated in the Intermediate Room experienced weight loss [9]. Progressive weight loss in individuals with HIV/AIDS is caused by malabsorption of nutrients, metabolism changes and inadequate intake [10].

Some participants complained of fever, headache/dizziness, low back pain and joint pain due to nervous system disorders. It is estimated that 89% of all people living with HIV/AIDS had a neurologic disorder [11]. Neurologic disorder included central nervous, peripheral, and autonomic neurological disorders. Neurologic disorder may happen due to opportunistic infections, primary or metastatic neoplasms, gastrovascular changes, metabolic encephalopathy or secondary complications due to therapy. The immune system response to HIV infection in the central nervous system includes inflammation,

atrophy, demyelination, degeneration, and necrosis [12]. As a result of disturbances in the central nervous, periphery and autonomous, the complaints experienced by individuals with HIV/AIDS vary widely from mild to severe complaints. Early clinical manifestations include memory impairment, headache, and concentration difficulties, progressive and apathetic confusion. Advanced stages include global cognition, delays in verbal responses, affective disorders such as empty views, seizures, and death [13].

Nausea was reported by postpartum women with HIV/AIDS as an unwarranted side effect of consuming ARV drugs, such as NRTI (Nucleotide Reverse Transcriptase Inhibitors) regimens. Those ARV drugs had side effects such as the occurrence of mitochondrial toxicity and hepatic toxicity. Symptoms may last for 1 to 20 months, after having an ARV treatment, including nausea, vomiting, and weakness. Some participants complained of body weight decreased during postpartum period. This condition happens as there were worsening in the immunity response, which is shown by the occurrence of opportunistic infections [14]. Nausea also can be a reason for decreased body weight.

The main effects of ARV was to reduce the viral replication and optimize health conditions of people living with HIV, especially for maternal and child health. However, some of HIV drugs produce side effects due to longer periods of consuming such as rash. Rash was a major side effect complained by postpartum women with HIV with majority of them consuming NNRT (Non-Nucleotide Reverse Transcriptase Inhibitors). Rash most commonly occurred within the first four weeks of starting treatment [9]. The HIV/AIDS treatment is a complex process with higher benefit for viral support but also produce many side effects. Approximately, about 25% of people living with HIV stop their therapy in the first year due to many side effects could not be tolerated and 25% of them do not take medication according to the recommended dosage and time due to fear of the side effects [15].

5. Conclusion

As one of the consequences of disease progression and side effects of HIV medications, postpartum women with HIV/AIDS encountered various physical difficulties. Increasing health care provider and patient understanding of poor physical conditions is needed and design an appropriate intervention to manage physical symptoms for postpartum women with HIV/AIDS.

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