Family matters

How patients and treatment supporters experience directly observed TB treatment in Kota Bogor, Indonesia

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Preface and acknowledgements

The present study was carried out as part of the Amsterdam Master’s program in Medical Anthropology at the University of Amsterdam. The study not only deepened my knowledge and understanding of TB control in general but it also increased my insight in the perceptions and experiences of patients and their families who are dealing with TB and its treatment in their daily lives. Moreover, the study confronted me with my ethnic roots. After all, my father was a Chinese Indonesian. I had only been to Indonesia on family visits; my last visit was 15 years ago. In 1974, my parents took me, my sister and brother to Indonesia for the first time. I can still remember the crowd of people that started waving when we disembarked the plane. Many “strangers” who appeared to be relatives greeted us at the airport and they were all very happy to meet us. We spent six weeks with my paternal grandparents and many, many other relatives. After this first visit, several other visits followed. In an way, my cousins and I grew up together, in different parts of the world and only seeing each other every few years.

When I arrived at Jakarta airport last May, the scene had hardly changed. Many relatives had come to welcome me. Surprisingly, they still recognized me and I recognized them. We only seemed a few years older. Some had married and had brought their children. Suddenly, I was a “tante” (aunt) for many children. The first few days in Indonesia were spent meeting many relatives. Strangers to a certain extent and yet so familiar.

A few weeks into my fieldwork, I realized that I was studying family relations while I myself was part of an extended Indonesian family. I experienced how comforting and providing relatives in Indonesia can be. Despite the 15 year gap, I was unconditionally received as a member of the family. However, at times, the family ties also gave me a suffocating feeling. Although everything my family did, was done with my well-being in mind and only intended to keep me safe and happy, after a while, I experienced also a need for more individual freedom. In Bogor, I was taken care of by an in law of one of my cousin’s in laws. Still, she regarded me as a relative and introduced me as her sister everywhere we went. These experiences enabled me to better understand
what patients meant when they were talking about family duties and obligations or about their family as a safe haven.

My time spent in Indonesia made me realize more than before that I am privileged to be part of this family. I would like to express my gratitude for their endless efforts in assisting and supporting me throughout my fieldwork. But also for making my time in Indonesia such a heart-warming experience and so much fun.

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Executive summary

The WHO global strategy for TB control is organized around the principle of direct observation of treatment (DOT). The aim of DOT is to improve adherence to treatment and treatment completion. Patients receive their drugs and take them under direct observation of a health worker or treatment supporter. In the Indonesian National TB Program (NTP), DOT is generally carried out by family members and supervised by hospital or health centre staff on a weekly basis. (Ministry of Health 2006). Having family members as treatment supporters raises many questions and objections from TB experts but has remained largely understudied.

The objective of this research was to explore treatment supporters’ contributions in family DOT to TB treatment. The study was exploratory with descriptive and comparative characteristics and was carried out in the municipality of Kota Bogor in Indonesia. It was mainly qualitative, although quantitative data were collected from the 2005 annual report and from 156 treatment cards. For the qualitative part of this study, 16 TB patients, half of them adherent and the other half defaulters, their treatment supporters and 4 health workers were selected and interviewed about their experiences with TB treatment and DOT.

The main findings are that all 16 patients and their treatment supporters are favouring DOT within the family above any other option. Keeping TB in the family has several advantages. First of all, the family provides a convenient environment for the patient. Secondly, it is regarded as a family responsibility to take care of a sick member. Thirdly, patients often fear being stigmatized. By keeping TB treatment a family secret, confidentiality is guaranteed.

Another important finding was that patients and their treatment supporters not only had little knowledge about TB, transmission and infectiousness but also knew little about the duration of treatment and possible side-effects. Furthermore, the treatment regimen presented problems with adherence, especially the transition from daily drug intake during the intensive phase to intermittent in the continuation phase.

Family DOT seemed a natural option in Kota Bogor because of the tight family relations. For family DOT to become an effective treatment option, the following activities and actions are recommended:
To the National TB program, to:

- Consider switching from an intermittent to a daily regimen during the continuation phase for patients receiving family DOT;
- Consider providing a treatment card for patients and treatment supporters to take home;
- Implement the national guideline on preventive therapy for children under the age of five;
- Provide adequate training for all health workers active in TB control. The training should include knowledge about TB, transmission, infectiousness, preventive measures, TB treatment and side-effects management. Communication and supervision skills should be included in the training of health workers to become competent and committed supervisors and encouragers of patients and their families;
- Intensify TB health education at individual as well as community level;
- Consider involving cured TB patients in community health education;
- Provide patients and treatment supporters with simple, written instructions about TB, treatment and preventive measures.

To TB health staff, to:

- Encourage patients and treatment supporters to ask questions and to come forward with any problems they have;
- Consistently follow up patients who do not show up at the health centre to collect drugs;
- Ask questions to patients and treatment supporters to assess how they are doing with treatment;
- Repeat health education to patients and treatment supporters several times.
List of abbreviations

DHO District Health Office
DOT Direct Observation of Treatment
DOTS Directly Observed Treatment Shortcourse
HIV Human Immunodeficiency Virus
MDG Millennium Development Goals
MDR Multi-Drug Resistant
MOH Ministry of Health
NTP National TB Program
PPM Independent health centre
PRM Microscopic health centre
PS Satellite health centre
TB Tuberculosis
CDC Center for Disease Control
IUATLD International Union Against Tuberculosis and Lung Disease
WHO World Health Organization

Kabupaten District(s)
Kota City
Malu Shame, embarrassment
Wasor Supervisor(s)
1. Introduction

1.1 TB and TB treatment in Indonesia

The Republic of Indonesia consists of approximately 18,000 islands spread over an area that is comparable to the size of Europe. It is administratively divided into 33 provinces comprising 440 districts (Kabupaten) and municipalities (Kotas), 5570 sub-districts, and 71634 villages. It has a population of approximately 231,330,000 people and is the world’s fourth most populous country after China, India and the USA. The island of Java alone has a population of 128 million people. Since the decentralization, several new provinces and districts have been formed and their number is increasing.

The World Health Organization (WHO) estimates tuberculosis (TB) prevalence for all cases in Indonesia to be 275 per 100,000 population. Indonesia is ranked third among the 22 high burden countries in the world, after India and China (WHO, 2005; MOH, 2006). The WHO recommended Stop TB strategy Directly Observed Treatment Shortcourse (DOTS) has been implemented in Indonesia since 1995, reaching DOTS coverage of 98% in 2000 (WHO, 2007). Case detection rates have just fallen short of the 2005 targets, while reported treatment success rates have remained high since 2000. Currently, there are only rough estimates of Multi-Drug Resistance (MDR) TB in Indonesia available. These are 1.5% among new cases and 12% among previously treated TB cases (WHO, 2005). A drug-resistance surveillance is being carried out at the moment. In the Indonesian National TB Program (NTP), Direct Observation of Treatment (DOT) is generally carried out by family members and supervised by hospital or health centre staff on a weekly basis. (Ministry of Health 2006). The treatment regimen consists of two phases: the intensive phase (2-3 months) with daily intake and the continuation phase (4-6 months) with intermittent intake of drugs (three times a week).

1.2 TB program structure

As a fully integrated program, the NTP makes use of all facilities within the national health care structure. Health centres have been categorized into three categories performing different tasks in the NTP structure:
Microscopy centres (PRM) have trained laboratory staff and perform smear diagnosis for their own patients and a group of satellite health centres (PS).

The satellite health centres (PS) do not have laboratory facilities. Sputum samples from suspects are processed to smears which are then transported to the PRM’s for diagnosis. After a diagnosis is received from the microscopy centre, treatment is organized at the PS level.

Independent health centres (PPM) provide diagnostic and treatment services, but do not collaborate with any satellite health centres (Witton, E. O’Carroll et al. 2003; Ministry of Health 2006).

1.3 Organization of TB services at district level

The district level of health services can be regarded as the “basic unit” for TB control in Indonesia. The average district size is 50,000 to 150,000 population. Each microscopy centre covers a population of ~20,000 (for a PPM serving a sub-district) to 100,000 (for a microscopy centre serving between two and five PS). The general organization of the NTP at a district is shown in figure 1. The research location is described in more detail in paragraph 4.1.
1.4 Statement of the problem

TB is one of the leading infectious diseases in the world. TB spreads through air. Every second, one person in the world becomes newly infected with the tuberculosis bacillus. Among them, 5-10% will develop active TB at some point in their lives. When people suffering from pulmonary tuberculosis sneeze, cough, talk or spit, they may distribute tuberculosis bacilli into the air. For another person to become infected, he needs to inhale some of these bacilli. Without adequate treatment, 50% of TB patients die whereas another 25% develop chronic forms of TB. These percentages are significantly higher in patients co-infected with HIV. TB can be cured by 6-8 months of treatment with a combination of drugs.
The WHO recommended Stop TB strategy is based on DOTS. The purpose of DOTS is to ensure proper diagnosis and treatment of TB cases on the one hand and to prevent the emergence of MDR-TB strains on the other.

Poor adherence to 6-8 month treatment regimens remains a problem in the global fight to stop TB (Sabaté 2003; Thiam, LeFevre et al. 2007). Therefore, DOT has been promoted by the WHO as one of the five components of the DOTS strategy (World Health Organization 2002). The aim of DOT is to improve adherence to treatment, ensuring that patients take the right combination of drugs for the required period. Patients receive their drugs and take them under direct observation of a health worker or treatment supporter. In general, the treatment regimen consists of two phases; the intensive phase of 2-3 months and the continuation phase of 4-6 months. Regular drug intake during the full course of treatment is essential to ensure cure and to prevent failure or relapse and drug resistance.

Research into the efficacy of TB treatment generally focuses on treatment outcomes. Failure of treatment and relapse after being declared cured may be due to poor adherence and/or pre-existing drug-resistance. Thus, ‘failure’ and ‘relapse’ can be used as proxies for pre-existing drug-resistance in settings with good adherence, whereas they cannot be used as such in settings with poor adherence. The quality of the treatment outcome data is thus highly dependant on well-functioning DOT. The better DOT functions, the more indicative relapse and failure rates are for drug-resistance. This is crucial for planning of MDR-TB programs.

Patients who relapse or fail due to irregular drug intake may develop drug-resistance. They are not only at increased risk of dying an unnecessary death, but are also a serious public health concern because of the risk of infecting others with MDR-TB. The proportion of relapse cases among notified smear positive cases in Indonesia is low (2-3%). This figure suggests a rather limited adherence problem. However, it only concerns notified cases within the public health system and does not include relapse cases diagnosed and treated within the private sector/hospital system. After all, relapse cases may prefer to seek care elsewhere as they believe the previously taken treatment to be ineffective. And indeed, hospitals face a relatively high proportion of relapse and chronic cases among their TB caseload.
The treatment supporter is appointed to ensure regular drug intake and to enhance adherence and thus prevent failure and relapse. In Indonesia, the treatment supporter is usually a family member. How s/he is selected and how s/he handles the tasks and responsibilities in providing TB treatment remains an understudied issue.

The precise implementation of DOT is even more crucial during MDR-TB treatment, as MDR-TB treatment involves 18-24 months of DOT with drugs that cause a lot of side effects. If MDR-TB treatment fails, there is no alternative anymore. Indonesia is currently planning an MDR-TB treatment program and urgently needs more insight in the functioning of the family treatment supporter. The treatment supporter plays a crucial role in treatment provision of both drug susceptible and resistant TB cases. Together with the health worker, the treatment supporter can take the role of observer, coach and mentor to the patient without taking away the patient’s responsibility to adhere. The way how patients and treatment supporters organize DOT, formally and informally, and the role of the health worker is to a large extent unknown.

