



Social Support for Pregnant Women with HIV/AIDS in Cilacap District: Qualitative Study

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ABSTRACT

HIV infection has a complex impact on the sufferer: lowering the body's resistance and the opportunistic infections that follow, psychological and social problems are experienced by people who are detected with HIV. Psychological distress, including low self-esteem, anxiety, fear, depression, and suicidal ideation as expressed in several studies of women with HIV. Support has an important role in improving one's coping adaptation to stressful situations, reducing morbidity, and disciplining treatment for patients so that indirect family support can improve one's physical health, including support for pregnant women with HIV/AIDS. The purpose of this study was to determine social support for pregnant women with HIV/AIDS. This study uses a qualitative design. The approach used is phenomenology. Participants were selected by purposive sampling technique until data saturation was achieved. Data analysis was carried out using thematic analysis using Open Code. Based on the interviews by two pregnant women and four families of pregnant women with PLWHA, it can be concluded in 4 themes: 1). Pregnant women feel insecure about their condition 2). The family accepts the condition of pregnant women 3). Families and pregnant women need support from health workers 4). Pregnant women and their families need a system to make it easier to remember ARV consumption.

Keywords: *Social Support; Pregnant Women; HIV/AIDS*

1. INTRODUCTION

The National AIDS Commission (KPAN) reports that the number of cases of Human Immunodeficiency Virus (HIV)/Acquired Immuno Deficiency Syndrome (AIDS) report every year continues to increase. World Health Organization (WHO) estimates that the prevalence of HIV cases in Indonesia is 660,000. However, cumulative HIV cases since 1987 have only been reported to be around 220,000 cases. It revealed that in the last five years, people living by HIV/AIDS in 2012 were 21,511 HIV cases and 10,862 AIDS cases. Central Java became the province with the fourth-highest number of cases in all of Indonesia in 2019, which was 5,600 cases [1].

Data from the AIDS Eradication Commission of Central Java Province (2015), there were 250 people with HIV/AIDS (PLWHA), of which 174 people were infected with HIV and 56 were positive for AIDS. From the data on people living with HIV/AIDS, 58 percent came from ordinary people, 8 percent of people infected through needles, 21 percent came from correctional

institutions, and gay reached 1 %, while 12 % of people living with HIV/AIDS were a prostitute [2].

Individuals who are positively infected with HIV, living their lives will feel difficult even if it is experienced by adults who have maturity in life because from a physical point of view the individual will experience changes related to the development of the disease, emotional stress, and psychological stress experienced due to HIV infection. Ostracized by family and friends for fear of being infected, as well as social stigma and discrimination in society. This has an impact on the patient's social (emotional) response, for example, the existence of social stigma that can cause behavioural disturbances in others, including avoiding physical and social contact [3].

HIV/AIDS sufferers have several problems related to health, morals, social and finance. Discrimination in the workplace is also a big problem. Opportunities to work are decreasing and income is decreasing, but the problems associated with dealing with HIV/AIDS are increasing. These things make the stress level of HIV/AIDS sufferers increase [4].

Perceived support can predict the effectiveness of coping, adjustment, and a person's physical and psychological well-being. It happens because individuals who feel that the support they need is available will have the potential to not experience excessive stress and be more motivated to maintain their health status [5].

HIV in pregnant women is not only a threat to the safety of the mother's life, but also a threat to the child she is carrying because transmission can occur from mother to baby. More than 9,000 pregnant women with HIV positive status every year and 30% of them will give birth to infected babies if there is no prevention of transmission from HIV positive mothers to children (Prevention Mother To Child Transmission (PMTCT) [6]. Social support given to pregnant women will increase adherence to taking ARVs, to reduce the risk of mother-to-child transmission of HIV. The purpose of this study was to explore social support for pregnant women with HIV/AIDS.

2. METHOD

2.1. Design

Descriptive phenomenological studies by semi-structured interviews were used in this study. This research explores the social support for pregnant women with HIV/AIDS.

