

Conference Paper

Life Experiences of Women (Housewives) Diagnosed Hiv – Aids in Serang

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Abstract

Background: HIV transmitted to the housewives who are not in sexual high risk behavior affects to the complicated and unique problem. It does not only trigger psychological, physical, social and spirituality problems but also the problem of responsibility to take care of their children and family. **Objective:** To explore the experiences of housewives infected with HIV in order find the new insights. The findings are expected to be the references in either educational or health care service of HIV patients. **Methods:** The research is qualitative-and the study design is phenomenological. The data were collected by using in-depth interview method upon 7 HIV-infected women in coastal area of Serang and Rangkasbitung. The data analysis used Colaizzi. **Results:** The results of the study showed 3 themes, including the unknowing of HIV information, losing a partner and the desire to get married, self-stigmatized and child-discrimination concern, telling the family members regarding the patients' HIV status and the treatment, and preparing for death. Several experiences of HIV-infected women covered physics, socio-psychology and spirituality. The new themes were discovered, including heredity, unknowing of HIV information before HIV-diagnosis, telling the family members regarding the patients' HIV status and the treatment, and preparing for death. **Conclusion:** Therefore, it is important for counselors to provide holistic and complete care in order to develop a program or exploring a discussion topic of HIV-infected women in counseling program.

Keywords: HIV-AIDS; life experiences; women (housewives)

1. Introduction

The phenomenon of wives' experiences with HIV – AIDS and the problems that arise requires handling and support. As sufferers, housewives with HIV are at risk of experiencing problems physically, psychologically, socially and spiritually. In terms of physical issue, HIV sufferers will experience health problems in the form of opportunistic infections due to decreased immunity, such as tuberculosis, candidiasis and chronic diarrhea[1]. Decreasing physical function generally will impact on psychological well-being. Some psychological problems of wives with HIV – AIDS include shame, fear and internal conflicts in which they have to hide themselves related to their status to their

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children, family, and social environment [2]. Housewives who suffer from HIV tend to keep their illness status as secret and are afraid to open up about it to their children [3].

In the socioeconomic aspect, [4] said that women with HIV who experience negative stigma from the community can result in job loss. Then, it has an effect on health care. The study notes that the costs of the care or medication are quite high [5]. The problems in spiritual aspect are also found when the process of receiving the illness fails. Spiritual distress occurs, such as loss of hope, helplessness and suicide plans [6]. Cumulatively, the negative effects mentioned above can worsen the quality of life of patients with HIV – AIDS [7], [8], [9].

The United Nations report [UNAIDS] in 2014 recorded 35 million people were infected with HIV worldwide, in which South Asia and Southeast Asia ranked as the second largest in the world with approximately 4 million people with HIV – AIDS; while, Indonesia is the country with the fastest growing HIV – AIDS in Southeast Asia [10]. During the period of 1 January to 30 June 2014, the number of HIV sufferers in Indonesia reached 15,534 with 1,700 of them suffering from AIDS [11]. The highest number of AIDS occurred to housewives (6,539 people).

The spread of HIV – AIDS in Banten Province continues to increase every year. The data revealed that HIV cases were increased from 263 in 2010 to 488 in 2011. The increase was influenced by several factors, such as the position of Banten Province on Java - Sumatra crossing path, industrial area, and international scale transportation facilities with a very high level of population mobility, resulting in changes of the people's lifestyle. Moreover, some Banten people work in Jakarta. In addition, Banten Province is directly bordered by two provinces with a very high prevalence of HIV – AIDS cases, namely DKI Jakarta and West Java Province [12].

Wives' susceptibility of being infected by HIV is caused by many things, including the unwillingness of spouses to share their status as sufferers to others (spouse/family). Some studies mentioned the strong stigma of community, including families and partners, against HIV sufferers prevents them from disclosing their HIV status to others [13],[14]. Other studies found that strong stigma hampers HIV prevention programs [15].

Besides stigma, gender inequality, biological, economic and socio-cultural factors also influence the high incidence of HIV in housewives. Furthermore, wives have a weak role in the decision making process relating to her health care. Centers for Disease Control and Prevention [16] in 2010 reported that women with HIV – AIDS are weak in making decision relating to disease management. The decision must still be in accordance with family rules; hence, they tend to experience inadequate access to health services.

