FACTORS INFLUENCING NON-ADHERENCE TO TUBERCULOSIS TREATMENT IN JEPARA, CENTRAL JAVA, INDONESIA

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Abstract. One of the most serious problems for tuberculosis (TB) control is non-adherence to TB treatment. We studied the factors influencing non-adherence to TB treatment in Indonesia to inform TB treatment adherence strategies. We conducted semi-structured interviews with non-adherent patients and key informants in Jepara, Central Java, Indonesia. Three major themes were found in reasons for non-adherence to TB treatment: 1) knowledge about TB, 2) knowledge about TB treatment and 3) choosing and changing a health care treatment facility. Respondents had an inadequate knowledge about TB and its treatment. Feeling healthy and having financial problems were the most common reasons for TB treatment non-adherence. Respondents sought treatment from many different health care providers, and often changed the treatment facility location. TB treatment adherence might improve by providing better education about the disease and its treatment to those undergoing treatment. Providing information about where to receive treatment and that treatment is free could also improve compliance.

Keywords: tuberculosis, treatment, non-adherence, Indonesia

INTRODUCTION

Tuberculosis (TB) is common in Indonesia (WHO, 2013). Indonesia ranks number four on the list of countries in the world with the largest numbers of TB cases (WHO, 2013). After introduction of the Direct Observed Therapy, Short course strategy (DOTS), which involves supervised administration of medicines, death rates have declined (WHO, 2003, 2011). In Indonesia the success rate for TB treatment using DOTS for all new smear-positive and/or culture positive cases of TB in 2011 was 90% (WHO, 2013).

Poor adherence to TB treatment remains the most serious barrier to the control of TB (WHO, 2009). Poor adherence increases the risk of morbidity, mortality, and multi-drug resistance (MDR); Indonesia is in the list of the top five countries in the world with MDR TB (WHO, 2013).

Factors for non-adherence to TB treat-

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ment can be categorized into four groups: structural factors, including poverty and gender discrimination, social factors, health service factors, and personal factors (Murno *et al*, 2007). The most reasons mentioned for non-adherence to TB treatment in a study from Indonesia were: feeling better, economic difficulties, side effects of treatment; other reasons mentioned included having a negative image of the health care staff, treatment and quality of medication (Widjanarko *et al*, 2009). According to a recent report high loss to follow-up rates in Indonesia are caused by socioeconomic difficulties and weak patient support (WHO, 2014). Social support, including having a treatment observer and health education about treatment are important for treatment adherence (Widjanarko *et al*, 2009). One study in a rural and urban district of the Democratic Republic of Timor-Leste found knowledge about TB, its treatment and provision of incentives (*eg*, reimbursement of transportation costs or food) contributed positively to treatment completion (Martins *et al*, 2008). Other obstacles to adherence included preference for traditional medicine, economical difficulties and geographical difficulties (Martins *et al*, 2008).

TB is a global health problem and major challenges in TB control in Indonesia remain identifying poor treatment adherence and developing corrective actions in order to solve problems (WHO, 2014). Therefore it is important to know the local reasons for non-adherence to TB treatment in Jepara, Central Java, Indonesia. No previous published studies in this area have been conducted.

MATERIALS AND METHODS

Interviews were conducted to identify factors associated with non-adherence to TB treatment. The study was conducted during November and December, 2011. Respondents were those who had received TB treatment at a community health center (CHC), the public hospital in Jepara, or at a private medical facility. Jepara is a rural district with a population of about 1,100,000 (District Health Office, Jepara Town, 2012). Jepara is famous for its teak furniture industry. The district has 21 CHCs, two public and four private hospitals.

The interviews were conducted in either the respondent's home or workplace. Respondents were interviewed using a semi-structured questionnaire based on in-depth interview guidelines based on information from previous researches (Murno *et al*, 2007; Martins *et al*, 2008; Widjanarko *et al*, 2009). The questions asked about personal factors, knowledge about TB and its treatment, health care workers, stigma attached to TB, traditional treatments, organization of health care for TB and incentives. An investigator who speaks English, Indonesian and the local Javanese language accompanied the first investigator to make sure the questions and answers were understood. Each interview lasted about 45 minutes and was recorded. All the recordings were transcribed into English, as soon as possible, after each interview and written notes were also taken. The transcriptions were checked by a third interpreter who had a knowledge of the local Javanese language.

