Six Months without Alcohol
Patients' Experiences in Adhering to Tuberculosis Preventive Treatment

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# Table of Contents

Table of Contents ........................................................... ii

Acknowledgements ......................................................... iv

Abstract .............................................................................. v

Chapter 1  
Introduction ...................................................................... 1  
Tuberculosis in the Netherlands ......................................... 1  
The Dutch Tuberculosis Control Programme ....................... 2  
Structure of the Dutch Tuberculosis Programme ............... 2  
Role of Tuberculosis staff ............................................... 3  
The Dutch Tuberculosis Control Strategy ....................... 4  
Problem Statement ....................................................... 6  
Objectives ..................................................................... 9  
Research Questions ...................................................... 9  
Conceptual Framework .................................................. 10  
The Explanatory Model ................................................ 10  
Risk ............................................................................ 13  
Compliance .................................................................. 15

Chapter 2  
Methodology and Research Setting .................................. 18  
Study Type, Study Design and Data Collection Techniques ... 18  
Research Process ......................................................... 18  
Informants’ Profiles ..................................................... 19

Chapter 3  
Tuberculosis: Disease of the Past .................................... 21  
Lay Concept of Tuberculosis .......................................... 21  
Professional View of Tuberculosis .................................. 24  
The Social Aspects of Tuberculosis .................................. 25

Chapter 4  
The Mantoux Test ........................................................... 28  
Lay View of the Mantoux Test ....................................... 29  
Reactions to the Result of the Mantoux Test .................... 31  
Risk of Being Mantoux positive .................................... 32  
Professional View of the Mantoux Test ......................... 33

Chapter 5  
Adherence to the treatment ............................................. 35  
Reasons for Taking INH ................................................ 35  
Completion of the Treatment ......................................... 36
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Aryanti Radyowijati
Abstract

Non-adherence to tuberculosis preventive treatment has been cited as a major barrier to the control of tuberculosis. It is known to be one of the principal causes of treatment failure in most tuberculosis treatments. Non-adherence is not only found among people with active tuberculosis, but also among people with tuberculosis infection. In the latter group, absence of tuberculosis symptoms makes the issue of adherence more complicated.

In this study, factors influencing adherence to tuberculosis preventive treatment were investigated. Information was mainly collected through open ended interviews. To allow optimal understanding of the situation, both lay people and health professionals were interviewed. This study is exploratory in nature. It is a first attempt to contribute to understanding the social aspects of tuberculosis control. In analysing the results, concepts such as people’s explanatory models, risk and compliance are used.

Respondents of this study are Dutch people with a positive Mantoux test. They were approached through collaboration with the tuberculosis department of the municipal health service (GGD) in Leiden, the Netherlands. Ten respondents, three females and seven males, participated in the study. In addition, interview with the tuberculosis doctor, tuberculosis public health nurse, observation of doctor-patient interaction and a focus group discussion on tuberculosis were conducted at the end of the study. Data collection activities were conducted in the Dutch language.

Due to the limited sample size of the study, it was not possible to relate demographic characteristics of the respondents and the health professionals to their adherence behaviour. Yet, adherence appears to be influenced by the respondents’ personality. In this study, respondents highly valued and acted upon their own decision to adhere.

Adherence appears to be positively influenced by respondents’ perception of tuberculosis causation, contagiousness and the social aspects of the disease. The epidemiological risk of being Mantoux positive indirectly supports adherence behaviour. However, in this study, occurrence of perceived side-effects and life style changes related to preventive treatment were not found to lead to non-adherence. Interestingly, respondents created their own personal story on how and by whom they got infected. Their story consists of biomedical facts of tuberculosis and information about their social network. The personal story appeared to be important in reducing respondents’ anxiety and uncertainty by providing an explanation on why they became Mantoux positive.

The provision of adequate and high quality information is regarded as important in ensuring adherence to tuberculosis preventive treatment. This information may help people to make the best decision for themselves. If people are allowed to have the power to make their own choices, they tend to stick to what they promised themselves.
Chapter 1
Introduction

Tuberculosis in the Netherlands

In most industrialized countries, tuberculosis control efforts have been applied successfully. Mortality has ceased to be an indicator of the tuberculosis problem, since effective drugs have become available. In the Netherlands, mortality in 1910 was 200/100,000, while it decreased to 0.2/100,000 in 1990. Morbidity decreased from 15,000 cases in 1950, to 1,226 in 1987, which is a decrease from 150/100,000 to 8/100,000. The annual risk of infection has decreased by 11-13% yearly since 1945 (van Cleeef et al, 1995; Styblo, 1991).

As in most industrialized countries, the decrease in tuberculosis cases stopped in the mid-eighties and changed to an increasing trend. In 1992, 1465 cases were notified, which means an increase of 19% since 1987. The distribution of cases is noteworthy. Among the indigenous population a majority of new cases develop among the elderly through endogenous reactivation of a remote infection. A second peak is seen in young adults. Micro-epidemic spreads easily, finding virgin soil in a population with an infection prevalence less than 5% under 45 years of age. Large epidemics have been attributed to dance halls, where young adults spend their weekend nights (Veen, 1992). Substance abusers are another segment of the society where transmission of tuberculosis occurs frequently. Over 50% of identified cases are now detected among immigrants, mostly young adult men. The number of cases is rising due to a vast increase in asylum seekers, who are all screened for tuberculosis upon arrival in the country (van Cleeef et al, 1995).

1. A micro-epidemic is defined as an outbreak in which one index caused 6 or more cases of primary tuberculosis in 2 or more families, or 20 or more positive skin test reactions or conversions (Veen, 1992)
In low tuberculosis prevalence countries, such as the Netherlands, the aim is to maintain the infrastructure of a tuberculosis service until elimination is achieved. Estimates of infection prevalence in the overall Dutch population in 1945, 1975 and for 2005 demonstrate that ‘elimination’ of infection is a preliminary condition to ‘elimination’ of the disease (Broekmans, 1994). Therefore, besides the overt tuberculosis cases, another important focus of the Dutch tuberculosis control programme is tuberculosis infections, defined as asymptomatic individuals infected with *Mycobacterium Tuberculosis* (O’Brien, 1994). In 1996, 1743 infections were reported in the Dutch population. Most infections (84%) were recorded in persons between 15 and 44 years old (KNCV, 1997). In the Netherlands, tuberculosis infections are detected by means of tuberculin skin testing, since BCG vaccination has never been applied on a large scale. A positive tuberculin test and a Mantoux skin test conversion are considered to be the result of a recent infection (van Cleeff et al, 1995). Cases detected in 1996 were found through contact screening (75%), pre-employment screening (11%), screening risk group (10%) and 3% because patients complaints or unknown reasons (KNCV, 1997).

**The Dutch Tuberculosis Control Programme**

*Structure of the Dutch Tuberculosis Programme*

The Dutch tuberculosis programme is characterized by its continued interaction between (local) government and the non-governmental organization KNCV. The focal point for tuberculosis control was the Tuberculosis Chest Clinic, assisted by a network of diagnostic and treatment

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2. BCG (Bacille Calmette-Guerin) is a vaccine against tuberculosis (ten Dam, 1993)

3. A Mantoux skin test conversion is defined as an increase of 10 mm diameter within one year after a previous test with a diameter less than 2 mm. Dutch people who are born after 1 January 1945 have been exposed to so little risk of infection that a positive tuberculin skin test in that group is regarded as a sign of recent infection. A Mantoux skin test conversion is by this definition also the result of a recent infection.

4. This section is summarized from van Cleeff et al, 1995.

5. KNCV (Koninklijke Nederlandse Centrale Vereniging tot bestrijding der Tuberculose = Royal Netherlands Tuberculosis Association).
facilities, owned by private associations. Diagnosis and initiation of treatment are done by clinicians (mostly lung specialists in hospitals), while follow up, supervision of therapy and contact tracing are carried out by the tuberculosis department of the Municipal Health Service/GGD\(^6\). The latter is also responsible for active case finding within risk groups, registration and reporting. Formulating control policies and development of protocols is the task of KNCV. To this end, KNCV has instituted a National Tuberculosis Policy Committee (CPT), in which all tuberculosis control officers and representatives of tuberculosis public health nurses, hospital chest physicians, the Ministry of Health Medical Inspector and others take part. Quality control of both the private and public sector is in the hands of the Ministry of Health.

**Role of Tuberculosis staff**

An average family doctor in the Netherlands sees only one tuberculosis patients in four years, while an average chest physician sees four patients in one year. Tuberculosis control officers manage on average 50-60 patients per year. The role of clinicians has increased since chest clinics became more prevention oriented.

The tuberculosis public health nurse is the linchpin of tuberculosis control. She/he is responsible for health education and compliance enhancement of the patient, which should already start while the patient is still in hospital. When needed, the public health nurse traces defaulting patients, and organizes contact tracing and source detection. For these tasks the nurse actively follows the patient and frequently visits him/her at home.

Support staff, which has had on-the-job training is usually multi functional and capable of tuberculin testing, vaccination, taking X-rays and carrying out sputum smear microscopy. Since

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\(^6\) GGD (Gemeentelijke Gezondheidsdienst) is a local health service, available in almost every municipality in the Netherlands. Tasks of the GGD are heavily focused on epidemiology, policy advise, prevention, and disease surveillance (Rengelink and Schrijvers, 1997).
strict guidelines have been developed, this staff can deal with suspect patients even in the absence of the doctor or nurse.

The Dutch Tuberculosis Control Strategy

Case-finding. Case finding has been mostly passive. Whenever a patient has a complaint, he/she visits either the tuberculosis chest clinic or the chest physician in the hospital. Municipal Health Service Tuberculosis chest clinics are distributed throughout the country and the service is free. Paradoxically in a low prevalence situation, active case-finding, targeted towards identified risk groups, is increasing in importance. Risk groups for tuberculosis are first of all recent contacts of infectious patients. Another important group are immigrants from high prevalence countries.

