

Original Article**The Lived Experience of Women with HIV/AIDS: A Qualitative Study****Marni, RN, MSc in Family Medicine**

Akademi Kependidikan Giri Satria Husada, Wonogiri, Jawa Tengah, Indonesia

Susana Nurtanti, RN, MSc in Family Medicine

Akademi Kependidikan Giri Satria Husada, Wonogiri, Jawa Tengah, Indonesia

Sri Handayani, RN, MSc in Family Medicine

Akademi Kependidikan Giri Satria Husada, Wonogiri, Jawa Tengah, Indonesia

Nita Yunianti Ratnasari, RN, MSc in Family Medicine

Akademi Kependidikan Giri Satria Husada, Wonogiri, Jawa Tengah, Indonesia

Tantut Susanto, MN, RN, PHN, PhD

Department of Community, Family, and Gerontic Health Nursing, Faculty of Nursing, University of Jember, Jember, Indonesia

Correspondence: Tantut Susanto, MN, RN, PHN, PhD, Department of Community, Family, and Gerontic Health Nursing, Faculty of Nursing, University of Jember. Jl. Kalimantan 37 Jember, Jawa Timur, 68121 Indonesia. E-mail: tantut_s.psik@unej.ac.id

Abstract

Background: The number of individuals living with HIV/AIDS keeps increasing. As this disease is transmitted mostly through sexual intercourse, the number of woman sufferers also increases. The aim of this study want to explore the lived experience of women with HIV/AIDS.

Methods: This qualitative research employed descriptive research approach. Six informants involved in the study were recruited using snowballing sampling technique. Sociodemographic data include age, education, occupation, number of children, and age of children. The interview guide was prepared based on the research objectives and the guide comprised a number of questions to explore the experiences of women with HIV/AIDS. Research data were collected through in-depth interviews. Data analysis was done to describe the life experiences of women with HIV/AIDS using the Colaizzi method.

Results: Women with HIV / AIDS were infected by their husbands because the husbands have other partners. Some cases are due to drug abuse. When HIV / AIDS was first diagnosed, the women were shocked. However, because of the support from their family, peers, and the government, the women live like other healthy women.

Conclusion and Recommendation: Women with HIV/AIDS could live like other healthy women if they receive support from their family, peers, and the government.

Keywords: Live experience; Women health; HIV/AIDS; Qualitative study

Introduction

The number of people with HIV/AIDS keeps increasing. In 2013, the number of HIV / AIDS sufferers reached 35 million people, including 16 million women and 3.2 million children aged <15 years. The number of deaths due to AIDS was 1.5

million, consisting of 1.3 million adults and 190,000 children aged <15 years. AIDS is a social problem (Koffas, 2012). In Indonesia, cases of HIV / AIDS were first discovered on the Island of Bali, and currently, they have spread to 386 districts/cities in all provinces in Indonesia. The cumulative number of HIV sufferers from 1987 to

September 2014 is 150,296 people, while AIDS patients were 55,799 people (Kementerian Kesehatan, 2014). However, it is still unclear why the people can be affected by HIV so that handling HIV / AIDS in Indonesia is not optimum.

In general, women with HIV/AIDS in Indonesia are infected because of heterosexuality (66.95%). This has impacted on women so that they become the most vulnerable group infected with HIV (Kemenkes RI, 2011). The HIV / AIDS cases among women are related to low socioeconomic conditions. According to the data, more than 50% of HIV / AIDS sufferers are from the low economy. As the treatment for the disease is expensive, the women mostly do not get optimum treatment. Women with HIV / AIDS have different experiences based on personal experience, education, and socio-economic factors. Therefore, a qualitative approach was used to explore how the participants got HIV / AIDS, and their lives in depth. So, this study aims to explore the meaning and meaning of life experiences of women with HIV / AIDS.

Methods

This qualitative research aims to explore the meaning and life experiences of research subjects by observing and interviewing research subjects as well as other relevant individuals. This research was carried out from August to September 2018 in Wonogiri, Indonesia.

This study involved six informants who were members of the Key Support Group. The key informants were selected using purposive sampling. The selection of the participants was based on predetermined criteria. The criteria for key informants in this study are

- 1). women with HIV AIDS;
- 2). informants are in adulthood;
- 3). informants can communicate well; and
- 4). willing to be an informant.