The first and second investigator independently used thematic analysis to identify, analyze, and categorize data patterns. This was done by reading and categorizing the data into themes. Triangulation was done by discussing the findings of the investigators with the third interpreter, after which final conclusions were made. Specific quotes were used to

represent themes.

Inclusion criteria were respondents aged ≥ 18 years, with pulmonary TB diagnosed by a positive sputum smear test who were treated following WHO recommendations using DOTS, and whose treatment was interrupted for at least one week or who did not complete the treatment. The exclusion criteria were terminal patients, those who had cancer, were undergoing chemotherapy, or were not able to understand a substantial number of the questions.

The minimum number of respondents needed was estimated to be 15. Interviews were continued until the necessary data was obtained. First respondents were chosen from the CHC Mlonggo I, Jepara regency, but there were not enough respondents. Therefore the district health officer of Jepara was asked to supply a list of eligible respondents.

Data triangulation was done by interviewing TB nurses and doctors to obtain more detailed information about the organization of TB treatment, adherence to treatment and their perspectives. We interviewed at least one key informant from each type of health care facility: CHC, public hospital and private clinic.

Ethical considerations

This study was approved by the medical ethics committee of the Faculty of Medicine, Diponegoro University, Semarang, Indonesia. Respondents gave written informed consent prior to participation in the study.

RESULTS

Seventeen respondents were interviewed for the study. Data saturation was achieved after the last interview.

Table 1 shows the respondents' characteristics. All the respondents had a high school education level or less and a low income, except for one respondent who had a bachelor degree and a middle high income. All the respondents had TB infection for the first time, except one. We also interviewed two TB nurses, one from a CHC and one from a private hospital, and one TB doctor from a public hospital, one internist working at both a public and a private hospital and the district health officer of Jepara.

Respondents mentioned a variety of reasons for dropping out, including feeling healthy, not having enough money for the medical consultation or transportation, side-effects of the TB drugs, not being allowed to continue treatment, no improvement, the need to treat other illnesses first, job related factors, and having other activities.

Three main themes for non-adherence to TB treatment can be made: 1) lack of knowledge about TB, 2) lack of knowledge about TB treatment and 3) the decision to change the health care location.

Knowledge about TB

The respondents lacked knowledge about TB. Most had no idea what caused the disease, how contagious it is, how it is spread, how long its treatment duration is. Their family, neighbors and other community members also appeared to lack knowledge about TB.

Examples of misunderstandings about TB. Most respondents knew TB can be a lung disease, but further knowledge was lacking.

> "My disease comes from chemical substance, melamine, or dust in the furniture factory where I worked. I got the first symptom when I worked at the factory and I saw blood in my

Table 1
Information and summary about study respondents.