In the NTP, regular treatment means that a patient picks up drugs every week as prescribed. On the treatment card, the health worker keeps track of the patient’s weekly visits. A patient will be registered as a defaulter when s/he has interrupted treatment for two consecutive months or more. This definition is in line with the WHO definition. (See also page 22).

1.5 Research objective and questions

Vermeire et al (2001) identify in their overview article on treatment adherence a gap in adherence research: the patient’s perspective. Escott and Walley (2005) come to a similar conclusion in their article on patients’ perspectives on DOTS in Swaziland. In my research I focused on both the patient’s and the treatment supporter’s perspective in the delivery of DOT. My interest in this topic is rooted in my experience in working in TB control in The Netherlands and China and the discussions I was engaged in trying to improve treatment adherence. The inclusion of family members is an interesting addition to the concept of DOT. Within family relations, however close, different sensitivities and tensions may play a role, and may indeed affect the provision of treatment support. I was
interested to find out how this temporary and, to a certain extent, strange relationship between family members manifested itself during TB treatment. With this research I aim to contribute to insight in the process of TB treatment and what can be done to improve adherence. I am convinced that more in-depth information about the every day experiences of people participating in DOT, either as patient or treatment supporter, can contribute to improving adherence to TB treatment. The research objective is, therefore:

To explore treatment supporters’ contributions in family DOT to TB control in Kota Bogor, Indonesia.

More specifically, my research focus was on the role of treatment supporters of both adherent and defaulting TB patients. These two groups of patients and their treatment supporters (family members) were expected to provide valuable information on reasons and circumstances why patients are or are not able to adhere to treatment. The research questions are:

1. How does family DOT work within the TB program in Kota Bogor?
2. How do patients and treatment supporters see their responsibilities in family DOT?
3. What does family DOT do to relations within the family, both from the patient’s and the treatment supporter’s perspective?
4. How do health workers perceive their role and responsibilities in family DOT and how do they fulfill this role?

### 1.6 Research location and period

The research location was the municipality of Kota Bogor in Indonesia. The NTP gave permission to do research and selected the location.

The research project was carried out between 16 May and 3 July 2007. The duration of field work was limited to six weeks due to the schedule of the Master’s program Medical Anthropology at the University of Amsterdam.
2. Literature review

In this literature review I will discuss adherence in general and in tuberculosis control specifically, focusing on the role of treatment supporters. The literature review is guided by three questions: 1) what makes patients adhere to treatment? 2) What are specific adherence issues in DOT in TB control? 3) What is the role of the treatment supporter in adherence to TB treatment? Particularly, the second and third question will be discussed more extensively as they form the basis for this research project on family DOT in Kota Bogor, Indonesia.

2.1 Terminology

Throughout the literature three terms are generally used to indicate patients’ capacity to start treatment and stay on treatment until they are cured or treatment has been completed: compliance, concordance and adherence. The three terms are used sometimes interchangeably, sometimes to specify or differentiate. But all three seem to point to the same phenomenon that occur in the interaction between patients and their treatments. Vermeire et al (2001) note in their review of research that most authors do not even bother to define the term that they use, possibly because they assume everybody knows what is meant by ‘compliance’. Compliance refers to the ability of the patient to use the treatment regimen as it is prescribed. Compliance has some negative connotations that imply that a non-compliant patients are disobedient, do not want to submit to treatment. It also implies that the advice given to the patients is good for the patients. The literal meaning of concordance is harmony and agreement (www.freetranslation.com). In the context of medical treatment, the term is used to indicate the patient’s decision-making ability and choice. Concordance occurs when patients’ decisions based on what they think is required and the health practitioners’ intentions with treatment coincide (Vermeire, Hearnshaw et al. 2001; Mishra 2006). Adherence reflects a broader understanding of compliance and puts more emphasis on the doctor – patient relationship and the ability of patients to follow a recommended treatment program and in addition, to
make changes in their lives that will contribute to their health. In my research, I will use the WHO definition of adherence (www.who.int 2007):

“The extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a healthcare provider”.

This definition clearly shows that adherence is much more than taking pills. It refers to any activity that will enhance the effects of treatment. Meichenbaum and Turk (1987) list the following behaviours as indicators to adherence: entering into and continuing a treatment program, keeping referral and follow-up appointments, correct consumption of prescribed medication, following appropriate life-style changes (e.g. diet, exercise), correct performance of a home-based therapeutic regimens, and avoiding health risk behaviour (e.g. smoking).

When patients, for whatever reason, stop treatment prematurely, they are said to have defaulted treatment. WHO defines a defaulted TB patient as a patient whose treatment has been interrupted for two consecutive months or more (World Health Organization, 2003:55).

### 2.2 Influencing factors to treatment adherence

From the many references to adherence problems in patient care, we might get the impression that extensive knowledge exists on factors influencing adherence. This is not the case. Still, reasons and explanations why some patients adhere and others do not, are not easily found. For health workers, it would be very helpful if they could predict patient adherence, so they could prepare for specific actions and interventions in cases of predicted non-adherence. Unfortunately, it is not that simple.

Adherence has different dimensions. The three dimensions that are described in most adherence literature are: patient, health service and disease. All three will be described shortly.

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1 www.who.int/topics/patient-adherence/en
**Patient factors** that influence adherent behavior, for example, the patients’ economic and social situation, their beliefs in the health service and treatment, their ideas and beliefs about disease and health (Vermeire, Hearnshaw et al. 2001; Waisbord 2007). If patients for whatever reason, do not believe in the treatment they are given, chances are considerable that they will stop treatment or take drugs irregularly. A similar prediction can be done when patients cannot continue working due to treatment. The chances to full adherence also drop considerably if patients feel better after taking part of the treatment. This is particularly problematic in treatments that last long and in which patients start to feel better early in the treatment. Stigma is another considerable factor that influences adherence. Goffman defines stigma as: “An undesirable differentness that discredits or disqualifies the individual from full social acceptance” (Burathoki 2004:76) Most patients cannot keep their health status a secret from the people around them. Fear and in many cases ignorance add to stigmatization of patients.

**Health services** can also contribute to adherence problems. A good understanding between health worker and patients is crucial for adherence to treatment (Vermeire, Hearnshaw et al. 2001; Sabaté 2003). Accessibility of staff in case of problems with treatment are a constraint which may result in patients (temporarily) stopping treatment. Depending on the quality of health services, stigma can play an important role in whether or not patients seek care. Stigma can impede adherence when people have no confidence in the health services and seek care elsewhere or delay seeking care. But stigma can also accelerate adherence when confidence in the health services is high among patients. (Burathoki, 2004; Idawani, 2002).

Confidence in health services offered is crucial in adherence to treatment. For health services to gain trust from patients and the community, they need to provide good quality care consistently. This means that staff should be competent and available. Training and supervision are essential in building and maintaining staff competence. Quality equipment and availability of supplies also influence people’s perception of health services.

Distance to health services is considered a major factor that influences adherence. If patients have to travel a considerable distance to a health service chances are they will not keep their appointments.
Disease factors can contribute considerably to adherence. Diseases that do not cause a lot of trouble in the patients’ lives are more likely to cause non-adherence. A contributing factor to the length and the complexity of TB treatment is that the patient will feel considerably better after a few weeks. One of the most important factors influencing adherence are side effects that some patients experience. If patients feel better without the drugs, it is very likely they will interrupt or stop taking them.

2.3 Short introduction to principles of TB control

Since 1991, the WHO has promoted as the global strategy to control TB, the framework of Directly Observed Treatment Short-course (DOTS). The DOTS framework consisted of five essential elements (World Health Organization 2002):

1. Sustained political commitment: commitment to increase financial and human resources and to include TB control in nation-wide health activities
3. Standardized short-course chemotherapy to all cases of TB under proper case-management conditions including direct observation of treatment
4. Uninterrupted supply of quality-assured drugs
5. Recording and reporting system enabling treatment outcome assessment: assessment of each individual patients as well as overall program performance

DOTS has now become the brand name for a comprehensive technical and management strategy that includes the five elements mentioned above. Short-course treatment refers to a treatment regimen that lasts 6-8 months and uses a combination of several anti-TB drugs. DOTS regimen consist of two phases: an intensive phase and a continuation phase. The intensive phase consists of 2-3 months of daily treatment with three or more drugs. These drugs are isoniazid, rifampicin, ethambutol and pyrazinamide. The continuation phase lasts 4-6 months of daily or intermittent (every other day) treatment with two or more drugs: isoniazid and rifampicin. This treatment regimen means that patients have take 4-5 tablets each day in the intensive phase and 4 tablets three times a week in the
continuation phase. Some countries (e.g. China and India) provide intermittent treatment in both phases.

In 2006, the WHO launched the new Stop TB strategy (www.who.int 2007). This new strategy is linked to the Millennium Development Goals (MDG’s) and aims to achieve TB target of the MDG’s: “to have halted and begun to reverse the incidence of TB by 2015“ (Stop TB Partnership 2006).

The direct observation component of the DOTS concept is of most interest to patients’ adherence to treatment. Direct observation of treatment (DOT) comes down to the patient taking a daily dose of drugs under direct observation of a health worker or another designated person, who may be a relative (see 1.1 for Indonesia’s decision). Patients and treatment supporters have to ensure intake of the right TB drugs, in the right doses, at the right intervals (Mishra 2006).

### 2.4 Tuberculosis control specific adherence issues

Tuberculosis control has its own specific strategy to fight the disease. Poor patient adherence to treatment was and still is the most important cause of treatment failure (Escott & Walley 2005; Mishra 2006). But does that mean that TB patients have specific adherence problems that are different from patients that are enrolled in other disease programs or follow other prescribed treatment regimen? First of all, it seems that adherence is defined differently in TB control and in its definition comes closer to compliance. Sabaté (2003) presents an adherence definition specific for TB treatment:

> “In terms of TB control, treatment adherence may be defined as the extent to which the patient’s history of therapeutic drug-taking coincides with the prescribed treatment”.

The definition suggests comparing historical data of the patient’s drug taking with the prescribed treatment. The DOT component of tuberculosis control is an intervention to improve adherence. Observation by a treatment supporter (health worker or family member) is the only way to be certain the patient swallows the given medication.
Large distances to the nearest health facility, rough geographical characteristics of the area and low socio-economic status of patients are the main barriers for a successful TB program.

2.5 **Treatment supporters as a means to ensure adherence**

The research articles that I have reviewed show no significant difference in treatment completion between different types of treatment supporters. If the treatment completion rates were high, they remained high, and vice versa. One of the problems with the research that has been done with different treatment providers is, that it concerns mostly quantitative research. One of the few qualitative studies, done in the Lubombo region of Swaziland, show that patients’ experiences with the DOTS program have an added value (Escott & Walley 2005; Ministry of Health 2006). The results, although context-specific show, that community DOT is not suitable in every situation and that lay treatment supporters should be supported by qualified health staff. Escott et al (2005) indicate positive experiences with family DOT in some cases. Another interesting finding is that patients provide an insight in what it means to them to have to take drugs under observation.

