

Barriers and Enabling Factors for Tuberculosis Care in Indonesia

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DECLARATION

Barriers and Enabling Factors for Tuberculosis Care in Indonesia

A thesis submitted in partial fulfillment of the requirement for the degree of
Master in International Health

by

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Declaration :

Where other people's work has been used (either from printed source, internet or any other source) this has been carefully acknowledge and referenced accordance with departmental requirements.

The thesis **Barriers and Enabling Factors for Tuberculosis Care in Indonesia** is my own work.

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LIST OF ABBREVIATIONS AND GLOSSARY

AusAID	Australian Agency for International Development
CSOs	Civil Society Organizations
DOTS	Directly Observed Treatment Short Course
FGD	Focus Group Discussion
GDP	Gross Domestic Product
GERDUNAS	Gerakan Terpadu Nasional
GNI	Gross National Income
HDI	Human Development Index
HICs	High Income Countries
JKN	Jaminan Kesehatan Nasional (National health insurance)
KNCV	KNCV Tuberculosis Foundation
LKNU	Lembaga Kesehatan Nahdlatul Ulama
LMICs	Low Middle Income Countries
MDGs	Millennium Development Goals
MDR-TB	Multi Drug Resistance Tuberculosis
MOH	Ministry of Health
NGOs	Non Government Organizations
NPS	National Tuberculosis Prevalence Study
NTP	National Tuberculosis Program
OTC drugs	Over The Counter drugs
PPM	Public Private Mixed
Puskesmas	Pusat Kesehatan Masyarakat (community health centers)
SDGs	Sustainable Development Goals
SITT	Sistem Informasi Terpadu Tuberkulosis (Tuberculosis integrated information system)
TB	Tuberculosis
The Global Fund	The Global Fund for TB, AIDS and Malaria
UNDP	United Nation Development Program
USAID	United States Agency for International Development
USD	United States Dollar
WHO	World Health Organizations

ABSTRACT

Background : Based on recent national survey on 2013, the estimated numbers of TB patients in Indonesia were almost three times higher than WHO estimation. There are high missing cases of TB in community. Delay of tuberculosis (TB) care which happens in Indonesia could hindered the TB control program. Thus, it is important to analyse the barriers and enabling factors which influence the timely and correct TB care in Indonesia.

Methods : A literature review study. Any papers from year 2000 in Indonesia's settings, quantitative or qualitative study, in English and Bahasa Indonesia and relevant other countries' studies were included. Exclusion criteria were diagnostic tests and TB treatment phase. Interviews with key informants were done to validate the findings and framework.

Results : The barriers which found in Indonesia were lack of knowledge; poor information; misperception of TB; stigma and perceived poor quality; distance; service fees; transportation costs; time spent and opportunity costs; lack of proper training; low suspicion index of TB; weak of regulation, monitoring and quality assurance. The enabling factors which found were awareness raising, information and education; community engagement; expanded coverage; community outreach; systematic facility screening; better training; and improved screening algorithms. Informal and private sectors played important roles for TB care in Indonesia.

Conclusion : The barriers of TB care were influenced by each others. Community and private sectors played the roles as potential actors for TB program. However, good governance was needed to reach successful TB program in Indonesia.

keywords : *patient delay, tuberculosis care delay, Indonesia*

CHAPTER 1

Background Information

1.1 Geography

The Republic of Indonesia is a large archipelago country in south east Asia. It lies between Asia and Australia continents. It consists of approximately 17,000 islands which spreads over 5000 kilometer. The five major islands from west to east are Sumatra, Java, Kalimantan, Sulawesi and Papua Islands. There are also groups of smaller islands such as Bali, Nusa Tenggara and Maluku. The capital city of Indonesia is Jakarta, which is located on Java island. More than 80% of the countries territory is covered with water. The country spreads along the equator lines which gives Indonesia a tropical climate. The country has a dry and wet season which is divided evenly every year.



Figure 1 : Indonesia map

1.2. Demography

Indonesia is the fourth most populous country. Based on the national statistic census of 2013, it has an estimated 248 millions citizens. (*Ministry of Health 2014*) The population is unevenly distributed among the islands. Most of the people live on Java island with almost 57% of the total population. Fifty two percent of the population are living in urban areas. It is reflected as the heavily rural-urban migration. The median age of the population is 28 years old, with the population below 15 years is 29% and aged over 60 years is 8%. (*WHO, 2015*) The widely spread and large number of islands made Indonesia a collection of hundreds of ethnic groups and diverse cultures. But, they unite under the national motto “unity in diversity”. Even though every ethnic group speaks their own language, most of the Indonesian speak Bahasa Indonesia. The illiteracy rate of the country is 5.8%, with the lowest rate in Jakarta province (0.8%) and the highest rate in Papua province (32.4%). (*Ministry of Health 2014*)

1.3. Governance

Indonesia is a republic and democratic country. It has 34 provinces which are divided into districts and municipalities. Since 2001, Indonesia has implemented a major change to decentralize its government. Based on the Law no 22, year 1999, local governance receives a transfer of authorities and decision-making and liberties to develop and enhance their own regions. Even though, there are some challenges in implementation, such as local capacity, accountability and the assignments of function from the central government.*(The World Bank 2003)*

1.4. Economy

Indonesia is categorized as a lower middle income country by the World Bank. The Gross National Income (GNI) per capita is increasing from 2,200 in 2000 to 3,524 in 2014.*(The World Bank 2015)* Based on the United Nation Development Program (UNDP) report of 2014, Indonesia's Human Development Index (HDI) is 0.681, which ranks Indonesia in 108th from 187 countries/territories.*(United Nations Development Programme 2014)*

The poverty rate in Indonesia is 12% in the 2013 survey.*(Ministry of Health 2014)* However, the threshold used to measure the poverty rate in Indonesia is people who have a daily income below United States Dollar 1.*(MoH Indonesia 2014)* This is in line with the World bank definition for extreme poverty. Meanwhile, the baseline of the daily income, being used as the definition of moderate poverty in the developing countries from the World Bank is USD 2.*(World Bank 2015)* If the baseline is applied to Indonesia, the estimated of 40% of total population are living under poverty line. It means that more than 100 million people in Indonesia are considered to be living under the poverty line.*(United Nations Development Programme 2014; MoH Indonesia 2014)*

The economy grew significantly over the past decades, but was distributed unequally among the population. The Gini index reached the highest rate of 0.41 in 2011.*(MoH Indonesia 2014)* The wide gaps and huge number of people living below the poverty line attributes to a significant challenge for tuberculosis (TB) control in Indonesia.

1.5. National Health System

The health services are organized in five levels : central, provincial, district, sub-district and village. The first main level of care is the primary care center (Pusat Kesehatan Masyarakat/Puskesmas) which serves basic care. Then, it has the referral system to district, provincial and central hospitals which provide the secondary and tertiary level.*(WHO 2009; MoH Indonesia 2014)* Based on the national survey of 2013, there are 9655 health centers, 1562 public hospitals and 666 private hospitals. Fifty seven of them are hospitals with special referral services or central hospitals (Class A hospital).*(Ministry of Health 2014)*

There is an increasing number of private health sectors across the country. By law, public sector staff is allowed to work part time in private practice, or having their own private practice. This policy leads to a positive and negative result. The Ministry of Health (MoH) sees this as a way to complement the low salary of public sector staff, and

also to increase investment in private sectors. It also leads to preferable areas to work, which are urban areas, with a high salary, which leads to unequal distribution.(WHO 2009) The equal distribution of health care workers across the country is still an issue. The problem is caused by the special geographical characteristic of the country and also the result of decentralization not yet resulting in to what it is expected of the distribution pattern, especially in rural and border areas.(Ministry of Health 2014) The national health budget is relatively low, only 3.1% of the total Gross Domestic Product (GDP). It is one of the lowest in the region.(The World Bank 2015; MoH Indonesia 2014) This low budget may hinder the effort for TB control in the country.

Since 2014, Indonesia has been implementing the national health insurance (Jaminan Kesehatan Nasional/JKN). The projection is that in 2019 all the citizens of Indonesia are covered by the insurance.(Ministry of Health Republic of Indonesia 2015; MoH Indonesia 2014) It aims to increase the equity for health service for all the citizens. This is an opportunity to reduce the financial burden related to TB care in the population since any kind of provider (public and private providers) will be more accessible in term of service fee, distance, etc.

1.6. National Tuberculosis Program (NTP)

Indonesia started NTP since before independence day under the Dutch colonial government. After the independence day in 1945, Indonesian government took over the lead of TB control by establishing a national program under the MoH. In 1995, Directly Observed Treatment Short course (DOTS) strategies included the national policy for TB care which was implemented on a primary care level (puskesmas).(WHO 2009; MoH Indonesia 2014)

In 2000, the DOTS strategy tried to expand the service to hospitals, as part of the Public Private Mixed (PPM) strategy. The program also included several private practitioners in Yogyakarta, Bali, Palembang and Medan as the project's models of the program. The PPM applied as national policy was based on the result of the study and first integrated as national policy on the national strategic plan for TB control on 2002-2006, until now. The TB care program in Indonesia, also includes a multi-stakeholders approach such as international Non Government Organizations (NGOs : KNCV, WHO, USAID, AusAID), civil society organizations (COSs : Aisyah, Lembaga Kesehatan Nahdlatul Ulama/LKNU, etc) academic, professional associations and students.(MoH Indonesia 2015) In 2014, NTP started a new system for case-based electronic registration called SITT (Sistem Informasi Terpadu Tuberkulosis/Tuberculosis Integrated Information System). The system covers all components of TB care such as human resources and drugs, as well as notified cases from health care services including private services, prisons, workplaces and NGOs.(MoH Indonesia 2014)

The NTP in Indonesia is generally underfunded, especially in district and provincial levels. Even though the national budget for TB care is increasing by 2.9% in 2014 compared to 2013, the overall activities of TB care in the country heavily depends (66%) on external resources, in this case The Global Fund and USAID.(MoH Indonesia 2014) The commitment of the government for domestic funding is important to maintain the results which are already gained and also to replace the dependency of external sources for TB care.