The instruments used in this study were interview guidelines and field notes.

Table 1. Characteristics of Key Informants

No	Name	Age	Education	Profession	Number of Child/Children	Age of Child/Children
1	Informant 1	31	Primary education	Housewife	1	12 ys
2	Informant 2	37	Primary education	Housewife		
3	Informant 3	48	Vocational high school	Private, Cooperative Cahayak di Wonokarto	4	3 married, Second grade of primary education
4	Informant 4	37	Junior high school	Housewife	2 Males female	Grade 5 and 2 of primary education
5	Informant 5 (Rina Sari)	35	Senior school	high Private	1	9 yo (grade 3 of primary education)
6	Informant (Feriana)	6	Senior school	high Laundry	-	-

Data collection used in-depth interviews (Wiarsih, Dewi, & Susanto, 2017). All interviews were recorded and verbal responses from the informants were recorded in field notes or observation sheets.

Then, the interview results were documented in the form of recordings and transcripts. Data analysis was conducted using the Colaizzi method. Four criteria were used to determine data validity,

namely credibility, dependability, transferability, and certainty.

Results

Description of the Research Location Gajah Mungkur Wonogiri Peer Support Group is a community of HIV AIDS sufferers which was established in 2012. The members of the group were 180 people, spreading in various regions, for example in DKR Sukoharjo, Muwardi, and Wonogiri. KDS provides motivation and encouragement for people with HIV/AIDS. For member sharing, WA group is available for the members. The social service department of Wonogiri district did not provide assistance.

List of Questions: the study involved mothers/women suffering from HIV / AIDS who joined the Gajah Mungkur Peer Support Group in Wonogiri Regency.

When diagnosed with HIV, what was the last CD4?

Informant 1 *in January 2018, CD4 751, at that time the husband had a lung disease; there was cold sweat. He was taken care at Amal Sehat Hospital, for one week with HIV/AIDS diagnosis. Now, she can work as a driver....*

Informant 3*was diagnosed after her husband passed away in 2014 and she immediately checked. She did not remember her CD4 results. Her conditions dropped and received a CD4 check in Bali 500....*

Informant 4 *received the test in April 2012 after the husband was sick and died. The last CD4 is more than 600 in 2017.*

Informant 5 *Diagnosed starting in 2012.... Informants 6.... Diagnosed HIV in 2015 at 10 months, CD4 31 results, the second 2016 increased by 244, the third in CD4 315, directly to Veralud at Karyadi Hospital, was undetectable, but still treatment. CD4....*

How did you get the HIV/AIDS? From where? Almost all informants said that they got HIV from their husbands.

Informant 1 *From Husband. The husband was taken to the hospital to be cared for lung disease. The doctor checked his blood for the treatment. He was a heavy smoker....*

Informant 2 *from her husband who used drug injection....*

Informant 3 *I was infected by my husband....*

Informant 4 *I was infected by my husband....*

Informant 5 *I was infected by my husband*

Informant 6 *Infected with HIV from a second husband in 2010, the husband died in 2012, so my husband died telling me a check from Pak Dalyono, after five years, in 2015....*

In your opinion, how did your husband get the HIV/AIDS? Husbands got the HIV virus from other women and drug injection (needles and syringes).

Informant 1 *Husband worked as a driver, having a prostitute, indeed, the girl selling it....*

Informant 2 *Husband used injecting drugs. The husband was often sick. He was brought to Dr. Oen Solobaru. His Condition stage 4.... husband worked in Jakarta foreman, 4 months and three months and a half, ARV treatment a year, worked hard again, slept late at night finally dro finally not helped....*

Informant 3 *Husband works as an expeditionary officer who regulates the items to be dismantled, infected with HIV does not know where, but the informant said he knew that her husband had a boyfriend, did not use injecting drugs, drank. Never transfuse. The informant had a blood transfusion after contracting HIV....*

Informant 5 of the husband migrated to Bekasi, used injecting drug injecting syringes with his friends....

Informant 6 My husband infected HIV from his ex wife, my husband working selling meatballs, , his ex-wife cooked at a café.

What is the current condition of the husband? At this time the condition of the husband had died, there was one informant whose husband had improved his condition and now could work again as a driver.