Respondent	Gender	Age (years)	Religion	Living area: urban or rural	Education (highest completed)	Work	Income (rupiah/ month)	Type of TB: first or second time	Year of TB	Place of treatment	Type of health insurance
1	Male	65	Muslim	Rural	Elementary	Retired	300.000[a]	Second	2008	CHC	National health insurance for (near) poor
2	Male	47	Muslim	Rural	Junior High	Furniture	500.000	First	2002	CHC + public hospital	No insurance
3	Female	47	Muslim	Rural	None	Farmer/cleaning	600.000	First	2010	CHC	National health insurance for (near) poor
4	Female	24	Muslim	Rural	Elementary	Jobless	360.000[a]	First	2011	CHC	No insurance
5	Male	55	Muslim	Urban	University	Elementary school teacher	3.700.000	First	2011	Family doctor	Health insurance for government employee
6	Female	52	Muslim	Rural	Elementary	Jobless	-	First	2005	Private lung clinic	No insurance
7	Female	45	Muslim	Rural	None	Furniture	360.000	First	2011	Family doctor + CHC	No insurance
8	Male	43	Muslim	Urban	Junior High	Security	1.500.000	First	2006	Public + private hospital	Private health insurance
9	Male	77	Muslim	Rural	None	Retired	100.000[a]	First	2007	CHC + private hospital	National health insurance for (near) poor
10	Female	45	Muslim	Urban	None	Market sales	1.000.000	First	2006	Private + public hospital	No insurance
11	Female	27	Muslim	Rural	Junior High	Furniture	288.000	First	2006	CHC	No insurance
12	Male	27	Muslim	Rural	Elementary	Furniture	500.000	First	2007	Private hospital	National health insurance for (near) poor
13	Female	30	Muslim	Rural	Elementary	Jobless	800.000[a]	First	2006	Private hospital	No insurance
14	Male	±70	Muslim	Rural	None	Retired	300.000[a]	First	2007	Private hospital	No insurance
15	Female	22	Muslim	Rural	Junior High	Hotel receptionist	500.000	First	2007	Private clinic + private hospital + CHC	National health insurance for (near) poor
16	Male	40	Muslim	Urban	Elementary	Furniture	600.000	First	2006	Private clinic + private hospital + CHC	No insurance
17	Female	53	Muslim	Rural	Elementary	Jobless	1.000.000[a]	First	2006	Public hospital	National health insurance for (near) poor
SUMMARY $n = 17$	Female: 53% Male: 47%	Average age: 46 years	Muslim: 100%	Rural: 72% Urban: 28%	None: 29% Elementary: 42% Junior High: 23% University: 6%	Furniture: 29% Jobless: 23% Retired: 18% Farmer/cleaning: 6% Teacher: 6% Market sales: 6% Security: 6% Receptionist: 6%	< 500,000: 60% 500,000-1,000,000: 29% >1,000,000: 12%	First: 94% Second: 6%	Average year of TB: 2007	CHC: 23%; Private hospital: 18%; Private + public hospital: 18%; Private clinic + private hospital + CHC: 12%; Family doctor: 6%; Private lung clinic: 6%; Family doctor + CHC: 6%; CHC + private hospital: 6%; Public hospital: 5,9%	No insurance: 53%; National health insurance for (near) poor: 35%; Health insurance for government employee: 6%; Private health insurance: 6%

[a]Income: this is the household income, because respondent did not had an own income. CHC: community health center.

sputum. I immediately thought this was TB." (R1, 65 years old man).

There were some respondents who did not believe TB was contagious because they did not know anyone who had TB as well.

"According to the TB nurse, it was an infectious disease. I have to cover my mouth while coughing, not allowed to spill my spit everywhere, because it can be transmitted by spit. But I am not sure, because my mother did not get TB, even though she was always around me." (R6, 52 years old woman).

The instructions for how to behave when they have TB given by the TB nurse or doctor was remembered by several respondents. The theory behind the behavior was also mentioned by the respondent.

"I had to put my spit in a cup and cover it with sand. I knew it from the CHC, because it can be infectious." (R1, 65 years old man).

Although respondents said they were not afraid to ask questions to the health care worker, many felt they did not know enough about their disease and wished they had received more information about TB and its treatment each time they returned from a medication refill. This was occasionally mentioned by respondents as an idea to improve the TB control program.

The key informants had different ways of providing information about TB to the patient. One key informant gave information about TB only at the first visit assuming that if patients came to every appointment they understand about TB. Another key informant gave information about TB multiple times at the beginning of treatment but after that they felt their job was only to motivate the patient to complete the treatment.

Self diagnosis of being healthy. The most common reason mentioned for discontinuing treatment by both respondents and key informants was that the patient felt healthy. Half of the respondents did not know the normal treatment duration was six months and what the consequences would be if they stopped treatment early.

"I did not know about the risks if you stopped with the treatment, I just knew that I felt better, so I could stop with it." (R13, 30 years old woman).

Attitudes about having TB. Most respondents, their families and their neighbors did not know about the infectiousness of TB. However one respondent was afraid to tell others he had TB. The overall reaction of family members and neighbors was unconcerned, they continued their socializing. At the time of the interview, one of the respondents with TB was still coughing. When the interviewer went to the respondent's home, many family members and neighbors were there socializing.

