

## Perception of HIV/AIDS Patients with Pulmonary TB on Family Support in Taking OAT ARV Medications

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### ABSTRACT

Family support in reminding sufferers to take ARV medication can influence their medication compliance. Sufferers can despair if there is no family support and this can have bad consequences. The aim of the research was to explore the perceptions of HIV/AIDS sufferers with pulmonary TB regarding family support in taking ARV oat medication. The research design is qualitative using a phenomenological study. Samples based on criteria for treatment, living with family and willing to be respondents. The research sample used a total population of 3 respondents. The results of the interviews showed support for the assessment, all respondents felt that they were well received by their families and that the family had an important role in getting well, thereby motivating them to receive regular treatment. Instrumental support: All respondents said that medical needs were met by the family and it was not uncommon for sufferers to be invited to go on recreation. Informational support, some families do not know enough about providing health information and the family has explained the importance of taking medication. Emotional support, respondents said they felt disappointed and a burden when the family understood about illnesses that could be contagious. Overall family support in assessment, instrumental, informational and emotional is good but can be improved regarding providing health information and maintaining motivation to take medication.

**Keywords:** Perception, Take Medicine, Family Support

### Background

Tuberculosis is an infectious disease caused by the bacterium *Mycobacterium Tuberculosis*. Tuberculosis causes people to become sick every year and is the second most infectious disease that can cause death after HIV. In 2020, globally 44% of PLWHA with TB were not diagnosed in 2019. So it was concluded that the TB suffered by 44% of people was an opportunistic syndrome. Indonesia itself ranks second with the most TB sufferers with a total of 845,000 cases. According to data from the Indonesian Ministry of Health in 2019, 51% of TB patients knew their HIV status (1). In 2022, the spread of HIV in Indonesia will now reach 519,158 people and TB in Indonesia will reach 824,000 thousand people (2).

Due to the high number of pulmonary TB cases and the high risk of transmission to other people, the government has issued a policy to control pulmonary TB through the procurement of anti-tuberculosis drugs (OAT). Tuberculosis is a treatable and curable disease. Pulmonary TB treatment is given in 2 stages, namely an intensive stage of 2 months of treatment and a follow-up stage of 4-6 months. Regular treatment for pulmonary TB patients can result in complete recovery, if the patient complies with the rules. It is important for sufferers not to stop taking medication and if sufferers stop treatment, germs will multiply again and Repeat intensive treatment for the first 2 months. If sufferers undergo treatment with direct supervision of taking medication, they are able to defend themselves against disease, prevent germs from entering from outside and can reduce the death rate caused by pulmonary TB (3). ARVs are drugs that can be used to prevent or inhibit the reproduction of the retrovirus found in HIV. ARV drugs work to fight infection by releasing HIV in the body and increasing CD4 counts(4). HIV/AIDS is allergic to medication and until now there is no therapy that allows the body to tolerate the virus. Treatment can prevent the body's immune system from deteriorating to the point where infections emerge. If left untreated, opportunistic infections can cause death around 3 years after being diagnosed with AIDS (5).

Based on WHO, the number of TB-HIV co-infected patients in the world is estimated to be 14 million people (6). Tuberculosis cases can happen to anyone, especially patients with immunological disorders such as Human Immunodeficiency Virus (HIV). TB with HIV positive and people with HIV/Acquired Immuno Deficiency Syndrome (AIDS) (PLWHA) with TB are referred to as TB-HIV co-infected patients. According to WHO, in 2013, there were 9 million new TB patients and 1.5 million deaths due to this disease. Of the 9 million, 1.1 million people or around 13% are HIV positive (7).

The WHO Global Tuberculosis report 2020 globally 44% of PLWHA with TB were not diagnosed in 2019, therefore increase TB detection among people with HIV(8). Some sufferers who experience side effects from anti-TB drugs also decide to stop treatment. Ultimately, it causes double immunity of TB germs to anti-TB drugs (9).