Tools in case-finding. The tuberculin skin test is a valuable indicator of a recent infection in the young Dutch population, as BCG vaccination was never practised on a large scale and environmental mycobacteria are of no great importance. The prevalence of infection is now less than 5% in individuals below person 45 years of age. This makes the tuberculin skin test (Mantoux test) the first choice for screening, when dealing with micro-epidemics. In patients with complaints, immigrants from high prevalence countries, drug addicts and detainees a chest x-ray will be the first choice. Whenever an abnormality is detected, sputum smear microscopy follows, often rendering results within 24 hours. In clinical settings, bronchoscopy is frequently used if patients do not produce sputum spontaneously. Some chest clinics use sputum induction. Culture and susceptibility testing is done in a few laboratories only. New methods of detection, such as amplification by the polymerise chain reaction (PCR) are currently being field-tested. A novel contribution to the identification of sources and the mapping of transmission within the community is the “restriction fragment length polymorphism” (RLFP), which identifies the DNA pattern (“fingerprint”) of the isolated mycobacteria.
Treatment. The National Tuberculosis Policy Committee recommends a standard regimen for uncomplicated cases. The intensive phase consist of isoniazid (H), rifampicin (R) and pyrazinamide (Z) for 2 months, followed by a continuation phase of 7 months isoniazid and rifampicin (2HRZ/7HR). No difference is made for sputum smear-positives or negatives. Patients with a prior history of treatment, or from a country with a high risk of multi-drug resistance, should initially receive four drugs, to which either streptomycin or ethambutol is added in the intensive phase. The choice of drugs in the continuation phase depends on the susceptibility pattern. There is currently a discussion going on decreasing the treatment period from nine to six months.

Compliance. Health education and active follow-up of patients by the tuberculosis public health nurse enhance compliance. Depending on the nurse’s assessment, patients are visited at home more or less frequently. Problems brought about by the disease or its treatment are discussed and the nurse will try to contribute to finding their solutions. Treatment compliance is sometimes monitored by pill-counts or urine checks. Occasionally, although increasingly frequently, treatment is directly observed. The nurse actively traces defaulters and convinces them of the importance of continuing treatment. It is felt that the nurse’s role is pivotal in preventing the emergence of (multi)drug resistance.

Prevention. Recently infected persons are offered chemoprophylaxis with isoniazid for 6 months. Persons with a fibrotic lesion consistent with previous tuberculosis, who have never been treated, are also offered chemoprophylaxis. Infants in a households where an infection source has been detected are given chemoprophylaxis until it has been established that no infection occurred.
Surveillance. Mortality has been continuously registered by the Central Bureau of Statistics since 1910. Morbidity has been registered since 1955 in a National Surveillance Register within the Ministry of Health. Notification has always been voluntary. Monitoring of treatment outcome was done from 1974 until 1986 only. Since it was felt that important information was lacking, a new National Surveillance Register was established in 1993. Mandatory notification remained the responsibility of the ministry of Health, but voluntary notification of main indicators is done by KNCV. To this end, KNCV has established an electronic database. Treatment outcomes are registered routinely, making cohort analysis possible. Since 1993, the National Reference Laboratory has received all tuberculosis strains for sensitivity testing, to monitor the evolution of (multi-)drug resistance. DNA fingerprinting is also done. Cross-linkage with the National Surveillance Register of the KNCV facilitates programme surveillance.

Problem Statement

Tuberculosis is not a chronic disease, but its prevention requires the use of medication for long period. Recently infected persons are offered chemoprophylaxis with isoniazid (INH) for six months (van Cleeef et al, 1995). The efficacy of this chemoprophylaxis is 90% or greater, provided the person adheres to this treatment by taking INH daily (O'Brien, 1994). Of the 1369 persons infected in the Netherlands in 1995, 1084 (83%) completed preventive chemotherapy, and 251 (17%) discontinued treatment. Maintaining adherence with this preventive regimen is found to be a major problem in the USA (Geiter, 1993). Persons with tuberculosis infections have no symptoms to convince them of the importance of taking their

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7. Adherence assume a balanced relationship between provider and user. The professional bond is characterized by "give and take", cooperation, information-sharing and social/emotional nurturance (Friedman and Di Matteo, 1989 as cited by Castillo-Carandang, 1988).
medication (Sumartojo, 1993). The main reported reason to discontinue the treatment in the Netherlands are the side-effects of Isoniazid, ranging from vomiting, nausea, anorexia, or the more serious sign of hepatitis (KNCV, 1997). Other reasons were fear and inability of abstinence from alcohol (J. Veen, personal communication). Similar finding on alcoholism as predicting factor for non-adherence is also found in Seattle (Nazar-Stewart and Nolan, 1992). Alcabes and coworkers (1989) reported that education was one of the major factors in predicting adherence among 63 adolescent inmates at Rikers Island jail in New York City. Inmates who have completed at least the eleventh grade and/or knew that tuberculosis is preventable, that their tuberculin test results were positive, and that INH must be taken daily for a year, were significantly more adherent than inmates without this knowledge. Another study in Hawaii concluded that patients’ reported intentions to take medicines were significantly associated with a positive attitude about the effectiveness of INH, strong feelings of being able to cope with the demands of the regimen, and positive beliefs about taking preventive therapy that in turn influenced by the support of participants’ social reference group (Dubanoski 1988, as cited in Sumartojo, 1993).

Adherence is a complex phenomena; it reflects the active role of the patients in self management of treatment and the importance of cooperation between patient and provider (Sumartojo, 1993). In trying to show the multiple quality of adherence, Castillo-Carandang (1998) listed the following factors which influence adherence to treatment: patient’s factors, economic factors, clinic factors, health care provider factors, the illness and treatment factors. To ensure adherence, many strategies have been published, such as modification of treatment strategies, presentation of incentives, social incentives, educational interventions, directly observed therapy (DOT), involvement of community health workers and provision of comprehensive services. However, most of these strategies were applied to cases of active Tuberculosis cases and/or conducted in
special settings, such as a homeless shelter (Nazar-Stewart, et al, 1992), thereby not providing the necessary basis for generalization. Secondly, most studies on ensuring adherence in tuberculosis were carried out in medically-oriented settings, and focusing on compliance\(^8\), within the notion of how and why people follow or deviate from doctors’ orders (Conrad, 1985).

Very little research on adhering to medical regimens has been done from the perspective of patients’ - or sufferers’-centred perspective. In this perspective the patient is seen as an active agent in their treatment rather than as “a passive and obedient recipients of medical instructions”. Patients have their own ideas about taking medication - which only in part come from doctors - and this affects their use of medications. People evaluate both the doctors’s actions and the prescribed drugs in illness and medication. A study found that some patients augmented or diminished their treatment regimens as an attempt to assert control on the doctor-patient relationship (Hayes-Bartista, 1976). Further research is needed to define the concept of adherence in tuberculosis preventive treatment, taking the patient as the point of departure, such as people’s own perceptions, their experiences in coping with the demand of their medication, as manifested in everyday life, and the social consequences of this condition (for example, stigmatization\(^9\))

In this research, factors affecting adherence of persons with tuberculosis infection will be investigated. The research will try to describe the experience of persons with tuberculosis infection in coping with the demand of taking their medication. The research will also try to include the role of tuberculosis public health nurses and tuberculosis doctor in ensuring adherence. The results will be of importance in improving the quality of the Dutch tuberculosis control programme which is hoped to lead to the elimination of tuberculosis in the Netherlands.

\(^8\) Compliance is the extent to which patients’ behaviour, in terms of taking medications, following diets, or executing life-style changes, coincide with the clinical prescription (Haynes, Taylor and Sacket, 1979, as cited by Castillo-Carandang, 1986)

\(^9\) Stigmatization is a social process in which group values are affirmed, and the ‘normal’ are separated from the ‘deviant’ (Goffman, 1963 as cited by Hardon et al, 1995)
Objectives

1. To document the problems surrounding adherence to tuberculosis chemoprophylaxis treatment encountered by patients, tuberculosis public health nurse(s) and tuberculosis doctor in a limited setting, in Leiden, the Netherlands.

2. To investigate the extent to which these problems are related to aspects such as: different illness perception, understanding of the preventability of tuberculosis, social influence, perceived quality of care of tuberculosis service and other life style changes of the patients.

3. To suggest recommendations on strategies to improve adherence to preventive treatment and ensuring the quality of care provided by the health workers.

Research Questions

1. Which patients characteristics might be related to adherence?
   - Age, gender, history of non-compliance, ethnic background, treatment status, etc.

2. What are knowledge, perceptions and attitudes of patients; their family and friends, tuberculosis public health nurses and tuberculosis doctor, towards tuberculosis?
   - Knowledge on tuberculosis, skin testing, preventability of tuberculosis and preventive treatment (Isoniazid).
   - Metaphors of tuberculosis, the meaning of the result of tuberculosis skin testing and beliefs on efficacy of Isoniazid.
   - Social consequences of being infected (possible stigma) with tuberculosis and opinions of family/friends about tuberculosis.

3. How are the acceptance and the ability to cope with the demand of the diagnosis and taking medication?

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10. The word 'patient' is defined as a person with medically abnormal signs and or symptoms, in this case, people whose tuberculin skin test is positive, or whose Mantoux skin test has converted.

11. Stigma is defined as an attribute, an undesirable differentness that discredits or disqualifies the individual from full social acceptance (Goffman, 1963, as cited by Hardon et al, 1998).
- Impact (changes in daily life) of their Mantoux test, the idea of their severity or susceptibility, what kind of changes do the patients have since they are tested?
- Perceived and actual side effects of Isoniazid, other problems related to taking Isoniazid, changes in daily life (if any).

4. To what extent does quality of care of tuberculosis service influence adherence?
- Opinions of patients, tuberculosis public health and tuberculosis doctor, on optimal ways the best way to ensure adherence, and possible clinic factors that need to be improved.

**Conceptual Framework**

In this research patients' experiences in adhering to tuberculosis preventive treatment will be documented. To allow for optimal understanding of the situation, both the lay people and health professionals were interviewed. This study is exploratory in nature. It is a first attempt to contribute to understanding the social aspects of tuberculosis control. In analysing the results, several social sciences theories and concepts regarding people's explanatory models, risks, and compliance will be used.

*The Explanatory Model*

Kleinman suggested a useful way of looking at the process by which an illness is patterned, interpreted and treated, which he terms the Explanatory Model (EM). This is defined as 'the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process'. EMs are held by both patients and practitioners, and they 'offer explanation of sickness and treatment to guide choices among available therapies and therapist and to cast

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12. This section is summarized from Helman, 1997 pp. 101-145.
personal and social meaning on the experience of sickness. In particular, they provide explanations for five aspects of an illness:

1. The aetiology or cause of the condition;
2. The timing and mode of onset of symptoms;
3. The pathophysiological process involved;
4. The natural history and severity of the illness;
5. The appropriate treatments for the condition.

