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Patients' and families' experiences in Lung Tuberculosis treatment in Kebumen District, Central Java Province: A phenomenology study of 'Drop Out' and 'Uninterrupted' groups

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ABSTRACT

Background: Tuberculosis (TB) is still a worldwide health problem based on the impact of the disease, difficulties in the eradication and drop out tendency in treatment. One of the problems of TB in Indonesia is the high incidence of drop out treatment. Discontinuation of treatment leads to treatment failure, a source of transmission and drug resistance.

Objectives: This study aimed to examine the process of meaning-making for the patients and their families' as well as their PMO (*Pengawas Minum Obat*) / DOT-TB (Direct Obverser Treatment of Patients with Positive Pulmonary Tuberculosis) experience in pulmonary tuberculosis treatment of 'Uninterrupted' and 'Drop Out' groups.

Methodology: A qualitative phenomenological approach was used with a purposive sampling strategy to select the participants. The data were collected by a psychologist with an in-depth interview with 7 patients and their families who continued the treatment until fully recovered ('Uninterrupted') and 7 patients and their families who dropped out the TB treatment ('Drop out') with the total subjects are 28 people. The location of research was in the Kebumen District which includes a *Puskesmas* (Community Health Center), Hospital and UP3 (Pulmonary Disease Treatment Unit). The Colaizzi method was used to analyze the data.

Results: Patients' and their family's knowledge about TB of both groups were insufficient. However, the 'Uninterrupted' group were found to be self-motivated and received all possible psychological, and physical supports from their family while encouraging treatment adherence as factors that support the sustainability of pulmonary TB treatment. Whereas, these factors were not found in the 'Drop out' group.

Conclusions: Self-motivation and family support / PMO for pulmonary TB patients is the key to the sustainability of pulmonary tuberculosis treatment until fully recovered. Education and counseling for pulmonary TB patients and their families / PMOs are absolutely necessary in Indonesia.

Keywords: *Drop Out, Phenomenology, Tuberculosis, Adherence to treatment, social supports*

BACKGROUND

Tuberculosis (TB) remains one of the world's major health problems although control efforts with the Directly Observed Treatment Short-Course (DOTS) strategy have been applied in many countries since 1995[1]. TB is not only a world problem but also a problem at regional, national and local levels. By 2014 there are approximately 9.6 million new TB composed of 5.4 men, 3.2 million women and 1 million are children. Approximately 1.5 million TB deaths have occurred consisting of 1.1 million TB with HIV (-) and 0.4 million TB with HIV (+). The TB deaths include 890,000 men; 480,000 women and 140,000 children[1]. In 2014 in Southeast Asia and Western Pacific Region there are 58% of the world's 9.6 million TB cases. Indonesia is the second largest country in the discovery of new cases of pulmonary TB. The sequence is India (23%), Indonesia (10%) and China (10%)[1]. In 2013 the prevalence of Indonesia's population diagnosed with pulmonary TB by health personnel is 0.4%, not much different from 2004[2]. Provincial TB prevalence data from Central Java in 2012 amounted to 106.42 per 100,000 population[3]. Based on Kebumen District Public Health Office data in 2014

there were 1553 TB patients[4].

TB treatment takes a long time and can cause boredom in patients. Non-compliance in treatment will lead to drop out. The inability of the patient to complete the self-administered regimen leads to treatment failure, the possibility of disease relapse, drug resistance and continuous transmission of infection[5].

Based on the data from Kebumen District Health Office from 2012-2014, showed that the value of "dropping out treatment" for pulmonary TB treatment was 13.81% in 2012, 12.59% in 2013, and 9.17% in 2014. Based on these data, there is a slight downward trend[4]. Based on data from the Central Java Provincial Health Office in 2014 "drop out of treatment" was 6.2% while the National data for 2014 showed the number was 5.4%[3].

The research question is: "How is the experience of patients and families / PMO in the treatment of pulmonary TB, in 'Uninterrupted' and the 'Drop out' groups?" The purpose of this study was to examine the process of meaning making of the TB patient and their family's experience in the drop out and uninterrupted treatment of pulmonary tuberculosis.

The benefits of research are 1) as sources of information that form the basis for policy making in order to improve public health, especially pulmonary tuberculosis prevention in accordance with the needs of pulmonary tuberculosis patients; 2) also as input for the development of pulmonary tuberculosis epidemiology and comparison with previous research so that it can enrich the patient and family knowledge / PMO in the both groups; 3) as basis for health workers who treat TB patients directly in order to understand the physical, psychological, social and financial problems of pulmonary TB patients; 4) provide a foundation for the development of research on drop out phenomenon for the treatment of pulmonary TB and 5) the results of research can be used as a reference frame for further research and provide preliminary information for future research development.

RESEARCH METHODS

This type of research was qualitative with a phenomenological approach. The research was conducted at the health facility in Kebumen Regency. The research area consisted of Community Health Center, Hospital and Lung Disease Treatment Unit (UP3). Participants in this study were patients and their families of 'Drop out' and 'Uninterrupted' treatment of pulmonary tuberculosis in Kebumen District in 2015. The family is a family member / PMO of the patients who are participants. Participants were 28 people, consisting of 7 'Drop out' patients of TB treatment, 7 families of 'Drop out' patients of TB treatment, 7 'Uninterrupted' patients of TB treatment and 7 families of 'Uninterrupted' patients of TB treatment. Sampling technique used purposive sampling. The purposive sampling strategy commonly used in phenomenological research applies specific sampling criteria.