CHAPTER 2

2.1 Introduction

Tuberculosis is one of the global burden diseases, especially in low- and middle-income countries. Most of new cases of TB are found in South East Asia and Western Pacific Regions (56%). Based on WHO data, in 2013 there were an estimated 9 million TB cases and 1.5 million of people who died because of TB. 95% of the people who died, because of TB, are coming from developing countries. (WHO 2014b)

Globally, the incidence rate of TB between 2000 and 2013 declined with an average rate of 1.5% per year. The Stop TB partnership project has set a goal on reaching a 50% reduction by 2015 from the baseline from 1990, in line with the Millennium Development Goals (MDGs) 6 target 6c. The region of the Americas and Western Pacific Regions have reached the MDG 6c goals by reducing half of the incidence of TB on the regions. Meanwhile, South East Asia regions seems to be on track of reaching the goals. At the end of 2015, the MDGs will be replaced by a set of 17 Sustainable Development Goals (SDGs). A new goal about TB is the end of the TB epidemic worldwide by 2030. (WHO 2014a) Even though it is a very ambitious goal, it might trigger a harder effort to fight TB both globally and nationally.

Recent World Health Organization (WHO) data showed that Indonesia ranks fifth on the list of 22 countries with a high burden of TB with an estimated 450.000 new cases of TB per year. (Collins et al. 2013) The TB prevalence, based on a recent survey from Indonesia's National TB Prevalence Study (NPS) 2013, showed a huge difference compared to the WHO estimation. Based on the NPS 2013 result, the estimated prevalence in Indonesia for all forms of TB among all ages is 660/100.000 population. It is 2.4 times higher than the WHO estimation, 272/100.000 population. Using the NPS 2013 result, the prevalence of TB in Indonesia will be 1.6 million and 1 million of new TB cases annually. These facts will put Indonesia as the 2nd highest burden of TB, following India. The NPS also reported a low notification rate of TB cases in Indonesia, with only 33%. In 2013 327.000 TB cases were notified in Indonesia, dominated by new cases (Figure 2). While referring to the new estimation, there are 670.000 missing TB cases each year. (MoH Indonesia 2014) The reasons behind these facts should be further analysed.

Other challenges in TB care in Indonesia are multi drug resistance TB (MDR-TB) and TB among vulnerable groups such as children, TB-HIV, poor and extremely poor people, inmates (prisons), elderly, pregnant women, and also people with diabetes and malnutrition. (WHO 2014b; WHO 2014a; MoH Indonesia 2014) MDR-TB is becoming a serious problem in TB control in Indonesia with the ninth highest burden of these strains worldwide. The estimated number of MDR-TB patients in 2013 was 6800 (uncertainty interval 95%; 5200-8500), with only 912 (13%) notified cases of MDR-TB in 2013. This represents 2.2% of MDR-TB cases globally every year. (WHO 2014a; WHO 2009) Based on recent modelling, childhood TB in Indonesia is between 10-15% of the total annual incidence of TB, which is around 120.000 cases per year. (MoH Indonesia 2014) The percentage of estimated HIV patients in overall new cases of TB nationally is 3.0%. (WHO 2009)

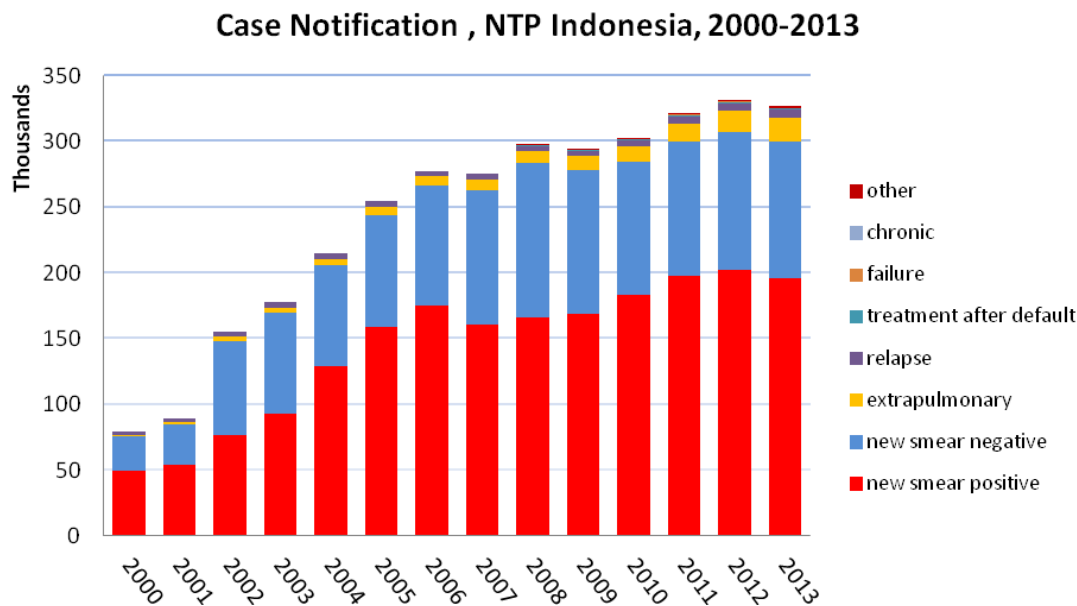


Figure 2 : Case Notification of Tuberculosis by NTP Indonesia 2000-2013 (MoH Indonesia 2015)

Based on a cohort study in 2011, an estimated calculation of US\$ 2.1 billion of the total economic burden is due to TB in Indonesia. Estimated cost of loss of productivity due to premature death is around 63% of the total cost, other loss due to disability [31%], medical costs[3.6%], and direct non-medical costs [0.4%] from patients and their households.(Collins et al. 2013)

Considering the high number of missed cases in TB care and high burden of TB in Indonesia, I hope to critically analyse the possible barriers and enabling factors of TB care in the population and health care services. By focusing on those factors, I hope it will result in better understanding of underlying root factors and will be able to come up with a clear strategy to scale up interventions to improve TB care in Indonesia on all levels.

2.2. Problem statement and justification

Tuberculosis is among the top three causes of deaths and number of years of life lost in Indonesia. According to a recent survey done by the NPS in 2013, the TB prevalence in Indonesia is 2.4 times higher than the WHO estimated prevalence in the latest WHO Global Report 2013. By using the NPS estimation, Indonesia suffers the 2nd highest burden of TB worldwide.

Even though there is an increasing TB notification rate since 2000-2013, the number of missed TB cases remains high.(MoH Indonesia 2014) The NPS survey noted that possible causes of the wide gap between prevalence and notification rate were due to : health seeking behavior, accessibility of care for TB, missed diagnosis, and under reporting. Based on this survey also, there were high numbers of smear negative culture positive patients who did not have a cough or haemoptysis but had abnormal thorax roentgen at the time of the survey, but proven to be infected with TB bacteriologically. Active screening of suspected TB in vulnerable and high prevalence groups should also include the non symptomatic patients.(MoH Indonesia 2014)

Health seeking behavior, low accessibility, and being misdiagnosed may result in a delayed TB diagnosis. The delay of TB care could amplify the transmission of infection and poorer outcomes. Longer delay will result in a higher burden for the people, for example, more visits to the health facility which means more time and more cost. This situation will bring more burden to poor people. Even though the DOTS strategy has been expanded and implemented nationally by NTP providers, some patients are still seeking care outside NTP providers which has a low suspicion of TB case.(*Ahmad et al. 2011*)

Implementation of PPM strategy and national health insurance are good opportunities to increase the coverage of TB care across the country and to reduce the inequity.(*MoH Indonesia 2014*) The wide gap shown from the survey has proven that there are still other barriers to access the service, from the communities' perspectives and also health care workers' perspectives.

Studies from Indonesia's neighbouring countries, Vietnam and Philippine, found that patient delayed the seeking care because of several causes, such as lack of information and misconceptions about TB, stigma, socio-economic factors, gender issue, access to health care, and being in rural areas.(*Hu et al. 2012; Johansson et al. 2000; Huong et al. 2007*) This study will review some possible barriers of TB care in Indonesia's setting, and also enabling factors which will help to reduce the barriers. The results may help to improve the strategy for TB control and to reach the national health strategic plan for TB by MoH 2015-2019.(*Ministry of Health Republic of Indonesia 2015*) The key to control TB is early diagnosis and treatment of TB patients from all the groups, including the vulnerable groups such as children and TB-HIV patient.

2.3. Objectives

To analyse the barriers and enabling factors of Tuberculosis care in Indonesia from the first symptoms occurring in an individual until reaching the diagnostic process in DOTS facility.

Specific Objectives

1. To investigate barriers and enabling factors towards timely and correct TB care in Indonesia.
2. To study the role of the informal and private health sector for TB care in Indonesiain timely and correct care of TB.
3. To formulate possible recommendations for improving TB care in Indonesia.

CHAPTER 3

Methodology

This study is done by literature review. The search strategy used electronic database searching from PubMed, EMBASE, Catalogues UVA and CINAHL. Information was also obtained from databases of the Ministry of Health Indonesia, WHO, Stop TB Partnership Indonesia and the World Bank. Only papers in English and bahasa Indonesia were included in this study. Other search strategies were by referring to the reference lists from the papers which suitable for the study, and also by using recommended papers given by the advisors and key informants.