2.2. Participant and setting

Participants consisted of pregnant women with HIV/AIDS in Cilacap District, husband of the pregnant women with HIV/AIDS, and head of the VCT polyclinic, Cilacap General Hospital.

2.3. Sampling

The sampling technique was purposive sampling. Participants were selected who met the inclusion criteria (pregnant women with HIV/AIDS, and are willing to become participants. The number of participants in this study were six people with details: three pregnant women with HIV/AIDS and their partners.

2.4. Data Collection

All participants signed an informed consent form at the beginning of the first meeting before fully participating in the study process. Participant meetings were counted as activity daily time, and participants were rewarded for attending.

The researchers met with the participant's accordance with the agreement of time and place and explained the description of the study and the possibility to become a participant, including explaining that the participant was allowed to withdraw as a participant at any

time. Informed consent forms were signed by participants who were willing to become research respondents. Triangulation of data was done through in-depth interviews with the head of VCT Polyclinic General Hospital Cilacap District and Coordinator of Kelompok Dukungan Sebaya (KDS)/Peer support group. This study has conducted an ethical clearance with the number NO KEPK 1110/KEPK/STIKES-NHM/EC/VIII/2021.

2.5. Instrument

The instrument in the research is the researcher. This research was conducted with semi-structured in-depth interviews. The interview guide was developed by considering the theory of social support for pregnant women with HIV/AIDS which has been construct validated by experts.

2.6. Data Analysis

The analysis technique in this study used thematic analysis.

Every interview result was transcribed and analysis is done directly verbatim making. The cognate code is allied made the category. Categories that have the same meaning are grouped into sub-themes, which are then grouped into themes

Credibility was done by member checking, where the results of the transcription were reviewed by the participants, to ensure that the transcription was in accordance with what was conveyed at the time of the interview. Source triangulation was done as a strategy to increase credibility in this research. Several things were done to increase the degree of trust in this study. Credibility is done by member checking, where the results of the transcription are reviewed by the participant, to ensure that the transcription is in accordance with what was conveyed at the time of the interview. Source triangulation is done as a strategy to increase credibility in this research. Triangulation was carried out to the head of polyclinic of VCT Cilacap District Hospital and head of *Komunitas Dukungan Sebaya* (KDS). Transferability testing is done by making research reports in a systematic, detailed, clear and reliable way. Dependencies and confirmability are carried out through peer review by the research team starting from the research process through to data analysis.

3. RESULT AND DISCUSSION

3.1. Results

Total of 6 people participated in this study, consisting of 3 pregnant women with HIV/AIDS dan three partners of pregnant women. The results of the study were described in the below table:

Table 1 Result of Study

Code	Category	Themes
Afraid doing activity out of house Ashamed Feel unhappy Worried about his health Fear of husband leaving Fear of death	inferiority Worries	Pregnant women feel insecure about their condition
The family always accompanies when checking the pregnancy Husband still provides physical and psychological support Household stays harmonious Husband fulfils all the necessities of life Husband still gives an attention Husband prepares for delivery needs	Family Acceptance Family Support	Families accept the condition of pregnant women with HIV/AIDS
Mother and family want to get information about their health-to-health workers Mothers and families want to get a quick response when there is a health problem Mother and family want health workers to remain friendly at serving Mother and family want health workers not to be afraid of physical contact Mother and family want to get ARV easily Mothers and families want ARVs to be easily available at the nearest health service Mother wants health workers to still respect them like other patients Mother and family want health workers not to discriminate against HIV status Mother wants someone to remind her to take ARV Mothers are sometimes reminded by Peer Support Groups to take ARV	Information support needs Emotional Support Needs Instrumental support needs Appreciation support needs	Pregnant women and their families need support from health workers
Mother is afraid of forgetting to take ARV Mother wants a reminder on the cell phone	Pregnant women and their families need a system for reminders of ARV consumption Easy-to-use Reminder Needs	Pregnant women and their families need a system for reminders of ARV consumption