Research in Indonesia found several problems in handling HIV patients. Health workers who are expected to be able to provide services and support for HIV sufferers have a negative attitude towards the care of HIV patients, especially in Papua region [17]. Research in other countries also found the same thing. [14] examined the experiences of women with HIV in India and found that Indian women experienced difficulties in accessing care due to the stigma and openness of health workers. All participants closed themselves relating to their HIV status to their family and friends and got negative experience from health workers due to stigma [15]. Based on the phenomena above, it is important to reveal in depth the experiences of Indonesian wives diagnosed with HIV.

2. Methods

The method used in this research is descriptive phenomenology based on Husserl's philosophy. According to [18], phenomenological research demands a description that is examined from ordinary daily experience, a description of various things as experienced by people. In this study, the researchers uncovered experiences and try to understand the responses of wives diagnosed with HIV – AIDS in Serang, Banten.

2.1. Research Setting and Context

The research was conducted at *Teratai* Room of dr. Dradjat Prawiranegara General Hospital, Serang, Banten Province and began from May 11 to May 30, 2015. *Teratai* Room of dr. Dradjat Prawiranegara General Hospital is a referral hospital for patients with HIV – AIDS or suspected HIV – AIDS in Serang Regency and other areas such as Rangkasbitung and Pandelang. The participants of the study were women with HIV – AIDS. 7 people were taken as purposive samples. Inclusion Criteria:

- 1) Women with diagnoses of HIV who have transmission from their husbands and registered as patients at *Teratai* room, of Dr. Dradjat Prawiranegara General Hospital.
- 2) General condition is good
- 3) Able to communicate well and cooperatively

The type of interviews used in this research is the in-depth interview category.

2.1.1. Core Question:

'How your experience when you found out you were diagnosed with HIV / AIDS?'

2.1.2. Probing question:

Developed in accordance with the answers or topics expressed by participants.

1. How about the current complaint that you feel?
2. How does the mother overcome the illness?
3. How are you feeling right now?
4. If the disturbing feeling condition, how do you do to overcome it?
5. How do social conditions such as friends, family, society treat mothers?
6. How is the economic condition that the mother feels at this time related to treatment or care?
7. How is access to care and medication received?

The interviews were carried out two or three times. The first and second interviews were mostly conducted at *Teratai* Room of Dr Dradjat Prawiranegara General Hospital, at the participants' house, and at a Cafe. The first interviews lasted for 60 to 70 minutes; while, the second interviews took 15 to 20 minutes to complete the previous interviews and validate the results of the interviews. In this study, the data were collected by using voice recorders.

2.2. Data Collection

Before the interviews, the researchers fostered a relationship of mutual trust with the participants. The researchers informed the purpose of the study and protected the confidentiality of the participants' data. The researchers created a comfortable atmosphere by sitting face to face, stating open body posture, and using a low tone of speech. Next, the researchers prepared the form of field notes and turned on the voice recorder to record the conversation between the researchers and the participants. They placed the voice recorder in an open place with a distance of less than 50 cms from the participants.

2.3. Data Analysis

In this study, the researchers used Colaizzi's analysis. To complete the analysis, they dis clarification to the participants. The stages of data analysis were according to Colaizzi as stated by [19].

2.4. Research Ethics

The study was approved by the ethics committee of Padjadjaran University in Bandung. It was also carried out by considering the principles of research ethics by fulfilling The Five Rights of Human Subjects in Research based on [18].

3. Results

3.1. The Findings of Themes

This section describes in detail the themes identified from the results of the study. The themes are grouped by several categories:

- a. The ignorance of looking for information about HIV
- b. The broken family cycle
- c. The fear of stigma towards self and children
- d. The preparation for death

The existing themes in this study are discussed below to reveal the meaning of various life experiences of the participants with HIV – AIDS.