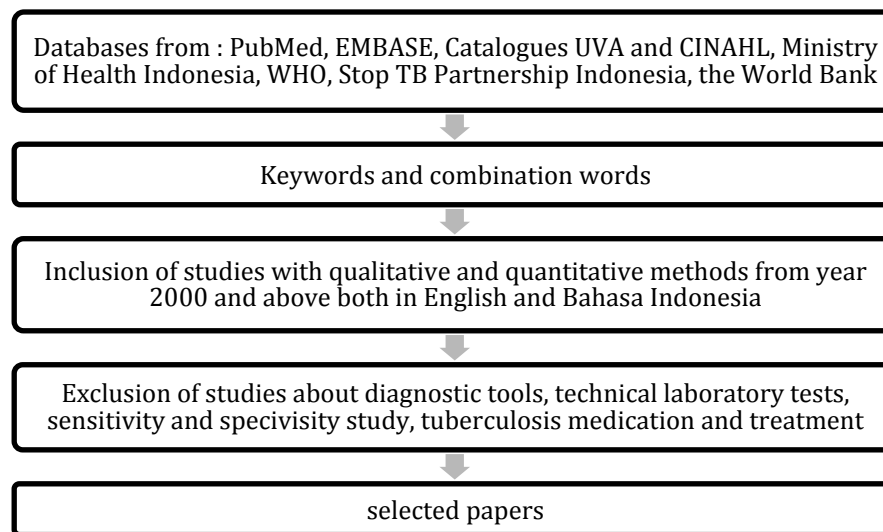
Keywords and combination words for the literature searching consisted of "tuberculosis" tuberculosis Indonesia", "patient delayed", "health seeking behaviour", "DOTS", "management", "barriers", "enabling factors", "stigma", "discrimination", "job loss", "economic loss", "access", "intervention", "private sector", "case detection", "Public Private Mix", "health workers" "information and education", "TB partnership program", "screening algorithm", "improving TB care", Improving TB care in Indonesia", "health care training", "Tuberculosis in South East Asia", "Tuberculosis delay in South East Asia", "task shifting". As well as keywords in Bahasa Indonesia such as "keterlambatan pasien tuberkulosis", "pencarian pengobatan tuberkulosis".

Any papers using qualitative or quantitative methods were included. Only papers from year 2000 and above were included in order to obtain recent data. The exclusion criteria were any papers about diagnostic tools, technical laboratory diagnostic, sensitivity and specificity, and TB medication and treatments.(Table 1) When relevant, all papers from other countries especially neighbouring countries were used to supplement and to check the evidence.

Three interviews were done with three TB experts in Indonesia. One source was an country director from an NGO in Jakarta which works closely with NTP in Indonesia. The other two were sources from Yogyakarta who work as university based researchers and also a health system experts for TB care and other tropical diseases. These interviews were done to validate the result from the literature study, as well as validation of the frameworks being used in this study.

The study is analysed and discussed using part of the framework designed by Uplekar M, et all (2013), the framework of the Pathway of TB care with barriers and interventions to improve case detection (Figure 3). This framework provides a pathway of possible entry points of barriers and possible interventions for improving TB care. The gaps between boxes are areas where patient with TB cases are often dropped out.(Uplekar et al. 2013; Blok et al. 2014)

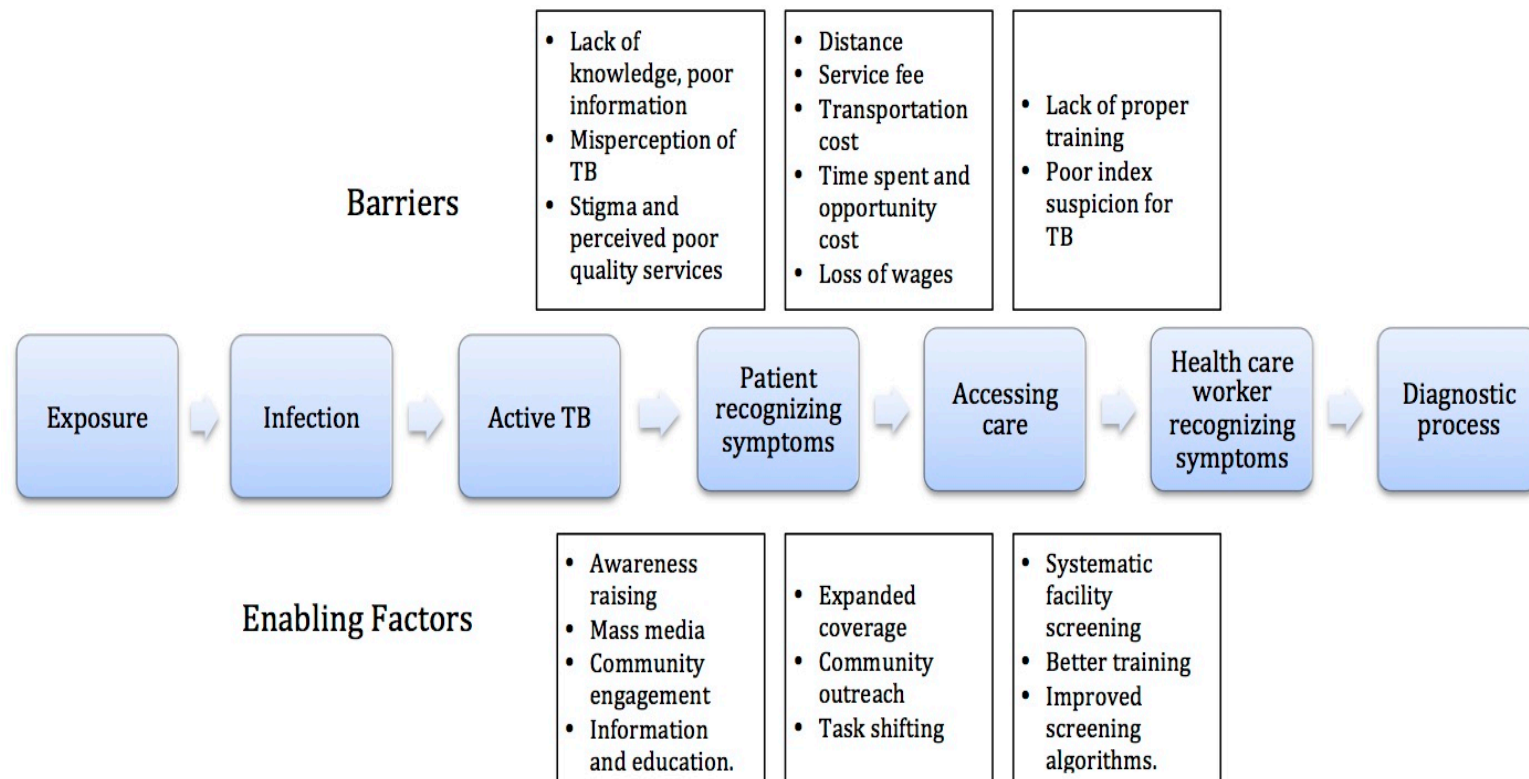
Table 1 : Papers search strategy



Total delay of TB care is defined as time interval between the onset of initial symptoms until the initiation of a correct anti tuberculosis drugs. The total delay is the sum of patient delay and health care system delay. Patient delay is defined as the time interval between first symptoms to occur until the patient decides to seek care at health care providers, could be public providers, private providers, or alternative providers such as traditional healer, pharmacists, etc. Health care system delay is defined as the time interval between the day of first seek care at the health care provider until patient received correct initial treatment of TB.(*WHO 2006*) This study will discuss the barriers and enabling factors within the pathway, from the moment the infection becomes active TB (onset of symptoms) until the patient reaches the correct diagnostic process for TB care in a DOTS facility (marked with (*) on Figure 4).

The suggested barriers and enabling factors of the framework can also be expected to be found in the Indonesian setting. Thus, making the framework suitable to analyse these factors in Indonesia. Objective two is discussed by analysing the role of the informal and private sectors in each step of the pathway using the same framework. The informal and private sectors might play a role in TB care barriers or enablers. After discussing all the roles of private sectors, per step of the pathway, in a separate chapter, the role of each relevant informal and private sectors will be discussed in details.

Figure 3. Pathway to TB care with barriers and enabling factors. It is a part of the pathway from Uplekar, et al's pathway of TB care with barriers and interventions to improve case detection.*(Uplekar et al. 2013; Blok et al. 2014)*



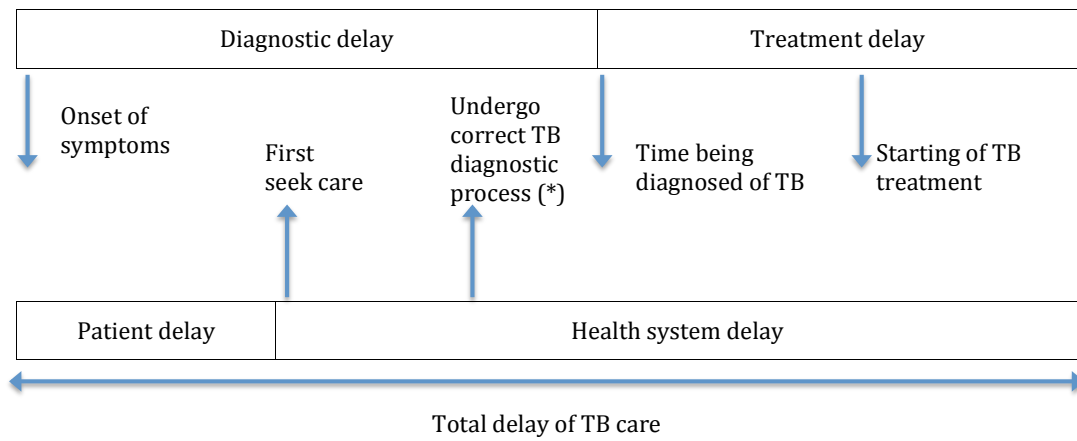


Figure 4. Diagram of pathway of TB care delays (WHO)

Note : the arrows shows the onset of each steps of TB care

CHAPTER 4

Results

Through literature search, fifteen papers of Indonesia's settings were identified using the search strategy above (table 2). Only fourteen papers were included in the result for factors influencing TB care within the framework; one paper was excluded because it was study about the total delay of TB care. This study was still important as an example of total TB care delay in Indonesia. Seven papers were quantitative studies, and the other seven were qualitative studies. Most of the papers' settings was Yogyakarta province (8 papers), and the rest of the papers were from Bali province (3 papers), Aceh province (2 papers), South Sulawesi (1 paper), and Papua province (1 paper). Another result was added from a national document about recent a national tuberculosis strategic plan. This document was a recommendation from one of the key informants. This data was relevant to answer the study objective. Studies from other countries which relevant for this study also included.

