ENCOUNTERS WITH POWER

Health Care Seeking and Medical
Encounters in Tuberculosis Care:
Experiences from Ujjain District, India

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ABSTRACT

Background: Tuberculosis (TB) has been declared a government priority in India and public TB care is delivered by the Revised National Tuberculosis Control Programme (RNTCP). Despite having achieved a significant increase in reported cure rates and coverage, the RNTCP is associated with access barriers and there is no indication that the incidence of TB is declining. Private health care providers play a significant role in the delivery of tuberculosis care. While medical encounters in the private health care sector are described as patient-friendly, the encounters in the public health care sector are reportedly poor.

Aim: This study examines health care seeking and medical encounters in the context of TB care in a rural district in central India. More specifically, the study focuses on how relations of power between health care providers and patients are created, altered and maintained during medical encounters in a diversified health system.

Methods: The study was conducted in Ujjain district, Madhya Pradesh, India. In paper I, we conducted a population-based screening survey within a demographic surveillance site (n= 45,719) to identify and interview individuals who had had a cough for more than three weeks (paper I). In papers II-IV, I used qualitative methods including semi-structured interviews with 22 health care providers purposively selected from the public and private health care sectors in rural and urban areas (paper II), non-participant observations, including qualitative interviews, in four private health care clinics (paper III) and at a district tuberculosis centre (paper IV) and, finally, semi-structured interviews with 14 TB patients (paper III).

Findings: Among the individuals with a cough (477 men and 167 women), 69% of the men and 71% of the women reported seeking health care, and the majority of both men and women visited a private provider first. Only 13% of those seeking care reported having had a sputum smear examination since the onset of their cough. In the medical encounters, health care providers adopted an authoritarian as well as a consumerist approach. The authoritarian approach was encapsulated in health care providers’ perceived need to persuade or force “the ignorant patient” to follow their advice. While young women in particular were perceived as incapable of understanding the doctor, the interactions between health care providers and female patients were often restricted because of gendered norms for communication. When guided by consumerism, private health care providers tried to meet patients’ needs and expectations, and an informal support system to the ‘poor’ was established through negotiations around treatment and payments between patients, relatives and providers. In the public health care facilities, on the other hand, hidden costs created an illusionary ‘free’ public TB care. In patients’ considerations of paying for care, affordability was defined in the interplay between perceived severity of symptoms, doctors’ status and capacity to treat and cure, opportunities to raise money, as well as considerations of social status and gender. A doctor’s dilemma within the RNTCP was identified as conflicting accountabilities. In an organization perceived as inefficient and resource-constrained, the doctor struggled to find a balance between meeting the obligations of the programme, and meeting the needs and expectations of the patients in the encounters.
Conclusion: When medical encounters were guided by consumerism, patients had the chance to be active and negotiate decisions with health care providers. However, at the same time, the patients’ ability to pay was subject to assessment by the providers, and young women, in particular, were in the hands of others when it came to negotiating treatment and payments. Hence, both empowering and exploitive mechanisms seemed to be at play in the encounters that take place in the private health care sector, and these need to be considered in the ongoing strategies of including private providers in TB control activities in India. The dilemma of conflicting accountabilities indicates that encounters within the RNTCP are embedded in a system where not only patients but also doctors lack power to act. This suggests the need to support doctors and health care providers in implementing the programme as one step towards also increasing patients’ involvement in the encounters. Furthermore, the hidden costs associated with the ‘free’ public TB care need to be recognized in efforts to successfully attract and treat patients in the RNTCP.

Keywords: Medical encounters, health care seeking, power relations, gender, tuberculosis, DOTS, RNTCP, India
LIST OF ORIGINAL PAPERS


III. Fochsen G, Deshpande K, Ringsberg KC, Thorson A. “If you don’t pay, you’ll die”: Exploring processes behind health care choices and related payments in the context of tuberculosis care in rural India. (Submitted)

IV. Fochsen G, Deshpande K, Ringsberg KC, Thorson A. Conflicting Accountabilities: Doctor’s Dilemma in TB control in Rural India. (Submitted)

The papers will be referred to by their Roman numerals.
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<tr>
<td>aOR</td>
<td>Adjusted Odds Ratio</td>
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<tr>
<td>BCG</td>
<td>Bacille Calmette Guerin</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>CXR</td>
<td>Chest X-ray</td>
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<td>DOTS</td>
<td>Directly observed therapy–short course</td>
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<td>DSS</td>
<td>Demographic surveillance site</td>
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<td>DTC</td>
<td>District Tuberculosis Centre</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>MDR-TB</td>
<td>Multi-drug resistant Tuberculosis</td>
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<td>MP</td>
<td>Madhya Pradesh</td>
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<td>RNTCP</td>
<td>Revised National Tuberculosis Control Programme</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>WHO</td>
<td>World Health Organization</td>
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1 INTRODUCTION

My entry into the field of international health and, more specifically, tuberculosis (TB) was a combination of chance and conscious planning. In 2001, I became interested in health from a global perspective as a master’s student in public health at Karolinska Institutet. Having previously worked as a nurse and also studied social anthropology, I was eager to use my ‘multidisciplinary’ background and gain experience of working internationally. I contacted the Division of International Health, and ‘by chance’ I met my future supervisors, who suggested a project in China within the field of TB and equity. At that time, I had little knowledge of TB or international health, but my two-month stay in China proved to be the beginning of a learning process which evoked many ‘new’ questions that I wanted to examine further. In 2002, a project on TB was planned in Ujjain district in India by my co-supervisor. This opened up the opportunity for me to continue my training in international health, and brought me to the stage of ‘conscious planning’ for a doctoral student project. In February 2003, I visited Ujjain for the first time and one year later I started my PhD training at the Division of International Health.

In 2004, the implementation of a global TB control strategy, known as directly observed therapy–short course (DOTS), had been in progress for 10 years. However, concerns about slow case-finding and top-down implementation processes had been frequently voiced in the research literature. In India, the Revised National Tuberculosis Control Programme (RNTCP), including the DOTS strategy, covered 67% of the population, and was delivered through the public health care institutions. The large heterogeneous private health care sector, however, had drawn attention to the necessity of integrating the numerous private health care providers into the delivery of TB care.

It was against this background that I started my thesis project. Among the research findings that I found intriguing in the initial stage of my work were the long delays before patients received their diagnosis and treatment, due to barriers after they had reached the health care facilities. This seemed to be especially true for female patients. In other words, despite the fact that they sought care, TB patients were not promptly diagnosed or provided with anti-TB treatment. This led to questions about how care is delivered to patients. In India, private health care providers were described as delivering patient-friendly but medically inadequate care. Public TB care, on the other hand, lacked patient-centred services and, as noted by Khatri and Frieden (2002), “the interpersonal communication skills of health care providers leave much to be desired” (p 462). The importance of improving the quality of provider–patient interactions was often mentioned, but I found little research on what actually happened in these interactions in the public and private health care sectors in India.

My research has thus sought to understand the experiences of health care providers and patients who act and interact at the local level of the health system. I have tried to understand how their experiences are shaped by the particular context they live in, while at the same time attempting to put these individual experiences into a larger context by relating them to the broader structures of the health system and TB control in India.
2 BACKGROUND

TUBERCULOSIS

Following the introduction of chemotherapy in the 1940s, researchers, policy-makers and clinicians started to believe that it was possible to eradicate TB. A steady decline in the annual risk of TB was observed in the industrialized countries between the 1940s and 1970s, but no such trend was observed in developing countries during this period (Raviglione & Pio, 2002). This created a false belief that TB had been controlled and a subsequent global neglect of the disease. Despite some activities to develop feasible and effective methods to control TB in countries where the disease persisted as a significant public health problem, knowledge from such efforts did not reach the international community (Ogden, Walt, & Lush, 2003). It was not until the re-emergence of TB in high-income countries during the 1980s that TB caught the attention of public health scientists and policy-makers at the international level. With the label of a “neglected disease”, TB entered the global public health agenda in the early 1990s (Walt, 1999), and was declared a “global emergency” in 1993 by the World Health Organization (WHO).

Today, TB remains a global public health challenge. An estimated 8.8 million new cases occurred in 2005, and 1.6 million people died (WHO, 2007). The burden of TB varies greatly across countries and regions. Around 80% of all new cases are found in 22 high-burden countries. Analysis of data reported to the WHO from 1980 to 2005 showed that the estimated TB incidence has declined continuously in high-income countries and in a few middle-income countries. In eastern and southern Africa where there is high prevalence of HIV the estimated incidence rate has increased steadily, although the rate of increase seems to have slowed down. In South-East Asia no clear reduction in estimated incidences has been observed (ibid). While TB mortality is declining in several countries, the number of deaths has increased in Africa due to the high prevalence of the HIV infection, and in Eastern Europe due to high rates of drug resistance (Dye, Watt, Bleed et al., 2005). The global male–female ratio for notified smear positive cases is 2.2:1, but varies from 1.3:1 in the African region to 2.2:1 in the west Pacific region (WHO, 2007).

The HIV pandemic and the increase of multi-drug resistant (MDR) TB have drawn attention to the additional challenges in global efforts to control TB (Gandy & Zumla, 2002). The impact of HIV, the most important predisposing factor for developing TB, is most severe in sub-Saharan Africa. In Botswana, for instance, the prevalence of HIV in adult TB cases is as high as 70%, whereas the corresponding figure in India is 5.2% (WHO, 2007). In 2004, China, India, and the Russian Federation accounted for 62% of the global estimated incidence of MDR-TB. In India, however, the rates are slightly below the global average, but due to the high burden of TB, this constitutes a large absolute number of patients with MDR-TB (Zignol, Hosseini, Wright et al., 2006).

Global TB control

The strategy of DOTS was launched in 1994, aiming at global implementation to control TB. A rapid global implementation followed and today 187 countries have adopted the strategy (WHO, 2007). The concept of DOTS emphasizes the direct
observation of patients’ drug intake, but the strategy also includes a broader public health strategy comprising five components: political commitment, case detection by sputum microscopy, standardized treatment of 6 to 8 months including the direct observation of treatment for at least the first two months, regular drug supply, and a standardized recording and reporting system (WHO, 2006a).

**Targets**
The recommendations by the WHO focus on case finding of the contagious cases, i.e. identification of sputum smear positive cases of pulmonary TB (WHO, 2007). In the early 1990s the global targets were set to detect 70% of the smear positive cases arising each year, and to achieve a treatment success rate of 85% among these cases by the year 2000. These targets were based on the assumption that if case detection and cure rates exceed 70% and 85%, respectively, TB incidence will decline at 5-10% per year in areas of low HIV prevalence (Dye et al., 2005). When it became clear that these targets would not be met by the year 2000, the target year was postponed to 2005. An analysis of data reported by national TB control programmes to the WHO between 1995 and 2000 suggested that while DOTS coverage increased geographically, the case finding did not necessarily improve (Dye, Watt, Bleed et al., 2003). The most recent analysis of data reported to the WHO indicates that the global case detection rate of smear positive cases by DOTS has increased rapidly, from 28% in 2000 to 60% in 2005 (Dye, Hosseini, & Watt, 2007). This global increase is mainly due to the rapid implementation of India’s and China’s national TB programmes. However, it has been pointed out that the case detection estimates contain a great deal of uncertainty due to weak surveillance systems in several countries with a high burden of TB (van der Werf & Borgdorff, 2007). For example, a prevalence study from Vietnam, a country which has reached the WHO targets, revealed an under-detection of TB cases in general and of female cases in particular, which was greater than expected if compared with national case detection estimates (Thorson, Hoa, Long et al., 2004).