Inclusion criteria for TB patients were:

a. Pulmonary TB patients
b. Aged over 15 years old
c. Patients in the treatment of pulmonary tuberculosis who "continued treatment until healed" and "dropped out of treatment" in Kebumen District in 2015
d. Patients were able to recount their experiences in treating pulmonary tuberculosis that "continued treatment until healed" and "dropped out of treatment"
e. Patients and their families / PMO willing to be participants proved by signing informed consent.

Family inclusion criteria for pulmonary TB patients were:

a. Families of patients in the treatment of pulmonary tuberculosis who "continued treatment until healed" and "dropped out of treatment" in Kebumen District in 2015
b. Family members involved with patients in the treatment process / PMO
c. The patient's family was able to recount their experiences in treating Pulmonary TB patients who either "continue treatment until healed" or "drop out of treatment"
d. The patient's family / PMO willing to be participants proved by signing informed consent.

The research instrument used was in-depth interviews with guidelines. Participants were divided into groups for the in-depth interview which lasted approximately 1 hour and were recorded using a camcorder. Data collection was done by the researchers and assisted by 1 psychologist who had previously been explained the research purpose. Data analysis used the Colaizzi Method. The transcript results were read and analyzed by 4 coders, found that the following keywords were grouped into categories and then grouped into themes and subthemes. For the validity of the research, triangulation process was applied, i.e. triangulation of data sources and resources between patient and patient's family.

RESULTS

The relationship status between patient and family / PMO in the 'Drop out' group is husband and wife (4 people); sister (2 people); and mother-child (1 person), while for the 'Uninterrupted' group is husband and wife (6 people) and sister (1 person). The age range between patient and family / PMO in the 'Drop out' group is siblings (2 years), husband and wife (1,2,5 and 12 years), mother-child (12 years), while for the 'Uninterrupted' group is husband and wife (0,2,3,5,7 and 12 years) and mother-child (26 years).

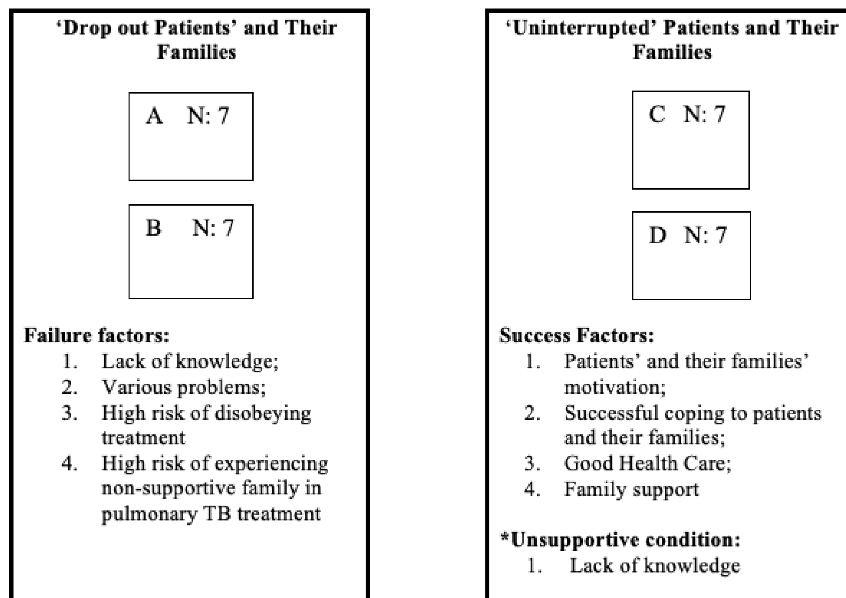

Figure 1. Illustrations of patient and family in the 'Drop out' and 'Uninterrupted' treatment of pulmonary tuberculosis

Captions: A for 'Drop out' patient; B for the 'Drop out' patient's family; C for the 'Uninterrupted' patient; D for the 'Uninterrupted' patient's family.

Both patients and their families who were in the 'Drop out' and 'Uninterrupted' groups had a lack of knowledge about TB disease, and had various social and economic problems. The 'Drop-out' patients had a high risk of disobeying the treatment and the family did not support the compliance of pulmonary tuberculosis treatment but the 'Uninterrupted' patients and families had several success factors: motivation, coping of patients and their families who succeeded in solving problems, good health care and family support so that patients can complete the treatment.