The framework of Uplekar, et al, describes four steps in the process from developing symptoms of TB, until a patient starts the diagnostic process in DOTS facility. From each step there were several possible barriers and enabling factors of the process. The result of this study will be described using the identified barriers and enabling factors within these four steps. First, the barriers and enabling factors which occur when the first symptoms have started until someone recognizes the symptoms of their disease. Second, other barriers and enablers which occur when a patient decides to seek care for their illness and accessing the choices of the providers. The providers can be medical providers (public or private providers) or alternative providers, such as self-medication with over the counter (OTC) drugs or a traditional healer. Third, barriers/enablers at the health care facility (public or private providers; DOTS or non DOTS facility). When a patient arrives at the health care facility, the diagnostic process for TB does not automatically occur. It often requires some time until someone undergoes the correct TB diagnostic process.

Before presenting the influencing factors of delay in four steps of TB care, an overview of total delay in Indonesia will be presented. A study, from all DOTS facilities in Yogyakarta province, showed that median total delay of adults with smear positive TB, was 10 weeks, with median total delay in urban setting areas were 8 weeks, and rural setting areas were 12 weeks. From this study, the urban-rural setting was the only significant factor for the total delay of a TB patient ($p=0.0001$). (Mahendradhata et al. 2008) For patient delay, three different studies, also in Yogyakarta province showed that median patient delay in adult new TB patients (smear positive and negative) was 7 days (Ahmad et al. 2011) and in suspected adult TB patients with a cough of two weeks or more was 14 days (Lock et al. 2011) and 17 days (Ahmad et al. 2013). From Ahmad (2011) and Lock (2011) studies, first visits to public health centres were not associated to shorter patient delay, compared to a first visit to private providers.

The median of patient delay is considered to be lower compared to the median patient delay of other high endemic countries such as India (20 days) (Rajeswari et al. 2002), Ethiopia (60 days) (Demissie et al. 2002), and Vietnam (21 days) (Huong et al. 2007).

Table 2. Summary of identified papers in Indonesia settings

Year	Author	Location	Methods	Participants	Residence	Sample Size	Result
2011	Lock	Yogyakarta, Government lung clinics	CS	Suspected adult TB patients	Urban/ Rural	194	Patient delay median 14 days Risk factors : Discussing symptoms with non family member (OR 2.70 (95% CI 1.19-6.16), p <0.001); first seeking care to public health care (OR 1 (95% CI, p=0.02); distance/travel time (OR 0.35 (95% CI 0.18-0.67), p<0.001)
2011	Ahmad	Yogyakarta, DOTS facilities	CS	New adult TB patients; smear positive & negative	Urban/ Rural	275	Patient delay median 7 days Diagnostic delay 37.8 days Risk factors : No significance socio demographic determinant for care seeking behavior patter. However, first seeking care at DOTS facility did not result to shorter delay. People in urban areas were likely to visit DOTS facility when first seeking care compared to people from urban areas (OR 2.01 (95% CI 1.15-3.50), p = 0.014)
2007	Mahendradhata	Yogyakarta	CS	PP : specialists, general practitioners, nurses, midwives	-	164	64.6% had practice for more than 5 years. 62.8% also worked in private/public facilities which offer DOTS service. 23.2% of PP has satisfactory knowledge of DOTS, with more physicians having satisfactory knowledge compared to non physician.
2011	Mudatsir	Aceh	Quasi experiment	<i>Tuha peut</i> (community figure) & Community members	-	210	There was significance difference before and after intervention of <i>Tuha peut</i> for increasing TB knowledge and awareness.
2011	Leida	South Sulawesi	Quasi experiment	informal community groups	-	15 of each groups	There was significance difference in knowledge (95% CI (-6.19-(-4.19), p 0.000) and behavior (95%CI (1.20-2.41),p=0.000) before and after intervention
2013	Kristiono	Yogyakarta	CS	Suspected TB patients	Urban/ rural	750	352 of 750 samples first seek care to alternative medication. 75,9% of 352 participants first seek care to pharmacists/local drugstore; 24,1% of 352 participants used traditional medication (self-medication; herbal medicine)
2013	Ahmad	Yogyakarta	CS	persons with suggestive TB symptoms	Urban/ rural	746	Patient delay median 17 days 11% were not seeking care; 40% seek care to medical health care facilities, mostly health centers; 48% seek care to alternative providers, mostly buy OTC at drugstore or local kiosks. Associated factors for health seeking behaviour : being women (OR 2.90 (95%CI 1.78-4.72) and severity of symptoms (OR 1.43(95% CI 1.16-1.75)
2009	Rintiswati	Yogyakarta	IDI and FGDs	TB patients; family members; community members	Urban/ rural	IDI : 67 patients; 22 family members; FGDs : 6 groups community	Factors influencing care seeking behavior : household income, distance, advice from family members and friends. 30 of 67 took over a month and seek care to two or more providers before reaching DOTS facility. Response from others : fear, worry and upset. Spouses (9/14) felt the need to separate cooking, sleeping, eating.

Table 2. Summary of identified papers in Indonesia settings (continued)

Year	Author	Location	Methods	Participants	Residence	Sample Size	Result
2004	Watkins	Bali	IDI	TB patients, suspected TB patients	-	11	Factors influencing health seeking behavior : severity of the symptoms, advice from family and friends, available service at convenient time, long queue, waiting time, perceived quality. Social stigma (+).
2000	Caprara	Aceh	Observation, IDI, FGD,	Community members and leaders, family of TB patients	-	28 FGD groups; 70 IDIs	Health seeking behavior were strictly influenced by the perception of cause of TB. It was different between ethnics and geographical areas
2006	Watkins	Bali	Semi-structured interviews	Private providers	Urban	22	Providers' perspectives : poor awareness and stigma in community (+), low perceived quality of public services (+), poor staff training, limited opportunity for training
2005	Watkins	Bali, DOTS facilities	Q-methodology	Health workers : doctors, nurses, lab analysts, staffs	Urban/rural	24	Barriers of TB care in Bali : poverty, poor community awareness and knowledge of TB and TB treatment, use of traditional treatment, social stigma, inadequate training for workers. Enabling factors : community involvement, education, clear guidelines, capacity building for workers
2007	Ardian	Timika	Conceptual model TB care of PPP	Routine surveillance data of health services : public and private sectors; Private mining company	Rural	2 hospitals, 5 community health centers, on-site mine clinics	Increased notification rate (+); maintained cured rate (+) 91% ; treatment default below 10%. Public-private partnership proved to successfully met the challenges of TB control in Timika. Political commitment and coordination were two areas for improvements, as well as the referral system.
2011	Probandari	Yogyakarta, engaged PPM hospitals	IDI	PPM actors : hospital & NTP staffs, hospital association representative, international consultant for PPM pilot project	Urban/Rural	33	There was a dynamic partnership from public and private actors for TB program from 2000-2008. Barriers of the partnership could be reduce by good strategies, equal relationship, trust, ownership feeling between actor. However, good governance was also needed to maintain sustainable and effective partnership.
2008 ⁹	Mahendra-dhata	Yogyakarta	Retrospective interview	Smear (+) TB patients	Rural	421	Total delay median 10 weeks; Significant factor : urban-rural setting (p<0.0001)

⁹ This study was not included in the result of the framework.

CS Cross sectional study
 FGD Focus group discussion
 IDI In-depth interview
 PPP Public private partnership
 PPM Public private mixed
 TB Tuberculosis
 PP Private providers
 DOTS Directly observed treatments short course

Another literature review, studied diagnostic delay for pulmonary TB patients globally.(*Storla et al. 2008*) Based on this study, the median of patient delay, defined as duration from the onset of symptoms to the first visit to the health care providers. While diagnostic delay was defined as the duration from onset of symptoms until a proper TB diagnosis. Tanzania had the longest diagnostic delay (136 days) with a median of patient delay was of 15 days. Surprisingly, a study from the United Kingdom in 2003 was the second after Tanzania (126 days) with a median of patient delay was of 63 days. The result of the study also placed both high endemic and low endemic in a random sequence.(*Storla et al. 2008*)

Another systematic study showed results that the average of patient and health system delay in low middle income countries/LMICs (31.7 days and 28.5 days) were comparable to high income countries/HICs (25.8 days and 21.5 days).(Sreeramareddy et al. 2009)

Factors influencing time to a patient recognizing symptoms

Lack of knowledge, poor information

Lack of knowledge as well as poor information about TB in general were found in several identified studies. (*Rintiswati et al. 2009; Watkins & Plant 2004; Watkins et al. 2004; Watkins & Plant 2005*) A qualitative study of newly diagnosed adult TB patients in Yogyakarta showed that 41 of 67 respondents did not know the cause of TB, and the rest of them (26) mentioned TB as an infectious disease caused by virus or bacteria. However, 57 of 67 knew that TB was a transmissible disease, and 51 of 67 respondents knew that a common known TB symptom was a cough, even though only 2 of 51 respondents thought of TB as the cause of their illnesses. Of all the respondents, most of these respondents (30/67) took over a month, since the first symptom occurred, before they reached a DOTS facility and consulted to two or more other providers. Only 12 of 67 respondents reached a DOTS facility less than a month or soon after the first symptoms occurred. Both of these groups answered that TB can be cured when a patient takes the TB drugs regularly. It showed that their knowledge of TB was not the only factor which determined their health seeking behaviour.(*Rintiswati et al. 2009*)

Besides TB patients, the study also interviewed family members and community members. The common knowledge about cause of TB was also low. From the Focus Group Discussion (FGD) groups where only 8 of 36 people knew that TB was caused by bacteria, the others stated stress, smoking, dirty air, heredity, and magic. However, all of the FGD groups knew that TB was an infectious diseases and could be transmissible.(*Rintiswati et al. 2009*) However, even though there were possibility of recall bias as well as highly desirable answers by participants, the result of this study could be used as an description of the common knowledge of TB in community.