Based on the results of a preliminary study at the Voluntary Counseling and Testing (VCT) polyclinic at Ngudi Waluyo Blitar Hospital, data on 5 patients who dropped out of medication and several reasons why patients dropped out of OAT + ARV medication were because they were not strong enough with the effects of the medication they were taking or changed jobs. Based on this phenomenon, the role of the family is very important in supporting compliance with taking medication for the patient's healing and recovery process, but in reality there are still families who are afraid, especially of being close to TB sufferers, so they are overly careful and afraid to talk. Family support in treating tuberculosis is encouraging sufferers to adhere to taking their medication, showing sympathy and concern, and not avoiding sufferers from their disease. If family support is not provided properly, the impact that will arise as a result of the patient stopping taking medication will result in the emergence of tuberculosis germs that are resistant to drugs (10) . The family can motivate/support the sufferer to continue to adhere to taking medication and the family must continue to monitor/prepare the medication for the sufferer to continue taking it. Tuberculosis is not only in the form of treatment but also in the relationship between the behavior of patients, families and society. Family support is the willingness and ability of the family to provide assistance to a family member who needs help in solving problems, providing security and increasing self-esteem. Individuals who receive this support feel that they are loved, cared for and valuable.

## Methods

The design used in this research is qualitative using a phenomenological study that comes

from awareness or how to understand an object or event by experiencing it consciously. Through this research, we want to explore the perceptions of HIV/AIDS sufferers with pulmonary TB regarding support family in taking ARV OAT medication.

## Results

The description of the research results displays the results of interviews with participants, namely people with HIV/AIDS and pulmonary TB. This research aims to describe how important the role of family support is for participants. The two participants in this study received good family support and the environment did not isolate the participants.

### 1. Assessment Support

The assessment of support felt by sufferers regarding family support is important to improve family coping which is needed by researchers. Results from in-depth interviews.

Sub theme 1 is about family acceptance. Participants stated that the family accepted what they were, did not distance themselves, remained supportive. This was expressed by participants as follows:

#### a) Family Acceptance

"The family accepts things as they are and the family does not distance themselves or reject them when they know the disease can be transmitted" (P1)

"My family supports me, tells me to take care of my health" (P2)

"my family still accepts me" (P3)

Apart from family acceptance, which must be equipped with sub theme 2, family support motivates you to take medication, such as every time you want to take medication, you are reminded not to forget. As stated by participants with the following statements:

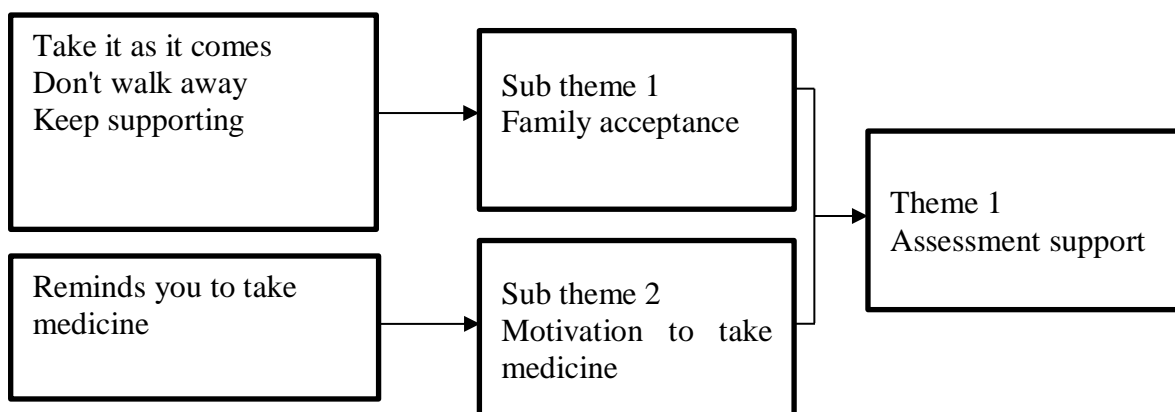
#### b) Motivation to Take Medicine

"The family just reminds me that there is more moral support for preparing the medicine yourself" (P1)