These models are marshalled in response to a particular episode of illness, and are not identical to the general beliefs about illness that are held by that society. According to Kleinman, lay EMs tend to be idiosyncratic, changeable, and heavily influenced by both personality and cultural factors. They are partly conscious, partly unconscious, and characterized by 'vagueness, multiplicity of meanings, frequent changes, and lack of sharp boundaries between ideas and experience'. He contrasts this with physicians’ EMs, which are also marshalled to deal with a particular illness episode, but mostly based on 'single causal scientific logic'. Explanatory Models are therefore used by individuals to explain, organize and manage particular episodes of impaired well-being.

Explanatory Models can only be fully understood by examining the specific context in which they are employed, since this usually has a major influence upon them. The context of an EM may include the social and economic organization, and dominant ideology (or religion) of the society in which the individual got ill.
Another way of looking at lay explanations of ill-health is to examine the sort of questions that people may ask themselves, when they perceive themselves as being 'ill' (or when they suffer from any misfortune), and how they weave the answers to these questions into the story or narrative of their ill-health. These questions are:

1. **What has happened?** This includes organizing the symptoms and signs into a recognizable pattern, and giving it a name or identity;

2. **Why has it happened?** This explains the aetiology or cause of the condition;

3. **Why has it happened to me?** This question tries to relate the illness to aspects of the patient, such as behaviour, diet, body-build, personality or heredity;

4. **Why now?** This concerns the timing of the illness and its mode of onset, sudden or slow;

5. **What would happen to me if nothing were done about it?** This considers its likely course, outcome, prognosis and dangers;

6. **What are its likely effects on other people (family, friends, employers, workmates) if nothing were done about it?** This includes loss of income or employment, or a strain on family relationships;

7. **What should I do about it - or to whom should I turn for further help?** Strategies for treating the condition, including self-medication, consultation with friends or family, or going to see a doctor.

Before these questions can be asked, or answered, the patient must see their symptoms or signs as ‘abnormal’, before grouping them into a recognizable pattern of a particular illness. This implies a fairly widespread belief in the patient’s community about what a particular illness is and how it can be recognized.
The term risk is derived from the French word *risque*, and first appeared in its anglicised form in England in the early nineteenth century. Originally employed in a neutral fashion as a wager made by individuals after taking account of the probability of losses and gain (Dake, 1982), it has come to refer in more recent times only to negative outcomes (Douglas, 1992); to the likelihood of some adverse effect of a hazard (Short, 1984).

Assessing risk has become a key element of public health. Epidemiologist calculate the 'relative risk' or numerical odds of a population developing an illness when exposed to a 'risk factor', compared with a similar population which has not suffered such exposure (Frankenberg, 1994). Public health discourse about risk can be divided into two kinds. The first concentrates on the environmental level and considers the risk to a particular population from nuclear waste, pollution and other hazards. The emphasis here is thus on the by-products of economic and social activity and the need for health promotion policies to maintain the purity of the natural environment. The second form of discourse, by comparison, constructs risk as the consequence of the 'life style' choices made by individuals, and emphasises the need for self control. This approach is clearly illustrated by the case of AIDS.

While epidemiologist have developed risk assessments methods based on measures of mortality and morbidity, psychologist attempted to incorporate public perception of risk in risk analysis. Involvement of psychologists was stimulated by the realisation that lay people perceive the riskiness of technology differently from expert risk analysts. Within the health field an example of this approach is the Health Beliefs Model, which examines factors that might predict health

13. This section is summarized from Gabe, 1993 and Douglas, 1985
behaviour. Readiness to embark on risky behaviour is seen as being based on one’s perceived susceptibility to a health threat and the perceived seriousness of that threat. In addition, the model recognises that certain triggers are necessary for a course of action to be taken. External events are seen as cues, perceived and appraised by the individual in an interactive way prior to deciding upon a course of risk behaviour or risk avoidance (Ogden, 1995). However, this model has been criticised for treating individuals as free agents in terms of their response to risk and ignoring social factors that constrain choice (Denscombe, 1993).

Other disciplines have treated risk as an objective phenomena to be measured and explain. Anthropologist and sociologist have argued that risk can best be understood as a social construct. Over the last three decades the anthropologist Mary Douglas has produced a series of influential publications in which the ontological status of risk as an objective measure has been questioned and redefined as socially constructed within a particular historical and cultural context. This approach illustrates Douglas’ concern with groups and institutions rather than with individuals, and with the way in which such collectivities’ response to risk is functional for the maintenance of a chosen form of social organization. The argument was formalised in an analytic scheme which has come to be known as grid/group analysis. By linking grid and group, four distinct world views or ‘cultural biases’ were identified, which justified different ways of behaviour toward hazard. Douglas and Wildavsky named these hierarchist (high grid/high group), egalitarian (low grid/high group), fatalist (high grid/low group) and individualist (low grid/low group). In practice this meant that hierarchist, for example, were said to be well integrated (group

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14. Grid/Group analysis is a way of checking characteristics of social organizations with features of the beliefs and values of the people who are keeping the form of organization alive. Group means the outside boundary that people have erected between themselves and the outside world. Grid means all the other social distinctions and delegations of authority that they use to limit how people behave to one another (Douglas and Wildavsky, 1982: 138)
axis) and accepting externally imposed expert risk assessments (grid axis) whereas egalitarians, whilst also being well integrated, challenged the dictatum that 'experts know best' on the grounds that these experts’ calculations threatened their group’s way of life (grid axis). The implications of this approach for risk assessment and perception are that ‘people select a certain risk for attention to defend their preferred life styles and as a forensic resource to place blame on the other groups’. When people feel that they are 'at risk' they focus on external sources such as stereotyped minorities and blame them, rather than concentrate on the dangers afforded to their community by their own members.

Medical sociologists analyse health-related risk by distinguishing those of micro level studies, which concentrate primarily on the individual’s self and those limited areas of social life of which she or he directly or personally aware, and the more macro level studies which concern the ‘public issue of social structure’. The latter refers to things which transcend the individual’s local environment and the range of his or her inner life and are seen by the public as threatening some cherished value. Micro level studies in the health field have been concerned with the meaning of risk and the ways in which these are used to achieve practical results. Studies taking this interpretive approach have tended to concentrate on two broad areas: perception of risk and risk behaviour; and the relationship between lay and expert knowledge of risk.

Compliance\textsuperscript{15}

The word compliant, typically used to refer to a patient who completes treatment, has the unfortunate connotation that the patient is docile and subservient to the provider. Given that patients decide independently about taking medications, away from the presence of the provider,  

\textsuperscript{15} This section is summarized from Peter Conrad, 1985.
and that effective completion of treatment demands their independent action, compliance might seem an undesirable characteristic. A better word, which reflects the active role of the patient in self management of treatment and the importance of cooperation between patients and provider, is adherence (Sumartojo, 1993). This word will be used in this report.

Compliance with medical regimens, especially drug regimens, has become a topic of central interest for both medical and social scientist research. Two dominant social science perspectives have emerged that attempt to explain variations in compliance and non-compliance. One is considered the source of the problem in doctor-patient interaction or communication, while the other postulates that patients’ health beliefs are central to understanding non-compliant behaviour. Both perspectives are multi causal and to some degree compatible.

Researchers have found that higher compliance rates are associated with physicians giving explicit and appropriate instructions, more and clearer information, and more and better feedback (Davis, 1968; Garrity, 1981). Other researchers have noted that noncompliance is higher when patients’ expectations are not met, or their physicians are not behaving in a friendly manner. In short, these studies locate the source of non-compliance in doctor-patient communication and suggest that compliance rates can be improved by making changes in clinician-patient interaction. The importance of patient beliefs in compliant behaviour is highlighted by the ‘health-belief model’. The health belief model is a social psychological perspective first developed to explain preventative health behaviour. It has been adapted by Becker (1979) to explain compliance. This perspective is a “value-expecting model in which behaviour is controlled by rational decision taken in the light of a set of subjective probabilities (Conrad, 1985). The health belief model suggest that patients are more likely to comply with doctor’s
orders when they feel susceptibility to illness, believe the illness to have potential serious consequences for health or daily functioning, and do not anticipate major obstacles, such as side effects or costs. Becker (1976) found general support for a relationship between compliance and patients' beliefs about susceptibility, severity, benefits and costs.

There is an alternative, less-developed perspective that is rarely mentioned in studies of compliance. This patient-centred perspective sees patients as active agents in their treatment rather than as 'passive and obedient recipient of medical instructions' (Stimson, 1974). Stimson argues that to understand non-compliance it is important to account for several actors that are often ignored in compliance studies. Patients have their own ideas about taking medication - which only in part come from doctors - that affect their use of medication. People evaluate both doctor's actions and the prescribed drugs in comparison to what they themselves know about illness and medication.
Chapter 2

Methodology and Research Setting

Study Type, Study Design and Data Collection Techniques

This is an exploratory study on factors influencing adherence to tuberculosis preventive treatment. These factors are studied through:

1. Open ended interviews on patient's experiences in contracting tuberculosis and adhering to the preventive treatment. Interviews were also held with the TB doctor and the TB public health nurse;

2. Focus group discussion on tuberculosis with Dutch people in their mid twenties;

3. Observation, during the consultation between a Mantoux positive person and the doctor;

4. Review of documents

Research Process

Since the respondents of this study are people with a positive Mantoux test, the only option for the researcher to reach the target group is through the GGD, in this case GGD Leiden. However, since the GGD is not allowed to provide information on patients to researchers, it was agreed that the GGD would write a letter of invitation to their patients to ask them to participate in the study. When patients agreed, their agreement was used as their consent to provide their name, address and their medical data (date of Mantoux test and the result) to the researcher. Only then the researcher was allowed to make contact with the patient and make an appointment for an interview. It was also agreed that interviews should be conducted in the Dutch language, and therefore the researcher should be accompanied by an interpreter.
Around 50 letters of invitation were sent out by the GGD. A total of 25 completed forms were received, of which 12 respondents agreed to participate. One person withdrew his agreement at a later stage, and one person was excluded because it concerned an Afghani child of five years old. The researcher tried to get more respondents during the data collection phase, since the number of respondents was considered rather small. However, due to the limited amount of available time and other influencing factors as the summer holiday was starting and most potential respondents were leaving; an outbreak of tuberculosis in Leiden which increased the workload of the GGD; and problems in finding new interpreters, it was not possible to increase the number of respondents. Nevertheless, at the end of the research, it was possible to do one observation of a doctor-patient interaction and conduct a focus group discussion on tuberculosis with university students.