Informant 1 Now my husband is working again, smoking again

Informant 2 has died

Informant 3 has died, currently married again with fellow HIV sufferers, like farmers

Informant 4 my husband has died

Informant 5 My husband has died

Informant 6 At the moment the husband has died, in 2012 he fell into a coma. Doctors say only complications

What is the mother's response when she was found to be infected by HIV? When they were diagnosed as being infected with HIV/AIDS, they were shocked. However, they live their life because of the support from family and peer support groups. There were informants who stayed in their homes for about a month due to embarrassment and feeling helpless, afraid of the diagnosis and traumatized by HIV AIDS. The informant felt excluded from the community. However, there was one informant who still kept his disease a secret so that the community did not know and still treated her family well without discrimination. The informant said that there was no problem of socialization in the community. Her neighbors could accept the informant's condition.

Informant 1 is feeling so not angry

Informant 2 When I was shocked, down, when the husband died, the village staff told me to test all family members. My

brother was not positive, but because many support, I got up again.

Informant 3 was shocked, for a month I arrived at my father-in-law's house in Bali. Changes in activity: morning vertigo

Informant 4 Shock, who were sure to be shocked, from the beginning there were no symptoms, from their marriage, had injecting drugs, maybe in 2000, but they were cured, they used to migrate to Lampung, workshops. Thank God, I have never dropped from the beginning, married in 2006. The husband died in Muwardi, then I was asked to check my self....

Informant 6 Pain is not cured, healed, tempo, no tuberculosis, asthma, weight loss, just 40 how much, times, frequent diarrhea, not healed, I am usually sore throat, doctor Karjo, I lost my taste, eat not tasty, not fast

What is the current condition of the husband?

Informant 1 At present the husband has died

Informant 2 Husband is currently trading in Jakarta, going home once a month....

Informant 6 Husband has died in 2012

Anyone in a house suffering from HIV: Most of the informants said that only their husbands and informants themselves were not infected by HIV. Has the child been checked? The child is checked, not infected with HIV.

Informant 3 ... my child 4, negative, not infected

Informant 4 when the second child was 9 months old, thank God in the negative check, ASI was given the first child until the age of 2 years, the second until it was found to be infected with HIV....

Informant 6 have no children from the first time.... found out from the doctor has

a cyst, adopted child 1, now adopted child.....

What medicine does the health worker give to the informant? When did the informant go to get the drug?

Informant 1 *Not receiving therapy from health workers, only taking bitter herbs, because CD4 results are still high at 751*

Informant 2 *Dufiral several Neviral for 6 years is the same, does 2x2....*

Informant 3 *Evapiren and Laminudin, twice a day, never forget, only hour difference....*

Informants 4 *Drugs given by health workers Nevirapine 200 mg 2x1 tablets. Dufiral. To the hospital to get medicine once a month....*

Informant 5 *Husband one year ARV treatment, recovered condition improved, worked for several months, relapse again continued to die. If the mother is with the drug, Neviral, twice per day....*

Informant 6 *Dufiral are the same as the small Evapirents which are yellow, 2 x....*

After your husband died, did you marry again? There were two informants who remarried, 2 informants did not remarry, and 2 informants' husbands were still alive.

Informant 2 *I remarried, is the same as the sufferer, has no children, if given it, please ...*

Informant 5 *I remarried with fellow HIV sufferers, met at Muwardi Hospital at the time of taking medicine, now husband works in Jakarta trading. Go home once a month*

Informant 6 *After the death of the husband not remarried*

Experience During HIV AIDS. Once a foster mother at Lentera Purwosari Shelter House now moves to Pucang Sawit Heroes Cemetery,

Surakarta. Other informants said they were still working as usual, for example, farming, laundry business, cooperative employees, and housewives. As said by the informant below:

Informant 2 *get assistance from the Ministry of Social Affairs that is given capital for the grocery business, laundry, goat livestock, Currently, this assistance is still the business of informants, namely laundry and goat livestock. No home environment provides assistance, the family gives support in the form of support. In the past before treating children with HIV before, there were 10 children in Lentera Shelter House, Purwosari, now moving to the Heroes Cemetery, the principle of life is beneficial for others, impressing on taking care of those children you know, you are still young. , at least one and a half years, if there are at least two months now, the mother here died. Now his foster mother is from Gunung Kidul, Purwodadi....*