3.2. The process of finding health information

The participants of the study were housewives who got HIV transmission by their husband's behavior. It occurred in participant 2, 4 and 6 whose husbands are the user of syringe. Meanwhile, participant 1, 5 and 7 got HIV transmission due to their husband who had sexual relations with other sex partners. Whereas, the husband of participant 3 got HIV from the previous wife.

The participants tended to not search for HIV information relating to HIV disease, transmission and treatment. They really felt the difference of the health condition compared to the time of being healthy. Five of seven participants did not search for information about HIV as the following expressions:

"... I haven't (searched the information) and never find it out..." (P2)

"... I haven't (searched the information) and never find it out... I never think about it."
(P3)

"... I never and I don't know. Why should I look for the information of HIV – AIDS? In this village there is no such disease..." (P2)

"... HIV is a deadly disease that has no cure. Before getting married, I did not know and never did HIV test..." (P5)

"... I don't know and I never find it out. Why should I find out about HIV / AIDS, shouldn't I? "(P6)

"... never and didn't find it out... why should I find out? I'm just a housewife. I never think of it before, moreover getting HIV..."(P7)

3.3. The broken Family Cycle

The transmission history of all participants did not relate to risky behaviors, such as drug users with needles and unhealthy sexual behavior (sex workers, changing partners), yet they received transmission from their legitimate husband. Nevertheless, almost all participants had a history of getting married more than once as the following expressions:

"... Oh, I married three times. Thanks God. With the first husband, I have two sons, the third child died because I had a miscarriage. For the second and third husbands, thanks God I do not have children. My marriages were not long. I was divorced by my husbands..."(P1)

"... before I got married to my first husband, I had 3 children. The oldest is 21 years old and he was married. The second and third are still students. I divorced with my first husband and he did not have HIV..."(P3)

"... I might have HIV from my first husband... I married my first husband and we had a son... maybe my first husband also had HIV... at that time I was very innocent and didn't know anything. He was also a drug user..."(P6)

The changes in the household life which were experienced by the participants is the feeling of mistrust. It is the loss of wives' confidence to their husband due to HIV: "... it broke my heart... how could I have a husband like that... I believed in him... but why was he mean to me at that time..." (P7)

The problem that occurred in other families was conflict and loss of partners. Two participants did not look for a new partner because they felt comfortable with the current conditions as the following expressions:

"... at the present I think, I am lazy and hopeless towards men..." (P1)

"... it's not necessary for me to remarry... The children and I are happy with our current condition. If I have a new husband... what if he does not accept my situation and the children... it can make me unhappy... I just want to be like this... I just wait for the children

to grow up and get married, have grandchildren and be happy... for me being alone is enough... (P7)

3.4. The fear of Self and Children's Stigma

The fear of self and children's stigma is something avoided by the participants. Therefore, they are afraid to disclose their disease status to both their families and the surrounding community. They thought their status will cause their children to experience stigma or discrimination.

"... people must not know my condition. But if they know themselves, it's OK. Just relax..." (P1)

"... I don't let the public know. I'm afraid of being insinuated and never talk about it. The villagers still think that this illness is a curse, so I rarely associate with my neighbors..." (P2)

"... the villagers assume that HIV is due to bad behaviors and the sufferers must be isolated. They don't know how the infection is..." (P3)

"... for me, to be shunned by people is not a problem. But if my child is shunned, I do not accept it. So, do not tell them about my illness... I hope I can see my child until I grow old, how successful my child is or how difficult my child is... the villagers don't know how the disease is transmitted..." (P5)

3.5. Preparation for Death

Many participants did not prepare the process of for death, as expressed below:

"... I don't know and I haven't even thought about it. Seemingly, it will be my family who bath my body..." (P5)

"... death is certain and the provisions are in Allah's Hands. I have no preparation..." (P6)

4. Discussion

4.1. The Ignorance of Looking for Information about HIV

Based on the research results, five of seven participants did not specifically seek information about HIV due to the unknowing of HIV. They knew the information about HIV but it is incomplete. They actually looked for the correct information after being

diagnosed with HIV. It is culture in Indonesia, especially in Serang area in which housewives who do not carry out risky behaviors still think that seeking information about HIV is not important. The knowledge of HIV gained by the participants is limited to know that the disease is deadly. They did not understand the transmission of HIV. The process is obtained through a combination of experience by transforming the experience itself [20].