Similar results were also found in a qualitative study in Bali, where five TB patients and six persons with suggestive TB symptoms had a generally poor awareness about TB and the seriousness of the diseases. They only seek care if the disease conflicted with their daily activities such as working.(*Watkins & Plant 2004*) Two qualitative studies, among health care facilities public and private providers, also performed in Bali, suggested there was poor knowledge and awareness of TB in the

community. These respondents believed that these factors were the barriers for TB control in Bali.(*Watkins & Plant 2005; Watkins et al. 2006*)

Poor knowledge and awareness of TB were also found as an important determinant of patient delay in other countries such as Thailand, China, Yemen(*Storla et al. 2008*)and Nigeria (*Biya et al. 2014*).

With whom a suspected TB patient discusses the symptoms, also seems to determine the duration of delay. Many suspected TB patients consulted other people to discuss their illness, such as family members (spouse, others family members) and friends. There was no information about other sources of information that they consulted with. Advice from other people was significantly associated with patient delay, both shorter and longer patient delay.(*Lock et al. 2011; Rintiswati et al. 2009; Watkins & Plant 2004*) From all of the studies it showed that patients and suspected patients admitted that advices from other people contributed to their health seeking behaviour.

Knowledgeable family members and friends result to a shorter patient delay. Poor information from respected people resulted in inappropriate care for health seeking behaviour in an example from a patient in Bali, where a suspected TB patient was given an advice from her husband to buy TB drugs at a local drugstore without consulting with health providers when she had the symptoms.(*Watkins & Plant 2004*) In contrary, from another study in Yogyakarta, discussing the symptoms with their spouses or family members proved to shorten the patients delay compared to discussing it with non family members ($p=0.001$).(*Lock et al. 2011*) It shows that the quality of information given to someone, even though from their close circle, determines the duration of delay as well as health seeking behaviour of a TB patient.

However, from an NGO officers perspective, there was also lack of demand about TB in general society in Indonesia. The community had a low interest about TB. This condition also amplified the lack of knowledge and information about TB generally.(*Voskens, personal communication, 2015*)

Misperception of TB

As mentioned before, there are only a limited number of TB patients and the community in general who had correct knowledge of the cause of TB. This poor knowledge often lead to misperception of TB. Several causes of TB, besides bacteria, were mentioned by TB patients, persons with suggestive TB symptoms and community members in three qualitative studies in Aceh provinces (*Caprara et al. 2000*), Bali (*Watkins & Plant 2004*) and Yogyakarta (*Rintiswati et al. 2009*).

In Aceh, the authors did 28 FGDs with community members and 70 interviews with community leaders, and family members of TB patients. They mentioned germs, poisoning, working hard, chewing *sirih* leaf (betel leaf) with tobacco. Since their health seeking behaviour was strongly related to their perceived cause of disease, the people who believed that it was caused by germs would go to medical providers, while the others chose to go to a traditional healer (*tabib*).(*Caprara et al. 2000*).

Similar to the study above, TB patients and suspected patients in Bali and Yogyakarta, mentioned physical factors (showering late in the day, working hard), psychological factors (worry, stress), environmental factors (dust, dirty house, dirty air), hereditary, and also magic/spirits. In both studies, their perception of the cause of TB determined how they sought care for their illnesses. Those with misperception seek care with traditional healers and also self-medication, beside medical health providers.(Watkins & Plant 2004; Rintiswati et al. 2009) This perception also determines how they behave in society, when someone else had the disease.(Caprara et al. 2000; Rintiswati et al. 2009; Watkins & Plant 2004) Because, misperception about the cause and transmission of TB might lead to stigmatization and isolation of the TB patient.

The study from Caprara et al., was done almost 15 years ago. An up to date study about the cultural meaning of TB in Aceh province should be done again to give a recent overview of the society. Because, even though the cultural condition of the Aceh people might not have changed a lot, the others factors such as an improved level of knowledge, an impact of TB promotion in the recent years might have influenced the recent understanding of the Aceh people about TB.

Stigma and perceived poor quality services

Stigmatization was found in two qualitative studies from Yogyakarta (Rintiswati et al. 2009) and Bali (Watkins & Plant 2004). Most respondents from the Yogyakarta study did not feel stigmatized because of their diseases. However, in Kulon Progo district, Yogyakarta, there was a low level of stigmatization, even though it did not lead to social isolation. In contrary, most of the spouses (9/14) of TB patients had the need for separate cooking, eating, and sleeping with them.(Rintiswati et al. 2009) It showed there was still stigmatization and isolation of TB patients in the community, even from the close circle of the patient.

While in Bali, based on TB patients perspective, stigmatization occurred due to misperception of the cause of TB, where some of the Balinese people believed that TB was caused by Balinese spirits/magic, dirty and inherited diseases. The stigmatization lead them to hid their diseases, resulting in longer delay to reach TB care.(Watkins & Plant 2004)

A literature review about stigma related to TB has been done to describe the phenomenon on the society in various countries settings. This study found three themes about stigma about TB : shame, isolation, and fear. Shame was mostly found from the literatures since tuberculosis was described as a bad disease which could lead to isolation. The feeling of shame led to act n secrecy of having a treatment which could affect the compliance of the treatment. Fear of having TB affected the people to seek care and undergo a diagnostic test for TB.(Juniarti & Evans 2011) The stigma related to TB was also found in a study in Vietnam where TB was defined as “dirty”.(Johansson et al. 2000) A study on Filipino women in rural setting reported that stigma in the community brought her to fear and to be isolated from the community.(Hu et al. 2012)

Delay in seeking care was also found in Ahmad, et al study in Yogyakarta. Eleven percent of seven hundred and forty six community members who had a cough for more than 2 weeks, were not seeking care at all at the time of study, and 48% of total respondents were seeking care at alternative providers, mostly self medication using OTC drugs. Significant factors contributing to this health seeking behaviour were being female and perceived the severity of the symptoms. While one of the significant factors, for those who seek care at medical health providers, was a good perceived quality of service.(Ahmad et al. 2013) This study showed that perceived quality of services determined the decision to seek care at the correct providers.

Awareness raising, information and education, community engagement, and mass media

Two studies were found which discussed the effect of community engagement for TB control program through awareness raising with information and education. One study analysed the potential role of the community figure, *Tuha peut* in Aceh province, as the messenger of the information(Mudatsir et al. 2011), another one studied the effect of TB promotion in informal community groups such as previous TB patients, cadres, religious groups, in order to increase awareness and knowledge of TB(Leida et al. 2011).

Involvement of *Tuha peut* as the community figure, proved to increase knowledge of TB in the community in Aceh province. The knowledge of the study group was significantly increased after the involvement of the *Tuha peut* compared to before intervention ($p=0.001 - 0.00$), as well as compared to the control group. It also reported that the number of visits to DOTS facilities from persons with suggestive TB symptoms was increased during the intervention period compared to the same duration last year, from 64 people (2008) to 112 people (2009). It means that awareness of the community about health seeking behaviour also increased during the study.(Mudatsir et al. 2011)

Another study discussed the effect of TB health promotion by community engagement in Gowa district, South Sulawesi. The study involved several known informal community groups which consist of elementary teachers, cadres, previous TB patients, traditional healers and religious groups. Using paired t-test analysis, there was a significance difference of knowledge of TB ($p=0.000$; 95% CI -6.19-(-4.19) and health seeking behaviour ($p=0.000$; 95 CI 1.20-2.41) in study groups compared to the control group before and after intervention. Cadres in the study group referred more TB suspected patients to Puskesmas during 3 months of monitoring.(Leida et al. 2011)

From both studies, it showed that awareness raising, through information and education and also involving the community, could become potential for enabling factors to reduce the delay of TB care. Considering that the characteristic of the community members of both studies are rather different from other areas, especially in Java islands or urban areas, similar research should be done to obtain additional evidences.