Informants' Profiles

The informants of this study are Mantoux positive Dutch people. The GGD provided a list of people with a positive Mantoux, identified during the years 1996 and 1997. From this list, the GGD made a selection on patients appropriate for inclusion in the study. In general, Mantoux positive individuals and eligible to take INH were selected by GGD. Children, people who had additional health problems such as being HIV positive, drug addicts or having diabetes, and foreign people, were excluded.

From the ten people who participated, there were three females and seven males. Their age ranged from 19 to 47 years old. Most respondents are in their twenties and thirties. All of them are indigenous Dutch people, while one of them has an Israeli father. Four respondents have a
university degree, three studied at a polytechnic level (HBO\textsuperscript{16}), and three studied up to the secondary level of education (MBO\textsuperscript{17}). Occupation are housewife, teacher, group leader, student, medical doctor, sport instructor, carpenter and aerospace engineer. Three respondents are married, each having two children, one respondent is married without children, one respondent is divorced, and five respondents are single. All of them are Mantoux positive, and two of them had active tuberculosis. All respondents took INH, except one person. From those who took INH, seven completed the treatment, two were still taking INH and one respondent did not complete the treatment (interrupted).

In addition to these respondents, a male tuberculosis doctor and a female tuberculosis public health nurse were interviewed. The doctor has worked as a Tuberculosis doctor for three years, whereas the nurse worked for eight years.

The consultation observed was that between a 47 years old male patient and the tuberculosis doctor. The group discussion was conducted with six (two females and four males) young Dutch people. They are in their mid-twenties and all of them are students of the University of Leiden.

\textsuperscript{16} HBO = \textit{Hoger Beroeps Onderwijs}

\textsuperscript{17} MBO = \textit{Middelbaar Beroeps Onderwijs}
Chapter 3

Tuberculosis: Disease of the Past

According to biomedicine, if somebody has a positive Mantoux, it is said that their lifetime risk to develop tuberculosis is 10% (Schein and Huebner, 1994). This biomedical risk definition is the respondents’ point of departure in their life with tuberculosis, a disease they thought no longer exists in the Netherlands.

Lay Concept of Tuberculosis

Foster and Anderson (1978) divide causation of beliefs into two distinct categories: personalistic and naturalistic. Personalistic theories point to a person or a personalized being (a witch, dwarf, divine being or sorcerer) as the cause of illness. The illness is caused by a willful act of such an agent. These notions are usually based on magical or religious beliefs. One can also include the modern notion of "germs" in this category, especially those causing fever (Helman, 1997). Naturalistic theories view illness as being caused by natural processes, imbalances in bodily function, or by environmental factors. Foster and Anderson argue that when the cause of the disease is perceived to be personalistic, the treatment needs an extensive diagnosis by powerful healers. They stress that in naturalistic disease etiologies, patients and their families tend to determine the cause of illness themselves. No extensive diagnosis is needed as the cause is known. People generally treat the symptoms and restore the body imbalance without consulting a doctor (Foster and Anderson, 1978).

In this study, a personalistic cause is referred to by all of the respondents. According to them, tuberculosis is a lung disease, caused by bacteria:
"Tuberculosis is a disease caused by bacteria that make wounds in the lung. This wound will become a scar and will pull the heart and the skeleton from its natural place" (6/M)

This finding coincide with findings from other studies in India, the Philippines, Colombia and Pakistan, in which tuberculosis is attributed to a personalistic causation such as lung injury, smoking, overwork, and sins (see Nichter, 1994; Jaramillo, 1998; Lifoghe, 1995, Baarnhoorn and Adriaanse, 1992).

According to Nichter (1994), the association of tuberculosis and germs is based on the faith in modern medicine, which killed germs and cured tuberculosis. Van der Veen (1984) suggests that medical belief systems are related to the world view of the people concerned (van der Veen 1984 as cited by Hardon, A.P, 1991). Personalistic disease theories exist in cultures where people see themselves as an integral part of a group sharing a world view. In the here presented study, the existence of personalistic views may due to the influence of other forms of "kinship" between the respondents and the health system. People try to find the cause of their ill-health based on concepts in modern biomedicine rather than concepts such as supra natural forces or magical power. Other categories of causation was not found in this study.

Continued coughing and fatigue are cited as the most common symptoms of tuberculosis. Since tuberculosis is perceived as the disease of the lung, people refer the first symptoms to abnormalities of the respiratory systems. Nichter (1994) found that inability to work hard or being easily tired to be one of the most popular symptoms of tuberculosis in the Philippines. Other symptoms mentioned are night sweating, weight loss, foot edema, blood spitting, fever, pressure in the chest and feeling sick.
All of the respondents believe that tuberculosis is contagious. Coughing is considered as the main mode of transmission. In contradiction with this statement, the majority of the respondents do not recall being in the close environment of a tuberculosis patient. However, they do believe that tuberculosis is contagious due to their personal and social vulnerabilities/susceptibilities. Personal susceptibilities refers to respondents' perception that they, themselves, are immune to tuberculosis. Social susceptibility refers to the existence of tuberculosis in their immediate surrounding.

Because of its potency to spread, respondents also perceive tuberculosis as a dangerous disease:

"tuberculosis is dangerous because it is easily spread. Imagine if there is a TB patient, who is not treated properly, and walking around freely. The whole city of Leiden could be infected by him". (9/M)

Respondents also consider tuberculosis a dangerous disease when it becomes un-treatable, and using the concept of drugs resistance as an example. Susan Sontag (1978), writes that tuberculosis used to be a dangerous disease in times when its cause and treatment were not yet understood, as it is now the case with cancer. When its etiology becomes clear and its treatment becomes effective, tuberculosis is no longer be a frightening disease. According to three respondents tuberculosis is less dangerous than AIDS/Cancer, since the first is treatable.

The majority of respondents believe that tuberculosis is curable through the use of medication. This belief is based on their idea of causation. Since they believe that germs are the cause of tuberculosis, they make the association that germs can be killed by medicine, thereby curing the disease. In this study, the same interpretation is found for tuberculosis, both as a disease and an illness.
Tuberculosis appears to be perceived as un-preventable. This means that anybody can attract tuberculosis and there is ‘nothing’ that can be done about it. What can be done is to stop the spread of tuberculosis. This can be done through health education so that the afflicted person can seek care immediately before infecting other:

“Tuberculosis can be prevented through public education/information about its early signs and symptoms, so that people will seek medical care so, before infecting other people” (7/M)

**Professional View of Tuberculosis**

Health professionals clearly share the biomedical view of tuberculosis. They agree that tuberculosis is mostly involving the lungs, however they believe that other organs may be involved as well. Not surprisingly, their view of causation is also personalistic, as they are convinced that the tubercle bacteria are responsible for causing tuberculosis.

When asked about symptoms, they mentioned coughing, weight loss, night sweating, fatigue, and fever. Coughing and fatigue are more frequently present, while the other symptoms are less often found. This is partly due to the present situation of tuberculosis in the Netherlands. Tuberculosis tends to be detected at an early stage in the Dutch population, when bodily changes such as weight loss are not yet present.

The amount of explanation on tuberculosis given to the respondents by the health professionals is not always the same. Some respondents are eager to know every detail about tuberculosis, whereas others show little interest. Only if respondents show interest, they will receive detailed explanation. In this way, it is not surprising that one of the respondents, a university student, is able to explain to the researcher the different scale of contagiousness in tuberculosis and its likelihood of infecting other people.
Health professionals do not see tuberculosis as a dangerous disease. Their opinion is based on two facts. At the society level, the number of cases in the Netherlands is relatively small as compares to countries in Asia or Africa. At the individual level, good health care facilities and good tuberculosis medication are available:

“We re-assure them a little bit. People with a positive Mantoux test are usually afraid, and they see tuberculosis as a very serious disease. We explain them, that they do not have to worry at all; if they do get tuberculosis, there are good medications and we can cure you.”

The Social Aspects of Tuberculosis

Although tuberculosis is considered as the disease of the past, all of the respondents appear to have heard about this disease. If micro-epidemics occur, local television, radio and newspaper tend to write about them. Medical encyclopaedia and the work place are additional information sources.

In the old days, tuberculosis used to be called the “tering” in the Netherlands. It comes from the word “uit-tering”, which literally means “waste”. This word is describing the main feature of a full blown tuberculosis, which is wasting the body. A similar meaning is found in the 1398 Oxford English dictionary, in which tuberculosis is translated as “consumption”, a disease that consumes the body (Sontag, 1978). At the present time, the word tering is not appropriate anymore. When Dutch people scold or curse each other, the word “tering” is sometimes used (“krijg de tering = may you get tuberculosis” or “teringlijer=tuberculosis patient”). Old names or local names usually indicate the social features that people associate the disease with. In the case of tuberculosis, the local name suggests that tuberculosis was once considered as a curse of bad habits. One respondent sais that the word “tering“ may be used to address other illnesses considered to be equally bad, for example typhoid fever.
Illness is sometimes used to describe the negative aspects of social life, or as a way of expressing feelings, sentiments and ideas that must otherwise be hidden. When an illness carries many symbolic associations such as danger, contagiousness, incurability, and immorality this may lead to stigmatization (Hardon et al, 1995; Sontag, 1978). Tuberculosis for example, is associated with old people, and this association implies that tuberculosis is something of the past and not anymore a future challenge as cancer and AIDS are. Tuberculosis also symbolizes poverty and it is linked to developing countries, asylum seekers, homeless people and poor health. Some of these symbols are not recognized by the respondents as the characteristic of the present day Dutch society, which is perceived to be free from infectious diseases or other poverty-related diseases.