Table 1. Statement of patients and patient's family

Failure phenomena	'Drop out'		'Uninterrupted'	
	Patient	Patient's Family	Patient	Patient's Family
1. Lack of knowledge	"I felt weak, weak and got a little lever" P3	"According to my knowledge, itu was not harmful." P4	"I had once, pulmonary disease" P7	"I di not really understand about that" P3
2. Various problems	"I get bored; the medicines were too many" P1	"Queuing was too long..." P5	"I always declined to consume medicines; I am afraid of medicines" P2	"It is always difficult to ask him to tak the medicines since a long tim ago" P2
3. High risk of disobeying the medication	"I felt better already" P1		"To be honest, I get bored" P1	
4. High risk of having un-supportive Family		"The medication was stopped when she/he wanted to vomit after seeing the medicines" P7		"She/he rejected the medication, she/he sulked did not want to consume the medicines, the medicines were huge she/he said" P2
Success factors				
1. Patient's and family motivation			"It is because of God; I want to be cured. I want to be recovered; I consume the medicines, all of them punctually" P5	"Be healthy altogether, and I am always busy all the time. We do tis together." P5
2. Successful paten and Family coping			"When I felt sick, I prayed" P3	"I am always with him/ her when he/she takes the medication. I am afraid if she/he throws the medicines away (if not accompanied)" P2
3. Good healthcare			"Do not run out of medicine, sir. Two or three days before the medicine run out, please come to the clinic" P1	
4. Family support			"Sometimes his wife, his uncle's neighbor, his brother-in-law" P4	

1. The experience of patients who were 'Drop out' pulmonary TB treatment
   A. Lack of patient understanding of pulmonary TB disease.
   B. The high risk of patients not complying with pulmonary TB treatment.
   C. Various problems experienced during pulmonary tuberculosis treatment.
2. The experience of families who were 'Drop out' pulmonary TB treatment
   A. Lack of family understanding of pulmonary TB disease.
   B. The high family risk does not support pulmonary TB treatment.
   C. Minimal support of family provided during lung TB treatment.
   D. Various problems experienced by the family in supporting TB treatment
3. The experience of patients who were 'Uninterrupted' of pulmonary tuberculosis treatment.
   A. Lack of patient understanding of pulmonary TB disease.
   B. Self-motivation.
   C. Factors that support tuberculosis treatment adherence.
   D. Problems experienced during pulmonary tuberculosis treatment.
4. The experience of families who were 'Uninterrupted' treatment of pulmonary tuberculosis
   A. Lack of family understanding of pulmonary TB disease.
   B. Family factors that support pulmonary TB treatment.
   C. Family support is given during pulmonary TB treatment.
   D. Problems experienced by families in supporting TB treatment.

Table 2. Qualitative analysis results

Groups	Themes	Sub-Themes	Category	Statement of Participants
'Drop-out' Patients	Theme 1: Lack of understanding of patients about pulmonary TB	Patient description of pulmonary TB disease	Understanding the term pulmonary TB	"Yes, a dangerous cough." (P1). "Here was sentenced by pulmonary poly, it's internal disease," (P3).
			Symptoms of pulmonary TB	"Yes, now he's still sick ... (while coughing ...) " (P2). "The condition is weak, it's just like weak and feverish" (P3).
			Pulmonary TB transmission	"May be through this glass, through the wind ... Through the wind." (P3)
			Treatment of pulmonary TB	"Six months" (P1). "I get regular treatment every 15 days (6 months) ..." (P3)
			Efforts to prevent pulmonary TB transmission	"Yes, I was told to wear a mask ... If you have to cough it should be like this (sidestep your head to the right) Don't close it like this (using hands) but like this ...(backward)" (P3)
	Theme 2: Factors that do not support the sustainability of pulmonary TB treatment	Wrong perception about recovery from pulmonary TB	Positive impact after treatment	"Yesterday, I actually had a chance to work again." (P1). "Already feel good" (P1). "I am very grateful, I just weighed it already, the family just didn't expect it, just weighed down until the body was thin. Previous checkup was 45 kg, thank God, now it's already over 50 kg, if not wrong, 56 kg "(P1). "I want to control, for example, the inside of me is really sick, but yes, thank God for work, it's good. To eat well, sleep well ... " (P5). "The changes are already good, so I feel healthy" (P7)
		There is no PMO from the family	There is no one to be reminder in taking medicine	"My husband never asked to take medication, never ... Yes, only my own awareness, take the medicine ...," (P2)
		Misperceptions of patients towards superiors	Blamed by superiors	"It's just that sometimes I feel like this ... I want to go for treatment, and ask for permission not to go to work, later I will be mistreated by the boss ... If I want to go for the first treatment, I take three days in a row ..." (P3)
		Lack of family support	No support from husband	"I have never been accompanied, I go alone, I am often asked like this ... 'Where is your husband, why never accompany you for treatment ...', 'My husband is still asleep ...', 'He should be woken up so that he can take you for treatment ', I answered 'Let him sleep well' (P2)
		Coping patients who are not successful in solving the problem	Psychological Problems	"Yes, because he is still young, maybe ... maybe I am already trying to do it ..." (P3).
			Medicine Problems	"How come there are so many. Yeah, usually the doctor, even though I was asked to take 5 medicines but drink them one by one ... Why are there 9 medicines, this is actually taken 4 times ... I will die, there are so many ... one by one like that..." (P2).
			Cost Problems	"For the cost, yes, although it is difficult, but thank God, my family still want to help for the treatment cost. Yes, I'm feeling uncomfortable because it's troublesome for my family. It's not comfortable, my mind is not calm. I was told to go there again, but I didn't go." (P1).
			Health Service Problems	"So, it's not like in Doctor Suroto, he is a specialist, so there aren't so many people ..." (P2)
			Comorbidities disease problems	"Well, I went to the general practitioner for treatment ... Now that's ... in the regional general hospital, I stopped ..." (P3).
			Distance Problems	"Borrow if I have any needs, like that I am ashamed ..." (P3).