Clinical staff, who worked at public health facilities that provide DOTS service in Bali, agreed that community involvement was a priority. They believed that it was important to educate the people about TB in order to reduce the delay of seeking care.(Watkins & Plant 2005)

Peer educator groups also had a potential role as the messenger for increasing community awareness and knowledge of TB. This group was found useful for TB control especially for MDR TB patients. *(Voskens, personal communication, 2015)*

There was no paper found about the role of mass media as the enabling factors of TB care in Indonesia. There was a need to use other means of communication other than newspapers and internet to increase awareness of TB in society. *(MoH Indonesia 2014)*

Factors influencing time to accessing care

Distance

Two studies showed that distance influences health seeking behaviour as well as the choice of providers. *(Lock et al. 2011; Rintiswati et al. 2009)* In a quantitative study by Lock, et al, persons aged 15 years and older, who had been coughing for more than 2 weeks, living in rural areas showed longer patient delay compared to urban areas (mean patient delay of 20 days vs. 17 days). The distance/travel time to health facility was significant determinant to patient delay compared to quality of the providers' service ($p=0.001$). Travel time longer than 14 minutes to facility was positively associate to longer patient delay ($p=0.054$). *(Lock et al. 2011)* This study showed similar determinant with another quantitative study about total the delay of TB care of smear positive TB patients where the urban-rural setting was the only significant determinants for longer total delay. *(Mahendradhata et al. 2008)* These two studies could be comparable because the respondents' characteristic were similar.

From a qualitative study by Rintiswati, et al, distance was the reason why they chose non DOTS providers when they first seek care, in this case, a private provider. *(Rintiswati et al. 2009)* This study was done in the same province as Lock's study, thus the result of this study could complement the result of Lock's study from a qualitative perspective.

These barriers were also found in other settings, for example Ethiopia and South Africa, where living in rural areas and low access to health care due to geographical or socio-psychological barriers were positively associated with delay. *(Storla et al. 2008)* In India, more than 2 kilometres distance from house to the health facility was one of significant factors to longer patient delay. *(Rajeswari et al. 2002)*

Service fees

Basically, all TB care is free of charge in all DOTS facilities. When a person with suggestive TB symptoms seek care and are diagnosed at providers outside NTP, most of the service fee, such as provider fee, lab test, chest X ray are not free. Thus, the service fee became a factor that determined which providers they would chose when seeking care. The perceived cost of service providers led a person, with suggestive TB symptoms, to choose either private providers or public health centres.

In a qualitative study in Bali, there was a misperception that Puskesmas was expensive, so they chose to seek care at alternative providers. This might result in

patient delay, it also leads to treatment delay where two patients did not continue their follow up treatments because they could not afford chest X ray examination.(*Watkins & Plant 2004*) In contrary, in an interview, a TB patient in Yogyakarta mentioned that health centres/puskesmas were the choice when first seeking care because it was cheap and affordable. People with higher income reported to reach DOTS facilities later than people with a lower income. Thus, they showed a longer patient delay because they went to other DOTS facilities such as private physicians. They chose private physicians because it was closer to their home, perceived better quality of service, insurance scheme, former experience. Interestingly, some FGDs participants from rural areas did not know that TB care was free at public health centres/puskesmas.(*Rintiswati et al. 2009*)

Transportation cost

Together with the distance from home to health providers, transportation cost also became a determinant factor for health seeking behaviour. Patients chose to go to private providers when they seek care because of its closer distance and the perception that it will cost lower.(*Rintiswati et al. 2009*) Even though TB care in Indonesia is free of charge in all DOTS facilities, transportation cost was not included. This is a huge burden for TB patients, especially MDR-TB patients while they were on treatment. This is a potential barrier for the TB control in Indonesia.(*Voskens, personal communication. 2015*)

Time spent and opportunity cost

Long queues, waiting hour, inconvenience opening hours, other responsibilities such as working and study were reported as the factors which determine health seeking behaviour for TB care in a study in Bali.(*Watkins & Plant 2004*) From Ahmad's cross sectional study about health seeking behaviour, being a student ($p=0.037$) and employment status ($p=0.005$) is significantly associated with longer patient delay.(*Ahmad et al. 2013*)

A person who works in the private sector significantly chose the DOTS clinic when first seeking care, more often compared to other type of jobs ($p=0.004$). This could be due to flexibility of working hours in the private sectors.(*Lock et al. 2011*) Similar barriers were found in study in a growing industrialised area in Myanmar. The authors found that an inconvenience opening hour for the clinic was one of the barriers for the workers to access DOTS facilities.(*Thu et al. 2012*)

Loss of wages

There were no papers found which discussed the loss of wages as the barriers for TB care in the community. For some TB patients in India, loss of wages were reported as the reason why they delayed to seek care.(*Rajeswari et al. 2002*) However, from the findings of other barriers such as the role of the service fee of providers, transportation cost, time spent and opportunity cost, it showed that the economic factor played an important role which determined health seeking behaviour for TB care.(*Watkins & Plant 2004; Rintiswati et al. 2009*)

Expanded coverage

Since the year 2000, DOTS already expanded its service to hospitals, both private and public hospitals, and also private providers. Nowadays only 30% of private hospitals and less than 2% of private providers were engaged to NTP.(*MoH Indonesia 2014*)

A surveillance study of a conceptual model of public-private partnership in Timika district, Papua province, showed the effectiveness of public-private partnership for TB provision. In Timika, district health department/NTP worked together with the mining company and private health providers under the mining company funds. This model showed the districts better performance compared to the Indonesian NTP statistic. It showed a higher case detection and notification rate compared to national data and WHO estimation rate for TB incidence. While the success treatment rate remained high (91%). The result was also supported by a high standard of TB care which was maintained by all the stakeholders in Timika, one of the example was a good research collaboration between the national and international research team which maintained the quality of the diagnosis process.(*Ardian et al. 2007*)

Expanded coverage should also target other vulnerable groups as well, such as people living in urban slums nearby big cities, diabetes patients, elderly people, children, prisoners, etc. These groups need more attention in order to reach an universal access for TB care.(*Ahmad, personal communication. 2015*)

Community outreach

There was no paper found which discussed the community outreach as the enabling factor for TB care in Indonesia. The CSOs such as community based organization, local religious based organizations (Muhammadiyah, Aisiyah, LKNU, etc), and also national and international NGOs played a potential role to participate in TB control. Many CSOs worked almost in every provinces, but only limited had participated with the TB control program.(*MoH Indonesia 2014*)(*Voskens, personal communication. 2015*)

Task shifting

There was no papers found about task shifting as the enabling factors in TB care in Indonesia. Task shifting could possibly be done from TB workers in DOTS facilities to community health workers and private providers in order to do active case findings. Another example also shows active involvement of local drug store owners, beside pharmacists, to refer to any people with suggestive TB symptoms to DOTS facilities.

Factors influencing time to health care workers recognizing symptoms and starting the correct diagnostic process

Lack of proper training

There was poor knowledge about the DOTS program from private providers (specialists, general practitioners, nurses, midwives) in a survey in Yogyakarta. Only

23.2% of 164 participants had satisfactory knowledge about TB and the DOTS program, where the physician had a significantly better knowledge than the non physician ($p = 0.0001$). Surprisingly, 68% of all participants also worked in public health facilities which provide the DOTS program. This study was done by telephone survey where respondents were selected randomly from the private practitioners register in Yogyakarta province. (Mahendradhata et al. 2007) Health workers who work at DOTS facilities in Bali agreed that there was insufficient training about the TB control program and limited chances for sharing skills and knowledge among them. They believed this fact influenced the TB control program in general. (Watkins & Plant 2005)

Poor index suspicion for TB

In correlation with the result about the lack of training of health care providers, a quantitative study in Yogyakarta showed that first seek care to DOTS facility significantly associated with a longer patient delay (Lock et al. 2011), with median patient delay was 23,6 days, compared to 13,7 days when first seeking care with private providers. In contrary, another study also in Yogyakarta, showed that visiting DOTS and DOTS facilities did not resulted in a different duration of delay. (Ahmad et al. 2011)

Low suspicion of TB was also found from a qualitative study in a newly diagnosed TB patient in Yogyakarta. Most of the respondents (38/67) were not requested to do a smear test by the first providers when seeking care, either DOTS or non DOTS facilities. Self-referral from a DOTS facility to a non DOTS facility occurred due to absence of improvement and the delay to undergo TB diagnosis process even after several visits at DOTS facility. (Rintiswati et al. 2009)

This result was similar in India that a first visit to government providers positively associated with patient delay. While a first visit to a private provider resulted in a longer health system delay. (Rajeswari et al. 2002)

Weak regulation, lack of monitoring and quality assurance

There were barriers from the health system to human resources for the TB control program. Even though private providers now have been included in the DOTS program, only less than 2% of private practitioners were participated in NTP, and the adherence to national clinical guidelines of TB care was still low. (MoH Indonesia 2014) There was a lack of monitoring and poor quality assurance in public providers as the majority of DOTS providers, as well as other facilities participating with DOTS. Even though there was regulation, it was not being implemented completely. (Voskens, personal communication. 2015)

Systematic facility screening

Systematic facility screening means a guideline of a pathway of care of a person with suggestive TB symptoms. This pathway shows how and where a correct procedure of diagnosing process, treatment, until TB patients declared as cured, as well as referral procedure from non NTP providers, also private providers who engaged with NTP such as private physicians, private lab, etc, takes place.

Even though from a searched paper, there was no identified paper discussed about this factor. Mahendradhata mentioned that a better systematic facility screening was an important factor to improve case detection of new TB patients. Because, in the field, there are many numbers of suspected TB patients who were lost in-between the referral process, especially from non DOTS to DOTS facilities. Being lost in referral also occurred when a correct TB diagnosis on process, usually when a patient undergoing a sputum test or chest X ray was due. This could have happened because of poor information from the health care workers about the process, and/or because of other determinants from the patients perspective about the process, for example economic factors, misinterpretation of the information from the health care workers, lack of trust, or “shopping doctor” behaviour.(Mahendradhata, personal communication. 2015)

Better training

There was an agreement from TB health workers in Bali, based on a qualitative study, where it was necessary to have an opportunity and access for training and/or continuing medical education for health providers. As well as an opportunity to share their experience and skills about TB amongst health care workers.(Watkins & Plant 2005)

Improved screening algorithms

Clear and existing guidelines for TB care, especially for private providers, where found as an important factor to improve TB care. This was found from interviews with TB health workers (Watkins & Plant 2005) and private providers (Watkins et al. 2006) in Bali. As the guidelines are available, the respondents believe that main challenges for TB control in Bali were finding new cases that do not currently access care and achieve high cure rates.