The Center for Disease Control and prevention (CDC) in the United States and the International Union Against Tuberculosis and Lung Disease (IUATLD) suggest that family members do not make appropriate treatment supporters because of emotional ties but research does not confirm this. (Pungrassami & Chongsuvivatwong 2002). The WHO is also hesitant to endorse the inclusion of family members in their Stop TB strategy (Sbarbaro & Frieden 2007). Sbarbaro and Frieden (2007) argue that family DOT is a “feel good idea that can give government leaders and programme managers a false sense of assurance that a greater percentage of patients are being treated successfully under family observation than would have been successfully treated by self-administration”.

The International Standards of Tuberculosis Care (Hopewell 2006) go into this approach in detail and do not exclude family members as possible treatment supporters. In line with the International Standards of Tuberculosis Care, family members are more
and more considered appropriate treatment supporters. From the literature, several specific reasons for this development can be identified. First of all, DOT by health workers puts a heavy burden on both the health worker and the patient. Lack of competent health staff is a worldwide problem, resulting in heavy workloads for available staff. Assigning family members as treatment supporters decreases the workload. Second, when health facilities are distant and not easily reached, the burden on the patient for having to travel daily to receive TB drugs is not a favorable situation and adherence is likely to be compromised. Alternative options that bring treatment closer to the patient’s home are worth exploring. Studies that assess the impact of the treatment supporter on treatment adherence do not show any negative treatment results that speak against the assignment of family members as treatment supporters (Akkslip, Rasmithat et al. 1999; Zwarenstein, Schoeman et al. 2000; Pungrassami & Chongsuvivatwong 2002; Pungrassami, Johnsen et al. 2002; Newell, Baral et al. 2006).

Overall there seems to be little to no evidence that speaks against the assignment of family members as treatment supporters. In fact, it is a good example of a more patient-centered approach that creates an environment for adherence to treatment. The literature available on treatment adherence and the role of family DOT does give an interesting insight in the debate that is going on about this subject. The research articles present no conclusive evidence that supports or contradicts the efficacy of family DOT.
3. Methodology

The overall characteristic of this study is exploratory. Varkevisser et al describe an exploratory study as “a small-scale study of relatively short duration which is carried out when little is known about a situation or a problem” (Varkevisser, Pathmanathan et al. 2003). Although mainly exploratory, the study carries descriptive and comparative elements. It is descriptive in the sense that it consists of a systematic collection and presentation of data to give a clear picture of a particular situation. The comparative element was established by including different patient categories in the study to do justice to various patient and treatment supporter experiences and perspectives. Additionally, quantitative data are used to describe the overall situation of the study location and to back up some of the qualitative findings, whenever possible.

The patient categories adherent and defaulter as indicated on the treatment card were used as selection criteria. Adherent in this context meant that the patient or his treatment supporter regularly picked up the drugs at the health centre. Patients are registered as having defaulted when they or their treatment supporters failed to pick up drugs at the health centre for at least 2 consecutive months (see also paragraph 1.4).

3.1 Sample and sampling procedure

In the research protocol, I planned to take a sample of 16 patients and their treatment supporters. The 16 patients would be selected using the following criteria:

- **Patient category**: 8 adherent and 8 defaulter as indicated on the treatment card
- **Treatment duration**: registered at least 3 months before
- **Sex**: 4 male and 4 female patients per patient category
- **Age**: (per category/sex) 2 patients between 15-30; 1 patient between 31-49; 1 patient over 50
- **Treatment supporter**: family member

The 8 regular patients were selected from the 2007 district register according to the criteria. For the selection of defaulters I had to adjust the procedure because the 2007
district register did not include any defaulters yet. Therefore, I decided to include the last two quarters of 2006 in the sample. With this inclusion I managed to select just enough defaulters according to the selection criteria. This meant that being able to find them was very important.

The 16 selected patients were registered at 8 different health centres within Kota Bogor. Five out of the eight selected defaulters appeared to be registered at one particular health centre. Upon inquiry it appeared that this health centre had had staffing problems which had severely compromised the quality of TB activities and registration.

For additional information on family DOT, I planned to interview 2 health workers but in reality I interviewed 4. The 4 health workers were selected because they had time and were willing to talk.

Quantitative data about the overall TB situation in Kota Bogor were selected from the 2005 annual report. Data about 156 patients and their treatment supporters were gathered from treatment cards of the first quarter of 2007 in the 8 health centres in the sample.

### 3.2 Description of the sample

The patients who were included in the sample were all living in the municipality of Kota Bogor but in different sub-districts. The sub-districts within Kota Bogor are urban areas, although some could easily be considered rural, specifically the outskirts of Kota Bogor.

All 16 selected patients had smear positive TB and were or had been on treatment. The adherent patients had been on treatment for three months or more to ensure enough experience with TB treatment. The treatment duration of the defaulters varied between two weeks and 3 months.

The overall socio-economic background of the patients was similar. All belonged to the poorer part of Bogor’s population judging by their living conditions. Some were obviously poorer than others.

All patients were married, except two men in their twenties who were not married yet. Three patients were widowed. All married patients had one or more children. Their religious background was Islam. All patients could read.
3.3 Research methods

For this study, both quantitative and a qualitative data collection methods were used to gain information. Available TB data were collected from the 2005 annual report to understand and describe the overall TB situation in Kota Bogor. To be able get more insight in the characteristics of family DOT, specific data were collected at the 8 health centres included in the sample. These data were gathered from 156 treatment cards and consisted of patients’ age and sex and their treatment supporters’ age and family relationship.

For the 16 patients included in the sample, information was collected from their treatment cards as well. The purpose of the patient analysis was to gain patient specific information before the interview, and at the same time, gain information about the family relationship between patient and treatment supporter.

The qualitative data were collected by using several data collection methods. First of all, the patients included in the study were interviewed about their experiences with family DOT. Treatment supporters were also interviewed about their experiences with family support during TB treatment. In addition, four health workers with TB responsibility were interviewed about their experiences with family DOT.

For an overall understanding of the structure of TB program and family DOT in Kota Bogor, several staff at the provincial and district office and staff at the health centres provided information about the TB program in general and their experiences with DOT in particular.

3.4 Ethical considerations

TB is a highly stigmatized disease in many countries. The link between HIV and TB may, in some parts of the world, burden patients with a double stigma. Fear of being stigmatized may make patients hide their disease status from their employer and co-workers, their community and even their families. Patients may also hold other beliefs and understandings about their condition that may make them hide their status. In this study, people’s autonomy was respected by informed consent. In practice, this meant that all informants in this study were made aware of the following:
- Participation was voluntary and withdrawal from the study was possible at any time;
- Every participant in the study was orally informed about the purpose of the study and provided with adequate information;
- All information that informants provided would be considered confidential;
- Full names and addresses are not used or published; fictional names were used instead.

For the qualitative part of the study, patients and treatment supporters were interviewed in their homes. None of the patients or treatment supporters objected to the interviews. In all cases, the responsible health worker came with us to show the way to the patients’ houses which were often hard to find. Health workers were asked not be present during the interviews to allow informants to speak freely. Other people who came in during the interviews, obviously curious, were requested to wait outside to allow privacy.

In five of the interviews, the district supervisor (wasor) acted as translator. As a staff member at the district health office, she had to wear a government uniform. There was a chance that patients might feel intimidated or restricted during the interviews by the presence of someone wearing a government uniform. To avoid this, the district supervisor changed clothes before visiting the patient.

### 3.5 Limitations

One limitation of this study is that Kota Bogor is a relatively small district with good infrastructure. Family DOT in other areas in Indonesia may provide different findings. Although no generalizations can be made based on the findings of this study, it provides an insight in patients’ and treatment supporters’ experiences with and practical consequences of family DOT. Taking into account local characteristics, this information may be used to improve family DOT in Kota Bogor as well as in other areas.

In this study, data from treatment cards were used to select patients. Patients who were regular in treatment were selected based on information about their attendance to the health centre to pick up their drugs every week. Regular attendance to the health
centre to pick up drugs does not necessarily mean that patients actually take the drugs regularly.

Five of the 8 selected defaulters appeared to be registered at one particular health centre. It appeared that this health centre had had staffing problems in the past that had severely compromised the quality of TB services and the administration. Although the 5 patients all had their individual difficulties during treatment, the quality of TB services may have influenced their decision to stop treatment.
4 Research findings

4.1 Kota Bogor

Bogor is a city in West Java with a population of approximately 800,000 people in the Central Business District area and 2,000,000 in suburban area. Bogor boasts a presidential palace, a deer park and a botanical garden in the town centre. Bogor is on a main road from Jakarta to Bandung. The suburban area of Bogor is part of Bogor Regency (Kabupaten), while the urban is Bogor City (Kota). Bogor bears the nickname "the Rain City" (Kota Hujan), it is very wet and it nearly always rains even during the dry season.

In Kota Bogor, each health centre has a director and several staff. A health centre is responsible for one or more satellite health centres. Health centre and satellite health centre staff work for several disease programs at the same time. Usually, there is one health worker assigned for TB. Each health centre has a specific day reserved for TB. On this specific day, TB patients or their treatment supporters are supposed to pick up the weekly dose of TB drugs and hand in the empty blisters. However, if a patient cannot make it on the specific day, s/he can always come another day. TB suspects can come in for consultation and tests any day. Health centres are also open on Saturdays.

Health centres are supervised by the district supervisor (wasor). The district supervisor visits each health centre under his or her responsibility once every quarter. S/he collects data and discusses the working procedures with responsible staff. The district supervisor also collects new patients’ information and enters them into the district register.

Performance of the TB program in Kota Bogor is summarized in table 1. The high cure rate and low default and failure rates indicate an effective TB control program. As DOT is provided by family members, these rates are based on monitoring of drugs collection and not on actual intake of drugs.
Table 1  Treatment outcome smear positive cases Kota Bogor (cohort 2005)

<table>
<thead>
<tr>
<th>Year</th>
<th>Notified sm+ (N)</th>
<th>Cure N/%</th>
<th>Treatment Completed N/%</th>
<th>Failure N/%</th>
<th>Death N/%</th>
<th>Default N/%</th>
<th>Transfer N/%</th>
<th>Total sm+ Evaluated N/%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>817</td>
<td>743</td>
<td>12</td>
<td>7</td>
<td>14</td>
<td>24</td>
<td>17</td>
<td>100%</td>
</tr>
</tbody>
</table>

4.2  Family DOT in Kota Bogor

The concept of DOT which should be carried out by health workers (see page 22), has been adjusted to the Indonesian context, and is carried out by family members. Several informants at health centres and at the district health office explained the procedure for family DOT in Kota Bogor.

When a person has been diagnosed with TB, the health worker explains the treatment procedures to the patient, discusses the concept of treatment support by a family member and asks the patient to identify someone in her/his family that would be eligible. The patient asks one of her/his family members to be his treatment supporter and together they visit the health worker. Ideally, the health worker then explains in depth to both patient and treatment supporter about TB and its treatment. Most patients make their visit to the health centre accompanied by a family member, which makes the discussion about family support obvious.

During the course of treatment, the health worker should closely supervise both patient and treatment supporter. If there are any problems, the treatment supporter should contact the health worker for assistance. The health worker should also make inquiries every now and then about the patient’s health and about treatment. The 16 treatment supporters in this study mentioned the following tasks as their responsibility:

- Collect drugs at the health centre once a week
- Remind the patient to take the drugs according to the prescribed regimen;
- Observe the patient take the drugs;
- Take care of the patient.
Patients who live far from the health centre are sometimes allowed to pick up the drugs once every two weeks or in rare cases once a month.