Informant 3.... *After the husband dies daily activities open the laundry in Bali, Mother in Bali, until now with your family is still good. The husband's family is getting better. Until now, no one knows, only the informant and the second husband know, the new in-laws do not know, if honestly his or her fear is lowered. The second husband's age is only 37 years old. Daily activities in the cooperative, living in Mes, returning to Batu once a week....*

Informant 4 *I take medicine once a month, I will take part in mentoring, so if there is a time I come here. I work as a farmer, living with my parents, but the house has been given to me. In the community, there are those support and isolate to me, but because I can maintain my health, finally come closer again, after one year. If my family doesn't even want to know, even though he knows I took the medicine, but he doesn't want to know. I have received business capital from the government, got a goat, it has grown to another 5 million because it can't afford*

much - so I buy cattle, the goats are gone, they are already sold. Cows are still there. Farmers' daily activities, social activities, training / mentoring, active participation in peer support activities, pleasant experiences, only the beginning are very sad, shunned by the husband's family, if the informant's own family gives support.

Informant 6 Socialization with ordinary people, maybe someone knows, I am a confident person, I think my neighbor already know, ordinary help neighbors, no discrimination, he or she accepts what he or she is, help makeup, besides laundry. Normal activities, I'm happy. Activities in the community all take part, help neighbors, karaoke, reunion. For the treatment, there are those who use BPJS, some pay for themselves, but it's cheap, only twenty, thirty so.

Discussion

Generally, women with HIV have low to middle education. The occupations of HIV-infected women in general are housewives and private employees. Husbands with HIV / AIDS have varied jobs, ranging from drivers, farmers, factory employees, workshop employees, market traders. This result aligns with research conducted by Kibret, indicating that the average HIV sufferers have a low socioeconomic status. The cause of HIV / AIDS among the informants is because their husbands were infected through sex intercourse with another partner and injecting drug (Kibret, 2018).

After her husband was diagnosed HIV/AIDS, the woman immediately checked whether they were infected HIV/AIDS, for getting treatment. The CD4 results of the informants were still above 300, due to the faster examination after knowing that her husband had died so that there was no worsening of the condition of the informant. These results are in accordance with the research conducted by Bartczak who said that HIV testing was carried out concurrently with CD4 cell counts to get treatment immediately and ARVs were started immediately, that they started ARV treatment 2.5 months after the inspection visit and stated HIV (Ankiersztejn-Bartczak et al., 2018).

Women with HIV / AIDS sufferers contract the disease from their husbands. Their husband has another partner, and there is also because of her husband injecting drug users. This result is in accordance with the research conducted by Marcy et al. stating that HIV / AIDS is a sexually transmitted disease, drug abuse by injection (Maracy, Mostafaei, Moghoofei, & Mansourian, 2017). For the future, it is necessary to provide health education about sexual diseases and ways of transmission so that couples are expected to be more careful if they want to change partners with sexual relations.

Her husband's condition has improved with the provision of ARV drugs, but some informants say that their husband died because of accompanying opportunistic infections such as tuberculosis, diarrhea, thinness, and thrush. While the informants said that there were an itch-herpes zoster and no appetite. The research is in accordance with research conducted by (Boniphace et al., 2011). For this reason, it is necessary to conduct an examination as soon as possible so that the HIV virus is immediately known and the immune system is reduced in patients with the CD4 examination, to get ARV treatment immediately (Ankiersztejn-Bartczak et al., 2018).

When her find out about his condition (diagnosed with HIV) Shock informants, drop, and lack of enthusiasm in living their lives in the future. But thanks to the support of family, fellow peers with HIV / AIDS sufferers, so that the sufferers who had not had the enthusiasm became more enthusiastic in living their lives, and were willing to take medication as provided by health workers. These results are consistent with Johnson's research that needs family support and peer groups to overcome difficulties while living with HIV / AIDS (Johnson, 2018). To improve the quality of life of women with HIV / AIDS, it is also necessary to provide support in the form of training to improve their ability to care for healthy and sick family members.