**The vertical approach**
In a historical perspective, TB control policies show a back and forth movement between vertically structured programmes, operating parallel to the general health care services, and programmes integrated into the general health care system (Raviglione & Pio, 2002). A vertical system approach, introduced after the Second World War, turned out to be successful in affluent countries, but failed in less affluent countries with the highest burden of TB (Walt, 1999). During the 1960s and 1970s, new strategies were introduced, aiming at integration of the TB control programmes into the general health care systems, but Raviglione & Pio (2002) noted that “the integration policies, although correct in theory, had resulted in a loss of visibility of TB control, and a gradual loss of expertise in organizing effective case-management activities” (p 777). With the introduction of the DOTS strategy a vertically structured system of specialized managerial functions at central, regional and district levels was promoted.

The development and implementation of DOTS have further been characterized by a top-down process, where the policy is formulated at the international level and then

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1 Case detection rate, expressed as a percentage, is calculated as the number of cases notified, divided by the total number of estimated cases for that year (WHO, 2007)
transferred down to the national and local level (Porter & Ogden, 2001). Along with the vertical structure of the programme, this approach has been criticized for ignoring local circumstances and culture; for focusing on short-term and target-orientated activities rather than capacity-building and holistic efforts over time; and for focusing on cases and control of transmission rather than individual rights and needs (Harper, 2005; Hurtig, Porter, & Ogden, 1999; Porter & Ogden, 2001).

The global embracement of the strategy, in particular the component of directly observed therapy (DOT), was also questioned by researchers due to the absence of evidence of its effectiveness (Porter & Ogden, 2001). In a recently up-dated Cochrane review of randomized controlled trials conducted in low-, middle-, and high-income countries, no evidence was found suggesting that directly observed therapy improved cure or treatment completion rates among TB patients compared with self-administered treatment (Volmink & Garner, 2006). However, the complex relation between DOT and treatment outcomes due to other simultaneous interventions has been recognized, indicating that evaluations cannot focus on the DOT component alone (Volmink, Matchaba, & Garner, 2000). In a similar vein, a systematic review of qualitative research revealed the variation in how DOT is adopted and implemented across settings (Noyes & Popay, 2007). It has also been pointed out that even though the component of directly observed treatment fails to prove its effectiveness in randomized control trials, the overall strategy has drawn attention to the global problem of TB and contributed to improving the TB health care infrastructure. This may benefit all patients, irrespective of whether they adhere to DOT or prefer self-administered treatment (Harper, 2005).

Given the variations across settings, an important question in the implementation of DOTS is how policy that is developed at the international level is translated into practice at the local level. A policy like DOTS defines clear objectives and goals, but the process of implementation is not clearly described (Porter, Ogden, & Pronyk, 1999). Several factors on the micro- and macro-levels influence the implementation of guidelines: individual beliefs, attitudes and knowledge of the clinical professionals, local, organizational and economic circumstances, priorities and commitment of the parties involved and the implementation process itself (Hill, 2002). Implementation is viewed as the most important part of the policy process (Walt, 1994), and brings to light how the actors at the local level are affected by and respond to the policy in question (Hill, 2002). In the context of TB control, these actors are the patients, their families and the health workers (Walt, 1999). Porter and Ogden (2002) argue that while technology and innovations are necessary, the “real issue for TB control is how we deliver care to patients” (p 397).

Shift in perspectives
Based on research and experience from the global implementation process there has been a shift in perspectives during the last few years from a top-down control approach to bottom-up strategies, emphasizing community mobilization and coordination between actors at different levels (WHO, 2006b). A new global plan, “Stop TB”, was introduced in 2006, aiming to extend and enhance the DOTS strategy in order to achieve the TB-related Millennium Development Goals of decreasing mortality and prevalence rates by half before the year 2015 (Stop TB partnership, 2006). The plan includes the following six main elements: pursuing high quality DOTS expansion and
enhancement; addressing TB/HIV, MDR-TB and other challenges; contributing to health system strengthening; engaging all care providers; empowering patients and communities; and, finally, enabling and promoting research (Raviglione & Uplekar, 2006).

**TB control and the Indian health system**

*TB in India today*

India belongs to the group of 22 countries with the highest burden of TB and alone accounts for nearly a third of the global TB burden. TB is the infectious disease with the highest mortality in India, causing more than 300,000 deaths each year (WHO, 2006). The estimated incidence in 2005 was 168/100,000 TB cases, of which the sputum smear positive cases accounted for 45% (75/100,000) (WHO, 2007).

In 2005, the male–female ratio among new smear positive cases was estimated to be 2.2:1. The notification rate of smear positive TB peaked among women aged 25-34 years (55/100,000), whereas most cases among men were in the age group 55-64 years (131/100,000) (WHO, 2007).

*The RNTCP*

India’s TB control programme dates back to the early 1950s when a TB health care infrastructure of district clinics and mobile TB teams was established. The high costs of establishing these clinics shifted attention to preventive actions through BCG vaccinations campaigns. However, operational research indicated little impact on the TB epidemiology, and strategies to integrate the programme into the general health care system were introduced in the 1960s and 1970s (Agarwal, Vijay, Kumar et al., 2005).

After extensive reviews and evaluations of the programme several shortcomings were identified and suggestions for a new control strategy were put forward in the early 1990s (Kishore, 1999). A revised national TB control programme was implemented in 1993 introducing the DOTS strategy recommended by the WHO. A large-scale implementation began in 1998 and countrywide coverage was achieved by March 2006 (Khatri & Frieden, 2002; RNTCP, 2007). The RNTCP builds on the infrastructure for TB control developed under the previous national programme. The aim is to integrate the delivery of TB care services into the general health care system, while the managerial system, including monitoring and supervision, is organized through a separate vertical structure with specialized centres and staff at the central, state and district levels (Agarwal & Chauhan, 2005).

The first phase of the RNTCP implementation was to ensure “high quality DOTS expansion” in the country, addressing the five components of the DOTS strategy (RNTCP, 2007). In line with this strategy, the objectives were to detect 70% of the smear positive cases, and to achieve a treatment success rate of 85% among these cases. The RNTCP has now entered into what is defined as phase II (2006-2015), which includes the components and aims proposed under the new WHO Stop TB Strategy for TB control.
As a result of the rapid expansion of DOTS, the estimated case detection of sputum smear positive cases within the programme has increased from 1.8% in 1998 to 61% in 2005. The treatment success rate reached 86% in 2004 (WHO, 2007). However, the notification rate of all forms of TB, both inside and outside DOTS areas during the same period, has remained roughly stable at around 105/100,000, indicating a flow of cases into the RNTCP rather than an absolute increase in case detection. In addition, there is no clear evidence that the incidence of TB is decreasing in India (WHO, 2006a). One of the major challenges in the implementation of DOTS in India is the poor public health care infrastructure and the vast private health care sector.

Public health care

The foundation of today’s public health care infrastructure was set by the Bhore committee report in 1946, which introduced a policy of a comprehensive state-run health care system. It was adopted by the newly independent government, but the aim of a well-integrated health care system including a strong referral system was not achieved. Instead, the development of the public health care infrastructure has been characterized by lack of finances, poor implementation strategies, and unbalanced focus on vertical single-purpose programmes (Rao, 2005b). Today, the public health care infrastructure is struggling to catch up with the population’s health needs. The current public investment in health is around 1% of the GDP, which places India globally among those countries with the lowest level of public health spending (Peters, Yazbeck, Sharma et al., 2002). A few public health insurance schemes exist such as the Universal Health Insurance Scheme, Employees State Insurance Scheme, and Mediclaim. However, these schemes are poorly implemented with limited coverage, especially in rural areas (Radwan, 2005).

The delivery of public health services and TB care is primarily a state responsibility, and primary health care is provided through a three-tier system consisting of community health centres, primary health centres and sub-health centres (Rao, 2005b). There are great variations between the states, ranging from a virtually non-existent public health infrastructure in poor states (e.g. Bihar and Uttar Pradesh), to better public access in more affluent states (e.g. Kerala) (Peters et al., 2002).

Private health care

While public spending on health is among the lowest in the world, private health care expenditures are among the highest. The private health care sector accounts for 78% of all health care expenditures, and the majority of this spending is out-of-pocket payments by individual households and patients (Ministry of Health and Welfare, 2005). Medical insurance coverage is limited to 3-4% of health care provision (Bhat & Babu, 2004).

The private sector has grown rapidly during the last 60 years. At the time of independence, the private sector accounted for only 8% of health care facilities; in the early 1990s the number had risen to 60% (Radwan, 2005); and recent figures suggest close to 70% (Rao, 2005b). In the 1980s, the private sector was encouraged to take a more active role in the delivery of care to meet the growing demand for health services, but this was done without provisions for regulations, standards and accreditation processes (Rao, 2005b). The utilization of private care has mainly been concentrated to
out-patient curative services followed by in-patient care, but the private sector is increasingly getting involved in preventive and antenatal care (Berman, 1998). Studies also indicate that the majority of TB patients seek private health care (Rajeswari, Chandrasekaran, Suhadev et al., 2002; Sudha, Nirupa, Rajasakthivel et al., 2003).

The private health care sector incorporates an array of health care providers and medical systems. Broadly speaking, it can be divided into an organized/formal and an informal sector (Bhat & Babu, 2004). The organized private sector consists primarily of profit-oriented institutions and includes all levels of private hospitals, dispensaries, nursing homes, general practitioners and pharmacies. The involvement of non-profit institutions and non-governmental organizations in the health sector is estimated to account for only 1.3% of the total registered private health care institutions (Rao, 2005b).

The majority of private providers are found in the informal sector. These providers have been defined as ‘less than fully-qualified’ and their practices are considered illegal (Berman, 1998). However, the wide-spread use of the informal sector tends to legitimize its practice (Deshpande, RaviShankar, Diwan et al., 2004). Although the providers represent a diverse group, they are generally described as profit-oriented solo practitioners offering curative services in rural and semi-urban areas. They combine methods from a variety of therapeutic systems (e.g. ayurveda and allopathic medicines) and prescribe and dispense medicines in their clinics (Radwan, 2005). There are vast differences between rural and urban areas with regard to qualified health care providers. A recent, comprehensive mapping of health care providers in Madhya Pradesh showed that there were an estimated 41 qualified doctors per 100,000 population in urban areas, whereas the corresponding number in rural areas was only 12 per 100,000 (De Costa & Diwan, 2007).

In addition to allopathy, the health care system in India contains several indigenous medical systems with official recognition, including ayurveda, unani, siddha and homeopathy (Khare, 1996; Berman, 1998). The majority of practitioners of the indigenous medicines work in the private health care sector (De Costa & Diwan, 2007), and there is a considerable overlap between the systems in practised medicine, especially among those practitioners without formal qualifications (Khare, 1996).