According to the respondents, tuberculosis is stigmatized. Its contagiousness is the main reason for its stigma. Since people think that there is no way to prevent getting tuberculosis, the least they can do is avoiding physical contact with the afflicted person, which can lead to social isolation. This stigma is considered to be more prevalent among people with low socio-economic status, whose social network tends to be closer than the one of the higher socio-economic class (Macionis, 1989). Persons of higher socio-economical status are less dependent of each other and this loose dependency allows individual success and achievement, as well as individual isolation. Low socio-economic status is connected to low levels of education. And the latter is often related to a lack of understanding of tuberculosis, which potentially supports the stigma:

"In the contact tracing that we are doing now, people react extremely emotional, and they are very afraid. I am surprised myself. I think this is because their level of education is very low, and it influences their way of thinking. We tried to explain to them what this is all about, but they do not get it. As you know, we can talk and talk and explain and ask questions, and still they do not know, they do not understand what we are saying. They don't get it. Their brain is not sufficiently open to what we are saying."
Yet, the limited knowledge on tuberculosis is also found among other social groups. One respondent experienced very bad reaction from his workmates when he got tuberculosis:

"I work in an international centre with people from all kind of nationalities. When they learnt that I had tuberculosis, they were panicking. The news spread very fast and went to the higher levels in the company. E-mails were sent to ask people to have tuberculosis skin test, and all of my colleagues had to be tested before coming on site. The most ridiculous thing was, nobody phoned me and asked about my tuberculosis. And my boss continued spreading the news about my tuberculosis to each and everybody (some of them I did not even know). I was so upset with this reaction, and I think this is because people do not anything know about tuberculosis. Things like these are probably handled differently in another country. In Holland, we are very discreet about this kind of thing, and I do not think it is the case in another country, specially the country where my boss is coming from" (11/M).
Chapter 4
The Mantoux Test

The Mantoux test is a skin test that is performed to find out whether or not someone has been infected with the *tubercle bacterium*. This infection does not always result in having tuberculosis. The majority of people, will stay healthy for the rest of their life. Respondents in this study considered their being Mantoux positive as a kind of misfortune, because it happens suddenly and unexpectedly. They do not perceive themselves as being ill, but they do realize that something inside their body is not as perfect as it used to be:

“It is strange, I feel perfectly healthy, but I know that I have something that does not belong to me”(3/F)

“It is a strange feeling, like a trap, I feel healthy and at the same time I know that I have a disease that can develop into a very serious condition. Although I feel the same as yesterday, there is something different” (2/F)

When people perceive themselves as suffering from misfortune, one of their ways to deal with it is by performing rituals (see Helman, 1997, pp. 239). The sudden onset of unexpected events causes feelings of uncertainty and anxiety in the person and their families. Rituals provide a standardized way of explaining and controlling the unknown, by converting the chaotic situation into a recognizable, culturally validated condition. In a psychological sense, the ritual itself is a form of treatment: converting the unknown into the known, and reducing the uncertainty and anxiety of a person and her/his family. To cope with the fact of being Mantoux positive, respondents create their own story or *narrative* about their misfortune, consisting of biomedical facts about tuberculosis and information about their social networks, on how and where they were infected and who is the afflicted person.
Lay View of the Mantoux Test

Almost all of the respondents in this study had their Mantoux test because they became involved in a contact tracing. Contact tracing is an outbreak investigation performed by the GGD, and aims at tracing people who may have been infected with tuberculosis. This means that it is an investigation into people’s social networks. In this way, also the respondents’ name and addresses were given to the GGD. Respondents are requested to do the same, once they are found to be Mantoux positive.

In contact tracing, the professional medical secrecy and the Dutch privacy law are applied. It means that the GGD is not allowed to reveal the identity of the tuberculosis patient to other respondents. However, after the respondents learnt that their Mantoux is positive, they usually start their own “contact tracing”, by collecting information about the Mantoux test and talking within their social networks: families, friends, workmates and neighbours. Knowing that tuberculosis is mainly transmitted through coughing, respondents try to recall whether there are people in their social network who have been coughing. In this way, most of the respondents managed to make their own story on how they got infected:

“A student in the university got tuberculosis, and therefore I was tested”

“There was a party of the company, and one of the guests had tuberculosis”

Some of the respondents had the “perfect” explanatory story, a match between biomedical facts and a tuberculosis situation in their social network. However, most others did not have this. For example, three respondents mentioned that they found the afflicted person in their social environment, but they did not recall that they were in close contact with her/him; Another respondent supposed she got infected by a studymate, who she did not know before. And another respondent, a teacher, supposed he had gotten tuberculosis from a student of another
class, and even being in a different building. Even respondents working in places with presumably high prevalence of tuberculosis (e.g. prison and centres for young criminals) provided nearly always well constructed explanation:

"Maybe I got it from one of the prisoners, because some of them came directly from the street, and might very well had tuberculosis. Or I might have gotten it from my previous job, working with teenagers from Morocco and Turkey. I do not really know" (5/M)

"I was informed that one of my boys had an open tuberculosis. So I was asked to do a Mantoux test. When the result was positive, I was almost sure that I got it from him, because my colleague was also Mantoux positive. Then the GGD did further investigation to this boy, and after a while they found that the boy did not have tuberculosis, but AIDS. So, I was left with a big question, how did I get tuberculosis" (6/M).

The personal story of each respondent appears to have had an important role in reducing their anxiety and uncertainty, by providing the cause of the condition. People consider their being around the afflicted person as the cause of their being Mantoux positive. People do find ways to overcome the privacy law and professional secrecy. Two respondents questioned the application of privacy laws against their own perceived right to know how and by whom they may have been infected. For example, one respondent argued that he was informed by the GGD on the existence of a tuberculosis patient in his environments, but at the same time, he is not informed in which environments (work, home or others). Respondents perceived that they may use this explanation to remove the blame from themselves, but not necessary to blame others.

"I want to know who had tuberculosis, not because I want to get angry to the person, but this whole thing is not nothing. I had to swallow heavy medication, and I have to live with the consequences, having 1-2% chance of developing tuberculosis, for the rest of my life" (6/M)

People also relate their personalistic view of causation to the purpose of the Mantoux test which is to know whether or not they have been infected with tuberculosis:

"The test was performed to see whether I have an antibody in my body. And if I have the antibody, that means I was recently infected and currently having the tuberculosis bacteria inside my body" (7/M)

"A positive result of the test means that I have the tuberculosis bacteria in my body" (11/M)
Reactions to the Result of the Mantoux Test

Since being Mantoux positive was highly unexpected, most of the respondents reacted with shock, surprise, nervousness and fear. These reactions were probably based on a combination of their personal and social susceptibility. Most of the respondents did not think that they could be infected with tuberculosis, and they did not imagine that tuberculosis still exists in their society. Fear of social stigma or adverse responses from others may also explain this reaction. Insecurity caused by limited knowledge of tuberculosis may also be a cause of their fear. One respondent felt more secure and quiet after being properly explained about her condition.

Although their being Mantoux positive was not perceived as increasing their personal susceptibility for tuberculosis, some respondents did change their behaviour perceived as related to tuberculosis. Some respondents became more alert to other people who cough and immediately ask the person to put her/his hand before her/his mouth.

Previous bad experience with the health care system influences acceptance of the expert opinion. One respondent who just lost his brother-in-law due to medical mal-practice, refused to fully believe the outcome of his Mantoux test. He did not remember having been in close contact with a tuberculosis patient, and is allergic to many substances. In addition, he is questioning the sensitivity and the administration of the test. This fact shows that nowadays it is acceptable to question experts’ opinion on certain aspect an ill-health condition, particularly when the trust between the patients and the doctor is not very strong. In the old days and still the case in is some parts of the world, the power relation between the expert and the patient is highly asymmetry. This asymmetry can result in a situation which the expert has the authority to impose her/his opinion on the patient, and the patients should accept this imposed opinion without question.
(Good, 1994). However, in the present day society, questioning experts opinion is becoming more and more accepted. According to Giddens (1990) we are living in a period in which expert judgements are constantly open to scrutiny or 'chronically contested', and either accepted or rejected by lay people on the basis of pragmatic calculations about the risks involved.

Despite the fact that their being Mantoux positive is not perceived as presenting danger to their environment, one respondent prefers not to talk about his condition to his family and friends:

"Anybody can be Mantoux positive at any time in their life, the difference is whether or not you know. I might as well have had this for a long time, and nobody knew about it. So I do not see the reason why I should inform them about my condition" (S/M)

Fear of avoidance due to the connection of the Mantoux test to tuberculosis may also prevent people to discuss their condition openly. People feel they risk being isolated from their social group, because of something they have, which is not characteristic of their social group (see Douglas 1985). Tuberculosis may be considered as a disease of marginalized people, and for some people, it is difficult to accept that they share the same characteristic with other social group, which is not their reference group.

Risk of Being Mantoux positive

People with a positive Mantoux are believed to have a 10% risk to develop tuberculosis in their life time (Schein and Huebner, 1994). In order to reduce and monitor this risk, they are advised to either take Isoniazid (INH) for 6 months or having regular medical checks and chest X-rays every 6 months for the next 2 years. When respondents are informed about their Mantoux test result, they are also informed about their epidemiological risk. With this information, people are expected to take necessary action in order to reduce their personal risk. However, people do not
calculate risk only on the basis of odds. According to Odgen (1995), people avoid risk when they perceive themselves under a serious health threat. All respondents appeared to understand the epidemiological risk as communicated to them by the health professionals. However, none of them perceive the threat to be that serious that they needed to do more efforts than what is advised by the health professionals. For example, nobody is found to change their life style (e.g. stop smoking, taking additional medication, have a more regular eating and sleeping pattern) in order to prevent attracting tuberculosis. This may be related to their perception that tuberculosis is not a serious or a dangerous disease. And the believe that there is little they can do to undo their being Mantoux positive status other than taking INH.

*Professional View of the Mantoux Test*

From the professional point of view, the construction of the respondents’ personal story is not seen as having as great importance as it is seen by the respondents:

"It does not matter if they know or do not know the source of infection. There are many possibilities to become Mantoux positive. Maybe because they were in contact with tuberculosis patient recently, or perhaps they lived abroad before, and only now they find out. What people often forget is that they can also get it here, for example in the HEMA. One day, the shop is full, and everybody has to queue in a row to pay, one person coughs near their face, and their Mantoux becomes positive. But most people do not believe this kind of transmission mode, because they cannot grasp it, and they need to blame somebody or this. What we do in the GGD is we try to make it clear to them and at the same time we show that we are not 100% sure about it."

However, they as aware that as much as they would like to hide the identity of the afflicted person from being revealed, it maybe impossible to do so, since nobody can stop respondents to talk to each other:

"The tuberculosis patient is somebody they know and have met. And the patient is being treated for some time. People do talk about this kind of thing."

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18. HEMA is a well known chain department store in the Netherlands
The health professionals did not consider people with a positive Mantoux as a sick person. On the contrary, they very much encourage the respondents to live and feel healthy as before. To support their explanation, the nurse is using the picture below:

<table>
<thead>
<tr>
<th>MANTOUX POSITIVE</th>
<th>HAVING TUBERCULOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>MANTOUX NEGATIVE</td>
<td>(OPEN OR CLOSED)</td>
</tr>
<tr>
<td>HEALTHY</td>
<td>NOT HEALTHY</td>
</tr>
</tbody>
</table>

"Somebody might be healthy and having Mantoux positive at the same time, but somebody is definitely NOT healthy when she/he is having tuberculosis".