			Health worker problem	"I want to go to the doctor, go to the BP4 again, I'm not happy with the one who examined me ... yes I am ... I'm afraid ... (laughing)" (P2).
	Theme 3: Various problems experienced while undergoing pulmonary TB treatment	**Comorbidities disease problems**	**Comorbidities diseases**	"Well, if the second one, the first disease is the stage where every time you go to the regional hospital, you have to take regular medication. But there were additions of other diseases ... I can't eat, also got hiccup ..." (P3).
		Medicine problems	**Dizziness effect**	"Well, if I saw the drug, it made me nauseous and dizzy, so I didn't continue taking the medicine" (P7).
			Fear of taking medication	"I took the medicine. It smelled ... the medicine was huge ... and then in one day I ordered to drink 18 tablets" (P5).
			Side effects	"Sometimes after taking the TB medicine, it feels like my stomach ache, this stomach feels nauseous. I bought medicines like this (pointing the medicine with the finger) if at any time it relapses again." (P6).
		Financial problems	**Financial constraints**	"Oh, every control 50 (rupiah), every control 50? Yes, the most expensive is when the x-ray starts. Yes, X-ray and also check to the laboratory I pay for it myself. Yes, the X-ray was 40 or 45, continued check to the laboratory 10, 60 treatments, up to 100... Yes, it's a bit burden, because my parents don't work every day" (P1).
		Psychological problem	**Feeling bored**	"I am bored; the medicine is a lot" (P1). "Yes ... I'm bored (while smiling)" (P4).
		Health care problems	**Long distance from health facilities**	"If there, the number one problem is that I don't have a vehicle ... 'Ambal' and have to go to regional public hospital..." (P3).
			Service is not so maximal	"Yes, my first time to the hospital ... from 7 am, I was called if I am not mistaken at 3 pm ..." (P5).
		Problems relating to health workers	**Health workers**	"Yes, Mr. Subur, who handled me at home, He wanted to give medicine again, replaced the medicine, but I know that the medicine is still a lot, then I was taken to the BP4 again and kept informed. Yes, I am not angry, he felt sorry for me, for not recovering soon ... I just continued ... I made a mistake, why I didn't take the medicines?? I am afraid sir to drink 4 medicines, 'yes this must be 4 medicines, you will not die' ... " (P2).
		Problems related to personality	**Introvert**	"It's rare, because if it's not too bad, I will keep it myself." (P1).
'Drop-out' Patients' Family/PMO	**Theme 1: Lack of family / PMO knowledge about pulmonary TB disease**	**Family description / PMO about pulmonary TB disease**	**Understanding of pulmonary TB**	"Disease that attacks the lungs, often coughs" (P7).
			Symptoms of pulmonary TB	"Yes, coughing like that ... and sometimes it feels hot (pointing at the chest)" (P2). "Just coughing. Can't sleep ... "(P3).
			Dangers of pulmonary TB	"According to my knowledge, it was not harmful." (P4).
			Causes of pulmonary tuberculosis	"If I ate it stray, like to cough and itchy. Sometimes if I ate peanuts, ate salted fish, continue to taste like that, felt itchy" (P4).
	Theme 2: Family / PMO factors that do not support the sustainability of pulmonary TB treatment.	**Family perception / PMO that is wrong about recovering from pulmonary TB**	**More enthusiasm, a sense of wanting to work again, normal body, strong work, can be active**	"Actually, I was worried, it was only two months, I was still anxious, just because he wanted to be excited again to continue looking for work again, after how many months his body had returned to normal, his weight was normal again" (P1). "Yes, Alhamdulillah, I will continue to recover, and until now I have been strong at work. At the time I was in treatment, I could not lift weights, I just slept eating, sleeping, eating ..." (P5). "The reality of being able to do ordinary activities, is already able to walk normally. Sometimes I am confused, but yes, I am grateful for being healthy." (P6)
		Family coping / PMO that cannot solve the problem	**Family problem**	"At that time, went alone" (P3).
			Psychological Problems	"Yes, it stopped yesterday, he said when he saw the medicine he wanted to vomit. I am still told to force him to take medicine but have been taken, after the medicine is taken, he continues to vomit. I've surrendered..." (P7).
			Problems with side effects of drugs and no changes after taking medication	Then he is at home also just sleeping ... He continues to throw up, He throws up, also I am the one who will ... yes, I continue to take him to the alternative, did massage treatment there ... up to 9x, then fortunately He is now strong again..." (P5). There has been no change after taking medication. I overcome it as follows: "I have taken medicine, but at home, I still weak, I still can't hold 5 kg of rice or else ..." (P5).
			Health care problems	"Sometimes there is no motorbike, I feel reluctant too if every time I go there, I always borrow their motorbike..." (P3).
			Wife's problem	"But never. I feel if my wife is independent." (P2).
			Financial Problems	Yes, if I'm there, sometimes I helped, but I also have my own needs, so how about it (smile)." (P1)