**Access to TB care**

Despite the global expansion of the TB control policy, case detection rates indicate that the provision of DOTS does not reach out to everyone. Dye (2003) outlines possible reasons to explain why nearly half of the TB cases are still ‘missing’. First, a relatively small group of people may be missed because they do not seek any kind of health care. Second, patients may go undetected if they visit health care facilities, public or private, without DOTS coverage. These patients may be diagnosed and treated, but they are not notified and their outcome remains unknown. Finally, patients may present to the public health system offering DOTS, but due to diagnostic shortcomings they remain undetected.
Against this explanatory framework, research in countries with a high burden of TB has shown that people often opt for private health care providers or ‘alternative’ health care services such as untrained allopathic doctors, traditional healers or providers practising indigenous medicine before visiting formally trained providers or public health facilities (Enwuru, Idigbe, Ezeobi et al., 2002; Lonnroth, Thuong, Linh et al., 2001; Salaniponi, Harries, Banda et al., 2000). There is also evidence that TB patients seek advice from several health care providers simultaneously (Auer, Sarol, Tanner et al., 2000; Macq, Solis, Ibarra et al., 2004; Steen & Mazonde, 1999). Studies from India indicate a strong preference for the private health care sector among TB patients, and their health care seeking is often described as shopping for diagnoses and treatment (Sudha et al., 2003; Uplekar, Juvekar, Morankar et al., 1998). Studies from low- and middle-income countries have also shown that female patients are more likely to seek health care from private and/or untrained health care providers (Ahsan, Ahmed, Singhasivanon et al., 2004; Thorson, Hoa, & Long, 2000; Yamasaki-Nakagawa, Ozasa, Yamada et al., 2001).

Barriers in accessing TB care have been illustrated by long delays, from the onset of symptoms to the point when diagnosis and treatment are given. A combination of patient characteristics (e.g. age, sex, literacy and income) and provider characteristics (e.g. qualification, public/private) have been identified as causing these delays. In a Chinese study, for example, factors such as low education, lack of medical insurance and the structure of the TB control programme were associated with diagnostic delays (Xu, Jiang, Xiu et al., 2005). In India, delays in diagnosis caused by the health system rather than by the patient have been shown when private health care providers were consulted first (Rajeswari et al., 2002; Selvam, Wares, Perumal et al., 2007). Other studies have shown that women are diagnosed later than men due to delays by the health care system (Long, Johansson, Lonnroth et al., 1999; Pronyk, Makhubele, Hargreaves et al., 2001). Differences in clinical presentations between men and women have been put forward as one likely cause for this delay. A recent collaborative study of gender and TB in India, Bangladesh, Malawi, and Colombia found that women had less typical TB symptoms compared with men (Weiss, Auer, Somma et al., 2006). Other studies have indicated that women are less likely than men to get a sputum smear examination even if they present with respiratory symptoms at health care facilities (Begum, de Colombani, Das Gupta et al., 2001; Boeree, Harries, Godschalk et al., 2000; Thorson et al., 2000)

Whilst the studies cited above relate mainly to ‘utilization’ of the health care system and its determinants, another approach to the study of health seeking behaviour looks more closely at the socio-cultural dimensions of TB. These studies focus on illness experiences and lay understanding of TB, and how this may influence health seeking behaviour and adherence to treatment (Atre, Kudale, Morankar et al., 2004; Liefooghe, Michiels, Habib et al., 1995). An illustrative example is a qualitative study from Vietnam which explored layman classifications of TB and how these were associated with gendered roles and perceptions (Long, Johansson, Diwan et al., 1999). Other researchers emphasize structural, political and economic factors as more crucial in understanding potential barriers to TB care (Ho, 2004). Farmer (1997) for example, demonstrates in a study among multi-resistant TB patients in Haiti how structural
factors such as poverty, rather than cultural beliefs, influence patients’ health seeking
behaviour and treatment adherence.

Medical encounters in TB care have received relatively less attention in research than
health care seeking. Qualitative studies from Vietnam indicate that the doctor–patient
relationship is often marred by mistrust and poor communication (Johansson &
Winkvist, 2002), and female TB patients seem to be particularly sensitive to the health
care providers’ attitudes and conduct (Johansson, Long, Diwan et al., 2000). Thorson
and Johansson (2004) draw attention to how medical doctors may become gender blind
if women’s unique experiences of TB are filtered through an ideology of ‘equality’
which aims at treating men and women in the same way irrespective of gender-specific
biological or social needs. In India, poor reception and communication skills among
health care providers as well as lack of health education to patients have been reported
from clinics offering DOTS (Jaiswal, Singh, Ogden et al., 2003; Weiss et al., 2006).
The absence of patient-centred care has been identified as one of the challenges in the
implementation and expansion of DOTS in the country (Khatri & Frieden, 2002).
CONCEPTUAL FRAMEWORK

In this thesis, health seeking behaviour has been studied with regard to the utilization of the health care system. This means that I have studied the actions taken by individuals in search of cure, and looked at the determinants that influence this pathway. As a point of departure, I was inspired by a framework developed to analyse the role of gender at various stages in the health care seeking chain, focusing on specific gender-related barriers to recognition, diagnosis, treatment and cure of TB (Long, 2000; Uplekar, Rangan, Weiss et al., 2001b). The framework assumes that factors such as self-image, status in the family and society, access to resources, manifestations and expressions of symptoms, and stigma attached to TB influence men and women differently in their search for TB care. During fieldwork, my initial questions about health care seeking became more focused on one particular step in the health care seeking chain, namely the encounters between patients and health care providers in the delivery of health services. This led me into new theoretical perspectives. The initial findings on power imbalances in the medical encounters (paper II) warranted further analysis and I became increasingly interested in how medical encounters were influenced by power relations.

Below, I will outline some theoretical perspectives that are concerned with power relations between health care providers and patients. I will begin by briefly looking at some accounts of medical dominance, and then describe various ways of conceptualizing relationships in the medical encounter.

Some accounts of medical dominance

The dominant Western ideas about ‘modern medicine’ have been expressed in the biomedical model of health. In essence, biomedicine represents a type of physical reductionism that separates the body from the mind, and views disease as being caused by a specific biological agent that can be isolated and treated (Giddens, 2006). One effect of this physical reductionism is the tendency to isolate, study and treat diseases as if they were distinct entities that are unrelated to other diseases, and separate from the social contexts in which they are found (Baer, Singer, & Susser, 2003). Within the context of TB control policies, it has been argued that the focus on ‘cases’ and ‘control of transmission’ reflects a strict biomedical approach, which tends to exclude considerations of individual rights and needs, as well as social context (Porter et al., 1999). Ho (2004) argues that research on TB from a socio-cultural perspective tends to reflect the privileged status of biomedicine by contrasting the “incorrect” lay beliefs with the “correct” biomedical knowledge.

Medical dominance has also been discussed from a gender perspective. Feminist involvement within the field of medicine has demonstrated how the definition of the woman as the ‘Other’, the ‘sick’ or incomplete version of the normative man, has created a male bias in health care research and practice (Clarke, 1983). Women’s exclusion from clinical trials is perhaps one of the most illustrative examples of the neglect of women in health research (Hamilton, 1996). Another question relates to how well women’s unique illness manifestation and experiences are captured by prevailing medical knowledge and practices (Malterud, Candib, & Code, 2004; Vlasoff, 1994). For example, Malterud and colleagues (2004) perceive “diagnostic activity in medicine
as a gendered, power-infused social interaction within a cultural context where the gold standard of medical knowledge is very narrowly set (p 16).”

The biomedical model is often labelled ‘Western medicine’ in an attempt to distinguish it from other indigenous medical systems. While medical pluralism, defined as the coexistence of several medical systems, seems to prevail in most countries, it is also argued that one system attempts, with the support of social elites, to exert dominance over other medical systems. For this reason, biomedicine is often regarded as the exemplary medical system in the world because of its scientific aspirations and curative efficacy (Baer et al., 2003). However, the dominant position of biomedicine is often negotiated by laypeople’s and professionals’ pragmatic use of distinct medical systems (Baer et al., 2003). This is particularly evident in the Indian context. As Khare (1996) notes, there is a considerable overlap between the different medical systems in India due to a contextual therapeutic reasoning in medical practice. Indian patients may use various systems in any sequence or combination, to ensure “best treatment”. Similarly, health care providers often combine treatment from various medical systems, irrespective of their training and background (ibid).

**Ways of conceptualizing medical encounters**

The various ways in which medical encounters are described and conceptualized in the literature are based upon the notion of ‘medical dominance’. A central theme in these descriptions is that the relationships between doctors and patients are based on an asymmetry of knowledge and decision-making power. However, the extent to which the relationship is defined as dominant or oppressive varies between theories. Theories around the doctor–patient relationship should be seen as products of their time as well as Western concerns with medicine (Lupton, 2003). However, “old” and contemporary theories tend to co-exist and overlap in recent conceptualizations of the doctor–patient relationship (Emanuel & Emanuel, 1992), and have influenced anthropologists and sociologists in cross-cultural fieldwork to a varying degree (Nichter & Nichter, 1996; Whyte, van der Geest, & Hardon, 2002).

One theoretical approach, referred to as functionalism, tends to define medical dominance as “legitimate, rational and necessary” (Maseide, 1991). An early conceptualization of this view was introduced by Parsons’ theory of the sick role (Parsons & Turner, 1999). This theory postulates that the sick role entails certain rights and obligations for the patients. While the sick person is entitled to withdraw from normal responsibilities, s/he is expected to cooperate in his or her recovery by strictly following the instructions of medical experts (ibid). In such reasoning, non-compliance with the advice of doctors is mainly defined as a medical problem due to deviant or irrational behaviour by patients (Lerner, 1997). The functionalist approach further suggests that the doctor–patient relationship is based on consensus, since both patients and medical experts share similar values and views of what constitutes a benefit (Emanuel & Emanuel, 1992).
Drawing on political economist and postmodernist thoughts, some critics reject the consensual assumptions and argue that there is an inherent conflict between patient autonomy and medical dominance in the doctor–patient relationship (Lupton, 2003). Advocators of this view contend that there is a social class division between doctors and patients, which acts to preserve power on the side of doctors in the medical encounter (Waitzkin, 1989). From this perspective, doctors’ authoritarian behaviour is criticized and perceived as a potential problem in the consultations (Mead & Bower, 2000), and it is considered important to include social structures, such as the interplay between gender, class and ethnicity, in the analysis of medical encounters (Borges & Waitzkin, 1995; Uskul & Ahmad, 2003; Werner & Malterud, 2003).

For many contemporary scholars, power and control should ideally be shared between the doctor and the patient (Charles, Gafni, & Whelan, 1997; Mead & Bower, 2000; Stewart, 2003). This view, referred to as patient-centeredness, emphasizes the need to integrate the biomedical understanding of disease with each patient’s unique experience of illness (Stewart, Brown, Weston et al., 2003). Mead and Bower (2000) have identified a number of key aspects of the relationship between doctor and patient that distinguish patient-centred medicine from the biomedical model. First, illness should be understood from a holistic perspective, including considerations of biological, psychological and social factors, as well as the personal meaning of illness for the patient. Second, the doctor–patient relationship should be seen as that between equals, where power and responsibility are shared with the patients. Third, the relationship should be based on a therapeutic alliance based on care, sensitivity, and empathy. Finally, the doctor is not only seen as an objective assessor of the patient’s disease (as often postulated in a biomedical health model), but also as a person with certain qualities that influence patients’ experiences and behaviours.

Critics have challenged a patient-centred model as representing an ideal approach that is unrealistic in the everyday practice of medicine. For example, Silverman (1987), a British sociologist, asserts that the patient-centred philosophy, while appealing in its holistic view of a person, tends to extend the medical gaze to all domains of patients’ lives. In other words, the ideology of patient-centeredness consolidates, rather than removes medical dominance and control. Those who are critical of the patient-centred model have moved towards a discourse in which control and power are seen as necessary in the medical encounters. From this point of view, power is seen as something good and not primarily abusive (Maseide, 1991).