Source: Primary data

3.2. Discussion

3.2.1. Pregnant women feel insecure about their condition

All participants briefly summarize their experiences with the same answer that they are very insecure about their pregnancy? The three participants said they felt fear and shame and various feelings that landed on them, including feelings of inferiority and lack of confidence in themselves. They also say they feel guilty. The three participants also said that they were afraid of being pregnant and their HIV with the reason of fear of death and fear if their child was infected with HIV like himself:

".....I was really embarrassed after I was detected pregnant and had HIV, I felt ashamed to leave the house because of my condition, I was worried that people would find out, but I felt I had to be strong because my husband still supports by me (P1, 36 years old)

Good family support has an effect on increasing self-esteem while poor family support increases the risk of depression in HIV/AIDS patients. Effective family support can reduce negative effects due to negative assumptions in a person [7].

"...I feel that my husband accepts me as I am, even though I don't believe in myself and am afraid that later I won't be able to take care of my child when it's born because I can be called at any time, that's why I always take HIV medicine regularly her." (P3, 32 years old)

As revealed in the results of Young's research which states that family support has a significant influence on health status, self-confidence in decision-making and social isolation.

Based on the research of Kotze, et al. in South Africa in 2012 that the ability of active coping mechanisms and support Positive social skills can increase self-esteem and

can reduce levels of depression, and elicit good emotional and physical responses during pregnancy. This is in line with [8] which states that the anxiety of pregnant women with HIV will increase related to maternal concerns if the fetus they contain is infected with societal stigma and the increasing needs of pregnant women.

3.2.2. Families accept the condition of pregnant women with HIV/AIDS

All participants need good support, especially from their families to be able to accept themselves who are pregnant with HIV. Two of the three participants said that the family still received it well even *though* they had HIV/Aids. Both also said that the family gave good support from his family

"...I went to the hospital for a pregnancy check-up and there I just found out that I was HIV positive, at first, I was afraid that my husband would be angry, but my husband accepted me well..." (P2, 36 years old)

"...even though my wife is sick like HIV, but yes, I still love it, especially now that I am pregnant with my child and I always accompany my wife to check with the doctor (P6, 40 years old)

Family support is one of the things that is most needed by a person in an effort to increase motivation so that it can affect individual health and can reduce depression caused by despair due to suffering from HIV/AIDS. With the support of one's family, one is not only motivated to continue living life but also creates a feeling of comfort and calm when one knows clearly that his family does not stay away from him, is not indifferent to him and supports him in living his life over his illness. Family support can also be interpreted as an encouragement which, however, will certainly mean a lot to HIV because they are desperate for their illness [8]. This study is in line with research that Family support is very much needed by HIV/AIDS patients as a support system or the main support system so that they can develop an effective response or coping to adapt well in dealing with the stressors they face related to their illness, both physical, psychological, and social [9]. Family is an important element in a person's life because the family is a system in which there are family members who are interconnected and interdependent in providing support, affection, security, and attention.

This support is needed so that they do not feel alone in solving their mistakes and there are still people who care about their fate. The results of this study are in line with another source of stress in pregnant women with HIV/Aids is stigma from the environment such as the negative view of society towards people with HIV/Aids (ODHA) [10]. As revealed in the results of Young's research which states that family support has a significant influence on health status, self-confidence in decision-making and social isolation.

3.2.3. Pregnant women and their families need support from health workers

All participants said that they urgently needed support from health workers in the form of informational, emotional, instrumental, and reward support. This is evident from the expression of participants and families needing health information support from health workers.

... I often worry about my pregnancy so I often ask health workers for health information. (P1, 26 years old)

.....I need information from the office so I can know my health and pregnancy progress... (P2, 36 years old)

The same thing was revealed by the chairman of KDS who revealed the following:

. Patients often ask us about their health and often ask about their pregnancies. There are even patients who say that they are in dire need of health information from health workers. (P7, 40 years old)

In addition to informational support, participants and families also need emotional support from health workers, illustrated in the participants' expressions as follows:

... I want officers to be able to always provide services with friendly, kind, and familial... So, I feel like someone can be a friend to share or confide in... The same officer who is always passionate and encourages me to always be passionate. (P3, 32 years old)

... Yes, my wife often says that she is happy with a good health worker and always provides motivation and encouragement. My wife who was a bit weakened into the spirit again... (P5, 38 years old)

The same thing was expressed by the officer and chairman of KDS about the desire or need for emotional support that *participants* expected.