	Theme 3: Minimum family support / PMO provided during TB treatment	**Minimum Family Support/ PMO**	**Instrumental Support**	"Sometimes...Only escort." (P1). "I'm still in school. But I take the medicine" (P4). "Yes, at that time, I took the medicine, when I went to the hospital, I waited for him ..." (P5)
			Information Support	"Often reminded ... Yes, I didn't want to, but first, I was advised, how to recover, how to take medication, so I want it." (P1). "Yes, tell my husband to go for treatment, stop smoking, if he wants to smoke it should be outside not in the house" (P7).
			Award Support	"Yes, I was involved in supporting him, so he could get well quickly, taking medicine, sometimes it was really difficult to take medicine." (P1)
	Theme 4: Various problems experienced by the family / PMO in supporting TB treatment	**Health care problems**	**Health services are not optimal**	"I was summoned by the officer and took the TB drug ... that's all" (P4). "Queuing is very long ..." (P5)
		Wife's problem	**Assume the wife is independent**	"Actually, everyday it's done alone. The husband and wife should not be like that. "(P2)
		Medicine problems	**Difficulty of taking medicine**	"He is difficult to take medicine; I have trouble there". (P6)
		Family problems	**Just gave birth**	"After the birth process, at that time I was treated alone." (P3)
			The child is still a baby	"Yes, at that time the child was still a baby." (P7).
		Financial problems	**Don't have a health coverage card**	"But He did not come out (health insurance card). His name did not come out. I submitted it to the officer but also could not. My family had 7 people, 6 people came out, only He didn't." (P6).
			Cannot pay in installments	"Yesterday He took a motorbike, just because He was on the job break so He couldn't pay off." (P1).
'Uninterrupted' Patients	**Theme 1: Lack of patient knowledge about pulmonary tuberculosis**	**Patient description of pulmonary TB disease**	**Understanding of pulmonary TB**	"Yes, it's very disturbing." (P6).
			Symptoms of pulmonary TB	"TB's disease complaints are??? (thinking a little longer) the coughing, if it is treated with a generic medicine, but then coughing again, and the breath will be tight. " (P3)
			Dangers of pulmonary TB	"The danger is, we can die quickly, our life will not be long ..." (P1).
			Treatment of pulmonary TB	"This treatment for my lungs and heart is still continuing, possibly 7 months, God willing for 7 months ..." (P1).
	Theme 2: Self-motivation	**Family**	**Children**	"Remember my children and grandchildren basically ..." (P1).
			Relatives	"At last, my relative came and said, 'You have to do this', so I was referred to PKU Sruweng Hospital. I thought about my relative who has been paying attention to me and caring, am I still stubborn and don't want to be treated? So, in the end, I went to PKU hospital, so from that time on, I started treatment with medicine and continuously on a regular basis. " (P2).
			Husband	"Yes, my husbands also feel sorry for not going to work...? Always take on leave? Yes, in the end (pointing the lungs) from here, it has to be cured, must be cured." (P2).
			Mother	"Because I see my mother, I basically need to be cured, whatever happens, I have to get well quickly." (P2).
			Wife	"Well ... if I am sick, if I complain, or whatever it is, she (the wife) needs to be by my side, so ... the main thing is definitely my wife." (P3).
		Oneself	**Oneself**	"I am healthy; I am thankful to God. So, it doesn't matter, that's a healthy form, I become enthusiastic in trying, there are no obstacles. "(P6). "No, I want to get recover." (P7).
		Value	**Benefits for prevention of transmission**	"I am also anxious about living in a community environment, remember my wife's children, grandchildren, neighbors ..." (P6). "Don't let the neighbors be affected by my illness so they won't feel disgusted or scared." (P6).
			Economic benefits	"I hope I can work again. If I don't work, how else, I'm not that well off. "(P5). "I hope I can work again." (P4).
			Benefits of medicine for healing	"If you are late for one day, two days if you don't get treatment completely, worry about the disease being immune from the medicine." (P3). "Yes, especially for myself, I am drained of energy." (P6).
		Beliefs	**Serious consequences of TB**	"Before, the doctor told me this was not a severe disease but a curable disease. He said it like that. "(P7).
			The confidence that TB can be cured	"I once took medication I didn't cough anymore; the blood didn't come out anymore. I carry it out according to the rules. There is no feeling of discouragement or anything, no. The important thing is to be cured, there is a cure for it. "(P7).
			Changes after taking medication	"Alhamdulillah, after two weeks of taking the medicine, thank God, it was better, if I went to treatment there it didn't feel like that." (P5). "If after taking medicine, you will be able to feel the work of the medicine (the effect of the medicine)," (P4).