Furthermore, it is acknowledged that medical encounters are not only influenced by particular characteristics of doctors and patients, but also by various bureaucratic controls exercised by corporate organizations, as well as state regulations and policies in health care systems (Potter & McKinlay, 2005). Dodier (1998), for example, addresses the tension that can arise from bureaucratic control by describing two frames of practices. The first frame concerns administrative boundaries, in which all people of the same category are treated in the same way. The second frame, referred to as the

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2 From a political economist perspective, medicine is largely an instrument of domination used by the ruling classes to maintain their powerful position, whereas postmodernists see medical dominance as negotiable, changeable and an opportunity for patient resistance (Lupton, 2003).
clinical, allows the doctor to follow a course that leaves room for the individual’s unpredictable particularities. How doctors position themselves between rules and particularities is the main focus of this analysis, according to Dodier.

The concepts of choice and autonomy inherent in patient-centeredness have taken on new meanings as health has become commodified through the business of medicine and consumerism (Lupton, 1994; Whyte et al., 2002). In theory, consumerism postulates an active and empowered patient who makes informed choices (Almond, 2001). Lupton (1997) depicts a relationship steered by a market economy approach, in which doctors are viewed as “suppliers of services, competing amongst themselves and seeking to maximize their income by selling their professional expertise” (p 373). For their part, patients resist ‘medical dominance’ by shopping around, evaluating doctors’ competence and seeking care elsewhere if services are perceived to be unsatisfactory (ibid). While the notion of consumerism in health care has challenged the traditional medical dominance by highlighting patients’ choices and preferences (Thompson, 2007), this is seen as problematic because of patients’ vulnerable position as ‘consumers’ (Bhat, 1999; Wiles & Higgins, 1996).

Marc Nichter (1996a), an anthropologist who has conducted extensive fieldwork in South Asia, finds the conceptualization of consumerism as well as Parsons’ view applicable to the Indian setting, especially to those doctors who practise allopathic medicine. However, he also describes a medico-religious ideal of moral bonding between healers and patients in ayurveda. Healing is performed in the name of the deity of ayurveda and not directly in the ayurvedic practitioner’s name. Hence, the responsibility for cure is placed in the hands of the gods, and the healing becomes a socio-moral activity. This healing relationship is contrasted with what Nichter defines as a ‘secular contractual relationship’ between allopathic health care providers and patients in the market economy (ibid).

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3 Commodification is used when non-material things such as health are price-tagged, and is translated into practice when medical practice, training and the distribution of medicines have become commercial undertakings (Bode, 2006).
A diversity of customs, religions, and languages characterizes India (table 1), and it is obviously outside the scope of this thesis to account for all this diversity. However, as mentioned in the introduction, I have tried to understand how individual experiences are shaped by a particular context, and before turning to the studies included in this thesis, I will present a brief cultural backdrop focusing on the interplay between class, caste and gender in a changing society.

Since the mid-1980s, India has pursued a policy of economic liberalization by deregulations and privatization, and in 1991 the first comprehensive policy on this liberalization was introduced (Ahuwalia, 2002). The liberalization has led to a growth of the middle class in India, and evidence suggests that wealthier households have grown and benefited from the economic liberalization more rapidly than poorer households (Ganguly-Serce & Scrase, 1999). There is also a sharp distinction between the states and between rural and urban areas. It is estimated that 26% live under the poverty limit, the majority of them in rural areas (World Bank, 2007).

The increasing gaps have fuelled the issue of class inequalities in India. While class structure is emerging as the major determinant of social positions, social scientists argue that it builds on rather than abandons hierarchies and divisions rooted in the Indian caste system (Kapadia, 2002b; Liddle & Joshi, 1989). The caste system is grounded in the Hindu religion and is a system based on groups with hereditary memberships. These groups are ranked hierarchically from low to high castes, and are separated or connected with each other through marriage, social and physical contact, and division of labour (at least in theory). The oppressive features of the caste system have been documented extensively (Shah, Mander, Thorat et al., 2006), and the Indian authorities have tried to level out the differences between castes through quotas for “scheduled castes”, and “scheduled tribes” and “other backward castes” in the public sector. The entrance of lower castes into public positions has changed the power dynamics of caste in many ways, especially in the political sphere (Gupta, 2004), but several discriminatory factors still exist. A correlation between caste and class in terms of economy, occupation, and education is still notable (Shah et al., 2006), but class differentiation within the castes in South India, for instance, has been observed in the wake of the capitalist market economy (Kapadia, 2002b). Despite diverse interpretations of the caste system’s roles and functions, there seems to be a general agreement that the caste system is continuously changing, weakening to some extent, but also transforming into “new” manifestations (Gupta, 2004; Rao, 2005a; Shah et al., 2006). These changes are viewed against the background of overall social, economic and political changes in Indian society (ibid).

A common, but simplistic way, of describing this hierarchy is in terms of four varnas: The Brahmins (priests), ranking highest, followed by Kshatriyas (warriors and kings), the Vaishyas (merchants), and the Shudras (artisans and workers). However, non-Hindu societies and ethnic groups called “tribals” also have castes. Furthermore, the “real unit” of the caste system is the jati, which is a small endogamous group representing a hereditary profession or craft (although not practised). Also, the study of caste has given rise to multiple interpretations of its role and functions in Indian society (see for example Gupta, 2004 and Khare, 1998).
Table 1 India at a glance

<table>
<thead>
<tr>
<th>Population, 2005*</th>
<th>1.1 billion</th>
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| Languages         | Hindi – official language  
|                   | English – language in official work  
|                   | Several other national languages |
| Religion          | Hindu – 80%  
|                   | Muslim – 13%  
|                   | Others – 7% |
| Population below national poverty line (%), 1999-2000 | 26.1 |
| Life expectancy at birth, 1992-1996 | Men: 60.1  
|                   | Women: 61.4 |
| Literacy (%)      | Men: 76  
|                   | Women: 54 |
| Sex ratio (females per 1,000 males) | 933 |
| Infant mortality (per 1,000 live births), 1999 | Boys: 69.8  
|                   | Girls: 70.8 |
| Fertility rate, 2005 * | 2.8 |
| Work participation rate for women (%), 2001 | 25.7 |
| Prevalence of HIV, total (% of population ages 15-49)* | 0.9 |

Source: Census of India, 2001 (unless otherwise indicated)  
*World Bank, 2007

A rise in access to education for women as well as a decline in fertility, suggest new opportunities for women in contemporary India. However, research concerned with the relationship between development and gender draws attention to the maintenance or exacerbation of women’s disadvantaged position in Indian society (Kapadia, 2002a). Perhaps the most conspicuous evidence of gender biases is the low female–male ratios in India. Neglect of girls from infancy, mirroring the strong culture of son-preference in most Indian families, is not a new phenomenon, and continues to provide evidence of higher infant mortality risk among girls (Sen, 2003). It is also argued that a new “female disadvantage” has emerged in the case of selective abortions of female foetuses (Sen, 2003; Sudha & Rajan, 2003).

In the field of work participation, market liberalization and structural adjustment policies seem to have had a contradictory effect on women (Ganguly-Scrase & Scrase, 1999). Women’s participation on the labour market peaked during the mid-1980s and has stabilized since then (Panda, 2003). While women’s work participation has created several advantages for women’s economic and social independency (Ganguly-Scrase, 2003), a great majority of working women are found in the unorganized sector.
characterized by poor work conditions, low wages and no employment security (Swaminathan, 2002).

It should be emphasized that it is not possible to treat women as a homogenous group in India’s diverse cultural, socio-economic, religious and political landscape. However, in the discussion of gender, health and development there is a tendency to divide India into north and south (and north-east). The southern states are historically known for women’s relatively favourable position in society. In Kerala, for example, female literacy is close to 90% (Govinda & Biswal, 2006), and the infant mortality rate and female–male ratio are comparable with middle- and high-income settings (Sen, 2003). In the light of this South–North distinction, a recent concern is the rise in gender differentials observed in the southern states (Basu, 1999; Kodoth & Eapen, 2005). For example, a spread of dowry has been observed in the southern states of Karnataka and Tamil Nadu where dowries traditionally have not been practiced (Kapadia, 2002b). These findings have been presented as alarming examples of the overall development in India, since they represent a break from the past trend of women’s favourable position. On the other hand, increasing gender differentials in northern states are seen rather as amplifying long-existing trends (Basu, 1999).

No simple explanatory model exists to explain the ideological “root” of women’s situation in India. Besides, in line with contemporary feminist thinking, differences between women are emphasized in the literature. However, social scientists have pointed to the ways in which certain socio-cultural and religious structures and beliefs have contributed to the construction of gender ideologies and orders in India (Dube, 2005; Kapadia, 2002a; Khare, 1998). For example, principles of female subordination have been related to “upper-caste” Hinduism, which views women as impure by birth and emphasizes control of female sexuality (Kapadia, 2002b). Caste supremacy was traditionally expressed through female subordination and seclusion. The practice of Purdah, ‘female veiling’, has thus historically been the upper-caste marker of social etiquette, speech and morality in north India (Khare, 1998). Low-caste women, by contrast, were not restricted to the rules of seclusion, and they have by tradition acted as important contributors to the household’s economy, often because of dire needs (Khare, 1998; Rao, 2005a). This pattern of high-caste seclusion of women is still observed in many regions of India, but female seclusion is also found in varying degrees across caste boundaries (Rao, 2005a).

Subordination of women is also understood and interpreted in the light of various forms of family structures that exist across the Indian subcontinent (Liddle & Joshi, 1989). In the southern states, which are known for their relatively high gender equality compared with the northern states, matrilineal family structures are more frequent. The northern family structures, on the other hand, are typically described as patrilineal (ibid). However, the family structures are not uniformly presented across India, and their ideologies and related practices are continuously negotiated as a result of social and economic changes.

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5 A matrilineal system is a kinship structure where membership and resources are inherited through the mother’s lineage, whereas patrilineality refers to kinship structures where memberships and resources are passed on through the father’s lineage.
3 AIMS

OVERALL AIM

This study examines health care seeking and medical encounters in the context of TB care in a rural district in central India. More specifically, the study focuses on how relations of power between health care providers and patients are created, altered and maintained during medical encounters in a diversified health system.

SPECIFIC AIMS

- To describe and compare health care seeking among men and women with a cough of more than 3 weeks or TB, with special focus on the utilization of private and public health care (I).

- To explore health care providers’ experiences and perceptions of their encounters with male and female patients (II).

- To examine how TB patients and private doctors act and interact in a market-oriented health care setting, focusing on processes behind health care choices and related payments during medical encounters (III).

- To analyse how the policy context of DOTS has shaped and influenced medical encounters within the Revised National TB Control Programme (IV).
4 METHODS

THE STUDY SETTING: UJJAIN DISTRICT IN MADHYA PRADESH

General description

The Ujjain district is situated in the western part of Madhya Pradesh (MP) and has a population of 1.7 million (figure 1).

![Map of India and Madhya Pradesh](image)

Figure 1 Map of India and Madhya Pradesh

MP has historically belonged to the group of six low-income states in India. During the 1990s a positive economic growth rate was observed in MP, but the state still faces challenges in overcoming poverty disparities (Ghosh, 2005). In 2000, 37% were estimated to live under the national poverty line in MP, as compared with 26% for India as a whole (HDR, 2002). The vast majority live in rural areas. The urbanisation level of MP was 27% in 2001, as compared with 28% for all India (HDR, 2002).

In table 2, census data on health and socio-demographic indicators by sex is presented for MP. Comparisons between 1991 and 2001 for selected health indicators show progress, but MP remains behind in the overall ranking of states in India.
There is variation between the districts and regions in the state, and the Malwa region where Ujjain is situated belongs to the most developed areas in MP. A further breakdown of the 2001 census data revealed differences between the rural and urban population in MP (not shown in the table). The rural infant mortality rate was as high as 96 per 1,000 live birth as compared with the urban rate of 55. The literacy rates were 58% and 80% in rural and urban areas, respectively.