"Family reminds me, if the medicine from the hospital is not strong enough for the body, it makes it even worse, so they are usually directed to herbal or traditional medicine to make themselves" (P2)

"The family still reminds them that if they want to take medicine, ask them what they want to eat" (P3)

The descriptive scheme of assessment support is depicted in the image below:



**Figure 1 Descriptive scheme of the theme "assessment support"**

## 2. Instrumental Support

The instrumental support felt by sufferers regarding family support for physical provisions such as services, finances and materials is important data needed by researchers. Results from in-depth interviews.

Sub theme 1 is about the role of the family. Participants revealed the role of the family such as financing medicines. This was expressed by participants as follows:

### a) The Role of the Family

"Thank God it's covered by BPJS, financing outside BPJS also helps each other" (P1)

"Using BPJS, the family also sometimes gives money for other medicines" (P2)

"I use BPJS but my family also gives me money" (P3)

Apart from the role of the family, sub-theme 2 must include family holidays such as traveling. As stated by participants with the following statements:

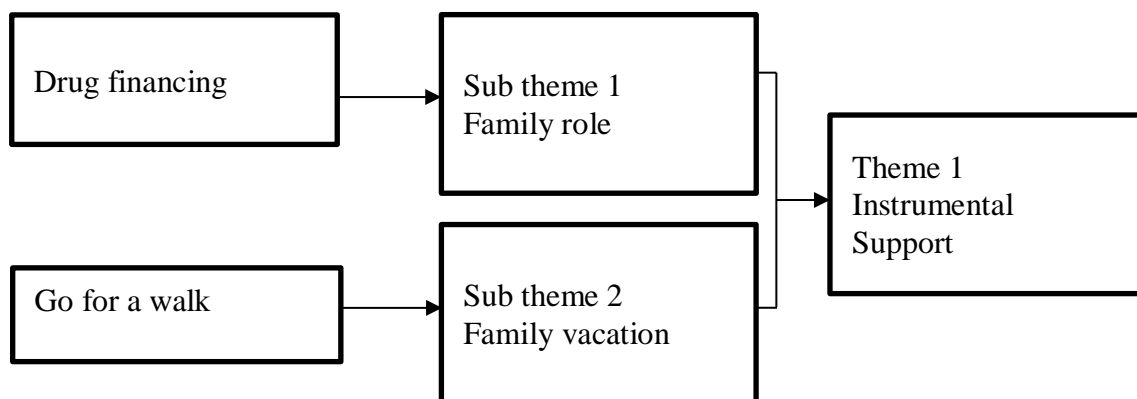
### b) Family Vacation

"If we don't do it often, we can just live a normal life" (P1)

"No, I don't like going out, I'm a person who doesn't go out easily, sometimes there's entertainment, I don't go (don't want to), I ask for it to be quiet, calm, if I hear anything, I get dizzy, so I don't want to, I only go out if my body is healthy, there's nothing." Is there any disturbance or is there someone taking me to work? What do I do" (P2)

"When I'm asked to go for a walk, I don't want to because I keep my distance, sometimes I go for a walk in the morning to the fields" (P3)

The descriptive scheme of instrumental support is depicted in the figure below:



**Figure 2 Descriptive scheme of the theme "instrumental support"**

## 3. Information Support

The informational support felt by sufferers regarding family support to provide health information or advice is important data needed by researchers. Results from in-depth interviews.