	Theme 3: Factors that support the sustainability of pulmonary TB treatment	**Coping patients who are successful in solving problems**	**Health service problems that are less than optimal**	"Although there are problems, for example there is a lack of service quality, I consider it normal." (P6). "The first one is using a health card, I made BPJS, I use BPJS (National Health Coverage). The last one I used BPJS for my X-ray examination."(P7).
			Medicine Problems	"I am actually bored, but I want to be healthy again ... I continued since I was bored, I still live it ..." (P1). "If it's nausea like that, usually I just pray ..." (P3). "When take medicine, it must be forced." (P4).
		Good health services	**Health worker support**	"Yes, I was explained before, it can be contagious. But I'm, my grandchild is gone, my niece is all grown up, my child is going to college to make a thesis and is not at home right now. I'm just with my wife. My other child is in another village but already works. The daughter-in-law is an only child. So, she doesn't live in my house. So, no, I'm afraid there's no child" (P7).
			Maximum health services	"Sir, if you want to get treatment again, don't let the medicine run out??? Less 2-3 days should be directly controlled "(P1). "If it's not wrong for a week will go to the PKU hospital again, the doctor gives encourage." (P2).
		Family support	**Children**	"The son asked me. 'Have you taken medicine yet?' 'Yes, I Have'. "(P5).
			Wife	"Yes, support me, even though I don't work, what important is I will be healthy. My wife used to work hard, 'you don't have to work, it's important to be healthy', I really can be healthy, recover." (P6).
			Relatives	"Those who take medicine or take care of all the needs for treatment (are relative), I only have to go see the doctor already. The medicines or any need are taken care of by my relative. "(P2).
			Husband	Husband too (who takes care of the needs) ... Thank you, I have a husband like that. Who bathed me (when sick) was my husband. "(P2).
			Uncle	"Yes, sometimes my wife, uncle's neighbor who drove me, my wife's brother." (P4).
			Parents-in-law	"The child doesn't help; my parents-in-law are helping me." (P4).
	Theme 4: Various problems experienced while undergoing pulmonary TB treatment	**Health care problems**	**Health services are not optimal**	"Yes, queue for drugs." (P7).
		Medicine problems	**Afraid to take medication**	"The treatment is usually normal, because I am the most anti-medication, I am most afraid of taking medication, that's why I avoid doctors" (P2). "I need medicine ... I cry. Until crying like a child, 'I don't want to take medicine like this'." (P2).
			Side effects	"Yes sometimes, uhmm, here is feeling hot (holding the lower neck and upper chest). The neck sometime was hot." (P6). "Yes. Even though there are some risks, there were problems of taking medicine. Like the stomach hurts, uhmm, the body felt feverish, can't sleep. Yes, it's a lot. Heartburn, nausea, and it seems like you want to vomit, your feet in pain, feverish." (P3).
			Large drug size	"Oh, ma'am, who never got the drug, can you say? One time take this medicine (compare with fingers)." (P2).
'Uninterrupted' Patients' Family/PMO	**Theme 1: Lack of family knowledge / PMO about pulmonary TB disease**	**Family description / PMO about pulmonary TB disease**	**Understanding of pulmonary TB**	"Just know about internal disease, but don't know what kind of bronchitis or anything else ... the point is lung problems." (P2).
			Symptoms of pulmonary TB	"If I ask, it's limp ... so limp, and the color of his face is like that, yes his face often looks moody." (P3).
			Dangers of pulmonary TB	"Yes, the cough is said to be contagious ..." (P1).
			Treatment of pulmonary TB	"In terms of level, if it's still low depending on the person. If it's still low on regular treatment for 6 months, take medication not to be late, do not stop it, God willing, it will recover. If it's already severe, but the dietary habit is still good and taking a routine medication, God willing, it will be healed." (P7).
			Efforts to prevent pulmonary TB	"If there is a room in the hospital, young children may not enter. Then I said to father, 'be careful if you can transmit it to your child later." (P1).
	Theme 2: family / PMO factors that support the sustainability of pulmonary TB treatment	**Self-motivation**	**Family**	"Yes, for the sake of children and families, as well as those who give encouragement." (P4).
			Value	"I thought about it already, the point is that if the disease will transmit to me, it is indeed from the Almighty, it's just like that. My determination is like that; the important thing is that my wife is cured. "(P2).
			Patient	"Because I have a hope for recovery." (P2).
			Experience	"It's the parents who are sick. 'Failed'. "(P4).
		Family coping / PMO who succeed in solving problems	**Medicine problems**	"I accompanied her, every time She took the medicine, I will beside her. I am worried that She will throw it away. So, of course I will accompany her every time She take medicine." (P2).
		Health worker support to family	**Health worker support to family**	"Yes, that is, told to do so, routine treatment should not stop until 6 months ..." (P1).