The role of informal and private sectors for timely and correct TB care

In this chapter, the role of 4 groups of non public providers were found for timely and correct TB care in Indonesia. The roles will be explained below.

Civil Society Organizations (CSOs)

Although participation with community organizations had a long history in NTP in Indonesia, the CSOs, for example LKNU and Aisyiah, had been formally involved as the government's partner in TB control programs since 2002. A meeting was held on May 2013 of the National Stop TB Partnership Forum, which purpose was to strengthen the partnership and increase the capacity building of the TB partnership program in Indonesia. There was a high expectancy that these CSOs could fill the gap between the governmental system with its DOTS program and providers and the communities accessibility. The CSOs expected to played roles in finding new cases, ensuring the community to be able to access the facility, and also supporting TB patients until they finished their treatment and were cured. The role of CSOs is also important on advocating the community needs for government on local level which was still limited.(MoH Indonesia 2014)

Pharmacist, local drug stores and alternative providers

Health seeking behaviour for alternative providers was found in a cross sectional study in a group of adults who had a cough for 2 weeks or more in Bantul district, Yogyakarta. There were a total of 352 samples who first seek care either at the pharmacists/drugstore or traditional medication, such as healing massage and herbal drugs. Of all samples, 75.9 % of samples chose the pharmacists/drugstore. There were no differences between age, sex, educational status and economic level. The pharmacists/drugstore was chosen because it was considered to be fast and closer to their place, and the main purpose was only to eliminate the symptoms. The other causes were high confidence of themselves about their behaviour and common suggestive ideas that an act of seeking care itself could cure them.(Kristiono & Wardani 2013) It showed that people do seek care outside medical providers, both DOTS and non DOTS, but some did not seek care at all. These also showed poor awareness and lack of knowledge about TB, especially the symptoms and severity of the disease.

Community figures and community groups

In correlation with the finding from Kristiono and Wardani, the role of other informal sectors, such as a local community figure and informal community groups, was proven to be effective on increasing the knowledge and awareness of TB in society.(Mudatsir et al. 2011; Leida et al. 2011) Since pharmacists and local drugstores were one of the common choices when first to seek care of persons who had suggestive TB symptoms, their role should be strengthened as part of the TB control program. Although pharmacists and local pharmacies already included on PPM for TB control, the study which analysed the effect and evaluation of the topic was still limited.(Ahmad, personal communication, 2015)

Private providers

Beside the public hospital, private hospitals and private practice providers also included on expansion program for TB, the PPM program. Since then, the DOTS program also provided by private providers in Indonesia in order to fill the coverage gap and improving accessibility, furthermore increasing case detection rate and cure rate also. However, only 2% of total registered private practitioners in Indonesia who are currently involved with NTP, with a very low notification rate to NTP as well. The NTP survey calculated that private providers are actually able to manage TB cases as much as 40% or more.(MoH Indonesia 2014)

A qualitative study on PPM, in all hospitals in Yogyakarta, revealed the general experience and views of the partnership with NTP from the perspective of local actors since the beginning of PPM in the year 2000 until 2008. The samples of the study are already selected in order to gain a rich and balanced information between all the local actors. They were health workers (medical doctors, a GP and a specialist, nurses, laboratory staffs, medical record staffs) at public and private hospitals, NTP staffs, a hospital association representative, and international consultant for the PPM pilot project. The study revealed a dynamic relationship between NTP and hospitals as the PPM providers from year 2000-2008 (figure 5). It showed there was a slowly but surely progress of the relationship between year 2000 until 2004 when the program had just

started and was adapted by the local actors. There was a fast progress from the year 2004 until it reached its peak in 2006 because the partners trusted each other and had optimism about the program. Since then the partnership was weakened again due to less interaction among the partners, low motivation and mistrust of the relationship especially the providers in a low resource settings, as well as weak governance.(Probandari et al. 2011)

The result was also similar with one of the informants opinion, that even though PPM was a potential and good approach, to increase the low coverage and low detection rate, the lack of monitoring and weak regulation could make the PPM and created more harm than good for the TB control program in Indonesia.(Voskens, personal communication, 2015).

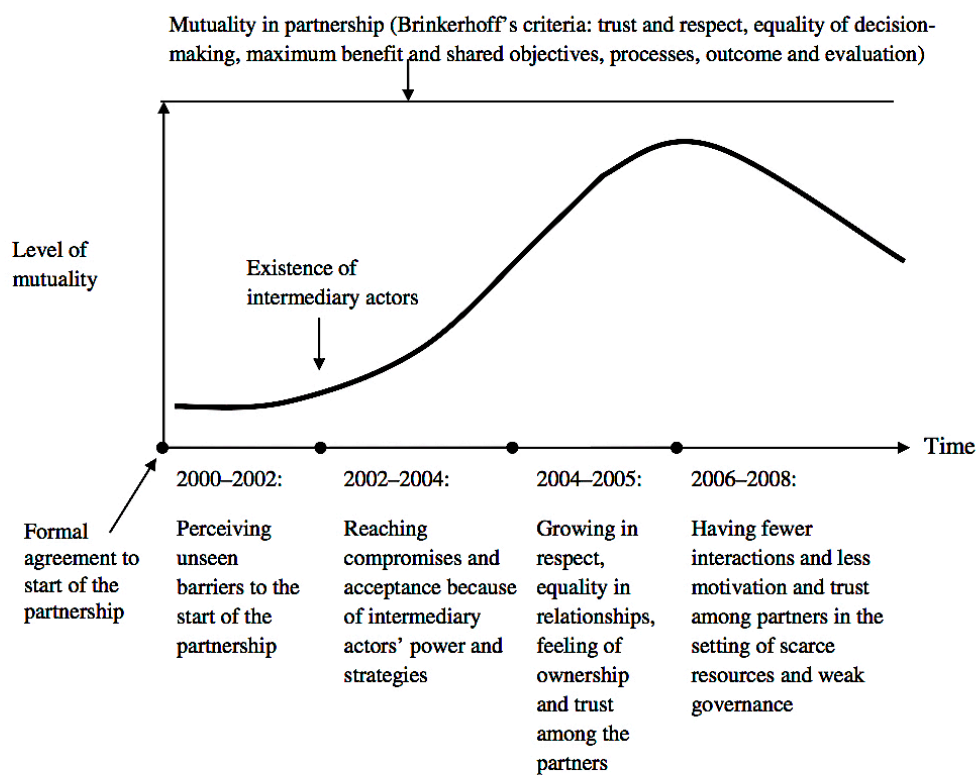


Fig. 2. A life course metaphor of the partnership.

Figure 5. A graphic of a dynamic PPM relationship in Yogyakarta Province.

CHAPTER 5

Discussion

Nowadays, TB control is still becoming one of the challenging public health problems globally. Prevention of TB transmission will not only protect an individual, but also the community in general. Timely and correct diagnosis processes as well as a successful treatment are important keys to address TB control. Delays on TB care happened globally, in both high and low endemic countries, as well as between LMICs and HICs. The delay of TB care was also found in Indonesia.

However, in comparison with other high endemic countries, the duration of the patient delay in a study in Yogyakarta, Indonesia showed a shorter delay. This is probably due to the difference setting from Indonesia's studies, where it was held on Yogyakarta provinces which already has a considerably strong TB control program, and also more urban respondents in the studies. Since Indonesia is a populous country with huge numbers of different characteristics of the people and is geographically spread along 5000 km of the equator line, which influenced the health access, the result for other islands might show different result.

Lack of knowledge, poor information, misperception of TB, stigma and perceived poor quality of services and lack of demand were identified as the barriers for a person with suggestive TB symptoms to recognize the symptoms. (*Rintiswati et al. 2009; Watkins & Plant 2004; Lock et al. 2011; Watkins & Plant 2005; Watkins et al. 2006; Caprara et al. 2000; Ahmad et al. 2013*) All of these barriers are related to each other. The lack of knowledge which was found in several studies mostly concerned the misperception of the cause of TB and the severity of the disease. Interestingly, even though the level of knowledge about TB, of persons with suggestive TB symptoms and a personal perception of the cause of TB determined which their health seeking behaviour, there were other factors which influenced the final decision. Information and advices from other people were found significantly influencing the decision. The information and advice could be from family members, spouses and friends. The quality of information and advice given by other people were not all good information, some can also be poor information. It can be expected that poor information will lead to patient delay. It showed that education about TB should also target people around the high prevalence populations, besides general populations.

Misperception about the causes of TB, closely related to stigmatization. The community still thinks of TB as a curse disease, or caused by spirits/magic, and also unclean and inherited diseases thus other people will isolate TB patients. Stigma could lead to fear and shame to seek treatment. People who live in a strong social stigmatic environment will hide their TB status. This behaviour could harm the treatment process as they would not want to be seen nearby a TB facility. It could lengthen the delay of TB care, even more, default of TB treatment which could lead to MDR-TB.

Interestingly, one of the studies showed that stigma and isolation of TB patients come from their close circle, the spouses. (*Rintiswati et al. 2009*) It showed the need of targeting people in the close circle of the TB patients to reduce stigma and isolation. Because, the support of TB patients' close circles is an important factor for a successful TB treatment phase. Besides improving a new cases detection, DOTS program will be

successful if the treatment phase was successful. It is understandable that, taking anti TB drugs regularly, can be challenging for TB patients. Full support from the family members as well as the community can be very helpful for treatment completion.