When the health worker discusses treatment support with the patient, the following (informal) criteria are used to identify a suitable treatment supporter:

- s/he should live in the same house or very near;
- s/he should preferably be older than the patient;
- s/he should have some authority in the household.

The selection criteria were mentioned by the 4 interviewed health workers as rules of thumb. The health workers explained that the criteria are informal and that because of practical reasons, a treatment supporter may be chosen who does not fit one or more criteria.

Data collected at several health centres (n=156) show that in 48% of the cases, treatment supporters (TS) are indeed older than patients. Still, in a substantial 35% of the cases, the patient was older than the treatment supporter. Patients older than treatment supporters

Figure 2  Age differences between patients and treatment supporters (n=156)
were often older parents supported by their children, or husbands supported by their wives. In general, husbands were older than their wives, although there are a few exceptions. Age unknown in this sample refers to community volunteers or nurses who provided treatment support. Their age was not registered on the patient’s treatment card.

Another interesting feature of family DOT in Kota Bogor is the gender distribution among patients as well as treatment supporters. In the sample of 156 patients, 42% is female and 58% male. Figure 2 shows the distribution of gender in patient and treatment supporter combinations. In 40% of the cases, a female treatment supporter supervised a male patient. This can be explained by the fact that male patients preferred their wife as treatment supporter and in many cases their wife was also available to fulfill this role. In 20% of cases, a female treatment supporter supervised a female patient. In total, in this sample, 60% of the treatment supporters was a woman.

In only 19% of the cases, a male treatment supporter provided DOT for a female patient. This may be because men are often less available around the house because of work. A similar explanation could be given for the least common combination of a male patient and a male treatment supporter. The unknown category refers to unknown sex of the treatment supporter. In these cases, the treatment supporter is a community volunteer or health worker.
The symbol on the left hand side represents the patient and the symbol at the right hand side the treatment supporter.

The implementation of family DOT in the urban setting of Kota Bogor has direct consequences for the patient and the treatment supporter. DOT is generally carried out by a family member or a member of the patient’s domestic group. Families in Indonesia are tightly knit networks of people either related by blood or through marriage. Families or parts of families usually live in the same house or in the immediate vicinity. Involving members of the domestic group in TB treatment is in this specific context an obvious choice. How TB patients and their treatment supporters experience family DOT and how they fit the treatment into their daily lives has remained largely understudied. The patient and treatment supporter perspective on family DOT and TB may prove useful to improve the implementation of family DOT and thus the chances of successful treatment.
4.1.1 The patient perspective on DOT treatment

All 16 patients, whether adherent or defaulting, male or female, young or old, had the same opinion about family DOT: they would not like it in any other way. Health and disease are family matters. All patients turn to their family members for treatment support and care. The family and their home is an environment where they feel at ease and safe. They also feel that only family members really care for one another which makes them suitable treatment supporters.

**Upi**, TB patient, is 45 years old, and a widow with six children. Her orange outfit together with her bright smile give a healthy and happy impression. She works as a cigarette seller in Bogor’s city centre. Upi lives in the rural outskirts of Kota Bogor. Her house is small and dark. She lives together with two of her children, their spouses and children. Her daughter in law Ela has agreed to be treatment supporter after Upi was diagnosed with TB. Ela is very caring and took Upi to hospital when she started vomiting blood. She also reported this to the health centre. Both Ela and Upi feel that a family member is best suited to be treatment supporter. Upi expresses this very clearly by saying: “I feel comfortable with relatives and we know each other’s habits which makes it easier for them [to remind me to take my drugs]”

**Malik** is a widower, 50 years old and a father of four. He has TB. When he introduces himself, he adds, smiling guiltily, that he is a smoker and has not managed to quit yet. Malik lives in the outskirts of Kota Bogor, in an almost rural area. His daughter, son in law and four grandchildren live with him. Malik’s daughter, Yo, is his treatment supporter. Yo had TB herself seven years ago. The house is small but nice and cool. It is clean and has a nice sitting room. Malik explains that he could never accept an outsider to be his treatment supporter because that would make him feel ashamed and embarrassed (malu). He raises his voice when he talks about the family responsibility to take care of family members that are sick.

Both patients explain the importance of family members in treatment support from a different angle. Upi maintains that family members know each other’s habits and are thus
well aware of the patient’s whereabouts, working schedule and daily activities. This inside information gives a family treatment supporter a clear advantage. An outsider would probably need much more time to figure out how to fit treatment in a patient’s daily routine. A family member, moreover, has access to the patient at any time which gives both of them more flexibility in taking treatment. The added value of having a treatment supporter within the family is that the patient is in familiar surroundings and feels comfortable there. Malik’s story rather stresses the family responsibility to take care of sick relatives. This implies that it is not only a free choice for family members to provide treatment support but something that is expected of them. This may explain why all 16 patients were able to identify a treatment supporter within their families. The question is not if the family is willing to provide treatment support but rather who within the family is available to take on the task.

When patients and their families are confronted with the diagnosis of a highly stigmatized disease like TB, they are forced to think about how they are going to handle the situation.

Nasir is a 43 year old man with TB and diabetes. Nasir is married to Nani. They have three children. His wife Nani is his treatment supporter (see page 38). Nasir is very skinny and looks worried. He tells us about how TB started with a severe cough with blood. He went to the health centre and was diagnosed with TB. He started treatment immediately with support from Nani. When he was on TB treatment for almost three months, one of his friends who is a doctor suggested to do a blood test because Nasir was very skinny. Nasir says that the blood test revealed that he had diabetes. Since the diabetes diagnosis, Nasir has stopped taking TB drugs because he is much more worried about diabetes. He says he is very confused about having two diseases. His “doctor” friend who diagnosed diabetes advised him to continue TB treatment. Several friends, Nani and the health worker have also tried to persuade him to continue TB treatment but Nasir refuses and keeps saying that he is very worried about diabetes. His “doctor” friend has suggested to consult a traditional healer because Nasir cannot afford regular diabetes treatment although he has not inquired about this yet at the health centre. Treatment by a traditional healer is much cheaper. Nasir has not gone to the health centre yet. He talks about how sick he feels after
dinner every day and that he has lost weight again. His cough has returned, sometimes with blood. So far, no one has succeeded in persuading Nasir to go to the health centre. He looks sad, sitting in his chair, when he says he will probably not receive any treatment for diabetes at the health centre (see paragraph 2.2). Despite his concerns about his health, Nasir is very outspoken when he talks about TB treatment support within the family. He has only told some family members that he has TB because he says it is better to keep it quiet. You never know what people might think when they hear about TB. Again he says that he wants to cure from diabetes first before continuing TB treatment.

Eneng (29) is a TB patient. She lives together with her husband and daughter. The neighbourhood is built on the slopes of a hill. The houses are built close together only to be reached by small alleys and paths. Her sister Ana and mother live next door. Their small houses are very neat and tidy, and in a good condition. Ana is Eneng’s treatment supporter, although she admits she does not do much because Eneng is very motivated and takes the drugs regularly. Eneng has not told anyone outside the family that she has TB. She feels ashamed (malu) because poor people have TB. She is afraid people might think they are poor, too. She also tells about her neighbour who was diagnosed with TB and moved house a while ago without any known reason.

Both stories demonstrate the fear of being stigmatized because of TB. Nasir gives a more general reason for not telling anyone outside the family, almost as a precautionary measure. Eneng, however, refers to other people that may form opinions about her and her family. She fears the stigma of poverty will be put upon her because of TB and therefore chooses to keep this information within the family and a secret to anyone else. Both talk about feeling ashamed (malu) about their condition although they do not clearly explain why. One reason could be that they blame themselves for being infected with TB. Another reason could be that they expect stigmatization by others and stigmatize themselves by keeping their condition a secret.

Connotations of the word “malu” are shame and embarrassment. All 16 patients used this particular word when expressing their reasons for not telling anyone about TB
outside their families. One treatment supporter showed how she handled the situation by only sharing part of the information and thus avoiding too many curious questions (see paragraph 2.2).

Yo is 35 and Malik’s daughter. Malik has TB (See also page 33). Yo is well aware of TB and its treatment because she has had TB herself about three years ago. She is now a healthy mother of three children and one stepson. She whispers when she tells her story and keeps looking at the door where neighbours and a community volunteer have gathered. She whispers: “I keep my father’s condition a secret. If people ask what is wrong with him, I tell them he has to take drugs but I pretend I don’t know what for”

The family responsibility stressed by patients is supported by data from the 2004 prevalence survey in Indonesia. These data show that 96% (n=13,635) of respondents expressed a willingness to look after a household member with TB (Ministry of Health, World Health Organization et al. 2007).

Although all 16 patients in my sample agreed on the need for family DOT, they expressed different reasons why. Most patients felt TB and its treatment is a family matter. A person with TB seeks support and help within the family. Most people do not make the first visit to the health centre alone but are accompanied by a family member. Health workers confirm this. Making TB a family matter has several advantages for the patient. In general, families (or parts of families) in Indonesia live within close vicinity of each other. Families often share the same house or live in the same area or neighbourhood. With this situation in mind, it is easy to imagine that, with some exceptions, a TB patient will have little difficulty in finding a family member that is available as treatment supporter.

Data collected at several health centres showed that most TB patients (n=156) choose a treatment supporter who is a member of the patient’s domestic group, e.g. spouse, parent, sibling. This can be explained by the fact that close relatives, in most cases, live in the same house or very near. More distant relatives, e.g. cousins, uncles and aunts, live further away, and thus are less familiar with the patient’s situation. In this
study, 3 out of 16 treatment supporters were male. The three male treatment supporters were all supporting female patients.

When patients approached a more distant relative to be treatment supporter, it was often because close family members were not available due to work or age. Older people more often asked one of their children to become their treatment supporter, or, if children were not available, their daughter or son in law, or cousin.

Figure 4  Distribution of family members among treatment supporters (n=156)

4.1.2 The treatment supporter perspective on DOT

The experiences and perceptions of treatment supporters were consistent with those of the patients. Treatment supporters of adherent patients obviously had a different view on their role and responsibilities from those who dealt with defaulting patients. Treatment supporters of the 8 adherent patients encountered hardly any problems. In most cases, both were highly motivated to finish treatment successfully. Two treatment supporters had had TB themselves and thus were fully aware of the importance of regular drug intake and the pitfalls of a six months treatment. All treatment supporters of regular patients were able to hold some kind of power over the patients in their care. Not only did
they have a supportive and caring attitude towards the patient, they were also able to demonstrate a tenacious and vigorous attitude.

**Tina** is Asep’s sister. Asep has TB and Tina is one of his treatment supporters. She shares the responsibility with Asep’s wife Endang. Endang prepares Asep’s breakfast and drugs early in the morning before she goes to work. Tina then visits Asep when he is having his breakfast so she can observe him take the drugs. Tina explains that she had TB herself seven years ago and knows about the long treatment. She was also the one who recognized the symptoms and made Asep go to the health centre across the street.

Former TB patients are usually very motivated treatment supporters as they themselves are living proof of the positive result of regular treatment (See also paragraph 2.2). It is plausible, although informants did not mention it, that they use their own experience of having gone through six months of treatment themselves in motivating, encouraging and supporting the patient. At the same time, it is likely that they are better able to understand what the patients are going through while on treatment. It is this additional knowledge and experience that make them competent and dedicated treatment supporters.

Being a treatment supporter to an old patient is not always an easy task.