During the first encounter with the respondents, the nurse and the doctor also provide some written information about the Mantoux test and tuberculosis. Beside written and on-site explanation, respondents are encouraged to contact them whenever they have questions.
Chapter 5
Adherence to the treatment

Adherence will be described in practical terms, in this chapter including reasons for taking INH, completion of treatment, medication taking, restrictions, side effects, and social reactions.

Reasons for Taking INH

Medication taking can be regarded as a sign of acceptance of the existence of an ill-health condition. Refusal may be translated as an efforts of the patients to remove the evidence that she/he has a disease (see Conrad, 1985). In this study, all of the respondents but one, decided to take INH for 6 months. Their reasons to take INH were instrumental, based on their belief that the INH will reduce their risk in contracting tuberculosis and psychological, to reduce worry, by controlling their perceived body malfunction caused by the tuberculosis germs. Beside these internal factors, there are also external factors. Two respondents working closely with other people, expressed the need to protect other people’s health. The same applied to another who saw the decision to accept INH medication as an obligation towards her status as a health professional.

One male respondent who decided not take INH explained that he did not see the need because he feels healthy and does not perceive tuberculosis to be a dangerous disease. However, his refusal can also be explained an to cut off the connection with tuberculosis, since he denied the fact that he was infected with a disease perceived to be stigmatized.
Completion of the Treatment

Almost all respondents completed the six months treatment, except for two. One respondent stopped taking medication because of heavily disturbed liver functions. Another respondent stopped two weeks before completion at own initiative:

“When they told me that I should take the 6 months medication, I was almost at the end of my internship. We usually have a big party for that. If I would start taking the pill, I would not be able to drink alcohol in the party, and that would not be nice. So I asked the doctor whether I could start 2 weeks later, and he said it was possible. At the date when I was supposed to have completed the treatment, they invited me to come to the GGD. They examined me as if I had completed the treatment, and they said that everything was fine again. Since they said that everything was fine again, I did not think I needed to continue with the pills, so I threw the rest away” (10/M)

Occasionally, missing a pill can be seen as a way of self-regulating. Some respondents missed their medication for varying periods of time, ranging from 1 up to 8 pills, due to the changes in their daily routine. For example, some respondents decided not to take INH on days when they wanted to take a lot of alcohol, knowing that INH and alcohol do not go well together. According to the TB doctor, missing pills up to 1-2 days is still tolerable. However, if the periods become longer than 1 week, he would still encourage patients to continue, but warns that the preventive effect may be less.

To stress the importance of completion, and to answer respondents’ questions regarding the duration of the treatment, 3 different illustrations are used by health professionals:

<table>
<thead>
<tr>
<th>Illustration 1</th>
<th>Illustration 2</th>
<th>Illustration 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>The bacteria inside your body is a very strong animal. So, it is really necessary to complete treatment for 6 months, also when the patient feels perfectly healthy. And even after that, the bacteria are not dead</td>
<td>If you do not complete the treatment, it means that you give the bacteria a little bit of medicine. And when you use this medication later again, the bacteria will recognize it and it withstand it. you will then need another medicine.</td>
<td>The 6 months periods is based on medical research. They have tried to use it for 3 months, 6 months and 1 year. Best results in term of adherence and risk reduction is reached by the one of 6 months.</td>
</tr>
</tbody>
</table>
Illustration 1 and 2 are constructed using the personalistic view of disease causation and aimed at making respondents aware of the risk if they do not complete treatment. Illustration 3 is facts from medical research. During the interviews some respondents referred to these messages when asked their reason for completing the treatment. However, it is not possible to get the respondents’ own idea about the duration of preventive treatment.

Upon completion of preventive treatment, respondents stated that they felt healthy and relieved, because they felt that they have done what they are expected to do:

“I allow myself to believe that I killed the bacteria inside my body, although I know that it is not entirely true” (2/F)

Medication Taking

From the perspective of the ‘health belief model’ adherence is more likely to happen when the patient feels susceptibility to illness; believes the illness to have potential serious consequences for health or daily functioning; and does not anticipate major obstacles, such as side effects and costs (Becker, 1976). However, although respondents in this study did not perceive their ill-health condition to have potential consequences for daily life and are aware of the possible occurrence of side effects, all of them adhered to treatment. According to Stimson (1974), patients may have their own ideas about taking medication. For instance, adherence can be seen as an attempt to assert control over a condition that at times appears to be completely beyond their control.

Adherence is proved to be difficult at the beginning of treatment. First because of the absence of symptoms and second because respondents need to integrate their INH taking into their daily routine:
"I was so occupied with this whole TB thing that I could not get it off from my mind. That's why I never forget to take INH. It has become part of my daily life that I think I will miss it when I complete the treatment" (3/F)

"After a while it became a habit. I was once having dinner in a restaurant with my girlfriend and I forgot to bring INH. I went to my friend's house, who is also taking INH and living near the restaurant, and borrowed a pill from him" (10/M).

The large majority of respondents take medication in the morning when they wake up, or at breakfast. Other respondents take it in the evening with dinner or before they go to bed. None of the respondents take INH at noon or with lunch. This may coincide with a certain lifestyle in which lunch is not considered as a real meal time. Due to the need to integrate medication taking into daily routine, adherence is thought to be easier for females because of concurrent use of the contraceptive pill.

Supports by friends and family is important in ensuring adherence. One respondent stated that adherence was easy because there was another family member who was also taking INH. Being out of the daily rhythm, such as during holidays or weekends, is a potential cause of non-adherence. In this respect, reminders by family members were very much appreciated. But adherence is also regarded as a test for the ability to control one’s own life. Some respondents stated that people should be able to adhere to the medication by their own means.

**Restrictions**

At the beginning of their treatment, three possible restrictions are communicated to the respondents. First, female respondents are informed that INH might lower the efficacy of the contraceptive pill. Secondly, they should be careful with sun; not that they should avoid the sun,
but they should be careful to stay in the sun for a long time (sun bathing). And thirdly, both INH and alcohol are metabolized in the liver, and it is advised not to take both concurrently:

"If they drink alcohol and take INH at the same time, the combination increases the chance to develop a hepatitis. But it is not 100% sure, so a lot of people do drink, and notice that it does not harm them. We always say ‘If you cannot stop drinking, please do not do it in the first two months, because in this period, we see most side effects. After that they can try, one glass, but never drink continuously in a long evening. If you notice you get drunk easily, or you have a bad hangover the next day, then do not drink at all’.

Most respondents perceived this restriction as the most serious one. Drinking alcohol is very much considered as part of the youth culture in the Netherlands. According to the younger respondents drinking alcohol has two functions. First, it elevates the moods in less-fortunate periods, and secondly, it has social functions, such as proving adulthood, creating group identity and providing ways to socialize. Drinking beer is closely related to certain sports:

"I play tennis every week, and after playing we always sit down and drink beer. During the treatment period, I asked for something else, and everybody was looking at me as if I asked for something very strange. Some of them even asked me why" (3/F)

One female respondent who refused to accept this restriction, continued to take alcohol during her treatment. Tuberculosis health professionals appear to be well aware of this phenomena, specially among the young people:

"We give them a bit of understanding so that they can help themselves. We put the responsibility at their end, not ours. If we tell to them “do not drink” then we are the “bad guys” and they will still do it. We always say, it is all up to you, it is your body”.

Surprisingly, respondents who are regular pub visitors and beer drinkers, accepted this restriction very well, specially in the first three or four months. Related to this restriction, one respondent reduced his frequency of going out:

"It is no fun to go out and not being able to drink, especially when everybody else is getting drunk, it is not nice to be the only sober person" (11/M).
Two respondents completely abstained from taking alcohol because of the occurrence of side effects, which perceived to be related to the combination of INH and alcohol. One respondent, even took this restriction as a challenge for himself.

Side Effects

Occurrence of side-effects is cited as one of the main reasons for non-adherence. In this study, almost all of the respondents experienced unpleasant side-effects. Some side-effects are manageable, but others are heavy, having major impacts on the respondents’ lives. Most side-effects happen at the onset of the treatment. Some of them disappear after some time, but some continue until the very end of the treatment. Respondents are informed of the possible occurrence of side-effects during their discussions with the TB health professionals and through brochures handed out by the GGD:

"My standard talk is that they may experience some fatigue, dizziness or sometimes headache. Those three I usually mention. But most people do not experience anything. I do not want to suggest that they are going to have these symptoms, I only want to warn them".

The kind of side effects that were experienced by the respondents can be grouped into physical and emotional side effects. The physical side effects are fatigue or being very tired, nausea, vomiting, weight loss, pimples, mouth blisters, hair loss, headache, and skin rash. The emotional side effects are irritability and easily getting angry, concentration disturbances and feeling of depression. Fatigue and nausea almost always happen at the beginning of the treatment. One respondent also complained of vomiting. The side-effects usually disappear after some 3-5 weeks. According to the TB health professionals this is because the liver needs time to adjust its capacity to metabolize INH.
After the disappearance of this “first group” of side-effects, others may appear. One respondent experienced weight loss and became very thin. Another respondents got a lot of pimples in her face and problems with concentration and memorizing. She complained of not being able to remember her PIN code (Personal Identity Number) of her bank card anymore, and having problems with studying as well. The situation has become so bad that she decided to discontinue her studies until the treatment is over. Another respondent got a severe headaches, which cannot controlled by aspirins. He went to his general practitioner to ask stronger pain killers, but did not get them. He became depressed, and resulting in problems at his school. Fortunately, a teacher understood his condition, which effectively helped him to get him through the six months period and avoided that he stopped his study. One other respondent reduced his workload and working hours since he feels very exhausted at 3 pm and need to go home to sleep. In an attempt to counteract the possible side-effect, one respondent asked for additional vitamins for his liver, because he believed that INH meant a heavy onslaught on his liver. He took vitamins for the first three months, but still had side-effects. However, he believed that things would have been worse without the vitamins.