The respondents did not always get effective support from their treatment observer or health care worker to continue treatment. Sometimes the reasons for stopping treatment were greater than their support and motivation to continue.

"My treatment observer was my wife. She reminded me to continue treatment when I stopped, but I felt better at that time and did not have money." (R2, 47 years old man).

Knowledge of TB treatment

Knowledge of TB treatment was inadequate. Respondents did not always know TB treatment was for six months. Some

respondents did not understand DOTS or when to get treatment. Some respondents were unaware where to obtain free treatment if they did not have the money for treatment.

Financial situation. The second most common reason for non-adherence listed by respondents was inadequate finances. Respondents often mentioned they did not have enough money to pay for the consultation or transportation.

> "It was an easy procedure, but I had to pay for it. That is the problem." (R2, 47 years old man).

Most of the respondents did not have any suggestions to improve the TB treatment program. The ideas that were put forth mostly involved finances. The respondents stated there were no incentives to complete treatment, such as assistance with food or transportation costs. However, some stated becoming healthy was more important than receiving incentives.

> "Regarding motivation to complete treatment, it does not matter to me if they give me a gift, a reward or a punishment. I want to be healthy; that is my motivation. I would have finished treatment if at that time I knew what disease I had. If I just had TB." (R8, 43 years old man).

DOTS

All the key informants said in theory every patient with TB should have a treatment observer, usually a family member. The treatment observer should be educated about TB and their role in treatment. When the respondents were asked about DOTS using the term in their language most did not know about the importance of this strategy.

> "I had no idea what DOTS was. I did not know my niece was my treatment observer." (R6, 52 years old woman).

After explaining DOTS during the interviews most respondents believed this strategy was helpful to ensure TB treatment adherence and motivation. Most preferred a family member as their treatment observer, because they felt more comfortable with someone close to them and said it would be more convenient because the family member is always at home.

The key informants had several ideas on how to motivate patients to be adherent. This included home visits by health care workers, educating the treatment observer, educating the head of the village, following up on patients who move and guiding them to another health care provider, giving reminders about appointments by telephone one or two days prior to the appointment, linking new patients with TB to former TB patients who have successfully completed treatment and giving more training for health care workers who are involved in TB treatment. They also emphasized the importance of motivating the patient to help himself.

Choosing and changing the health care location

There are several health care options from which to obtain TB treatment in the Jepara regency. Respondents frequently changed from one option to another during treatment.

Choosing a health care setting. There was not just one place the respondents chose to get treatment for TB. Sputum smear positive TB patients can receive free treatment at CHCs and public hospitals. Many private health care providers also provide TB medication free of charge, but usually charge for the consultation, laboratory

tests, and X-rays. Although many of the respondents are poor, they often chose to obtain treatment from private institutions where they have to pay. They believe the health care there is better.

> "The staff at the private hospital told me I could receive free treatment at the CHC, but I had more faith in the medical treatment at the private hospital because the doctor is a specialist and the equipment is more complete than at the CHC." (R13, 30 years old woman).

Changing health care location. Several respondents changed treatment locations during the course of their TB treatment. Multiple reasons were given for this, such as having no improvement at the previous place, having to wait a long waiting time at the previous places / faster treatment; the desire for faster treatment, treatment costs, and because of the recommendation of others. Some respondents even travelled long distances to seek treatment for their TB because they thought it was a better option for them.

> "I let it checked at the doctor of a private clinic, but nothing improved. Then I went to the CHC, but also nothing improved. I am just a person from the village, so I wanted to know more. They told me the disease could not be healed anymore. My brother-in-law told me to go to a doctor at a private hospital, I paid about 72,000 rupiah there. I had check-ups there about four or five times." (R16, 40 years old man).

DISCUSSION

Health seeking behavior is complex and influenced by many factors. In this study, we identified and clustered important factors intervening completion of TB treatment in Jepara, Central Java, Indonesia.