... Patients often confide in us about various things, pregnancy problems, their health and sometimes even family problems are also told. Patients also often ask for advice related to anxiety issues, concerns about their pregnancy. (P5, years old)

Participants also revealed that they need instrumental support from health workers, in the form of easy access to the provision of medicines, this is illustrated by the following expressions:

... The medicine wants it to be easier to get. Even if it is at the nearest health centre so there is no need to go far... (P1, 26 years old)

... Sometimes my wife is pregnant with drugs far away... if the medicine is prepared in a closer place so it does not need to be far away... (P4, 26 years) old

The same thing was expressed by health workers and the chairman of KDS as follows:

...Patients sometimes forget that the medicine will run out and have not come to take so KDS who helps remember, also helps bring to the nearest health service or the patient's home. (P7, 40 years old)

Participants and families also need the support of awards from health workers, illustrated in the following expressions:

... well, he gave the same thumbs-up as the officer when I delivered my pregnancy said the normal doctor... The officer is top, so the spirit still appreciates me as much as the treatment of other patients (P2, 36 years old)

... See the wife spirit so happy, because indeed this disease still needs to be cheered and also appreciated... We need to be rewarded with our condition and our family like this... (P4, 26 years old)

The same thing is expressed by health workers as follows:

... The patient still wants to always be appreciated regardless of the disease and circumstances. Patients often say they can often be treated differently or discriminated from the community so that it makes the patient psychologically disturbed. (P7, 40 years old)

The use of services in people with HIV / AIDS is one form of behaviour to seek health services. The lack of health care utilization is likely due to several factors that include predisposing factors that can be manifested in knowledge, attitudes, stigma, trust, values; possible factors that are realized in the availability of facilities, infrastructure, accessibility, and ease of achievement of health services both in terms of distance, cost, availability of transportation facilities, and the existence of regulations and community commitments in supporting these behaviours; as well as reinforcing factors such as family attitudes and behaviour, health workers, community leaders [11].

Health workers have an influence on the community in utilizing a health service. This influence can be in the form of the support of health workers who are a driving factor in the utilization of VCT clinics. The support is especially in the form of information support in form of information about how HIV transmission and prevention, and provide motivation to the public to conduct voluntary HIV examinations. Health workers are an important component in the implementation of health services. Therefore, the ability of health workers as motivators, communicators, and counsellors is a possible factor that affects the utilization of a health service including VCT clinics.

Rao et al (2016) said the provision of emotional support and services will greatly help patients while the obstacles experienced in the patient themselves in the form of changing emotions, after being given support, some patients experience emotional changes that improve. Masquillier Says emotional support is the main

but the barriers in the level of knowledge greatly affect it. But emotional support makes sufferers have hope to carry out their daily activities, including in the routine running of ARV therapy [12].

ARV therapy must be lived for life by HIV / AIDS patients to maintain patient immunity. Therefore, the use of ARVs requires high adherence to achieve therapeutic success and prevent resistance. The use of ARV drugs carried out over a very long period of time, even for life, and the still negative stigma against HIV / AIDS patients gives the responsibility of health care providers to provide other facilities that support the treatment of HIV / AIDS patients themselves, especially in monitoring patient compliance in using drugs [13].

Instrumental support, informative support, emotional support is important but the obstacles encountered are patients' depression when accepting the reality of their illness and coping turns into depression. Health services and social support including the support of health workers in the form of informational, emotional, instrumental, and rewarded patients with HIV AIDS can carry out treatment regularly and live a quality life. Improving the quality and life expectancy of people with HIV / AIDS requires various efforts from the government and the community including health workers and families. The government in this case the Ministry of Health and related agencies has a very important role in relation to the provision of medicines and the provision of ODHA health services. Likewise, in policies to allocate funds in the fight against the spread of the HIV virus and the provision of drugs for free to patients. In addition, society as a unit of social control has a major influence on the social interaction of HIV [14].