Respondents perceived the side-effects to be heavier than tuberculosis itself:

“I was healthy, then I had that test, and now I have to take this medication. It does not make me better; on the contrary, it makes me more sick” (3/F)

“The medication has made me more sick than the tuberculosis itself” (9/M)

“This medication is not a good one, it is heavy and not the best. I dislike it very much” (6/M)

Health professionals share this opinion. According to them, it is understandable that people complain or even stop taking the medication due to the occurrence of side effects:

“The most problematic thing in my work is my fear that people will have their liver function disturbed, or get hepatitis because of the medication I prescribe. I hate that. If there is TB, I will accept it, I will
check it and make sure that something is done. But if it is because of prophylactic treatment that people get hepatitis, or they get other side effects, it is me who is making them ill. This is bad, and I dislike that. That’s why I am very hesitant to prescribe the medication. But I do it, because this is the line of thought in the Netherlands; the standard protocol.

Social Reactions Towards the Treatment

Friends and relatives react with concern. Most respondents are open to their friends and family. One respondent stated that her friends took a great interest in her health situation. Because she always presented herself as healthy, while now she needed to take medication. One respondent gets two different kind of reactions from his friends when he was about to start treatment. One group suggested him to take INH; while the other group suggested not to take INH. Both groups came with evidence for their advice. Having these two different suggestions, the respondent decided to ask for a third opinion:

"I went to my GP, showed her the skin rash of the Mantoux and told her that I had doubts about the result. I went to her because the consequences of this test are heavy. She took a look and told me that I should not worry about taking INH. However, some days later, she phoned me and told that she talked it over with the doctor at the GGD. Both agreed that I should take INH. It is not only for myself but also for my students. Because I work with children in classrooms, I can infect them if I do not take INH" (4/M).

Not surprisingly, curiosity of friends and family start when respondents do not take alcoholic beverages anymore.

"What is so wrong with not drinking alcohol? Isn’t it actually better? (2/F)
General Remarks

This research was conducted as part of a Masters’ education in Medical Anthropology at the University of Amsterdam. The purpose was to practice anthropological methods and to learn how to conduct medical anthropological research. It was designed to provide specific information on people’s experiences in adhering to tuberculosis preventive treatment in Leiden, the Netherlands. Open ended interviews were used as a research method as it is the most appropriate technique to obtain the necessary information. Interviews were conducted in the Dutch language, at the respondents’ residence or other places where the respondents felt most comfortable.

Due to the specific research topic, it was not possible to organize the research without involving the official Dutch health care system. Collaboration with the GGD in Leiden has been fruitful, they were supportive and accommodative. However, this sort of collaboration may also have introduced some bias. For example, the fact that letters were sent to “selected” patients (people with a positive Mantoux and taking INH) automatically left out Mantoux positive people who refused to take INH. Furthermore, there was a high non-response rate (50% of the approached people) and because of administrative and privacy reasons it was not possible to follow up on these non-responders. Ideally, a separate study should be done to uncover motivation of these non-responders and the extent of which they differ from the responders. The fact that only people who agreed to participate are studied may have been another source of bias. People who are motivated to participate may be different from overall the study population of people taking preventive TB medication, for instance their attitude towards the tuberculosis clinic at the GGD.
Time allocated for this research was 13 weeks, including report writing. However, to organize the research, setting the ground, contacting patients, finding interpreters, and interviewing respondents, the allocated time has been very short. Timing of critical events (such as appointment for interviews, getting new respondents) proved to be difficult, and delaying completion of data collection. Appointments for interviews should be conveniently scheduled for both the interpreter and the researcher, and the respondents. Interestingly, respondents always kept their appointments, and informed the researcher/the GGD in the case of cancellation. In one case a respondent was willing to travel about 100 km on a motor bike to be interviewed in an agreed location in Leiden. The fact that the research was conducted at the start of the summer holiday season presented another problem. Some potential informants could not be reached, and by the time this became clear, there was not enough time left to approach another group of potential respondents.

However, this research has been an excellent experience in learning to organizing and conduct medical anthropological research. The experience gained by it clearly transient the field of tuberculosis control.

Keeping in mind that the sample size has been small, and taking into consideration possible bias in sampling, this exploratory study does allow for some preliminary conclusions. In addition, exploratory nature of this study may enhance the formulation of more relevant research questions in various research disciplines.
Factors Influencing Adherence

Findings of this study are discussed according to the sequence of the research questions:

Socio-Demographic Characteristics

Adherence of young respondents in this study has been equally good as that of older respondents. Older age has been associated with better adherence (Bell and Yach, 1988), but no clear association could be demonstrated in other studies (see Baarnhoorn and Adriaanse, 1992; Alcabes et al, 1989; Armstrong et al, 1984). Women are perceived to better adhere than men, but gender has not been associated with adherence in other studies (see Baarnhoorn and Adriaanse, 1992; Alcabes et al, 1989; Armstrong et al, 1984).

According to Sumartojo (1993), demographic factors such as age, sex, race, ethnicity, occupation, income and education are inconsistent or unreliable predictors of patient adherence. In addition, the use of demographic factors to predict adherence present two important problems. First, variables such as age, income or occupation are not inherently causal. Rather, they represent other factors about the patient that may be the real causes of poor adherence such as lack of access to good information about health and illness, lack of financial resources to support medical treatment, or mistrust of the culture of the health care system. Second, the use of demographic characteristics is less than practical since intervention by a tuberculosis control programme will not influence demographic characteristics. For instance, changing the patients’s age or sex to improve adherence will not be possible.

Socio-economic variables such as family income and educational level seem to be more consistently related to poor adherence (Baarnhoorn and Adriaanse, 1992; Alcabes et al, 1989;
Armstrong et al., 1984; Corcoran, 1986). In this study however, the level of family income is not a factor of consideration since tuberculosis treatment is covered by all health insurances. The educational level of the respondents was relatively high, which may be the cause of the high sense of responsibility, apparently related to the intention to adhere. Low educational level has been found to be significantly associated with nonadherence (Corcoran 1986, Alcabes et al. 1989).

In this study, it has not been possible to relate demographic characteristics of respondents to their adherence to tuberculosis preventive treatment. The small sample size does not allow quantitative analysis and respondents represented variety of demographic characteristics, which made it difficult to generalize and relate to a certain aspect, such as adherence. A preliminary conclusion from this study is that adherence to tuberculosis preventive treatment is not associated with the respondents' and health professionals' socio-demographic characteristics.

**Tuberculosis, Mantoux test and Tuberculosis treatment**

Helman (1997) classifies germ theory into what he calls patient-centred explanation. In this category, responsibility for illness falls mainly (though not completely) on the patient himself. This belief is especially common in the Western world (and often encouraged by government health education campaigns), and where ill-health is increasingly blamed on 'not taking care' of one's diet, dress, hygiene, lifestyle, relationships, sexual behaviour, smoking, drinking habits and physical exercise. Ill-health is therefore considered as clear evidence of such carelessness, and the sufferer should feel guilty for causing it. This type of explanation is important in determining whether people take responsibility for their health, or whether they see the origin and cure of ill-health as being largely outside their control.
Respondents in this study held the personalistic view of tuberculosis causation. Germs are considered as the cause of tuberculosis. This view is also reflected in their perception of the purpose of Mantoux test. Similar views on causation are found in Pakistan and the Philippines (see Liefooghe, 1995; Nichter, 1994).

This causation lead respondents to believe that they need to kill the germs and cure the disease, by taking medication. Thus, this belief seemed to be positively associated with their adherence. As in Pakistan, this belief significantly increases treatment adherence than other believes of causation (Liefooghe, 1995). However, another study in the United States found that people who correctly associate their positive skin test result with infection were less adherent than those who believed incorrectly that the reaction indicated active disease (Alcabes et al, 1989). In conclusion, adherence is influenced by people perception about their ill-health condition.

The combination of the respondents' perception of tuberculosis as a contagious disease and the consideration of its likely effects on other people's health support the respondents' intention to adhere. According to Conrad (1985) people continuously evaluate the cost and benefits of actions related to their ill-health condition. In this study respondents tried to avoid being a source of infection by taking the medication and being adherent. This idea is also strengthened by the idea that they do not only protect their own health, but also that of other people.

Because tuberculosis is perceived as a stigmatized disease, associated with some less positive aspects of life in the present day Dutch society, it has double consequences for adherence. First, being stigmatized, people absolutely do not want to have tuberculosis in their life. To avoid this disease, they are motivated to adhere to the treatment. This kind of situation is likely to occur in
a society people can be treated and taking their medication without being exposed publicly. As a second consequence, medication taking can be seen as evidence of the existence of tuberculosis. This evidence of a connection between a person and a stigmatized disease may result in social isolation. Elsewhere, stigmatization has been cited as a major obstacle for adherence (see Nichter, 1994; Liefooghe, 1989; Rubel and Garro, 1992).

The respondents' own personal story on how and by whom he got infected is not clearly related to adherence behaviour. Respondents adhere to the treatment regardless whether or not they have a plausible story. Nevertheless, the personal story appeared to be important in reducing anxiety and uncertainty by providing an explanation for why they are Mantoux positive. According to Brody (1987), telling such 'stories of sickness' is a way of giving meaning to the experience of ill-health, by placing it into the context of the individual's life history, and relating it to the wider themes of the society and culture in which one lives. These narratives or personal stories are not only personal; they also draw on the repertoire of language, idiom, metaphors, imagery, myths and legends, provided by the culture in which the experience took place. Many narratives may be created with the help of other people including the healer, as also proved to be the case in this study. For example, one respondent created his story by combining the doctor's information on tuberculosis with his own 'investigation'. He concluded that he got infected through talking to many kind people who he met in his work.

Respondents were aware of their epidemiological risk in developing tuberculosis. However they did not perceive themselves as being ill or as possessing a serious health threat. Interestingly, in this study both, the health professionals and the respondent have the same opinion about the health status of the latter. Both treat the epidemiological risk as their instrumental reason for
adherence. Both also share the belief that the medication will reduce the epidemiological risk from 10% to 1-2%, provided the treatment is adhered to. It also appears that taking INH for six months is regarded as the only valid, effective and protective action, and that its benefits outweigh its perceived cost (Bloor, 1995). In addition, being Mantoux positive is not perceived as having social consequences nor is considered as presenting any danger to the social environment.