**Ina** is 70 years old (or so she thinks) and has TB. She lives in an old part of Bogor along the banks of a river. Her simple stone house has a small shop in front which is managed by her husband and one of her grandsons. Ina and her husband have six children. One of her daughters, Narsih, is Ina’s treatment supporter. Narsih is 40 and lives very near. Narsih talks about the difficulties she experiences in keeping her mother on regular treatment. Her mother is forgetful and if Narsih does not remind her, she forgets to take the drugs. Sometimes she has to remind her mother three or four times before she takes the drugs. Some days she has to give her mother a glass of water and the drugs and insist Ina swallows them. (See also page 37)

In situations like Ina and Narsih’s, the role of the treatment supporter in treatment is crucial. Old people can be forgetful and sometimes stubborn and refuse to take the drugs.
regularly. Treatment supporters may sometimes find themselves in difficult situations, although they all seemed to find ways to persuade their patients take the drugs. But it is not only old patients who can put their treatment supporters in a difficult position and make their task almost impossible despite their good intentions and efforts.

Malik (50) is very impatient when he talks about his treatment. He is unhappy with the results of treatment because it takes far too long. He wants to get better quickly and feels the drugs are not working. Yo, his daughter, told him to keep taking the tablets and that he would feel better soon. She was right. Now Malik says he is much more motivated to take the drugs although still he feels bored with them. When Yo offers him the drugs, sometimes he complains to her: “Not again.." But Yo always insists by saying: “If you love me, you take the drugs” and then Malik gives in. (See page 32 for more about Malik)

The above example showed how the family relationship between patient and treatment supporter provides an opportunity to use “emotional power” as a means to persuade the patient take the drugs. Emotional “power” may be a powerful means, it is also a means that an outsider, e.g. a health worker, cannot use. There are, of course, limits to persuasion. In the end, treatment supporters cannot force patients to swallow their drugs but neither can health workers, as the following example illustrates.

Nani (40) is treatment supporter to her husband Nasir (43). Nasir stopped TB treatment because he was diagnosed with diabetes (see also page 33). Nani wanted him to continue but he refused. When she insisted he became angry with her. She admits that after a while she stopped trying because Nasir refused to change his mind and has his own ideas about TB and diabetes. The health worker visited him at home and tried to persuade him to continue but he did not want to unless he gets diabetes treatment first.

Patients are sometimes stubborn and hard to deal with. Some have their own ideas about TB and treatment. In these cases, as the example of Nani shows, it can be very difficult if not impossible for a treatment supporter to persuade them to keep taking their drugs. Among the defaulters in this study, the two young men also prove to be difficult patients.
They had other priorities in their lives and had irregular schedules. Both of them also did not really seem to care about whether they were cured or not. Their mothers were assigned to be the treatment supporters. Although both mothers were positive about their son’s attitude and motivation at first, they had to admit that they did not manage to keep their sons on treatment. The impression was that these mothers did not hold enough power over their sons and could not make them take the drugs. The concerns are in these cases that resisting patients are left untreated and if infectious, are a serious health concern for the people they live in close contact with. Responsible health workers acknowledge that they are sometimes unable to provide solutions as well.

Treatment supporters who deal with motivated patients admit that their support is somewhat superficial. Motivated patients remind themselves to take their drugs, they are aware of the importance of adherent behaviour. In these cases, the tasks of the treatment supporter are somewhat adjusted. Instead of reminding and observing the patient take the drugs, they usually limit themselves to monitoring the patient and providing care by cooking healthy food or taking hygienic measures (see also 5.2.3).

4.2 Disease and infectiousness

People who get infected with TB are generally poor and do not have easy access to health services. Their perception of the disease and infectiousness impacts the way they deal with it and their behaviour towards others. Patients and treatment supporters talked about their ideas and perceptions of TB and its treatment during the conversations about family DOT. Their stories provide an interesting context that helps to understand why patients succeed or fail treatment and how they explain success or failure.

4.2.1 TB awareness

TB awareness refers to general knowledge about the disease, its treatment and prognosis. In a high prevalent environment, it can be expected that most patients know about TB before they are diagnosed themselves, or know of people with TB. 15 patients had indeed heard of TB before they were confronted with their own diagnosis. 14 out of he 16
patients and their treatment supporters also knew someone in their social circle or in their family who had TB.

Patients as well as treatment supporters should be informed by health workers about TB and its treatment. Some patients were more aware of TB than others but this was not always due to the quality of health education, as the following example shows:

**Umyati** is a sturdy and very friendly woman in her early thirties. She is treatment supporter to Zumri, her 63 year old father in law. She has four small children. Zumri lives in a simple stone house where his grandchildren as well as some chicken and roosters run in and out. Umyati lives just around the corner with her family. Zumri and Umyati suspect that Zumri’s wife died of TB.

Zumri has had TB for a very long time, he says, but was unaware of its symptoms. Umyati says she has never received any information about TB nor treatment from the heath worker. All they were told is that Zumri has TB and needs to take drugs. What they know about TB, they have learnt from television.

Other patients seem well aware of TB prevalence in their neighbourhood or social circle. Some mention that they know people that have or had TB, sometimes they know of someone that died of TB. Two patients mention the high number of TB cases in their neighbourhood. The exception is one older female patient who had never heard of TB before she herself was diagnosed; her treatment supporter had also been unaware of TB.

**Salbiah** (55) is a fragile looking woman in a yellow dress with a black headscarf. Salbiah has TB and visits the health centre with her niece Uun (42). Uun is her aunt’s treatment supporter. Salbiah has just finished a prolonged intensive phase and is still smear positive. She now has to come to the health centre every day for the next two months to have a streptomycin injection. Both Salbiah and Uun had never heard of TB before Salbiah’s diagnosis. They also do not know of anyone with TB. One of Salbiah’s cousins told the neighbours about Salbiah’s condition. The health worker advised Salbiah to have her husband and two sons tested as well because they live in the same house. They tested negative.
It seems almost impossible in a high prevalence area for someone to have never have heard of TB. Still, Salbiah also told people outside the family that she was diagnosed with TB. If she had been aware of TB and its social consequences, she might have chosen not to do so. The 2004 prevalence survey data revealed that the oldest age group has the least knowledge of TB (Ministry of Health, World Health Organization et al. 2007).

### 4.2.2 Symptoms

Ati is a 63 year old widow with four sons and nine grandchildren. She first discovered something was wrong with her health when she visited relatives outside Bogor. They told her she had lost weight. She also had a persistent cough. When she returned home, she went to the health centre (See page 43 and 51).

All 16 patients tell similar stories. Their health problems started with a cough, sometimes with blood, breathing problems, fever and weight loss. In most cases, the cough with blood was the reason to seek healthcare. Twelve informants said that they were advised by a neighbour, friend or family member to go to a health centre when they witnessed the informant cough up blood. The older informants also mentioned stomach problems as a symptom and complained about them not disappearing after they had started treatment. Except patients with a cured TB patient in their families, no patient said s/he went to the health centre because they were suspecting TB. They went because they had persistent health problems. Ex-TB patients recognized the symptoms right away and advised the family member to go to the health centre to get tested.

### 4.2.3 Infection control

Although all informants mentioned a cough as one of the indications of TB, they did not mention it again in the context of infectiousness and infection control. All informants, including several health workers, were convinced that transmission of TB takes place by sharing cups, plates or cutlery with a TB patient. Some informants gave detailed accounts
of their attempts to keep other family members healthy by using different cups, plates and cutlery.

All patients were living with several, sometimes up to nine, relatives in just a few rooms. In every household visited, children below the age of five were found. Only one child was taking six months of preventive therapy; the others were never tested nor on preventive treatment, although this is a national TB guideline. The explanation of parents and grandparents was always the same: “The children look healthy, they are fine”. There seems to be no understanding of TB infection without being sick. The dangers of TB infection for young children, such as meningitis, are also unknown.

All patients’ homes were rather small and dark. Because of the heat people avoided direct sunlight in their living room, so they either had very small windows or they closed and covered the windows during the day. Some patients were poorer than others, judged by the appearance of their houses. In the poorer homes, hardly any sunlight came in during the day, nor were there windows that could be opened to provide some kind of airflow. During the first few visits, the translator suggested to have the interviews outside because of the condition of the houses. Yet, all interviews were held inside, because I was concerned to compromise the informants’ confidentiality. Communities are tightly knit and people are curious and try to sit in on interviews whenever they can. A friendly explanation and request to leave us alone for the interview was usually enough for people to go outside and wait there, although some tried to sit near the window or in the door opening. The following descriptions give an indication of the housing situation of two informants.

**Ardi’s house** is small and dark. It is dirty, there is nothing on the floor and his bed is made out of a wooden frame with carton on top. The living room is small, with nothing more than a chair and a small table. On the table is a TV set. Ardi works in front of the house. The front resembles a wooden stable that provides shelter from the sun (See also page 46-47).

**Ati’s house** is a simple house, dark and rather empty. There is only one chair available which she gives to me. Toti (translator) and Ati sit on the floor. I try several times to sit on the floor as well but Ati will not let me. At the small table is a plate with some fruits covered
with small insects. Every time someone moves closer to the table, the insects fly away, only to return when they can (See page 41 and 51 for more about Ati).

One informant talked about the health worker’s visit to his home:

**Asep**, a TB patient, lives with his wife and son in a small room behind a shop. Asep runs the shop with his brother. They sell telephone cards. The room is full of old electronic equipment. There are no windows. Behind the room is a small kitchen and bathroom. The health worker visited the house twice to check the air circulation. He told Asep that the air circulation was not good. Asep says: “What can I do? It is the way the house is and I have no money to make changes”. (See also page 37)

Infection control measures and knowledge about transmission are important tools in controlling TB from spreading. Information from patients, treatment supporters as well as health workers show that there are several misconceptions about transmission in particular. Most people believe that hygienic measures like providing a separate plate and cup for a TB patient will prevent TB from spreading among those in close contact. This understanding of TB seems to be deeply rooted. Health workers even advise patients and families to take the traditional hygienic measures. A Dutch TB nurse who treats TB patients in The Netherlands confirmed hearing similar remarks and beliefs among Indonesian patients. In itself, there is nothing wrong with taking hygienic measures and if it makes everybody feel better, they should certainly do so. But people should not be made to believe that they are taking measures to protect one another from getting infected. They should be made aware of the actual mode of transmission.

### 4.3 Factors influencing adherence to treatment

Regular TB treatment takes six months, which is a relatively long time. To achieve cure, it is important that patients complete the full six months treatment. A major pitfall during treatment is that patients start to feel better after a few weeks. Not much later they feel as if they are healthy again. To continue treatment although there seems to be no need is
incomprehensible for many patients. One of the main reasons for implementing DOT is exactly to help patients through this difficult phase of treatment. This study on the role of family members in DOT, provided interesting information regarding factors that influence adherence to treatment, which will be discussed below.

4.3.1 Duration of treatment

When discussing TB treatment one of the first questions patients asked pertained to the duration of treatment. Patients found it clearly difficult to oversee such a long period of time. Questions about how many months they were on treatment or how many months they still had to go, proved very difficult to answer, also for treatment supporters. Some had no idea about the duration of treatment at all.