Table 2 General information of Madhya Pradesh (Census of India, HDR 2002)

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<thead>
<tr>
<th></th>
<th>1991</th>
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<th>2001</th>
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<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>Literacy %</td>
<td>29.4</td>
<td>58.5</td>
<td>50.3</td>
<td>76.8</td>
</tr>
<tr>
<td>Infant mortality (per 1,000 live births)</td>
<td>106</td>
<td>101</td>
<td>89.5</td>
<td>89.6</td>
</tr>
<tr>
<td>Life expectancy at birth*</td>
<td>54.7</td>
<td>55.1</td>
<td>58.1</td>
<td>59.2</td>
</tr>
<tr>
<td>Sex Ratio (Females per 1,000 males)</td>
<td></td>
<td>912</td>
<td></td>
<td>920</td>
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The health care system and TB control in Ujjain district

Public health care to the rural population is provided through the three-tier system of community health centres, primary health centres and sub-health centres. In urban areas, public care is delivered through civil dispensaries, district hospitals and specialized centres. According to the third human development report of Madhya Pradesh (HDR, 2002), the rural health infrastructure in MP and Ujjain is still weak and lacks health care facilities and staff at all three levels.

The RNTCP was implemented in 2003, and the delivery of care is organized through the district tuberculosis centre (DTC) and three treatment units consisting of supervisory and monitoring teams, which serve as a link between the district level and the peripheral health care institutions (figure 2). Sputum microscopy services are provided through designated microscopy centres. At the local level, DOT centres with health care workers or community workers are responsible for providing directly observed treatment to the patients.
The programme relies primarily on sputum investigations with direct microscopy of patients who present to the public health care services with a cough they have had for three weeks or more. The diagnostic procedures follow the criteria set by the WHO (WHO, 2007; see appendix 3 for more details). The treatment regimens within the RNTCP are divided into three categories according to sputum smear results, history of previous anti-TB treatment, disease classification (pulmonary or extra-pulmonary), and severity of illness. The treatment period ranges from 6 to 8 months depending on the category of treatment, and is divided into an intensive phase of 2 to 3 months, and a continuation phase of 4 to 5 months.

In 2006, the notification rate of all new cases was 109/100,000 in Ujjain district. The case detection of new smear positive patients and cure rates were 56% and 84%, respectively (RNTCP, 2007). Sex-specific data were not reported at the district levels.

Similar to India as a whole, the district has a large, heterogeneous private health care sector. An attempt to map health care providers showed that there were about 2000 practitioners in addition to those officially registered. The majority were men, and 56% had no formal health care training. Formally trained doctors were highly concentrated in urban areas (Deshpande, RaviShankar, Diwan et al., 2004).
Table 3 Overview of study design

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
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<tbody>
<tr>
<td><strong>Design</strong></td>
<td>Population-based cross-sectional survey (Quantitative)</td>
<td>Interview study (Qualitative)</td>
<td>Observational study (Qualitative)</td>
<td>Observational study (Qualitative)</td>
</tr>
<tr>
<td><strong>Specific aim</strong></td>
<td>To describe and compare health care seeking among men and women with a cough of more than 3 weeks.</td>
<td>To explore health care providers’ experiences and perceptions of their encounters with male and female patients.</td>
<td>To examine how TB patients and private doctors act and interact in a market-oriented health care setting.</td>
<td>To analyse how the policy context of DOTS has shaped and influenced medical encounters.</td>
</tr>
</tbody>
</table>
| **Study population/Participants** | - 14,858 households with 45,719 individuals aged ≥15 years.  
- 941 individuals with a cough ≥ 3 weeks.  
- 644 individuals interviewed. | Purposeful selection of 22 health care providers. | Purposeful selection of 4 private health care providers and 14 TB patients. | Medical doctor and staff at the district tuberculosis centre. |
| **Data collection**    | Structured questionnaires on health care seeking. | Semi-structured interviews. | Non-participant observations and qualitative interviews (semi-structured and unstructured). | Non-participant observations and qualitative interviews (semi-structured and unstructured). |
OVERVIEW OF STUDY DESIGN

Qualitative and quantitative methods have been combined in a complementary way in this thesis (table 3). The choice of specific research methods was made with regard to the research questions in the different papers.

In paper I, we aimed at describing health care seeking among individuals with symptoms suggestive of cough in a rural population, and a population-based survey within a demographic surveillance site was carried out. In the subsequent papers (II-IV), my research questions were open-ended because of the relatively limited knowledge about medical encounters in the Indian setting with regard to TB care. I therefore considered qualitative method to be appropriate, given its explorative and discovery-oriented approach. However, the aim was not only to explore but also to examine medical encounters and health care seeking in depth and in context. One of the main assumptions in qualitative inquiry is that such knowledge can only be fully captured through involvement in the field, and close interactions with the participants and/or events under study (Fangen, 2005). Thus, using qualitative inquiry and methods allowed me to get close to the participants in their own environment, which provided insights into their lives and work that would have been difficult to access through quantitative methods.

The qualitative research process followed an emergent design in that the analysis and findings in study II formed the basis for questions explored in studies III and IV. Data collection and analysis for each paper were performed simultaneously, which provided opportunities to raise new questions for further exploration and additional sampling of participants.

PARTICIPANTS AND DATA COLLECTION

As will be described below, data collection in the qualitative studies involved observations and interviews in both Hindi and English. The interviews in English were performed by me, whereas the interviews in Hindi were performed by an Indian female medical doctor, with whom I worked closely throughout the thesis project. I was present during the interviews in Hindi and at the end of each session my colleague would give me a summary of the main points, allowing me to ask additional questions. Our interaction in the fieldwork will be further described in section 6.

Population-based survey (Paper I)

Study I is based on a population-based screening survey for individuals with a cough of more than three weeks (figure 3). The study was carried out during February–August 2004 within a demographic surveillance site (DSS) –Palwa Field Laboratory – established in 1999, and run by R D Gardi Medical College and Ujjain Charitable Trust Hospital. The site covers 60 villages, representing 14,858 households, with a total population of 71,306. The villages were selected from three development blocks (administrative units) based on their proximity to a rural health care centre run by R D Gardi Medical College. The villages were located at a mean distance of 11 km from the centre. The study population consisted of all persons aged 15 years or more in the DSS (n= 45,719).
During the baseline survey of the DSS, trained male village health workers identified persons with a cough lasting 3 weeks or more by interviewing the household representatives. Individuals aged ≥ 15 years who reported having a cough for 3 weeks or more at the time of the interview were invited to the out-patient clinic at the medical college for investigations and interviews. They were asked to undergo chest X-ray (CXR) and to provide three sputum samples for acid-fast bacilli and mycobacterial culture. Individuals with a positive smear and/or culture were diagnosed as pulmonary TB cases (n=50). A pre-tested structured questionnaire was used to obtain information on the various health care actions taken by the individual because of a cough.

Figure 3 Overview of study population and data collection in study I

**Semi-structured interviews with health care providers (Paper II)**

In study II, semi-structured interviews were carried out with 22 health care providers, 17 men and 5 women. The participants were between 24 and 60 years old. The health care providers, both qualified and unqualified, were purposively selected from the public and private health care sectors in rural and urban areas of Ujjain district. The health care providers were included if they worked in out-patient practice and had experience of consultations with both male and female patients who had general complaints of cough, fever, and other symptoms suggestive of pulmonary TB.
The unqualified doctors included 8 individuals with no official medical qualifications or training, and all but one of these practised in rural areas at the time of the study. The qualified doctors were general practitioners or specialized in medicine or lung diseases, and 11 out of 14 practised in urban areas. We conducted the interviews at the health care providers’ clinics or homes and, in a few cases, at the medical college where the research team worked. We asked them to describe freely and reflect on specific and recent encounters with male and female patients in general and TB patients in particular. We used probing during the interviews to explore aspects of communication, interaction, positive and negative experiences, and perceived problems and challenges in the encounters. Ten interviews were performed in Hindi, and 12 interviews in English.

Observations and interviews (Papers III, IV)

In papers III and IV, I conducted observations and unstructured interviews in private health care clinics and the DTC, respectively. The unstructured interviews were an integral part of the observations. These interviews did not start with any predetermined questions. Instead, I used the immediate surroundings, and what I saw and observed, to develop and ask questions. During the observations, the health care providers also spontaneously reflected on how they experienced the consultations without being asked any specific questions. Before and after reception hours I also interviewed the doctors in a more structured way by asking questions that came up while transcribing field notes and tape-recordings.

In study III, four private health care providers were chosen to reflect different types of qualifications and out-patient practices: two health care providers (female and male) with a formal medical degree, and two health care providers with no formal medical training (female and male). They all worked in out-patient practice and their income was directly based on user fees and/or drug sales, with the exception of the qualified male doctor who was employed in a not-for-profit clinic. The patient load varied between the clinics. The qualified female doctor and the unqualified male doctor received between 10 and 20 patients per day, whereas the other two received between 50 and 80 patients. They mainly practised allopathic medicine, but a mixture of indigenous and allopathic medicines were often dispensed or prescribed by the doctors.

Each clinic was observed for 5 to 7 days during the peak hours for patient visits (between 9 am and 1 pm, or between 6 pm and 9 pm). I conducted the observations and took extensive field notes focusing on doctor–patient interactions and the doctors’ experiences of the consultations. The field notes were transcribed to computer immediately after the observation sessions. The observations included informal conversations and unstructured interviews with the doctors between and after the consultations. They reflected extensively on their own as well as patients’ roles in the medical encounters, and on the health care market at large. The conversations were in English, except for the unqualified female doctor who preferred to speak Hindi. An Indian research assistant who was fluent in Hindi accompanied me and acted as an interpreter and interviewer during these observations. The consultations in all four clinics were in Hindi, and were tape-recorded during two days in each clinic. They were then transcribed and translated into English for analysis.
In study IV, the DTC was selected as the study site because it was the nodal point for the delivery of public TB care in the district. The staff consisted of 1 male TB doctor, 2 male TB community workers and 1 male treatment supervisor, 5 male laboratory technicians, 3 female nurses and several paramedical staff. The data collection was carried out in the DTC for seven days during reception hours (9 am to 1 pm). The focus was on the encounters between the TB doctor and his patients, and how the TB doctor experienced these encounters. Extensive field notes were taken each day and transcribed into the computer immediately afterwards. The doctor’s experiences were elicited through spontaneous reflections and informal conversations between the consultations, and were further elaborated on in tape-recorded semi-structured interviews after reception hours. The doctor was asked to reflect on previous consultations and describe how he perceived his and patients’ roles in the medical encounters within the TB programme. Additional interviews were performed in English with some of the DTC staff to obtain background information on daily routines in the DTC, their work conditions and responsibilities. The consultations were in Hindi, and a total of 41 consultations (18 women and 23 men) were tape-recorded and transcribed verbatim from Hindi into English for analysis.

**Semi-structured interviews with TB patients (Paper III)**

Fourteen interviews were conducted with males and females diagnosed with TB. We used a purposeful and emergent sampling strategy aiming at a variety of experiences, by including men and women of different ages and in different stages of their treatment. Four patients (three men and one woman) were recruited from the participating clinics. Our initial aim was to recruit at least one male and one female TB patient from each private clinic observed in the third study, but this proved to be difficult as few TB patients came to the clinics during the time of the observations, and two patients declined participation. We therefore decided to include five patients (two men and three women) from the DTC and one primary health care centre. In order to refine and elaborate on the emerging themes, we performed additional interviews with five TB patients (three men and two women), who were recruited from two different villages in the district. The ages of the female and male participants, respectively, ranged from 23 to 35 years, and 30 to 70 years.