Acceptance and Ability to Cope with the Demand of Medication Taking

Abstinence from alcohol taking is perceived as a serious restriction by most respondents. This restriction does impact on respondents' life styles. Nevertheless, it is not directly associated with non-adherence, a finding which is not consistent with findings from other studies. Prescribed treatment requiring major long-term changes of daily life are shown to be associated with non-adherence (Hunt et al, 1989). When people saw their medication practice as hindering the ability to participate in routine social affairs, they were less likely to adhere (Conrad, 1985). To explain or understand this inconsistency, follow-up research should be conducted, focusing on the meaning and value of alcohol use as attached by the respondent, and how they weigh these values when their health is at risk.

Occurrence of side effects has been identified as a major problem for respondents and the health professionals in ensuring adherence. Some of the side effects change the respondents' life style considerably, though temporarily. The occurrence side effects is the most common drug-related cause of non-adherence or defaulting (KNCV, 1997). In this study, one respondent discontinued treatment because of his liver disturbances showed by the abnormal test values. Liver function has been used as the valid indicator to prove the occurrence of actual side-effects and determine
whether one can continue treatment or not. In the case of other respondents, when they inform the doctor about their perceived side-effects, their liver function was also checked but they did not find any abnormal test values. Thus, perceived side-effects is apparently not considered as a strong reason to discontinue treatment. According to Conrad (1985) in his study among epileptic patients, side-effects of drugs, even those that impair social skills, do not sufficiently explain the level of self-regulation in medication taking. When people decide to stop, alter or change their medication practice, it is due to much more than only annoying or uncomfortable side effects. It is an active and intentional endeavour.

Clinic Factors and Other Factors

In ensuring adherence, the GGD has a name of being very supportive and accommodative. Most respondents agreed about that. People who are Mantoux positive are given a set of information brochures about their condition, and its medication, including possible side-effects. On top of that, GGD welcomes any telephone call related to problems in medication taking.

According to the nurse, home supervision is not applied to people with a positive Mantoux, unless people indicate the need for such supervision visits. Besides time and staff constraints, not all people appreciate home supervision. Some respondents stated that they see home supervision as not at all necessary, and that may impact negatively on adherence (“as if I cannot take care of my own health”). Home visits are almost always applied to tuberculosis patients, because they need to take several medications and adherence must be absolutely secured.

The TB doctor voiced similar opinion. According to him, it is not necessary to put much time and energy into forcing people with a positive Mantoux to adhere. He realized that adherence
may be difficult for them, because, they are healthy; without symptoms, and the occurrence of 
side effects may easily lead them to discontinue treatment. He neither perceived adherence to 
preventive treatment to be as crucial as that in active tuberculosis treatment. He encourages 
people to adhere, but does not see the need for doing direct supervision to ensure adherence. If 
people cannot adhere, they can have chest X-rays every six months for two years, which is an 
alternative just as good as taking INH for 6 months. If later they do get tuberculosis, there is still 
the option of effective curative medication. Studies show that the effectiveness of preventive 
therapy, defined as the reduction in the incidence of tuberculosis, among persons receiving INH 
and those receiving placebo, with good adherence is 90%. Even people who take the drugs 
irregularly are still protected. This shows suggests that intermittent INH preventive therapy still 
be significantly effective. However, more scientific proof is needed to support this impression 
(O'Brien, 1993).

Another factor which seems to determine adherence is personality. From the way respondents 
presented their experiences, it became clear that people carefully evaluate their situation and 
options to handle it. When they were informed of their positive outcome of their Mantoux test, 
they were given the option of doing nothing, taking INH for six months or having chest X-rays 
every six months for two years. They appeared to have processed this information cautiously and 
have made a conscious decision on what to do. Once the decision was made, they appeared to 
stick to it, even if it implied enduring un-pleasant side effects and life style changes for six 
months. However, this impression must be treated with cautions due to the possible bias in 
sample selection: people who agree to participate in this research may have similar personality 
characteristics (they were all educated, had an organized life and were clearly all in control of 
their lives). Nevertheless, this impression should also be seen as an invitation for further research
in understanding of decision making processes, and the meaning and values attached to this type
of decisions, especially when unpleasant side-effects and/or life style changes are involved.

Ways to Ensure Adherence

During the interview, respondents were asked to give their opinion on better ways to ensure
adherence. Their responses can be grouped as follows:

1. The form of treatment should be changed from the badly tasting pill into something that can be
taken with coffee or other drinks. Or, the medication should be put in a special container to help
the respondent to remember whether or not they have taken their medication for the day.

2. Home supervision during the treatment period or formation of patient groups to remind people of
the importance of adherence were mentioned.

3. Quality information in oral and written form should be made available, to convince people of the
need to adhere to treatment. For instance, they should be informed that they do not only take
medication for themselves, but also for their social environment.

Realizing that the personality of respondents is an important determinant to adherence, it should
be taken into account when adherence is absolutely needed. The provision of proper and correct
information, will reduce fear and anxiety and help them to make the best decision. If people are
allowed to have the power to make their own choices, they tend to stick to what they promised
to themselves.
Chapter 7

Conclusions and Recommendations

Conclusions

This study aimed at making an important contribution in the field of tuberculosis control by focusing on the perspectives of the patients on preventive treatment. The Netherlands is cited as one of the leading examples in the world of a successful tuberculosis control program. Yet, the success of such a program cannot be determined from a technical point of view only; the perspectives of both the clients and the providers of the service should also be considered. They might as well be the key importance in the effectiveness of tuberculosis control activities.

Keeping in mind the limited scope and sample size, a number of conclusion can be drawn:

1. Adherence to TB preventive treatment is not influenced by socio-demographic characteristics of the respondents or the TB health professionals. Other studies have shown that demographic factors are inconsistent and unreliable predictors of adherence. However, socio-economic variables such as family income and educational level did have a significant association with non-adherence. In this study, no such association was found because tuberculosis treatment is covered by all health insurances and the level of education of the respondents was quite high. Another important consideration is that to establish this kind of association, a quantitative analysis involving a larger sample is absolutely required. On the other hand, respondents of this study highly value and act upon their own decision, indicating that adherence appears to be influenced by the respondents’ personality.
2. Adherence is influenced by the respondents' understanding of the purpose of the Mantoux test, their perception of causation, contagiousness, and the social aspects of tuberculosis. However, these understandings and perceptions influence adherence in both positive and negative ways. Understanding of the purpose of the Mantoux test, perception of causation, and the perceived contagiousness of tuberculosis strengthened the respondents' intention to adhere to the treatment. Stigmatization of tuberculosis may hinder adherence through the perception that taking medication is proof of the existence of the stigmatized disease in a person taking the medication. On the other hand, taking medication can also be seen as an effort to remove the stigmatized disease, which in this respect, supports adherence. The large majority of the respondents perceived that adherence to INH will remove tuberculosis from their body. The understanding of the epidemiological risk of being Mantoux positive indirectly supports the adherence behaviour. This risk perception was clearly used as an instrumental reason in adhering to INH by the respondents.

3. Although many studies cite the occurrence of side effects as a major reason for non-adherence or for interruption of treatment, this phenomena was not found in this study. Even though all respondents experienced long-lasting unpleasant side effects, and some of them were forced to change their life style accordingly, all of them were able to cope with their situation until the end of the treatment. Instead, respondents put the extent of self control and self responsibility towards their own health and their own life, higher than the annoying side effects and life style changes. Respondents were very much stuck to the decision they had once made, to take and adhere to INH. In conclusion, in this study, occurrence of perceived side effects and obligatory life-style changes did not appear to influence the respondents' adherence to tuberculosis preventive treatment. It is observed that respondents
in this study were very much active in evaluating their situation, including their decision to adhere, stop, alter or change their medication practice.

4. Respondents' own personal story on how and by whom they got infected appeared to be important in reducing their anxiety and uncertainty, and help them to make their decision on their being Mantoux positive. As with many other important life events, respondents in this study were eager to have a plausible explanation of what had happened to them, more than only technical information. Even though the GGD has provided a proper technical explanation about their situation, the respondents still tried to come to grips with the fact of being Mantoux positive, by organizing facts into a recognizable and culturally accepted pattern. At the later stage, they used these facts to make decisions and to act upon them. The role of the GGD in ensuring adherence is equally as importance. Most respondents agreed that the GGD has been very supportive and accommodative during their course of taking medication, and the role of the GGD remains a critical one in ensuring adherence.
Recommendations

This study identifies several interesting factors as having a major role in ensuring adherence to TB preventive treatment. Although the limited sample size does not allow for general conclusions on the Dutch population, the findings of this study do point to crucial factors of influence in ensuring adherence and quality of care of tuberculosis service in the Netherlands.

A similar study with a bigger sample size, involving more TB patients, health care providers and policy makers, could further elaborate on these factors. A combination of quantitative and qualitative methods will allow for a more in-depth understanding of the interrelation between the above mentioned factors and impact on adherence behaviour.

In this study it was observed that the respondents' personality, in a context of Dutch cultural and social values, plays an important role. For instance, respondents' high motivation to take INH in order to be fair to their other country fellow, that they will not be a source of infection for people around them. Due to limited time and language barrier, it was not possible for the researcher to elaborate on the Dutch social and cultural context. Research is warranted on the contrast between the Dutch social and cultural values with the extent of life-style changes and occurrence of side effects in the course of tuberculosis preventive treatment. This could result in identifying determinant factors for adherence among the Dutch people.

The concept of risk and prevention in tuberculosis is another important area for future research. The availability of tuberculosis medication allows the health care providers to reassure Mantoux positive people: even if they do get tuberculosis, there is a cure!. These facts influence the risk perception held by patients and TB care providers, as well as their understanding of prevention
in tuberculosis. A closer look at how treatment alternatives are presented (e.g. INH or 2 years of x-ray controls) will strengthen our understanding of the decision making process of the patients, which in turn, is influencing their intention to adhere to the treatment.

Another important research question is how the concept of prevention in tuberculosis is understood by the patients. Is it different than the one of the providers? During this study, some respondents gave the impression that they put a lot of trust in the hand of the professionals, but at the same time, they were also eager to find information from other sources. Knowing this, it is clear that the role of health care providers in this specific cultural setting is equally worth investigating.

When complex behavioural phenomena such as adherence need to be secured, and people are allowed to make their own choice, they tend to stick to what they promised themselves. In this study, the provision of quality information on tuberculosis helped respondents to make the best decision for themselves. In turn, their firm decision positively influenced their adherence behaviour. A quality tuberculosis control programme should make information easily available either as printed materials or through timely communication with health professionals. And in the case of a TB control programme in a multi-cultural settings such as in the Netherlands, it is important to have this kind of information translated into several different languages, as they way it has been done so far.
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