Distance, service fee, transportation cost, time spent and opportunity cost were found as the barriers to access the health care facility, both DOTS or non DOTS facilities.(*Lock et al. 2011; Rintiswati et al. 2009; Ahmad et al. 2013; Watkins & Plant 2004*) The loss of wages was not found in the papers as barriers for accessing health facilities in Indonesia. This might be because of the limited number of researches which include this factor as the determinants in Indonesia. However, in relation to someone's employment status, inconvenient opening hours of DOTS facilities and household income were determinants of the choice of health providers. Private providers became the most chosen provider of this case.(*Ahmad et al. 2013; Rintiswati et al. 2009*)

It was common that public health centres provide service only in the morning hours on weekdays, while many people who actually needed the service were on work duty and could not leave their work or other responsibilities at their own convenience. For example public servants. They will then choose to seek care at private providers such as private physicians, nurses, or midwives, or even local pharmacists which offered easy access, in terms of time, distance and sometimes low service costs.

Economic reasons were commonly found as the factor to delay the decision of seeking care, not only for the TB disease. Most of the TB patients have a low level of income.(*MoH Indonesia 2015*) The economic consequences of TB will add more burden to their already existing economic problem. Even though the TB program is free from out of pocket expenses in all DOTS facilities, it is known that many people still access providers outside DOTS due to many reasons (close proximity, good perceived quality), even worse, did not seek care at all (misperception of the cause of TB). Those providers outside NTP are not free of charge, and often persons, with suggestive TB symptoms, visit these providers more than once until they are eventually diagnosed with TB at the DOTS facility. This fact shows the poor quality of the providers to identify TB.

The issue of costs other than TB care such as transportation cost, opportunity cost, and loss of wages were the most concerning problems for MDR-TB patients on treatment in Indonesia, because even though all the service fees and anti TB drugs are free of charge, transportation costs are not included. If the government cannot not address this problem, there will be a high possibility of missing TB cases detection, treatment default, and more TB transmission in community and finally more people living under the poverty level.

Accessibility issues of TB care in Indonesia are also strongly influenced by the geographical factors of the country. Distance between the islands influence the delivery of the TB supplies, as well as availability of the human resources. There was an inequality of health providers in Indonesia, which leads to the scarcity of human resources for TB care in rural areas, especially the ones which are located far from the central. Available TB workers are experiencing an overload of work because they also are responsible for other diseases, such as malaria, maternal and child health, etc. Even though the decentralization gives an opportunity to local governments to overcome this

scarcity of resources, in fact, this problem is still found in many areas, especially outside Java-Bali islands.

Lack of proper training, poor index suspicion for TB, weak regulation, lack of monitoring and quality assurance were found as the barriers in health system which could longer the delay.(Mahendradhata et al. 2007; Watkins & Plant 2005; Lock et al. 2011; Ahmad et al. 2011; Rintiswati et al. 2009)(Voskens, personal communication, 2015) This study also found that the first seeking care at DOTS facilities did not result in a shorter delay. The first seeking of care at public facilities was an important determinant, which resulted in longer delays compared to private providers.(Lock et al. 2011) Poor satisfactory knowledge of the DOTS program was also found on private providers, which engaged in the NTP in Yogyakarta.(Mahendradhata et al. 2007) These facts showed the challenges of the DOTS program which happened on all health providers, both public and private providers. If the backbone of TB control program, the DOTS facilities, is still weak, it will be difficult to improve the quality of TB care in Indonesia. There will be more missing cases due to the inability of DOTS workers to recognize the TB diseases. The role of the government as the pilot of the TB program should be strengthened. Even though, reducing the numbers of TB cases, was one of the national health goals for many years, if there is lack of willingness to maintain an overall quality of the programs, it will be difficult to reach the goal.

Several factors were identified which could facilitate the TB care in Indonesia. Awareness raising, information and education, community engagement, expanded coverage, community outreach, systematic facility screening, better training, and improved screening algorithms were found to be enabling factors to reduce the barriers mentioned above.(Mudatsir et al. 2011; Leida et al. 2011; Watkins & Plant 2005; Ardian et al. 2007; MoH Indonesia 2015)(Voskens; Ahmad;Mahendradhata. personal communication, 2015)

Community involvement proved to be effective in health promotion. A culturally sensitive TB program will reduce the barriers of the communities acceptance. Besides increasing the awareness of TB generally, health promotion could potentially increase a new TB cases detection rate with more passive case findings. The engagement of a community figure and an informal group, which is close to the local community, could fill the gap between government and community. This role also applies to other stakeholders such as national and international NGOs, and CSOs.

Expanded targeted vulnerable groups of people living in urban slums were found to be important, because this group was still neglected, compared to other vulnerable populations such as prisoners, elderly, diabetes and HIV/AIDS.(Ahmad, personal communication, 2015) Considering the growing number of diabetes patients in Indonesia and the fact that there was not yet an engagement of a TB program for diabetes patients in Indonesia, makes this group also very vulnerable. Numbers of HIV/AIDS in Indonesia also increased, but voluntary test for TB for HIV/AIDS patient are still limited. There was already a stigma about HIV/AIDS patients in community, thus introducing a TB test which also related to a stigma for this group is difficult. More research to find acceptable approaches to these groups should be addressed in order to reduce the delay of TB care.

Health systems barriers, which occurred as the barriers of TB care should be addressed with improvement of health systems actors. There should be better opportunities for health workers to do more training and workshops about TB, as well as available and clear guidelines of TB care in all health providers, including private providers. Even though private providers nowadays already are included in the PPM program, if there was a lack of determination of the government to monitor the quality and adherence of DOTS program of private providers, this potential actors could become the barrier instead of the facilitator of TB care. This also applies to other partnerships with informal sectors.

The evaluation study of partnerships between NTP and its partners' (*Probandari et al. 2011*) showed the importance of the government's willingness to maintain good governance in order to maintain a good partnership. Otherwise the partnership will not successfully work. Both government and NTP partners' should also be critical on others performances.

The Timika model of the government-private sectors relationship for the TB control program, could be one of the good examples of partnership. (*Ardian et al. 2007*) This model showed a good capacity of all stakeholders, strong monitoring of service quality, and a local approach for the combination of this model, beside the role of its mining company. This model could be used for other areas, even though some approaches should be adapted to local conditions. This model showed that cooperation of government and private sectors can be successful.

Another opportunity to increase accessibility of TB care, which not found in the papers, was the national health insurance/JKN. This national insurance scheme will help the government to reduce the gap of accessible TB services. It is a potential factor for TB care. Strong regulation and monitoring should take place in order to maintain its quality. The community should also play a role to monitor this program.

This study has limitations in terms of a low variety of the studies' settings where most of the studies were from Yogyakarta province. There was limited data available to describe the condition of Indonesia in general. This study might not be able to fully represent the whole picture of barriers and enabling factors of TB care in Indonesia. Geographical aspects of Indonesia could differentiate the accessibility of health care for all populations, and the inequality of numbers of health providers nationally where people in Java-Bali islands have a better access to health care.

CHAPTER 6

6.1 Conclusion

Median patient delay in Yogyakarta provinces showed a considerably lower result than compared to other high endemic countries. However, the result might be different in other provinces in Indonesia.

This study showed barriers for TB care which are divided into three groups from each process of care. When a patient had been infected with TB, there were several barriers which delayed him/her to recognize the symptoms as TB symptoms. They were; lack of knowledge and poor information; misperception/misconception of TB, especially about the cause of TB; the stigma's in the community, and the perceived poor quality services of the DOTS program. From the study, all of these barriers can influence each other. For example, misperception about the cause of TB can lead to stigmatization. Misperception of TB is also due to lack of awareness and poor information in the community about TB in general.

Barriers to access health care or the decision to seek care, which were found in this study, were distances/travel time to health providers, service and transportation cost, inconvenience opening hours of the DOTS facility, difficulty to leave work or other responsibilities which often resulted in loss of wages. Many persons with suggestive TB symptoms chose to delay their care seeking activity due to the factors above, or went to incorrect providers to seek care for TB, or even did not seek care at all. Economic factors were seen as related factors for these barriers.

The barriers on health providers were lack of training and low index suspicion of TB diseases. DOTS and non DOTS facilities contributed to the delay. The DOTS facility was found positively associated with patient delay. It showed the importance to improve the quality of the public health centers/Puskesmas as the backbone of the TB program in Indonesia. One of the solutions is giving opportunity to health care workers for more training and capacity building.

Community engagement was found as a potential approach to reduce the gap of knowledge and awareness in community. A community figure, informal community groups, and CSOs could play important roles in filling the gap between the government system and the community. Beside the promotion program, these stakeholders could play a role in increasing the case detection rate, as well as advocating the community to the government.

Expansion of TB programs are not only needed on the providers aspect, but also other vulnerable groups, such as urban slum population, HIV/AIDS, diabetes, etc. Private providers were a good potential for increasing quality and coverage of TB care in Indonesia. It is important to improve the monitoring and quality of the services of the providers. Otherwise, private providers would only amplify the delay of the TB care process.

6.2 Recommendations

- Health promotion and awareness raising should target high risk populations as well as environments around them, such as family members. This includes vulnerable risk groups.
- Maximising community engagement activity in TB control programs since it was proven to be effective to reach the community and to increase the community knowledge and awareness about TB.
- Providing regular training and knowledge updates for health care workers who work in the first line of TB care.
- Implementing regular monitoring and evaluation to reduce the health system delay in all DOTS facilities and NTP partners, especially public health centres/Puskesmas as the backbone of the NTP program in Indonesia.
- Maintaining good partnership with the informal and private sector by strengthening good governance.
- Increasing quality and quantity of TB researches for other areas in Indonesia outside Java-Bali islands, in order to develop an evidence based approach for TB control which considered the local contexts.

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