The interviews were performed in Hindi. Eleven interviews were conducted in the patients’ homes, and three interviews were performed in a secluded room at the premises of the DTC. We used a thematic guide covering questions on health care seeking patterns, provider choices and related decision-making processes, experiences of services, payments and costs, and perceptions of providers and medical encounters.

**DATA ANALYSIS**

**Statistical analysis (Paper I)**

Health care actions were divided into public providers, private providers, medical store (pharmacies) and self-medication. Public health care providers were defined as providers working in a governmental health care facility. Private health care providers
were defined as persons practising in any medical system outside government employment, including practitioners without medical qualifications or official training.

Comparisons were performed using chi-square tests for categorical variables and Student’s t-test for continuous variables. Logistic regression analyses were used to assess the impact of socio-economic, demographic and clinical factors on any type of treatment sought, visiting a public provider, and performance of sputum smear examination during the disease period. The outcomes were first analysed in relation to each variable separately, and variables that proved statistically significant at P-values less than 0.25 were further studied in logistic regression. The results are presented as adjusted odds ratios (aOR) with 95% confidence intervals (CI).

**Qualitative content analysis (Papers II-IV)**

Qualitative content analysis originates from media and communication research and has been defined as a flexible method for analysing text data (Hsieh & Shannon, 2005). The method focuses on communication, and addresses the content and contextual meaning of the text. The flexible nature of qualitative content analysis has created some confusion about its theoretical foundation and conceptual definitions. Graneheim and Lundham (2004) have tried to sort out some of the confusion by reviewing the literature and defining concepts pertinent to qualitative content analysis. Following their approach, my analysis consisted of a dynamic process between the descriptive and interpretive levels of the content.

The descriptive level is referred to as the manifest content and describes the visible and obvious components in the text. The interpretative level is defined as the latent content of the text and deals with interpretation of the underlying meaning of the text (Graneheim & Lundman, 2004). In practice, however, the distinction between the descriptive and interpretative level is vague. The manifest–latent division is often seen as a continuum from highly manifest to highly latent (Neuendorf, 1994), and attention should be paid to both the manifest and latent content throughout the analysis (Berg, 2001). Graneheim and Lundman (2004) believe that both deal with interpretation, but that the interpretations vary in depth and level of abstraction.

From this perspective, I have not seen the manifest and latent analysis as mutually exclusive. I have approached the data by moving back and forth between various levels of abstraction. My final goal, however, was to discern underlying meanings and interrelationships of the data. In this process, I identified meaning units in the original text material and assigned codes to these. The coding was then followed by comparison and grouping of codes into tentative categories. The next phase involved interpretations of the codes and categories by searching for themes representing their latent content. In paper I, this process was done manually. In papers II and III, I used the Nvivo computer software program (Nvivo7, 2006). I was responsible for coding and categorization of the data, but I worked closely with my co-authors. I will elaborate on the roles of co-authors in the analysis process in section 6.
CLARIFICATION OF TERMS

In the articles I have used the terms ‘medical encounter’, ‘provider–patient interaction’, and ‘doctor–patient relationship’ interchangeably, and some clarification is needed here before turning to the main findings. The medical encounter is used as a general term to denote the meeting between medical professionals and patients in a particular health care setting (such as a clinical consultation). The term ‘provider–patient interactions’ specifies what takes place during a medical encounter, in which the doctor–patient relationship represents one particular form of interaction within the health care system (Bury, 2004). By research tradition, the doctor in a ‘doctor–patient relationship’ refers to medical doctors with formal medical training and a degree. However, in this thesis the ‘doctor–patient relationship’ is used in a broader sense, as it also includes ‘doctors’ who perform medical work (e.g. diagnosis and treatment prescriptions) without being formally licensed to do so.

ETHICAL CONSIDERATIONS

Ethical approval was received from RD Gardi Medical College, India and from Karolinska Institutet, Sweden (dnr 03-650, 03-651). Informed consent was obtained from the health care providers and the interviewed patients. In paper IV, we could not guarantee the confidentiality of the TB doctor because of the study design. Prior to the study, we visited the TB doctor and provided all project details in written and orally. To ensure his confidentiality as far as possible we did not specify the name of the study district in the paper.
5 MAIN FINDINGS

HEALTH CARE SEEKING

Utilization of health care (Paper I)

Of 644 people interviewed, 71% of the women and 69% of the men reported using some type of health care, including self-treatment, for their symptoms. Of the 445 individuals who had sought health care, the majority of men (64%) and women (72%) consulted a private provider first (Table 4). Only 23% consulted a public provider during the course of their illness.

Of those who first consulted a private provider, 127 (43%) took at least one more health care action. The majority (n=96, 76%) visited a private provider again, whereas 29 (23%) patients consulted a public provider. Of those who first went to a public provider, 52 (46%) continued seeking health care, but only 11 (21%) returned to a public provider. The majority (78%) changed to a private provider.

Sixty seven percent of all respondents seeking health care reported that they were not satisfied with the treatment from their first health care action, with no differences by type of provider (public/private). Lack of symptom relief was the main reason for not being satisfied. Unsatisfied respondents were more likely to take at least one more health care action than satisfied respondents (49% vs. 37%, \( P = 0.02 \)).

Table 4 Health care actions among women and men with a cough lasting more than three weeks.

<table>
<thead>
<tr>
<th>Health care action 1</th>
<th>Health care action 2</th>
<th>Health care action 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (n=118)</td>
<td>26 (22)</td>
<td>11 (20)</td>
</tr>
<tr>
<td>Male (n=327)</td>
<td>87 (27)</td>
<td>20 (14)</td>
</tr>
<tr>
<td></td>
<td>5 (24)</td>
<td>9 (20)</td>
</tr>
<tr>
<td>Private</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (n=55)</td>
<td>11 (20)</td>
<td>14 (67)</td>
</tr>
<tr>
<td>Male (n=144)</td>
<td>20 (14)</td>
<td>30 (65)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-treatment/medical store</td>
<td>7 (6)</td>
<td>4 (7)</td>
</tr>
</tbody>
</table>

TB examinations (Paper I)

Of the 445 individuals seeking health care, 13% reported having had a sputum smear examination, and 31% had had a CXR since the onset of their cough. Public providers performed TB examinations more frequently than private providers; 27% of all visits to a public provider, as compared with 5% of the visits to a private provider, resulted in a sputum smear examination (\( P = 0.000 \)). The corresponding numbers for CXRs were 39% and 24%, respectively. Patients with a cough who first consulted a public provider were more likely to submit a sputum sample than those who initially visited a private provider (27% vs. 3%, \( P = 0.000 \)). No significant differences were found between men and women. Table 5 shows the adjusted OR for performance of sputum examination based on logistic regression. Haemoptysis, history of TB and having visited a public provider were significant factors associated with increased likelihood of a sputum smear examination.
provider were factors significantly associated with having had a sputum smear examination.

Table 5 Multivariate analysis of factors influencing sputum smear examination among cough symptomatics seeking health care (n=445).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total</th>
<th>n (%)</th>
<th>Adjusted OR† (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>118</td>
<td>16 (14)</td>
<td>1.2 (0.5-2.9)</td>
</tr>
<tr>
<td>Male</td>
<td>327</td>
<td>44 (13)</td>
<td>1</td>
</tr>
<tr>
<td>Age (years):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-24</td>
<td>20</td>
<td>4 (20)</td>
<td>1.2 (0.2-8.3)</td>
</tr>
<tr>
<td>25-34</td>
<td>51</td>
<td>7 (14)</td>
<td>0.7 (0.2-2.8)</td>
</tr>
<tr>
<td>35-44</td>
<td>77</td>
<td>10 (13)</td>
<td>1.4 (0.5-4.3)</td>
</tr>
<tr>
<td>45-54</td>
<td>77</td>
<td>17 (22)</td>
<td>2.1 (0.8-5.9)</td>
</tr>
<tr>
<td>55-64</td>
<td>81</td>
<td>11 (14)</td>
<td>1.1 (0.4-3.4)</td>
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<tr>
<td>65+</td>
<td>139</td>
<td>11 (8)</td>
<td>1</td>
</tr>
<tr>
<td>Literacy</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>183</td>
<td>30 (16)</td>
<td>2.0 (0.9-4.3)</td>
</tr>
<tr>
<td>No</td>
<td>256</td>
<td>29 (11)</td>
<td>1</td>
</tr>
<tr>
<td>Haemoptysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77</td>
<td>20 (26)</td>
<td>2.6 (1.2-5.8)</td>
</tr>
<tr>
<td>No</td>
<td>368</td>
<td>40 (11)</td>
<td>1</td>
</tr>
<tr>
<td>Duration of cough (in weeks)</td>
<td></td>
<td></td>
<td>1.0 (0.99-1.01)</td>
</tr>
<tr>
<td>History of TB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>88</td>
<td>41 (47)</td>
<td>11.2 (5.5-22.7)</td>
</tr>
<tr>
<td>No</td>
<td>357</td>
<td>19 (5)</td>
<td>1</td>
</tr>
<tr>
<td>TB*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>33</td>
<td>11 (33)</td>
<td>2.3 (0.8-6.7)</td>
</tr>
<tr>
<td>No</td>
<td>412</td>
<td>49 (12)</td>
<td>1</td>
</tr>
<tr>
<td>Visiting public provider</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>147</td>
<td>44 (30)</td>
<td>5.4 (2.7-11.1)</td>
</tr>
<tr>
<td>No</td>
<td>298</td>
<td>16 (5)</td>
<td>1</td>
</tr>
</tbody>
</table>

†Adjusted OR are shown for variables with \( P \) values less than 0.25 from the bivariate analyses. Sex and age has been included as basic variables. * According to diagnosis performed in this survey.

Health care choices and affordability (Paper III)

According to the patients in paper III, paying for treatment was perceived as absolutely necessary and sometimes the only way to survive, illustrated in such comments as: “if you don’t pay, you’ll die”. The emphasis on payments for care invoked the question of affordability, but it was clear from the patients’ stories that affordability was not fixed according to a certain income level or socio-economic status. Rather, affordability was defined in the interplay between perceived severity of symptoms, doctors’ capacity to treat and cure, opportunities to raise money, as well as social class and gender.
Severity of symptoms and doctors’ capacity
In patients’ considerations of health care choices and related payments, severity of symptoms and doctors’ ability to treat and cure various symptoms were carefully accounted for. Village doctors, referred to as “small” doctors, were considered to be capable of only treating light symptoms such as fever, common cold and cough. These doctors, it was contended, were not able to treat a serious disease such as TB, but they were still acknowledged for their low fees and flexible payment modes. “Big” doctors, by contrast, were desired because of their perceived expertise in certain diseases. They were often located in the cities, and one “big” doctor was repeatedly mentioned as an expert on TB and recognized for his good treatment. Their fees and costs of treatment were known to be high, but worth paying for if the illness was “serious”. As patients’ accounts suggested, tuberculosis was one such severe disease that was perceived as absolutely necessary to treat, whatever the cost. While most participants mentioned that they did not have cash at hand and could not afford private treatment, they talked about several strategies for raising money to pay for private TB care. These strategies included taking loans from relatives or acquaintances, pawning their belongings, selling land, or doing more labour work.