Sub theme 1 is about providing health information. Participants reveal health information as told by a doctor, reminding them to take care of their health. This was expressed by participants as follows:

### a) Providing Health Information

"The family is usually immediately notified by a doctor" (P1)

"Yes, the family reminds me to take medication regularly" (P2)

"I was told to drink and then my wife also had TB, I explained that if I had a headache like this, I would get a massage, sometimes my family would give me a solution" (P3)

Apart from providing health information, sub-theme 2 must explain the importance of

taking medication. As stated by participants with the following statement:

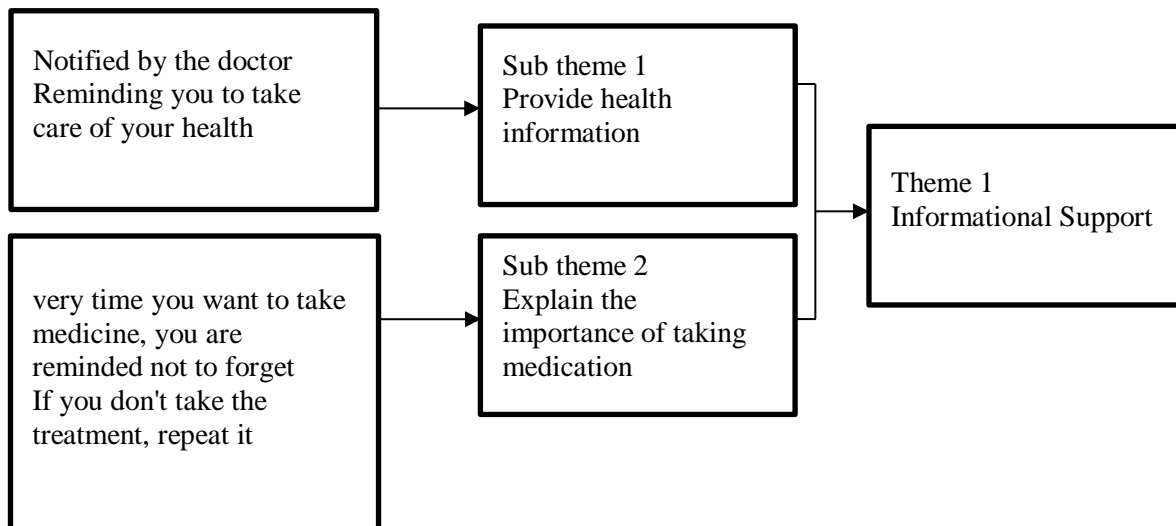
b) Explain the importance of taking medication

"Yes, but not in detail, just reminding" (P1)

"Take medicine to keep your body healthy, you have to take care of it, be careful about eating regularly" (P2)

"My wife said that if I don't take the medicine, I'll repeat the treatment again" (P3)

The descriptive scheme of informational support is depicted in the figure below:



**Figure 3 Descriptive scheme of the theme "informational support"**

#### 4. Emotional Support

The emotional support felt by sufferers towards family support to reduce a person's feelings about things they own and love in the form of empathy. enthusiasm, a sense of trust in important data needed by researchers. Results from in-depth interviews.

Sub theme 1 is about providing a family feeling. Participants expressed their family's feelings, such as disappointment, they definitely exist, but when they listen to them they are no longer hoarse, which means they are good. This was expressed by participants as follows:

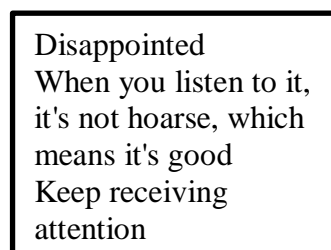
##### a) Family Feelings

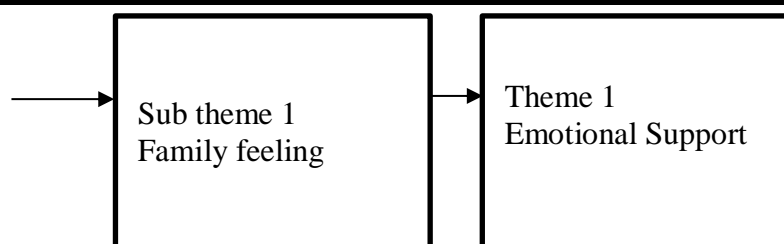
"In my opinion, there will definitely be disappointment, but that's all I know, but then there's no need for something like that, so my family environment is fine, accepting what is" (P1)