**Hadi**, TB patient, is a 60 year old married man with two children. He lives together with his wife, his daughter Salima (27), her husband and two children. Salima is her father’s treatment supporter. The health worker gave them some information about TB and the required treatment. Hadi stopped treatment after two months because he could no longer cope with the side-effects. Both Salima and the health worker have tried to persuade Hadi to finish his treatment but so far he refuses. Hadi says he does not know how long the treatment is and that he will not start treatment again unless he knows how long it is. Salima smiles apologetically but she does not know how long treatment is either (See page 48-49).

**Ina and Narsih**, mother and daughter, look puzzled when asked how long Ina’s treatment will take. They discuss a little bit among themselves and then answer that they think it will last 6 months. It is clear from their faces that they are not sure. Then Narsih opens the little Tupperware box that she carries with her and takes out a yellow card. She starts counting and in the end confirms that treatment will take six months. (See also page 37)

**A health worker** at one of the health centres told us the story of Aishya, who defaulted treatment after two months of irregular treatment. Aishya is a house servant and asked her
boss to be her treatment supporter. Aishya stopped treatment because she got married and moved away to live with her husband. Her boss told the health worker that Aishya had told him that her treatment had finished. He believed her and let her go.

Although patients and their treatment supporters almost all said that they had been instructed by a health worker, the focus of the information seems to be on adherence. Patients should take their drugs regularly and consistently. This is not wrong but adherence may become compromised if patients do not have some sense of duration. It may very well be possible that patients find it more difficult to be adherent without knowing the end date than when knowing exactly when all will be over.

4.3.2 Treatment characteristics

In Indonesia, the national guidelines prescribe a two month intensive phase with daily intake of drugs and a four month continuation phase with a drug intake of three times a week. In the continuation phase, patients are recommended to take drugs on Monday, Wednesday and Friday (see also paragraph 1.1).

Regularly adhering patients and their treatment supporters did not report many problems with the switch from a daily to an intermittent regimen. They were more than aware of the importance of regular intake of drugs. Patients proudly told stories of never having skipped a dose:

Iah is a woman of 32, TB patient, and married to Asep (42); together they have three children. They are very shy and speak softly. They live in a modest home without any visible furniture. Grandmother lives with them the same house. Asep is his wife's treatment supporter. Both Iah and Asep say they have no problems with taking the drugs and that they have never forgotten. Asep says that he often has to go away for work. He smiles broadly when he introduces his daughter of 14 and explains how he has instructed her to take over his tasks of treatment supporter. The daughter knows exactly which days her mother has to take the medicines. All agree that it works very well. Grandmother nods approvingly. Iah goes on to tell that she was diagnosed with TB when she was pregnant
but only started treatment after the baby was born. Now, she suffers from headaches due to the drugs. They are very uncomfortable but she says she has never skipped a dose (see paragraph 2.2).

Other informants admitted that they sometimes simply forgot to take their drugs. However, daily intake seems to present less problems than intermittent because it becomes a routine more easily.

**Upi**, a 45 year old outgoing woman, told us about her good intentions to take the TB drugs with her when she left home for a few days. Her treatment supporter Ela also reminded her several times. Upi was convinced she had put the tablets in her bag but when she arrived in the city and wanted to take her drugs, they were not there. (See page 32 for more about Upi)

Simply forgetting to take drugs, because the daily routine is interrupted is, of course, very recognizable. It probably happens to everybody once in a while without major consequences. In TB treatment, *repeatedly* missing a dose during the course of treatment, however, may hamper cure significantly, especially during the intensive phase. Even very motivated patients and treatment supporters may sometimes forget. Some were honest about it; others kept it to themselves. One health worker remarked that although many patients finished their treatment, she was convinced that many were irregular during treatment.

An important problem was that patients and treatment supporters seemed to be at a loss what to do after they realized they had forgotten a dose. The following situation of a patient and his treatment supporter illustrated that they were unaware of the consequences of forgetting a dose and did not know how to solve the problem of what to do with the leftover dose.

**Ardi** is a 22 year old, shy and soft voiced man. A Javanese man, he adds. His wife Nina is 19 and Sundanese. They had two children: one was a stillborn; their 8 month old daughter

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2 Javanese means coming from Central Java
is still alive. They talk about their experiences with Ardi’s TB treatment which seems to progress without any troubles. Nina tells about her strategy to remind Ardi to take the drugs when she is away: she tapes them in the middle of the television screen. Ardi says that he can never miss a dose because they are right in front of him. When Nina is at home, they have also never forgotten. After a moment of silence, they look away and smile awkwardly. Last Monday, they confess, both of them had forgotten about the drugs. They don’t know what to do now. Should Ardi take those drugs the next day or forget about it and continue on Wednesday? They look puzzled and embarrassed at the same time. They have not told the health worker yet, but they say they want to tell her (See also page 42)

The switch from the intensive phase to the continuation phase proved to be difficult for many patients and treatment supporters. Both patients and treatment supporters had to adjust their newly developed routine of taking drugs daily to taking drugs three times a week.

**Nasir M** (40) has TB. He lives with his wife Aminah and their six children in a very poor area in Bogor. The health worker and the head of the health centre say that it is very difficult to live in this area because of poverty and disease. Nasir has no regular job. He keeps a few sheep in a barn behind the house. Aminah says it has not been easy to keep Nasir on treatment because when he felt better he wanted to stop. When she could not make him take the drugs and he had missed three times the health worker came to check and managed to persuade Nasir to continue. Nasir looks away and seems to be ashamed. The switch from daily to three times a week was difficult but Nasir feels much better. He explains that it is easier to remember to take drugs daily but they made him feel sick. Three times a week makes him feel better but it is easier to forget.

Regularity and routine are important to ensure adherence to treatment. The switch from a daily to an intermittent regimen makes it more difficult for both patients and treatment supporters to be adherent. The daily routine probably fits in more easily with other activities that are done on a daily basis. And there is no need to think very hard about

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3 Sundanese refers to West Java
what needs to be done. Having to take drugs three times a week presents more trouble for both patients and treatment supporters. They will have to keep track of the days and remember which days are drugs free and which are not. Forgetting is much easier, understandably so. One treatment supporter put it very accurately when she was talking about her tasks: “Who will remind me when I forget?”

To ensure a smooth switch from a daily to an intermittent regimen patients and treatment supporters should receive adequate health education. Health workers play a crucial role in supporting both patient and treatment supporter through the transition. They can provide support and show understanding. A simple tool like a treatment card could be helpful in remembering and keeping track of the days.

4.3.3 Drugs

Apart from the duration of treatment, the drugs themselves may also cause difficulties for patients. Quite a few patients, whether adherent or defaulting, questioned the effectiveness of the drugs. They expressed different concerns regarding the effectiveness. Some said they felt the drugs were not working, their health deteriorated and symptoms became worse. For some, this was a reason to either stop treatment or seek (additional) care elsewhere. Additional or alternative care meant either a private clinic, a hospital, or a traditional healer. All these options required fees of some sort.

Patients who experienced discomfort from drugs were more likely to quit treatment. Some patients complained about side-effects like rash and itch all over the body and headaches. For three patients, this was a reason to stop treatment, often without consulting a doctor or health worker (See paragraph 2.2).

**Hadi**, a 60 year old man (see also page 44), got an itching rash over all of his body and stopped taking drugs after two months. His daughter told the health worker about the itch. The health worker told her that Hadi should continue taking his medicines and that the itch would go away. But Hadi refused. He had trouble sleeping because of the itch.
A TB treatment regimen consists of several drugs. In general, a TB patient has to swallow 4-5 tablets a day. For two patients, both men, just the number of drugs, was enough to make them stop treatment. Sooner or later, they became so aversive to the number of tablets that they simply gave up (see paragraph 2.3). Soleh put his experience with the drugs into the following words:

**Soleh** is a shy and skinny young man, 20 years old. He lives with his mother and two brothers in a small, dark house. The house is very difficult to reach. Soleh has just started work in a tire-making plant in Jakarta. His mother is his treatment supporter. Soleh stopped treatment after two weeks. Although his mother is worried about his health, she has not contacted the health worker. Soleh says he cannot take the drugs anymore because he thinks they are horrible. He cannot make himself swallow them. He says that he doesn’t understand why people with other diseases only have to take one or two tablets while he has to take eight every day. He says he prefers to live with a little cough and he feels much better already.

### 4.3.4 Socio-economic factors

Even though, eight patients are very motivated and able and willing to take their drugs regularly and do not seem to need treatment support, there is always the threat that they will stop treatment. There are many factors, experiences, beliefs and events that influence adherence. Yusup, a young man was called: “the most adherent patient we have ever had” by his health worker but interrupted treatment after two months because he could not afford the weekly registration fee at the health centre any longer (which he was not supposed to pay!).

The 16 patients in this study all had similar socio-economic backgrounds, although two were a little bit more well off. These two patients had the benefit of a government pension or a husband with a steady job. For one of them, the better socio-economic situation could be deduced from the amounts of money, she said, she had to pay for private health care; for the other, the state of the family house, suggested no
financial issues. It should be made clear that there were no indications to suggest that respondents belonged to a very different socio-economic group than the others.

Many patients talk about well-meant advice the health workers gave them which they were unable to follow because of financial reasons. Some borrowed money to be able to enhance their chances of cure. Financial issues often become a burden for patients and their families. Patients may be too sick to go to work, particularly during the first weeks of treatment. On top of that some are afraid to go to work because they either fear infecting others or that their colleagues will ignore them. The financial consequences of patients not being able to work are strongly felt in the family. The people in this study were all poor; none had the financial resources to bridge a period of not working. Some tried to borrow money from family or friends, others cut down their expenses by choosing cheaper options for meals. One of the health workers commented on this situation: “It is not easy to live in this conditions, people often become depressed”. The financial burden weighs heavily on TB patients and their families in these circumstances. Not only do patients suffer from TB but they also suffer mentally from seeing their relatives dealing with the financial consequences. Three of the four adherent male patients had irregular work or worked around the house. Two of them managed to adjust their treatment regimen to their working schedule, which enhanced their chances of finishing treatment. Five of the eight defaulting patients went back to work after they felt better and had problems maintaining their treatment because of irregular working hours and working locations.

4.3.5 Health services

The perceived quality and reliability of the health services are a key factor in adherence to treatment (See paragraph 2.2). The patients’ perception, whether true or false, can make or break adherence to treatment. As TB patients often depend on public health services, their perception of these services is crucial. For most patients in this study, the health centre was their first choice and they did not complain about the services provided. However, one patient had her doubts about the quality of the health services albeit
Ati is 63 and a widow (see also page 41 and 51). She lives in a small and dark house with one of her four sons. She proudly says that she has nine grandchildren. Ati initially started TB treatment at the health centre when one day she had trouble waking up and had bloody stools. As she is also taking diabetes medication, the doctor proposed to stop TB treatment for a while and when the diabetes was under control, to restart TB treatment. Ati agreed but never went back to the health centre again. She says she does not trust the doctor at the health centre. She also does not like the health centre as it is always crowded with people everywhere. On top of everything she does not trust the free drugs. She is afraid the free drugs are not good for her health. Instead she now goes to a private clinic and follows diabetes and TB treatment. She admits she has to pay quite a lot of money for the drugs as well as the consultations but she does not seem bothered by the costs. She explains she receives a small pension from her husband who used to be a government employee.

Patients as well as treatment supporters often expressed doubts about the health workers’ commitment. Complaints included lack of home visits, information about TB and concern for patients. An important issue for patients as well as treatment supporters seemed to be that health workers hardly ever visit patients at home. Many expressed their dissatisfaction.