		Support from family	**Emotional**	"As much as possible if I have a college problem, dizzy, I will think for myself which one I should tell my parents which one is not. Even if I can handle it myself, I will do it myself ... " (P7).
	Theme 3: Family support provided during pulmonary TB treatment		**Instrumental**	"Farmers (jobs), income to buy medicine." (P5). "Escorted by." (P4).
			Informational	"I told him/her which the type of drug to be taken" (P5). "When it's time to take medicine, I will ask, I will be tolerant. Yes, that is the same, keep reminding him to take medicine." (P6).
			Appreciation	"Yes encouraged." (P4). "Yes, to stay motivated ..." (P6).
	Theme 4: Problems experienced by families / PMO in supporting TB treatment	**Psychological problems**	**Bored**	"Sometimes I'm bored to take the medicine." (P4).
		Medicine problems	**Medicine**	"He doesn't want to, the term about it is breaking down. Because if he saw the medicine, he will be like 'Holy!' the medicine are too big." (P2).

DISCUSSION

Both patients and their families who were 'Drop out' and 'Uninterrupted' have less knowledge about Tuberculosis. Knowledge is a very important domain for the formation of one's actions. The knowledge covered in the cognitive domain includes 6 levels: knowing, understanding, application, analysis, synthesis, and evaluation. The participants were only up to the stage 'knowing' and 'understanding' but have not used the knowledge in real conditions[6]. To overcome this problem, health workers provide an explanation about pulmonary TB disease at the beginning of treatment and during treatment.

Patients and families / PMO in both group, 'Drop out' and 'Uninterrupted', have experienced various problems. The problems such as family problems, problems with comorbidities, medicine problems, financial problems, psychological problems, health care problems, problems relating to health workers, problems related to personality. Medicine problems are always present in each group. The number of problems in the patient and family group / PMO in the 'Drop out' group were more than the patient and family / PMO group in the 'Uninterrupted' group. To overcome this, a health worker can identify the problems of pulmonary TB patients before taking treatment and during treatment. Patients in the treatment of pulmonary tuberculosis who are 'Drop out' have factors that do not support the sustainability of pulmonary TB treatment, as follows:

1. Incorrect perceptions of TB recovery.
   Participants had a perception of healing that was 'feeling good', weight gain or normal weight, and already feel healthy. Symptoms of TB can disappear within two to four weeks after taking the drugs. This incident often causes patients to stop taking medication, because reduced complaints of illness are often considered by patients as a sign of healing. Pulmonary TB medicines provide a clinical cure faster than the complete bacteriological cure[7]. To overcome this, a health worker should provide a routine explanation in pulmonary TB patients about signs of recovery of pulmonary TB.
2. There is no supervisor for patient's medication from the family.
   The level of observance of taking TB medicines by empowering family members is better than without the use of family members in supervising the actual swallowing of medicines[8]. To overcome this problem, health workers ask patients to appoint their families who will become PMOs.
3. Lack of family support.
   Emotional relationship between family members is very important for family well-being. Families with good emotional ties will be able to deal with challenges and stress well[9]. To overcome this, health worker should adjust family centered care.
4. Incorrect patient's perception of superiors.
   Patients were afraid of being blamed by their superiors if they did not work due to pulmonary TB treatment. Individuals included in social support are spouses (husband or wife), parents, children, relatives, friends, health teams, superiors, and counselors[10]. To overcome this, health workers conduct routine counseling to pulmonary TB patients.
5. Coping with patients who are not successful in overcoming the problems.
   Various problems are encountered by patients who dropped out of treatment. Problem-solving can be done by both the patient and family. The effort made is simply called 'coping'. Coping is a common tendency that individuals use to handle stressful events in various ways[11].

For patients who dropped out of treatment, the coping did not succeed in solving the problems. Sometimes, coping for patients in overcoming the side effects of medicines is with alternative medicine. Confrontative coping means the attempt to change the situation that is considered a source of pressure by doing things that are contrary to the rules that apply even though there is sometimes a considerable risk[12]. The coping with psychological problems often involves 'a feeling of despair' that causes treatment interruption or drop out. Behavioral disengagement means the individual reduces effort in the face of stressful situations that can even result in surrender or doing nothing about the source of stress[11].

The coping with the response of health workers sometimes involves feelings of shame and fear with the result that it causes patients to switch to other health facilities. The coping with distance problems often involves this frustration. The coping on the cost issue includes how the patient feels they are an inconvenience or burden to their

family. Sometimes, the coping with comorbid problems is to seek a general practitioner and stop treatment from the Regional General Hospital. The coping with the problem of health services that are less than optimal, such as long queues, often involves moving to a specialist. There are two factors that influence the individual in carrying out coping strategies namely internal factors and external factors. Internal factors are factors derived from the individual: characteristics of personality traits and coping methods used. External factors are factors that come from outside the individual: time, money, education, quality of life, family and social support and the absence of other stressors[11].

The health workers who perform a person-centered approach, provide more personalized care to address the various problems and challenges and possess an ability to work together to face the problems challenging the patients. The health workers also can more effectively consult with patients and their families so that a closer relationship can develop between the healthcare provider and the patients[13].