The quality of life of patients including pregnant women with HIV / AIDS must be considered because the disease is chronic and progressive that will affect physical, psychological, social and even all aspects of the patient's life, so that support in HIV / AIDS patients can help continue living well. The better the support provided by health workers, the regularity of patient treatment will increase and the patient's life is more qualified.

3.2.4. Pregnant women and their families need a system for reminders of ARV consumption

All participants said that pregnant women and their families need an application to remind mothers to take ARVs. It corresponds to the following expression:

.....' I'm afraid of forgetting to take his ARV, while my husband sometimes doesn't remind me, because he also often forgets, actually, it's good when there is a special reminder that keeps on reminding me, so I don't forget " ... (P2, 36 years old)

This expression is supported by the expression of the head of the KDS which states as follows:

....." Yes, ma'am. sometimes I have to remind them to take medicine, while I'm not just taking care of one person, ma'am, not to mention I also have to remind myself too, so sometimes I forget to remind myself. (P7, 40 years old)

All participants said they were worried if they forgot to take ARVs because it would affect the *transmission* to their babies. This is by the statement below:

..... I was really worried that I would forget to take ARVs because according to the health workers, they said that if I often forget, my child will be infected.... (P1, 26 years old)

All participants said they needed a good reminder system, to reduce the risk of forgetting to take ARVs. This is by the statement below:

.... yes, I want someone to remind me constantly, for example, using a cell phone, ma'am, right, if you use humans, sometimes you forget... (P3, 32 years old)

The head of the VCT polyclinic at RSUD Cilacap said the same thing:

.... Yes, indeed there should be a sophisticated reminder system to remind patients with HIV, not only pregnant women, Ma'am, but all patients with HIV so that they do not miss their ARV consumption, because if we only rely on KDS, right, they will still have to wake themselves up too, so there should be a strong system to remind patients... (P8, 40 years old)

Adherence to a treatment schedule is very important. If the drug level in the blood of PLWHA becomes too low, then the virus in the body can become more resistant (resistance) to antiretroviral drugs used. If this happens, then the drugs used become ineffective against this new type of virus. Several Experts consider that if more than twice a month forget to take medicine, then resistant strains of the virus may emerge. When this happens, therapy will begin to fail so maybe have to replace all drugs used [15].

The founders of KDS are PLWHA, who from the start had a strong need to gather. Their initial motivation formed groups, all based on a need to share. It's good to share feelings, share knowledge to share ways to do it overcome the various problems they face. Starting from a passion for each other support because of the strong need for mutual support. Initiatives like this appear because as a person who is also infected having the same problem [16].

The implementation of ARV therapy is in the form of outpatient services so that staff is unable to monitor patient compliance in undergoing ARV therapy. Officer Monitor patient compliance by asking questions with the patient when the patient visits an HIV/AIDS treatment clinic because, at the time of therapy, the patient was not under the supervision of the officer directly. Therefore

we need a service in the form of an application that can record the patient's drug consumption time, then the data on the drug consumption is sent to ARV therapy officers so that officers can monitor compliance patients without having to meet directly with HIV/AIDS patients [17].

Currently, the use of information technology is one of the options in preventive and promotive efforts in the public health service system. HIV is a viral infection that requires sufferers to take medication every day at the same time to improve the patient's quality of life. Based on Literature Review by Balla et.al, show that Mobile phone is effective tool to support management of HIV and TB for long term. Cell phones have an important role in the care of patients with HIV/AIDS and their use is very acceptable [18].

4. CONCLUSION

Pregnant women with HIV/AIDS is needed to increase the confidence of pregnant women so that the motivation of pregnant women to take part in the HIV/AIDS treatment program is recommended by health workers. Support can be given in the form of informational, emotional, instrumental and reward support. Good support can improve the quality of life of pregnant women with HIV/AIDS. The better the social support provided, the higher the health status of pregnant women with HIV/AIDS

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