Conveying messages of social class
The desire for private care and related efforts to raise money were also grounded in considerations of how health care choices carried messages of social class. Some patients suggested that seeking private care signified higher class status, and distinguished the “rich” from the “poor”. In doing so, the patients frequently described public care as an option only for the poorest people. Patients mentioned how they tried to avoid public health care facilities because of their associations with “crowds of sick and poor patients”. Several of the patients’ accounts indicated that the rich–poor distinction in health care choices was often challenged when “poor” people tended to follow “rich” people’s behaviours. From this perspective, being charged high fees in the private health care sector was not necessarily defined as exploitation of poor people, as the act of paying meant that it was possible to demand good quality care on the same terms as “rich” people.

Not being granted a choice: the effect of gender
The concepts of choice and affordability inherent in health care seeking were intimately connected with established gender ideologies and norms. Images of an active health-seeking patient portrayed by the doctors and several male patients often contrasted with the female patients’ stories. Their relatively young ages, all being between 20 and 35 years old, clearly influenced their position in the households, and, thus, their opportunities to make decisions about their own health. They talked about how they relied on their family’s permission to seek care and how they had to be chaperoned by older women (mother-in-law) or male guardians (often husband or father) if they travelled to doctors located outside their villages.

Although some women revealed a typical ‘shopping’ behaviour by seeking multiple providers in search of diagnosis and cure, they had relied solely on their husbands’ or other family members’ decisions. A 23-year-old female patient, who had been to seven different private providers during her TB illness, recounted how her husband decided
where to go and how she sometimes tried to resist: “He takes me so I go along with him. If I say that I do not want to go then he gets angry”.

The perceived need to pay for care created distinct vulnerabilities for women. Some of the women’s stories revealed that they were sent back to their natal homes by their husbands or in-laws when they fell ill. The most common explanation put forward by the women was their reduced ability to work in the marital household and the expensive treatment for TB and other costs associated with seeking care. A pregnant female patient, who had moved to her parents’ house, said: “My husband left me, and said ‘let her die’”.

The recounting of financial hardships and vulnerability tended to dominate women’s stories, but some of them recognized the social support that they had received from their husbands and mothers-in-law during their illness. However, as all their stories suggested, the meaning of choice and affordability were qualitatively different for women compared with men, as they were not in a position to make decisions on their own.

THE MEDICAL ENCOUNTER

The consumerist approach (Papers II, III)

Reliance on patients’ satisfaction (II)

In many of the private doctors’ accounts, patients were perceived as consumers rather than as individuals in need of health care. This perception was placed against the background of the diversified and unregulated health care sector in the district and had a great impact on how the doctors enacted and perceived their role in encounters with patients. The doctors frequently described how they experienced a difficult and, sometimes, futile struggle to make patients return for follow-up visits, as patients were constantly changing providers in search of a cure. Hence, an important aim of the consultation was to satisfy patients through meeting their requests and expectations, often in terms of quick relief at low cost. Private doctors often recounted how investigations were performed and treatment prescribed according to the patients’ request and/or financial situations, and diagnoses were often based on symptoms and signs. When money was scarce, treatment, rather than an adequate diagnosis, was the first priority.

Reliance on patients’ satisfaction and preferences became particularly evident when private providers talked about patients as a source of publicity. Patients’ recommendations influenced doctors’ reputations and were considered crucial for private providers to attract and retain patients.

Supporting the poor (III)

In the observation study, the private doctors frequently recognized that most patients coming to their clinics were poor and would have to struggle to meet the costs of private care. It was evident in several of their reflections that they experienced tensions between financial interests on the one hand, and ethical obligations to help patients, on the other. Observations showed that the doctors tried to reconcile these conflicting
views in their daily practice by offering support services to some of their patients. In the unqualified doctors’ clinics, these services included treatment on credit, reduced or exempted consultation fees, and provision of free drug samples received from pharmaceutical representatives. When the unqualified female doctor was asked to reflect on her support services, her comments illustrated how she provided them in negotiations with patients:

If the poor patients come and say ‘Madame, we don’t have money for buying medicines’, I give it to them. I also give free samples to people that I know, and those who can’t afford it, I give it to them too.

Echoing patients’ earlier accounts of “big” and “small” doctors, this doctor attributed patients’ negotiations to her relatively lower rank compared with that of “big” doctors. According to her, patients were only prepared to pay a certain amount of money for her services, whereas they would go with a “bag full of money” to a qualified doctor. In contrast, the qualified female doctor did not provide any free treatment or consultations. Although she felt “embarrassed” to ask for money from poor people, she justified her charges by referring to their “preparedness” to pay when they came to her clinic. At the same time, she emphasized how she tried to help patients indirectly by carefully considering costs before prescribing treatment or investigations.

Assessing affordability (II, III)

The question of patients’ socio-economic status was inevitably brought into the consultation rooms. The doctors had to find out not only who could pay, but also what they were prepared to pay. In their assessments, cues such as residence, occupation (father’s or husband’s occupation for women), salary income or physical appearance were used. This assessment could be manifested in an explicit way by probing about occupation, salaries, and affordability, or in a more subtle mode, where assumptions based on previous experiences about patients’ preferences guided the doctor. The qualified male doctor commented on a consultation with a male patient in the following way:

Since he is a qualified man, I’m also suggesting him some tests. I’m prescribing this because I know that he is capable of paying 100-150 rupees for some tests, he has his own wine shop.

In several consultations, these assessments turned out to be as crucial as the medical history and examinations in the doctors’ considerations of investigations and treatment. However, the negotiable features of what patients could afford, as described earlier, sometimes made the doctors suspicious towards the patients. This tended to create tension in the consultations, especially when patients declined suggested investigations or treatment. For example, the qualified doctor exclaimed in frustration after a consultation with a man who said that he could not afford to go for a chest X-ray: “They have the money, but they are not willing to pay”.

In paper II, the most evident reason for referral to the governmental facilities was the patients’ inability to pay for treatment. Private doctors were anxious to stress that they referred all TB patients to the district TB centre, but this socially acceptable action also
revealed a selection of patients for doctors’ financial gain. In study III (field notes), the doctors touched upon the existence of a commission system on the “market”, in which some doctors received payments for referring patients to private pathology laboratories or specialists for consultations.

The doctors regarded the socially and financially dependent role of women as influencing female patients’ ability to pay. A general view was that they were hesitant to spend money on their own health, as their priority was to ensure the good health of their children and husbands. One doctor described how a female patient asked for a cheaper method of treatment, as she could not afford the first treatment the doctor had offered. It was also mentioned that the person accompanying the female patient (her husband or another family member) was in charge of the money and paid the doctor.

**Vulnerability (II, III)**

Being at the mercy of patients’ judgments also made doctors feel vulnerable (II). Some doctors expressed fear of losing their reputation because of dissatisfied or noncompliant patients. Fear of making mistakes, expressed in statements such as “I don’t want to take any risks,” was also mentioned as a reason for referring the patient to another doctor. One male doctor, in particular, described how he asked all patients for written consent before treating them, after an experience of being sued for malpractice by a patient.

In the context of TB care, some doctors were reluctant to treat TB patients because of the problems associated with long treatment, as exemplified in the following quote:

> If you start a particular treatment with a patient, and if the patient doesn’t take the medicine the reputation of a doctor will totally fall. . . . The patient will say that, “I have spent 2,000 to 3,000 rupees for 3 months and I am still suffering from cough”. That’s the problem, the patients will not believe in me anymore, that’s why I can’t do that treatment. (Unqualified male doctor)

This vulnerability was also expressed during observations in the private health care clinics (III). The tension experienced in consultations when affordability was being assessed drew on the limitations doctors experienced when market-oriented imperatives such as affordability steered their decisions. For example, while trying to meet patients’ requests, they knew that their diagnosis or treatment might not be correct. They were often anxious to safeguard their reputation as a “reliable” doctor, and mentioned how they tried to balance between patients’ cost considerations and preferences, and what they perceived as the best possible treatment.

**The illusion of free TB treatment (III)**

While both patients and doctors legitimized charges in the private sector by referring to doctors’ practices as “business” or to patients’ preparedness to pay, broken promises of free public care were expressed with disappointment or irritation. Free treatment in the public sector was described as being “free in name only” and included many hidden costs, according to the patients. Several patients explained how the public doctors suggested investigations in the private sector, or prescribed treatment from the “market”.

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The majority of doctors employed in the public health care sector were said to have their own private clinics after working hours. Some patients explained how the government doctors gave their patients the option to choose between their private services or government treatment. According to one male patient, the severity of his disease after several failed courses of treatment made him choose the public TB doctor’s private clinic. While consultation fees and treatment had to be paid out of the patient’s own pocket, the following quote also illustrates how the patient was referred back for diagnostic tests offered in the public care:

Outside he has his clinic, if you visit him there, he takes 50 rupees and 100 rupees, and then he sees you and he writes good medicines from the market. He saw me there for half an hour (…) and then he asked me to go to the hospital and said ‘I will have your X-ray and tests done there’.

Informal payments to staff employed in the public health care facilities were described as further adding to the hidden costs of “free” treatment. Such payments were considered widespread and an “accepted” part of the system, reflected in such comments as: “It is not under the table, they ask you directly.” As indicated earlier, the main beneficiaries of free treatment were considered to be the very poorest. Free treatment, however, was perceived to put them in a dependency position where they could not expect good care or attention from doctors and health care personnel. Informal payments had thus become a way of being treated properly and with respect. A female patient illustrated this by saying: “The sisters asked for money, otherwise they scolded you, but we gave money to the sisters and then they took care of everything.”

The doctor-centred approach (Papers II-IV)

The ignorant patient

The doctors’ accounts of the medical consultation in paper II demonstrated how doctors’ expertise was perceived as undisputed and normative, whereas patients’ knowledge was often reduced to “misconceptions,” “pre-formed ideas,” and “classifications in their minds,” which were seen as not worth taking into consideration. The doctors, in particular, pointed to the ways in which patients lacked the ability to understand the information provided by the doctors.

I talk to them, you know, explain things, and they say, “yes and yes and yes,” and then in the end of the interview or something they will ask some silly questions, you know, it’s like talking to a wall, they are blank and they haven’t understood a thing. That’s it. (Qualified male doctor)

The belief that patients lacked the necessary knowledge to understand doctors’ information was expressed when the doctors discussed ways of communicating with the patients. They stressed the importance of persuasion and repeating information to patients. They often used wording such as “we keep telling them”, “we try to convince them”, and “we reinforce and repeat information”. Strictly following doctors’ instructions was considered the only way to recover, and those patients who did not stick to doctors’ advice were described as “irresponsible”, “lost”, and beyond help.
The qualified doctors interviewed and observed in papers II-IV distinguished themselves from the unqualified doctors when they talked about the difficulties in establishing a relationship with patients because of the differences in their social backgrounds. The following quote encapsulates this view well:

"We don’t have sort of a social linkage, we don’t have any relationship. They are very, very different, that’s the big problem, that’s what I feel. It happens to the majority of doctors, who are coming from a very different strata. . . . We are very different from them, that’s a big obstacle between the doctors and the patients. (Qualified male doctor)"

**Gender as an influencing factor**

Women were perceived as having an inferior status, which was, to a large extent, reproduced in the doctor–patient relationship. The woman would normally be accompanied to the doctor by either her in-laws or her husband, if she was married, or by her parents, if she was unmarried. The picture of a ‘passive’ female patient who did not talk in the consultations described in the initial semi-structure interviews (II) was also observed in the health clinics (III, IV). Some providers experienced this as having an adverse effect on the consultation and said that they wanted to hear the problems from the “female patient’s mouth.” A more dominant view, however, was that the involvement of a family member in the consultation was considered necessary because of female patients’ reluctance to disclose information and/or their inability to account for their own situation:

"A couple walks in, the woman will come to sit and the man does the talking, “OK she has this and she has this,” which is a little irritating, it puts me off a little . . . .Some women want the men to do the talking, and they are really not smart enough because they have never been exposed to a doctor. It is the first time that they have been brought to the doctor, so some women they are hesitant and want the husband to do the talking. (Qualified female doctor)"

The doctors’ perception of women as less capable of understanding and communicating “medical issues” became more nuanced during the observations (field notes paper III) when the doctors reflected on the difficulties they faced while trying to break cultural practices related to certain gender norms for interaction and communication, which, among other things, require women to keep silent in the presence of an elderly relative or their husband. As one female doctor noted directly after a consultation with a female patient: “did you see how she hid her face? When I tried to talk to her she hid it even more”. Although the veiling was not always observed, the consultations with younger female patients were often guided by gendered norms for interaction. A 23-year-old female patient described a visit to a private doctor when she was diagnosed with TB:

"I was outside [the doctor’s consulting room] and he [husband] was inside. He sent me out and then I don’t know what the two of them were doing (…) I was wondering what had happened. Why were the two of them talking by themselves?"
When she reflected on her wish to talk to the doctor herself she said: “I am a woman, what would he say to me? Generally they talk to the men.”