"Currently, I'm monitoring it on my cellphone. If I listen to it, I'm not hoarse, wet, like I'm not sleepy, that means I'm good, my younger siblings' family monitors me like that, so every time they come home from work, there's time to ask how I'm doing at home, whether I'm good or not, if it's not okay, get treatment" (P2)

"My family still accepts me as usual and is more attentive" (P3)

The descriptive scheme of emotional support is depicted in the picture below:





**Figure 4 Descriptive scheme of the theme "emotional support"**

## Discussion

### Family acceptance

Participants stated that what was given in the assessment support was acceptance of the family. The family accepts, continues to support and maintain health. The acceptance process is rejection, anger, bargaining, depression, acceptance (11). The assessment support focused on family acceptance, remaining supportive, and maintaining health. This is in accordance with the statements of research respondents.

### Motivation to take medication

Apart from family acceptance, another thing that must be done is to motivate taking medication. The motivation that is usually given by the family reminds them more of moral support, the medicine from the hospital which is not physically strong is directed towards herbal medicine, the family still reminds them that if they want to take medicine they are asked what they want to eat. Motivation to take medication, especially OAT, is influenced by treatment from health workers with certain considerations (12)

### The role of the family

The role of family experienced by participants is that apart from being covered by BPJS (Health insurance agency in Indonesia), families also help each other, sometimes giving money to their siblings. Families are able to make the right decisions regarding health service actions, take them to health services, help pay for treatment, remind them to take (13). Several factors that influence the compliance of pulmonary tuberculosis sufferers in taking medication include knowledge, attitude, family support, motivation, side effects, the role of health workers, and perceived stigma (14). The role of the family is very important in supervising TB patients so that taking Anti-Tuberculosis Drugs (OAT) regularly until they are cured can create a greater chance of successful treatment (15)

### Family vacation

Apart from the role of the family, there are other things, namely family holidays with walks which are usually done to the fields in the morning, not going out with the family often, going out if you are healthy or have work. Vacation with the family will reduce tension with the family and also act as therapy for conditions of boredom due to too long treatment (16). Our results shed light on what types of holidays are most effective for well-being. This will contribute to the well-being of tourists (17).

### Providing health information

In this research, informational support is providing health information by being told directly by a doctor, taking regular medication, explaining if you have a headache, getting a massage/providing a solution. In providing information to patient families, health workers must pay attention to existing media. Family involvement in providing information will have an impact on patient treatment. Some of the media recommended in today's digital transformation include: media website that is almost owned by health services (18), and educational videos as well as medication reminder cards (19)



### **Explains the importance of taking medication**

Apart from providing health information, another thing is to explain the importance of taking medicine by reminding you, not in detail, to take medicine so that your body is healthy, don't take medicine and then repeat the treatment. Better communication and better information about medicines appear to be important factors for patients. The findings of this scoping review may help those planning further interventions to improve medication adherence (20)

### **Family feelings**

In this research, emotional support is the family's feelings when they know the participant's current condition is that they are definitely disappointed, but don't overdo it, the family is just more attentive as usual. Emotional support gives individuals a feeling of comfort, help in the form of encouragement, empathy. Family disappointment is not only due to the health condition of family members, but research results also show disappointment due to difficulties in building relationships with doctors and facing isolated experiences: family members experience difficulties in building relationships and bonds with other health workers and understanding medical information and limited access to communication (21)

### **Conclusions and Recommendations**

All respondents felt that they were well received by their families and that the family had an important role in getting well, thereby motivating them to receive regular treatment. Instrumental support: All respondents said that medical needs were met by the family and it was not uncommon for sufferers to be invited to go on recreation. Informational support, some families do not know enough about providing health information and the family has explained the importance of taking medication. Emotional support, respondents said they felt disappointed and a burden when the family understood about illnesses that could be contagious. Overall family support in assessment, instrumental, informational and emotional is good but can be improved regarding providing health information and maintaining motivation to take medication.

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