The correct information about HIV is needed to prevent the transmission. Information seeking is needed by the participants when diagnosed with HIV. According to [21], HIV transmission is based on three categories, namely: (1) lack of knowledge about HIV, (2) risky behaviors, and (3) the use of syringes. In accordance with the results of the study, lack of knowledge impacts on the exposure to HIV. According to [22], good knowledge helps patients avoid HIV transmission.

4.2. The Broken Family Cycle

Based on the results of the study, the theme of broken family cycle was found with the sub-themes: history of more than once marriage, existence of conflicts in marriage, desire to remarry, and history of HIV transmission from husband. The stages and tasks of family development experienced by the families with HIV tend to be abnormal. Every couple who suffers from HIV is unable to complete the eight stages and tasks of family development.

The condition of the family cycle experienced by seven participants was disconnected. The stages of the family development cycle are at different stages. Participants 1 and 7 were in the fifth stage, namely family with teenagers with the oldest kid aged 13-20 years old. Participants 2, participant 3, participant 5 were in the third stage, namely families with pre-school age children with the oldest child is 2-6 years old. Participant 4 was in the second stage, namely childbearing families who take care for the first baby aged 30 months. Participant 6 was in the fourth stage, namely families with school-aged children, which the oldest child aged 6-13 years. The stages and tasks of family development of each participant's family were not completed properly. The stage that need to be completed well is the first stage.

Due to the impact of HIV, some changes are existed in and affect the participants' family lives, including economic changes, socio-cultural changes, and family changes [23]. The changes that occur in the families are caused by high divorce rates, changes in the role of mothers as single parent and breadwinner who need to meet the children's necessities of life. In other words, women become workers. In explaining the information

above, a spiritual-based approach is required to reduce risky sexual behavior [24] and efforts of promoting healthy behavior are needed [25].

4.3. The Fear of Stigma towards Self and Children

Fear of self-stigma is one of the triggers of psychological change which is a negative emotion felt by five of seven participants, especially fear of stigma against them and their children. Therefore, the participants tried to avoid social contact with the community. Participant 2 and Participant 3 rarely socialized with their neighbors; they assumed that the community still consider HIV as a curse.

However, participant 5 is more ready to accept stigma from others about herself but not about her children. Thus, she kept her status more confidential to the social environment. Participant 6 and 7 worried that others would know their status, causing their children to be excluded. It is the roles of mother who must protect her children from HIV transmission and the stigma. To play the roles need family support and social support. When support is received and fulfills psychological needs, motivation arises to uncover HIV sufferer's status [2]. However, not all people can accept HIV status because they still think that HIV is a disease caused by previous risky behaviors, such as syringe users and sex workers [26].

4.4. The Preparation for Death

Based on the results of the study, three of seven participants had not thought about preparations for their death. The attitude of thinking about death is influenced by culture, the role of family and religion. The other four participants considered it taboo to talk about death, so they tend to not prepare. All participants are Muslim, and Muslims believe that death is destined by Allah [27]. All participants expressed more resignation as death was in the Hands of God; thus, no special preparation was needed.

However, it is different from participants 1 and 7 who thought of their death, such as their corpse management should be done by the hospital. The experience of receiving illness and the state of being prepared for death were felt by some patients with chronic or terminal conditions, so that they have prepared their death. One's attitude of preparing for his death provides several choices whether after death care will be done at home, hospital or community service [28]. Besides the preparation of death by the patient, family role is needed to support the patient's decision. Family role is very decisive for patients who experience terminal conditions [1].

5. Conclusions

This research is qualitative with a phenomenological approach. The study found something new that was not found by previous studies, namely: the broken family cycle, the ignorance of seeking information about HIV before being diagnosed, and the preparation for death. The results of this study are expected to be a reference or study material which relates to the topics that need to be studied in the management of women/wives positive HIV.

For health and nursing practice, the study provides holistic and complete health services to patients and families, especially children with HIV and to anticipate children with HIV and children affected by HIV.

Conflict of Interest

The authors declare that they have no competing interests.

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