Health education about the TB, its treatment and infectiousness was crucial for both patient and treatment supporter. In many cases, both complained about the amount of information they had received. Treatment supporters only had been told that they should take care of their family members with TB. The principles of DOT were, however, hardly ever discussed and explained, nor were they instructed about what to do in case of side-effects.

Public health services have their own problems that may refrain them from providing adequate care. These problems include lack of adequate funding, shortage of competent staff, high staff turnover and lack of transportation and other facilities.
Delegating part health workers’ tasks in TB treatment and patient care to family members does not excuse health workers from their responsibilities to provide adequate health education, supervision to patient and treatment supporter and assistance when needed. At the same time, it is the health service’s responsibility to supervise health workers, to build their competence by providing training, and to ensure facilities that enable them to do their job.
5. Discussion, conclusions and recommendations

In Bogor, as in all of Indonesia, the TB program follows the WHO recommended strategy of DOTS. In Indonesia, a family member is generally appointed as treatment supporter. The aim of the present study was to explore the treatment supporters’ contributions in family DOT to TB treatment adherence in Kota Bogor.

Patients and treatment supporters all agreed that involving family members in treatment is the only way they would like it. The family and the family home is where patients feel comfortable and at ease. They do not have to hide the TB diagnosis from their relatives. It is often a family member that urges someone to see a doctor if TB symptoms present themselves, and also accompanies the patient on his first visit to the health centre. In general, treatment can easily be fit into the family routine. Also, because of the family ties, there is always someone around that can be the treatment supporter and family members do not allow someone to suffer on his own. Overall, it is fair to say that patients are content with the support of a family member. In this respect, there were no differences in opinion between adherent and defaulting patients, nor between their treatment supporters.

Family life in Indonesia is very closely knit. Indonesian families can be described as extended families. Family is a broad concept. Not only are blood relatives regarded as family, in laws and their relatives are also considered “part of the family”. It is within this specific context that family DOT is such a natural and straightforward option. In Kota Bogor, approximately 60% of treatment supporters are women which is consistent with their role to provide care and being available at home. 14 out of 16 patients had female treatment supporters. Depending on age, male patients had either their wife, daughter (in law) or mother as a treatment supporter. Female patients also had female treatment supporters, usually a daughter or sister.

Family DOT has been debated for quite some time now among TB experts worldwide. The WHO has not endorsed the alternative of family DOT yet, although they acknowledge the need for alternative DOT strategies adjusted to local circumstances. In the traditional concept of DOT, a qualified health worker is supposed to carry out the DOT tasks. The main argument against family DOT is that the emotional bond between
patient and treatment supporter and the power relations within the family could impede adherence to treatment. Family members would want to avoid conflicts at the expense of treatment and the easiest way to end an argument about the treatment is to stop the treatment. In this study, no evidence was found to support this argument. Emotional bonds seem to motivate treatment supporters to take care of patients and to do whatever it takes to ensure cure. However, it cannot be denied that it is sometimes difficult to support a resisting and stubborn patient. Treatment supporters sometimes struggle to make the patients take their drugs. And, of course, they do not always succeed in keeping their patients on treatment. However, health workers struggle as well with resisting patients; they also cannot force an unwilling patient to be adherent. Failure of treatment happens despite the best intentions and efforts to keep patients on treatment and to support them through the six months, whether it be by a family member or a health worker.

The argument of the power relations within a family being a barrier to adherence to treatment holds some value. One of the criteria for selecting a family member to be treatment supporter is that s/he has some authority in the household. This is not always feasible, for instance, when parents are old and their adult children have to provide DOT. Sometimes then difficult situations may arise, especially when patients are unwilling and stubborn, because the patients have more authority. But motivated treatment supporters appear resourceful and find other ways of persuading the patients to take the drugs. Some use emotional power, others are extremely patient and in the end seem to be able to persuade their patients to take the drugs. Despite these more negative experiences of patients as well as treatment supporters, their ideas about family DOT remain positive. Health and disease are family matters and should be dealt with within the family.

TB is a highly stigmatized disease, globally and also in Indonesia. Thus, TB patients are very keen on keeping TB a secret. The less people are aware of a patient’s condition the better. Fear of stigma is mentioned as another important reason for patients to prefer family DOT. Through family DOT, they will be able to keep TB within the family and they can rely on their family’s confidentiality. It is interesting to see that 15 out of 16 patients had only exposed their condition to (part of) the family while only 1 patient had also told someone outside the family. Treatment supporters confirmed this and also did not tell anyone outside the family. Family DOT thus becomes a way of
safeguarding the patient’s as well as the family’s reputation. They do so by keeping the amount of information they give to other people vague, by making sure the patient does not have to go to the health centre to pick up the drugs every week, by keeping a patient inside if necessary, by taking hygienic measures, by accompanying the patient to the health centre for check-ups, and by preparing the drugs and reminding the patient to take them.

All 16 patients and treatment supporters mentioned feelings of shame and embarrassment, *malu* in Indonesian, when they talked about having TB. This feeling of shame prevented them from disclosing to people outside the family, not even to friends or neighbours. For some, this feeling of shame is a reason to be very adherent, for others it is a reason to default. Patients who are meticulously adherent because of shame are very eager to get rid of the disease that may make other people get the wrong ideas about them or fear exclusion from the community or social groups. In these cases, feelings of shame or embarrassment are as an incentive to be adherent. For defaulters, it works the other way around. Defaulters talked about feelings of shame and wanting to resume their normal lives as soon as possible. They chose to stop treatment when feeling better to avoid being identified as a TB patient. Defaulters talked about different experiences that made them fear disclosure, like regular visits to the health centre. Defaulters were also less able to stand up to side effects of TB drugs. Adherent patients seemed able to withstand side effects while defaulters used them as a reason to quit treatment.

It is striking to hear how little some patients, treatment supporters as well as health workers actually know about TB and treatment and what misconceptions still exist. Health education and adequate training is key to TB control in general but also to improving individual adherence to treatment in particular. When patients have been diagnosed with TB, they and their treatment supporters should receive extensive and repeated health education.

All but one old patient and treatment supporter were aware of TB at diagnosis, which meant that they had heard about TB before and sometimes knew someone, inside or outside the family, with TB. Two patients were also aware of the high prevalence of TB in their neighbourhood or district. Overall knowledge of TB and its transmission was very low. None of the patients mentioned a cough as a means of transmission. During the
interviews, all 16 patients seemed convinced that the members of their domestic group were healthy because they looked healthy and felt fine. This indicates also unawareness of the difference between being infected and active disease. All patients easily summed up the TB symptoms that they themselves had suffered from: persistent cough, sometimes with blood, weight loss, fever. Other symptoms mentioned were difficult breathing and stomach pains. The main reason to go to a health centre was coughing up blood. Apparently, patients as well as treatment supporters did not know that a persistent cough might be an indication of TB and is enough reason to visit the health centre. Most waited until they coughed up blood and were very sick.

Part of the efforts to control TB is preventing TB from spreading. Knowledge of transmission and preventive measures are essential for both patients and household members. The accounts of patients and their families and their perceptions of TB transmission and disease give enough reason for improving and increasing health education both to the general public as well as to patients. However, high awareness of transmission and risks of infection may cause other problems. People may become scared of TB and fear becoming infected themselves. This may lower the willingness to support a TB patient within the family.

**Factors influencing adherence to TB treatment**

Several factors seem to influence adherence to TB treatment. First of all, there are the specific treatment characteristics like duration of treatment, the treatment regimen and drugs. Second, there are factors in the patient’s situation that can determine adherence: social economic factors and health services. Family support and care are also influencing factors for adherence. They were discussed separately in the previous paragraph.

Some patients and treatment supporters said that they did not know how long TB treatment would take. The relative long duration of treatment is in itself already influencing patients’ adherence, in particular when they start to feel better again. Having to take a substantial number of drugs and not knowing for how long may at a certain point discourage patients and make them decide to quit. Having a clear idea on when treatment will end and how long it will take is essential for finishing treatment. Adherent
patients never complained about the duration of treatment, even though sometimes they did not know how long they had to continue treatment. Their focus seemed on the treatment outcome. By contrast, defaulters complained about both long duration and not knowing how long a full course of TB treatment would last. In both cases, they took this lack of information as a reason to stop treatment instead of asking the health worker.

The complexity of TB treatment is often mentioned as an influencing factor. In this research there were two patients that explicitly mentioned the number of tablets that they had to swallow each day as a reason to stop treatment. Although this is perfectly understandable, there is not much that can be done at the moment. TB treatment means swallowing at least eight tablets each day during the first two months. The other part that makes TB treatment complex is the prescribed regimen. The switch from intensive to continuation phase increases the risk of forgetting. Patients and treatment supporters mention that having to take drugs daily is much easier than taking drugs three times a week. On top of this, it takes some time to develop a daily routine. By the time it works well, this routine has to change to three days a week. Forgetting a dose in the continuation phase presents more problems than daily intake. Treatment supporters do not know how to solve this problem.

Side effects are an unfortunate consequence of the treatment regimen. Not all patients experience side-effects but patients who do find them very difficult to cope with and some decide at a certain point to stop treatment. Most mentioned side-effects are headaches and an itching rash all over the body. Itching rash in particular is an important reason to stop treatment. Side effects can to a certain extend be controlled but they can only be controlled if the health worker or doctor knows about them. Feedback of patient and treatment supporter to the health worker and effective action by the health worker is essential in dealing with side effects.

The experiences of patients and treatment supporters therefore reveal that a substantial number of reasons why patients stop treatment are related to treatment characteristics. Not all can be improved to enhance adherence, for instance the number of tablets. But the difficult switch from daily intake to three times a week is a factor is worthwhile reconsidering. Treatment regimen in other countries such as The Philippines
Tanzania and Kenya demonstrate that it is possible to evade switching by prescribing daily intake in both treatment phases.

In TB patients’ lives many situations may occur that can influence adherence to treatment. Literature shows that factors influencing adherence are for a large part universal and disease-independent (Vermeire, Hearnshaw et al. 2001; Sabaté 2003). More general factors related to adherence that came up during this research are socio-economic factors and factors related to health services.

Most TB patients in Kota Bogor live in poverty. They were already hesitant to come forward for treatment because of the financial burden that having TB implies. It is therefore very important to make sure that patients receive the diagnosis and treatment that they are entitled to, which means free of charge. All patients in this study received diagnosis and treatment free of charge. However, several of them talked about additional costs such as money to buy healthy food and registration fees, that they were sometimes only able to pay after borrowing money. The ones that could not afford the additional costs decided to stop treatment.

Health services are an important factor in whether or not patients are adhering to treatment. For some patients in this research, the public health services (including health workers) were not the first choice. Many patients did not know that diagnosis and treatment were free and, for financial reasons, turned to other options. Patients with people around them that knew about free TB services, often went to the health centre right away. Positive experiences of others seem the best advertisement for the TB services. The attitude of health workers towards patients is also a decisive factor to adherence. Most patients mentioned scarce contact with health workers. Patients do not turn to health workers when they experience problems, neither do treatment supporters. On the other hand, most health workers only talk to patients and treatment supporters on their first visit to the health centre and incidentally when they pick up their drugs. Feedback and communication between patients and health workers and between treatment supporters leaves much room for improvement. Now, health education to patients and treatment supporters is very limited and sometimes incorrect. Health workers often lack adequate training which hampers solid health education.
5.1 Conclusions and recommendations

Patients and treatment supporters prefer family DOT for reasons of confidentiality and convenience. However, for family DOT to be an effective way of providing TB treatment, health workers should intensify health education to and supervision of patients and treatment supporters. This may include regular home visits and follow up visits when drugs are not picked up regularly. Generally, patients and treatment supporters are unfamiliar with TB treatment and have to deal with often difficult issues. Family DOT should be more than just instructing a family member to make the patient take drugs regularly. On top of intensified health education and supervision, health workers should work on a trusting relationship with patient and treatment supporter to lower the barriers for them to report irregularities and side-effects and discuss them but also to ask any question about what may be bothering them about TB and treatment.