In the 'Drop out' group of patients' families / PMOs, there are some risks and challenges of the family that does not support TB treatment, as follows:

1. Incorrect family perception of TB recovery.
   If the patient is able to work, have the active spirit and look healthy (doing his own daily activities) then he/she is said to be healed. This can result in lower family support given, thus impacting family members to stop the treatment. If the family reminders about the importance of continuing treatment regularly for the sick family are not given, then there can be treatment failure for patients with chronic diseases that require long treatment [14].
2. Family coping that did not solve the problem.
   The coping to solve family problems sometimes involves letting patients take care of themselves. For example, in coping to overcome the wife's problem, the husband may assume that his wife is independent. The coping for health care issues can involve 'shame'. The coping for cost problem is done out of 'desperation'. Ultimately, the coping for drug side effects and no changes after taking the drug is 'an alternative treatment'.

Health workers can use a family-centered care approach to better meet the problems experienced by patients. In this approach, the family has a level of closeness and involvement in health services as well as in making decisions related to patients and providing health services. Patients who maintain 'Uninterrupted' treatment have self-motivation and factors that support medication adherence. The 'Uninterrupted' patient's family has factors that support treatment: family motivation, successful family coping in solving problems, and health workers support to families.

Self-motivation can come from family and self-factors. Self-generated motivation is shaped by personal beliefs and patterns of values adopted. Confidence is the foundation, where a core belief can give rise to multiple strengths for concrete action[15]. Two dimensions of the traditional Health Belief Model include vulnerability and severity which can be interpreted as a fear of the disease. Fear is a powerful motivational force[16]. Values are an assessment of what is desirable, appropriate and valuable and can influence the social behavior of the patient[17]. The values adopted support awareness of the benefits for healing, economic benefits, and benefits for prevention of transmission.

Patient factors that support medication adherence in 'Uninterrupted' group are:

1. Coping patient successful in overcoming challenges.
   The coping on the cost issue is to follow the national health coverage program (BPJS). One dimension of problem-focused coping is active coping. Active coping means that individuals use steps to try to eliminate stressors or improve the effects of stressors[11]. The coping of drug problems involves still undergoing treatment because of the desire to recover. Patients sometimes must be forced to take medication, and can try using a mashed banana or a food considered not a problem. Family belief system is the key to the importance of the family because the centrality of religion and culture is the main source of spirituality or transcendence[9]. A self-controlling and accepting responsibility applies coping skills which are oriented on emotion-focused coping[12].
2. Good health services.
   The long distance from the health service causes irregularities of some patients to seek treatment. TB patients whose homes are far from health services are at risk of dropping out of medication, because they may take a long time to reach a healthcare facility and require substantial costs for transportation[18].
3. Family support.
   Family support is given to the patient who undergoes TB treatment as expected by him/her. This can occur because of a good communication process between the patient and family. If a patient is not working, then the form of support provided may be the wife of the patient working to replace the patient's position. Family support is very supportive action of patient's treatment success by constantly reminding the patient to take medicine, giving a deep understanding to the patient and encouraging them to remain diligent in doing the treatment[19].

Family factors of 'Uninterrupted' group that support adherence of pulmonary tuberculosis treatment are:

1. Family Motivation.
   Motivation is due in large part to the family (wife, husband, parents-in-laws, children, and relatives), values, and patients who have the spirit to recover and complete treatment. One aspect of family resilience (family's ability to survive) is the family belief system. The family belief system is the core of family function that includes values, attitudes, beliefs, and basic assumptions about health and healing[9].
2. Successful family coping in solving problems.
   The common form of this coping is 'grinding the medicine' and 'supporting the patients' who are undergoing treatment at the time of taking the medicine.

Factors that influence coping strategies include age, education, socioeconomic status, social support, personality characteristics, and experience. Social support is obtained from people around patients such as parents, relatives, close friends and the community[20].

3. Support of health workers to families.
   Support provided by health workers to the family in accordance with that required by the TB patient. TB patients who can no longer work then are often replaced in that support function. Family interests consist of family cohesion, family belief system, and communication. One of the components of communication is a collaborative problem solving that involves working together to identify challenges and solutions to solve family problems[9].

Suggestions

1. For patients who were dropping out of pulmonary TB treatment: Health check-ups at health facility, provide motivation to complete the treatment, and if experiencing problems it should be discussed with family and health care workers.
2. For family of patients who were dropping out of pulmonary TB treatment: Support to patients who are in accordance with the needs and advice from health workers. If any problems occur during treatment it should be consulted with health workers.
3. Suggestions for health workers: Apply patient and family-centered care approach, providing information about pulmonary TB disease for patients and their families, services without walls or separation and family empowerment, good evaluation to patients and their families with checklist, and health workers are more active in treatment process of pulmonary TB, especially in helping patients and their families in dealing with problems experienced.
4. The Public Health Office can conduct training for health workers about patient and family-centered care and make policies regarding the regulation of the referral system between Hospital, UP3, and Community Health Center.
5. For researchers: To conduct research on training health workers associated with the success of carrying out their role in reducing pulmonary TB treatment drop out incidents and conducting in-depth interviews more than once if the data has not reached saturation and provide more time in discussing with the psychologists about the questions that will be asked.

CONCLUSIONS

Self-motivation and family support / PMO for pulmonary TB patients is the key to the sustainability of pulmonary tuberculosis treatment until fully recovered. Education and counseling for pulmonary TB patients and their families / PMOs are absolutely necessary in Indonesia.

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Conflict of Interest

None

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