The first factor was lack of knowledge about TB among respondents and the community, along with poor TB education given by health care provider. A study from Cape Town, South Africa, found that educating a TB patient reduced the risk of treatment non-adherence (Dick and Lombard, 1997). However, only giving the patient information is insufficient (WHO, 2003). The information–motivation–behavioral (IMB) skills model, uses information, motivation, and behavioral skills to understand and change behavior; knowledge is a prerequisite for changing behavior, but in itself is insufficient to maintain this change (Fisher and Fisher, 1992).

Our study found patients wanted to learn more about their disease and practical information was more easily remembered than theoretical information. Health care providers should be trained in how to provide this information within the context of the patient's educational background and customs.

The second factor was lack of knowledge about TB treatment. Even though free TB treatment is available, financial problems can still affect treatment adherence (*eg*, costs of transportation). Many of the respondents in this study were poor. WHO TB treatment guidelines state patients may receive incentives in order to encourage them to be compliant with treatment (WHO, 2010). It is unclear if health care providers in Indonesia are aware of and follow this suggestion. A review of eleven randomized controlled trials regarding use of material incentives to manage TB concluded that the incentives probably improved treatment adherence for treatment for latent TB infection

to prevent it becoming active disease (TB prophylaxis) but also concluded there is insufficient evidence to determine if incentives improve long term adherence to TB treatment (Lutge *et al*, 2012).

A third factor discovered in our study was the knowledge of the treatment observer affected treatment adherence. DOTS requires a treatment observer (WHO, 2010). DOTS can improve TB treatment adherence (Fisher and Fisher, 1992; WHO, 2010). But does not having a treatment observer decreases TB treatment adherence? A review of six randomized controlled trials found DOTS did not appear to have an effect on treatment completion or cure rates (Volmink and Garner, 2007). This led to the questions of why the DOTS strategy has a 90% treatment success rate and what causes the 10% failure rate (WHO, 2013). Does having a treatment observer contribute to this high success rate or not?

To improve TB treatment adherence, more motivation and support of the patient are needed (Liu *et al*, 2008). It is helpful to remind the patient to come for their next appointment through letters or phone calls and following up patients who fail to show up (Liu *et al*, 2008). These reminders may be sent by text messaging, since many people in Indonesia, even in poor rural areas, own a cell phone (Person *et al*, 2011).

Another important factor in our study was that many of the respondents did not complete treatment at one location. Many respondents sought treatment at a variety of health care locations. Although many respondents were poor, they still chose to receive treatment from private health care providers where they had to pay for TB treatment. They believed health care at the private facilities was better than at the government facilities. Although most respondents stated the TB treatment was easy, moving from one health care provider to another could have contributed to a delay in treatment or an adherence problem. Similar findings were also reported for Indonesia (Indonesia JEMM, 2013). WHO guidelines suggest engaging all health care providers to take on TB treatment tasks, but lack of collaboration among providers and institutions can lead to treatment adherence difficulties (WHO, 2011). Our findings suggest every patient needs to be informed he can receive high quality treatment free of charge at the nearest CHC or public hospital. This may improve treatment adherence and reduce dropout rates, hopefully reducing the total TB burden in Indonesia (Indonesia JEMM, 2013).

Our study had some limitations. Two investigators were present at each interviews. One of them could not fully understand or speak the local Javanese language. This could have influenced the flow of the interview and led to misinterpretation of questions and answers. Keynotes and headlines probably were not influenced, because digital recordings were made and double checked by the investigator. Findings were also discussed among investigators until agreement was made.

Following the semi-structured interview the investigators started with open questions first in order to broaden the responses. Although the investigators used as many open questions as possible, some of these questions were not understood and had to be rephrased or simplified, turning them into closed questions. This could have caused investigator bias or only narrow responses. This could also have happened because many

respondents had a low education level. The interview contained questions about what happened during the previous years.

The interviews took place at the respondent's house or workplace. In most cases a family member or neighbors was also present at the interview. This could have influenced the answers of the respondents, but most of the respondents seemed at ease during the interview and were not afraid to speak. Sometimes the family members or neighbors also participated in the interview, even though they were not asked, giving the investigators additional information about the patient and explaining their role in the treatment.

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