The informant said that the sick family members were the informants themselves, there were 2 informants whose husbands were also still living with HIV / AIDS. Almost all informants said that their children had been tested for HIV and were

negative, because there was no direct contact through the birth canal, sexual or injecting drug abuse with previous HIV / AIDS sufferers, and the average age of HIV / AIDS sufferers were adults (30 -65 years) as in the research conducted by Steward. et. al. (Steward, Koester, & Fuller, 2018). So that health needs to be improved for children so as not to contract HIV / AIDS.

Drugs that have been given by health workers are Nevirapine 200 mg 2x1, Neviral, Dufiral 2x2 per day, and one informant said that he did not take medicine from health workers, but drank Sambiloto herbs. The husband of the informant on average has died, and the informant is reluctant to remarry, there are two informants who remarry with HIV / AIDS sufferers as well, on the grounds that they already know each other's condition with HIV. The informants have been able to live their lives well, every day the informants become housewives, employees, farmers, traders in the market, and have a laundry business at home. The Indonesian government through social services has provided assistance in the form of business capital and training so that people living with HIV / AIDS can still work to fulfill their lives, such as laundry, livestock, making crafts and so on. This condition is in accordance with the research conducted by Kibret that the Government must strengthen the household economy so that HIV / AIDS sufferers are able to care for and support their families (Kibret, 2018). Community activities were also followed by informants without discrimination, but there were two informants who were not ready to open their status in the community because they were afraid of discrimination.

Conclusion

The experiences of women with HIV / AIDS vary greatly. When new HIV / AIDS was initially declared, they were generally shocked. However, because of the support from families, peer groups and the government through social services, they can accept it and live their life just like other healthy women. The woman can participate in community activities without discrimination. They can work to meet their needs and take care of their family. However, there are 2 HIV / AIDS sufferers who do not share their HIV / AIDS status because of their fear of discrimination. A holistic approach

for patients who do not share their HIV / AIDS status is required, so that they are brave to accept their status and ready to enter the community with the status.

There is a need for health education in the community related to HIV / AIDS, so as not to discriminate against HIV sufferers. The disease must be prevented from being transmitted and treated, and people with HIV/AIDS should not be socially isolated.

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References

- Ankiersztein-Bartczak, M., Firlag-Burkacka, E., Czeszko-Paprocka, H., Cybula, A., Horban, A., & Kowalska, J. D. (2018). Simultaneous HIV and lymphocyte CD4+ testing as an intervention for improving linkage to care – experience of a voluntary counselling and testing facility-based pilot programme. *HIV & AIDS Review. International Journal of HIV-Related Problems*, 17(1), 8–11.
- Boniphace, I., Omari, M., Fred, R. S., Ferdinand, M., Marcel, T., Dar, B., & Salaam, E. (2011). HIV / AIDS Clinical Manifestations and their Implication for Patient Clinical Staging in Resource Limited Settings in Tanzania, 5, 9–16.
- Johnson, E. J. (2018). A case study on the consequences of HIV/AIDS within the Caribbean: Issues faced by a teenager born with HIV. *HIV and AIDS Review*, 17(2)152-157.
- Kemenkes RI. (2011). *Pedoman Nasional Pencegahan Penularan HIV dari Ibu ke Anak (PPIA)*. *Journal of Indian Society of Periodontology* (Vol. 15).
- Kementrian Kesehatan, R. I. (2014). Pedoman penerapan terapi hiv pada anak. *World Health Organization*, 1–81.
- Kibret, S. (2018). The effect of HIV / AIDS on household 's healthcare expenditure and income in Addis Ababa: a propensity score matching approach, 17(2)103-110.
- Koffas, S. (2012). Social Dimension and Work with the families of AIDS Patients and Carriers., 5(2), 87–93.
- Maracy, M. R., Mostafaei, S., Moghoofei, M., & Mansourian, M. (2017). Impact of HIV risk factors on survival in Iranian HIV-infected patients: A Bayesian approach to retrospective cohort. *HIV & AIDS Review*, 2(2), 100–106.
- Steward, W. T., Koester, K. A., & Fuller, S. M. (2018). Shaping the Patient-Centered Medical Home to the

Needs of HIV Safety Net Patients: The Impact of Stigma and the Need for Trust. *Journal of the Association of Nurses in AIDS Care*, 1–15.
Wiarsih, W., Dewi, I., & Susanto, T. (2017). A

phenomenological study of families with drug-using children living in the society. *International Journal of Pediatrics and Adolescent Medicine*, 4(3), 100–107.