Health education to both patients and treatment supporters is an essential part of ensuring adherence to treatment. The more people understand what they have to do and why, the bigger the chances for a successful treatment. Providing incidental, unnecessary or incorrect information increases the risk of non-adherence. Patient and treatment supporter receive oral health education only and often only after they have just been told that they have been diagnosed with TB. Next to intensifying health education, it is recommendable to provide patient and treatment supporter with written instructions such as a booklet or leaflet. This should include instructions about TB treatment and the treatment supporter’s tasks. Information about side-effects should be also included with clear instructions about what actions to take. Finally, a simple tool like a treatment card or box may help the treatment supporter keep track of the days and the necessary dosage. Considering the size of families and their living conditions, messages and instructions regarding infectiousness and transmission of TB should be accurate and clear. Families with TB should not only be made aware of the risks of having an infectious TB patient in their midst but also about preventive measures they able to implement without too much effort or costs.

The TB treatment regimen is long and complex. The switch from intensive to continuation phase after approximately two months means altering a newly developed daily routine to a three times a week routine. This change enhances the chances of
irregular drug intake due confusion and forgetting, and in some cases of stopping
treatment. It is worth considering streamlining both phases, preferably to daily intake in
both phases to avoid the above mentioned threats to adherence. The national guidelines
on preventive therapy for children under the age of five should be implemented.

Family DOT proves to be an important means for families to keep TB a secret from the outside world. Apparently, it is still necessary or families perceive it as
necessary to secure the patient’s reputation. Stigma, whether real or perceived, is a strong
motive for secrecy. Health services not only have responsibilities to individual patients
but also to public health and therefore should continue to pay attention to educating and
informing the community. It is worth exploring the possibilities of inviting cured TB
patients to participate in community education. In leprosy control, experiments with
cured patients participating in community education held much promise, especially when
they contradicted community stereotypes (Idawani, Yulizar et al. 2001). Health
education to the community could help alleviate stigma and stigmatizing behaviour.
Therefore, information about TB should also be widely available to the community.

TB patients often live in underprivileged circumstances. Although diagnosis and
treatment is free for all TB patients, patients’ reports on why they stopped treatment
include social economic circumstances. Special attention should be given to avoidable
errors and misinterpretations of procedures to avoid unnecessary financial burden for
patients. There should be no financial surprises for patients. Well-meant advice to
patients and their families that require additional finances should be carefully weighed.
Rather give advice that is achievable without any financial consequences.
Summarized recommendations

To the National TB Program

TB treatment:
- Consider streamlining the two phases of the treatment regimen, preferably to one daily regimen
- Consider providing a treatment card for treatment supporters
- Ensure and facilitate the implementation of national guideline on preventive therapy for children under the age of five

Training:
- Provide adequate training for all health workers active in TB control. Training should include knowledge about TB, transmission, infectiousness and preventive measures. Communication and supervision skills should be included in the training for health workers to become competent and committed supervisors and encouragers for patients and their families.

Health education:
- Intensify TB health education at individual as well as community level
- Consider involving ex-TB patients in community health education
- Provide simple written instructions about TB, treatment and preventive measures to patients and treatment supporters

To TB health staff
- Encourage patients and treatment supporters to ask questions and to come forward with any problems they have
- Be consistent in following up patients who do not show up at the health centre to pick up the drugs
- Ask questions to patients and treatment supporters to assess how they are doing with treatment
- Repeat health education several times
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World Health Organization 

World Health Organization 

Annex 1   Interview guide for patients

A.   Introductions
Greetings and introductions
Explain purpose of interview and confidentiality
Ask permission to proceed

_The focus of the patient interviews will be on every day experiences with family DOT._

B.   Introductory questions
1. Start of the disease: roughly how long ago?

C.   Treatment
1. Did the health worker tell you about DOT? What is it?
2. What options were you given for DOT? What made you choose [name family member]? What is your family relationship?
3. Have you received any assistance in choosing a treatment supporter? If yes, what did they tell you?
4. Does the health worker know who your supporter is?
5. Have you changed supporters over time? What were the reasons for this?
6. Where does your treatment supporter live? (if outside the patient’s residence: how far away?)
7. Do you manage to take your drugs every day? If yes, is your supporter always present? If no, reasons?
8. What happens if you do not feel like taking the drugs? How do you deal with your supporter? What does he/she do in this situation?
9. What happens at times when your supporter is not available? Has this ever happened? How did you deal with this situation?
10. Who collects the drugs at the clinic? How often?
11. How often do you have an appointment at the health clinic?
12. Have you managed to keep all appointments at the clinic so far? If no, how may missed and why?
13. What happens if you miss an appointment?
14. Do you ever go together with your supporter to the health clinic? If yes, why?
   How often?
15. Does the health worker visit you at home? If yes, how often?
16. What does the health worker do during home visits? How do you feel about these home visits?
17. Have you ever stopped treatment for a few days/weeks? Why? What made you start again?
18. Do you experience any side effects? If yes, who do you tell about this? supporter/health worker/doctor?
19. Could you explain how you and your treatment supporter organize DOT? Specific place, time?
20. Is your supporter helping you in any way to stick to treatment? How? Examples?
21. How do you feel about your supporter being a family member?
22. Are there other people in your life that you would have preferred to be your supporter?
23. Do you know if the treatment supporter has received instruction from health worker? How often? Do you talk about this together?
24. Could you have managed your treatment by yourself? Why do you think that?

F. Personal data
These data were collected from treatment cards and were verified during the interview.
- Age
- Marital status
- Number of children
- Educational level
- Religion
- Occupation
- Date start of treatment (as on treatment card)
- Type of TB (as on treatment card)
- Regularity of treatment (as on treatment card)
- Treatment supporter (kinship)
Annex 2    Interview guide for treatment supporters

A.   Introductions
Greetings and introductions
Explain purpose of interview and confidentiality
Ask permission to proceed

*The focus of the treatment supporter interviews will be on every day experiences with family DOT.*

B.   Disease history
1. When did you first hear about your family member’s disease? Roughly how long ago?
2. Who told you?
3. Had you heard of TB before?
4. Did you know anyone with TB before?
5. Did anyone in your family ever have TB before?
6. Have you had TB? If yes, did you receive any treatment? How long? Where?
7. Were you afraid when you heard of TB in your family? Why (not)?
8. Did you tell other family members about the disease?

C.   Training and instructions
1. Who asked you to become treatment supporter?
2. Did you agree right away? Why (not)? What made you decide?
3. Did the health worker tell you about DOT? What is it?
4. Do you know what side effects are? What do you do in case of side effects?
5. What are your specific tasks as treatment supporter?
6. Do you meet regularly with the health worker? If yes, how often? What do you discuss?
7. Do you receive any support from the health clinic? If yes, what and how? (financial, emotional, etc)
D. DOT
1. Does your family member manage to take drugs every (other) day? If yes, are you always present?
2. Who collects the drugs at the clinic? How often?
3. How often does your family member have an appointment at the health clinic?
4. Have he/she managed to keep all appointments at the clinic? If no, how many missed and why?
5. What happens if he/she misses an appointment?
6. Do you ever go together to the health clinic? How often? Why?
7. Does the health worker visit the patient at home? If yes, how often?
8. What does the health worker do during home visits?
9. Has your family member ever stopped treatment for a few days/weeks? Why?
10. What did you do to try to persuade your family member to continue treatment?
11. Have you reported this to the health worker? If no, why not? If yes, what did the health worker do?
12. Does your family member experience any side effects? If yes, what are they? Did you mention them to supporter/health worker/doctor?

E. Patient – family member
1. Does the health worker know that you are [patient name]’s treatment supporter?
2. Have you ever asked someone else to take over your task of supporter? Who? How did that go? Any specific reason why?
3. Does your family member live in the same house/neighbourhood/town? If not in the same house: how far?
4. Could you explain how you and the patient organize DOT? Specific place, time?
5. Do you feel that you are helping your family member in any way to stick to treatment? How? Examples?
6. How do you feel about the patient being a family member?
7. Are there other people that you would have preferred to be the supporter?
8. Do you know if the patient has received instruction from health worker? How often?
9. Do you think the patient could have managed the treatment by himself/herself? Why do you think that?

G. Personal data
These data can be collected from treatment card and be verified during interview if necessary.

- Age
- Marital status
- Number of children
- Educational level
- Religion
- Occupation
- Kinship to patient
Annex 3  

Interview guide for health workers

A.  

Introductions:
Greetings and introductions
Explain purpose of interview and confidentiality
Ask permission to record and proceed

B.  

Responsibilities and problems
1. Do you have any responsibilities for TB patients? What are they?
2. How many TB patients are under your care?
3. Are there any serious problems in doing your job? In general? In the field of TB?

C.  

Treatment and DOT
1. What are the different treatment options for TB in this district?
2. Which option do people use the most, as far as you know?
3. Do you provide information to patients about TB and treatment? If yes, what do you tell them? Do you use materials like leaflets, etc?
4. How often do you provide this information to patients?
5. Are there any specific criteria for the selection of treatment supporters? If yes, what are they? Do you discuss these selection criteria with the patient?
6. Do you train treatment supporters? If yes, what do you train them for? When? How often? Use of materials?
7. Who is supposed to collect the TB drugs at the clinic? In your experience, who collects the drugs regularly: treatment supporter, patient, someone else?
8. How do you monitor their treatment?
9. Do you ever visit patients at their homes? What do you do during the home visits?
10. Do you ever meet with the treatment supporter? What do you discuss with him/her?
11. What are the patient’s responsibilities and tasks during treatment?
12. What are the treatment supporter’s responsibilities and tasks?
13. How do you check if they take their responsibilities and do their tasks?
14. How often do patients have appointments at the health clinic? Do most of them keep their appointments? What happens if a patient misses an appointment?
15. Do, as far as you know, treatment supporters report side effects? What do you do with this information?
16. What happens if you find out that a patient has stopped treatment (temporarily)?
17. Do patients and/or treatment supporters receive any additional support from the health clinic? If yes, what and how? (financial, emotional, etc)
18. Do you receive any incentive when patients complete their treatment? If yes, how much and when?

D. Training
2. Have you received any specific training in TB control and prevention? If yes, when? Training materials?
3. Any refresher courses? If yes, when was the last one?
4. Have you received specific training in supervision? If yes, when? Training materials?
5. How often do you get supervision for TB control? When was the last time?

E. Patient – family member
1. Do you feel that family members make good treatment supporters? How? Examples?
2. Do patients ever complain about their treatment supporter? If yes, what do you do?
3. If you were a patient, who would you prefer to be your treatment supporter, inside or outside your family? Why?
4. Are there other people that you allow to be supporters? Any specific cases?
5. Do you think the patient could have managed the treatment by himself/herself? Why do you think that?

F. Personal data
- Number of years working in TB control
Annex 4  Analysis diagram

TB program

Health worker

Patient - ? - Treatment Supporter

Family relation