In contrast to the image of the dependent and passive woman, the man was described as mobile and active by the health care providers. Consequently, male patients were sometimes perceived as less cooperative than female patients, as they challenged the doctors’ dominance by being more demanding, switching doctors more frequently, and questioning doctors’ knowledge and skills. In this sense, shy and reluctant women, as well as demanding men, were both recognized as creating problems in the consultations. However, a more general view was that it was easier to establish a close relationship with male patients, which, in turn, facilitated communication and treatment adherence.

With male patients I behave as with close friends. At that time I’m not a doctor, usually I feel that I’m his friend and the patient will get more confident in me and, of course, he will tell all his problems and he will easily take the medicines properly. At that time I don’t have any problems with the patients, or about the injections or the treatment, that’s why I feel comfortable. (Unqualified male doctor)

The above statement also indicates that the power imbalances between doctors and patients can be less prominent when patients and doctors are of the same sex, which was supported by some doctors’ arguing that male patients preferred male doctors and female patients preferred female doctors. In particular, female doctors were reported to behave and talk in certain ways that make women feel more at ease and willing to talk.

Gender was never discussed independently of other factors. For example, challenges related to female patients’ shyness and reluctance varied according to their age, education, and symptoms. Young newlywed women living with their husbands’ families were perceived to be particularly vulnerable, with no, or very little, decision-making power in the households; these women were also described as being more reserved in the doctor–patient encounter. Women’s opportunities to exercise power over their own lives and over the lives of others were seen to change as they grew older. Some doctors also mentioned that the situation of women was changing, and female patients had become more open in their consultations with doctors.

**Conflicting accountabilities (Paper IV)**

Our analysis from the DTC showed that the TB doctor seemed to be working with a dilemma in the medical encounters: he tried to find a balance between meeting the obligations of the DOTS programme and meeting the needs and expectations of the patients and their relatives. Thus, the dilemma consisted of conflicting accountabilities, and the strategies used to deal with these were identified as (a) limiting patients’ involvement, (b) struggling to maintain authority without losing patients’ trust, and (c) transferring responsibility.

The conflicting accountabilities seemed to stem from a work situation characterized by a diversity of responsibilities including both clinical and administration work. This
involved a shift of professional focus from treating the individual patient to taking the organization of the whole control programme into consideration. The multiple responsibilities had to be balanced against several organizational constraints within the programme. He talked about problems such as an inefficient work organization, unmotivated staff, and lack of doctors and staff in the district programme. These conditions invoked feelings of distress because of not being able to see the patients properly, and the counselling and health education were especially mentioned as impossible to carry out due to time constraints.

The doctor welcomed the programme’s “clear guidelines”, and a sense of commitment to the programme was exposed when he talked about it as “my programme”. His accountability to the programme, however, seemed to create pressure to perform according to the targets of 70% case detection and 85% cure rates. He reported to the programme management at the state level on a regular basis, and he described an informal reward and punishment system at these meetings: if he did well he was recognized for his good performance, but if he could not meet the targets he would suffer the consequences, and described these as being “tortured” and “scolded” in front of the management. The employment conditions of doctors and their staff were further described as insecure, with a threat of being “suspended” if their performance was considered to be poor.

This kind of bureaucratic surveillance, along with the administrative responsibilities, seemed to create tension in the doctor’s professional role. He often perceived himself as the programme’s extenuated administrative arm, which he ironically described as: “I’m like a secretary”.

The need for the doctor to act within the limitations of the programme, in terms of guidelines, “secretary” work and organizational constraints, contributed to a mechanical and stereotyped way of meeting the patients. The majority of consultations had the characteristics of a short meeting restricted to technical requirements such as filling in forms for investigations, checking test results and reviewing treatment cards. There was only a short time for taking down medical history, which mostly concerned current symptoms. Physical examinations by the doctor were rarely performed. Patients were further expected to accept the terms provided by the programme without any objections. If they opposed advice and treatment they were often reprimanded in one way or another. The patients’ communication was limited to answering the doctor’s questions, and if they raised other issues not directly related to investigations or treatment they got little or no response.

However, when guidelines and available services conflicted with expectations from patients and relatives, the doctor was challenged by their questions, doubts concerning diagnosis or treatment, or requests for treatment. He adopted several ways of dealing with this, which were identified as struggles to maintain his professional authority without losing the patients’ trust. While the doctor’s spontaneous reaction to any resistance from the patients or relatives was anger and frustration, he also used other strategies to deal with the patients’ doubts towards him and the programme. One strategy was to avoid disclosing a bad prognosis, and another was to avoid advising referral services that caused inconvenience to the patients and their relatives. In
practice, this could mean putting a patient on treatment for the third or fourth time, even though he knew drug susceptibility tests and second-line drugs were necessary. Meeting the preferences of patients was also illustrated in the routine use of chest X-rays. Although the guidelines stated that this investigation should only be used for confirmatory purposes in diagnosis, the doctor emphasized that chest X-rays were considered necessary because patients “want this”. In his attempts to gain the patient’s trust, the doctor sometimes reflected on his own shortcomings. These reflections indicated a connection between challenged authority and perceived professional limitations, as illustrated in this quotation when he talked about his communication skills:

“When I fail to convince patients I feel it is my fault…I’m not telling them in the right way. We have no training in this. I tell them once, twice, three times, five times but still they don’t want to listen to you. Then I think I must be doing something wrong. You never learn these things, how to communicate with the patients. This is something which you acquire over the years.”

The conflict between serving the programme or the individual patient raised the question of responsibilities in the encounters. The doctor’s accounts often implied that the patients, rather than the programme or other structural factors, were responsible for problems in diagnosis or treatment. For example, patients not fulfilling the criteria of a three-week cough were “wasting” his time. Whereas the programme was perceived to “run smoothly”, patients were considered uncooperative and a “threat” to the programme if they discontinued their treatment. Within the programme organization, confusion about work tasks resulted in blaming someone else for doing something wrong. For example, the doctor expected the treatment supervisor to provide the recommended prophylactic treatment to children with smear positive mothers, whereas the TB staff considered this to be the doctor’s responsibility. Further, the doctor expected the laboratory technicians to instruct patients during sputum collection, while the technicians did not consider that it was their job.

Another aspect of responsibility was brought to attention in the management of smear negative patients. According to the guidelines of RNTCP, these patients should receive symptomatic treatment and broad spectrum antibiotics for 10 to 14 days. If the symptoms persisted, repeated sputum investigations and, if necessary, a chest X-ray, should be performed. However, priority within DOTS is given to the most infectious cases, i.e., the smear positive cases. As a consequence, the doctor and the DTC staff were left with limited resources at hand to take care of these patients properly. The antibiotic course had to be paid out-of-pocket by the patients, and in practice no proper follow-up of smear negative patients was carried out. The lack of attention to these cases clearly influenced doctor–patient interactions. The majority of the consultations were very short; the doctor looked at their results, immediately declared them as “no TB”, and prescribed 2 to 3 days of antibiotics, antipyretics and cough syrup. Although the doctor emphasized the importance of following up the smear negative cases, the patients’ behaviour rather than the programme was again pointed out as a problem, since they would not take the antibiotics or come back for evaluation.
Table 6 Overview of main findings

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6 DISCUSSION

METHODOLOGICAL CONSIDERATIONS

Internal validity (Paper I)

A strength of study I is its population-based design including more than 45,000 adults. This design reduces the selection bias compared with a hospital-based design or similar, since it also captures the health care seeking of those individuals with a cough who did not seek care or those who only sought care in the large informal private health care sector.

However, some limitations were observed in this study. The major difference in cough prevalence between men and women (2.8% vs. 1.2%) raised questions of a possible underreporting of female cough patients. A previous screening survey in Vietnam, for example, showed similar cough prevalence rates among women and men (Thorson et al., 2000). A likely cause might be that all interviewers in the study were men and the majority of the respondents were the male heads of households. An ongoing pilot study in four demographic sites, including Ujjain, explores how the validity of data collected in DSS may be biased due to the gender of the interviewers and respondents. Preliminary findings from Ujjain showed that the interview situations were strongly influenced by social norms and expectations of how men and women should talk and behave. Distinction was made between “typical” male and female questions, and this influenced the interaction between interviewer and respondent, indicating that gender needs to be considered in the data collection of demographic sites. However, further investigations are needed to discover how it influences a survey such as cough screening.

Another limitation of this study was a higher dropout rate among female cough cases than among male cases (39% vs. 28%, p=0.001). This may have introduced a selection bias in the study, but follow-up visits indicated that the main reason for dropping out was lack of expectoration or the fact that their cough had subsided.

Trustworthiness in qualitative inquiry (Papers II-IV)

Variations in qualitative inquiries have contributed to different perspectives on how qualitative research should be evaluated (Patton, 2002; Tobin & Begley, 2004). The perspective emphasizing positivistic assumptions of a neutral researcher and objective world holds that qualitative research should be assessed using the same criteria as in quantitative research (Miles & Huberman, 1994). In contrast to this, other researchers argue that qualitative research relies on different assumptions than quantitative research, and qualitative study is likely to lack validity if it is judged using quantitative criteria (Creswell, 1998). The concept of trustworthiness was developed by Lincoln and Guba (1985) to fit the assumptions of qualitative inquiry, and was adopted across a range of disciplines and traditions. Trustworthiness contained three interlinked components of credibility, transferability, and dependability, which corresponded to the quantitative concepts of internal validity, generalizibility and reliability, respectively (ibid). However, researchers anchored in postmodernistic thoughts argued that developing such parallel terms to validity were problematic, since these terms still
relied on the positivistic assumptions of seeking objectivity and the one and only truth (Patton, 2002).

Instead, attempts were made to deconstruct the established way of thinking about validity. For example, Kvale (1997) does not reject the concept of validity as such, but perceives it as a social construction that acquires its meaning depending on the context, the audience and the researcher. “Truth” of an interpretation, according to Kvale, is negotiated through continuous conversation and dialogue between the participants, the general community and the scientific community. It should be recognized here that the criteria of trustworthiness have changed and developed over the years in response to the criticism of trustworthiness as replicating rather than abandoning quantitative criteria for validation. For example, Lincoln and Guba (1986) introduced the concept of authenticity, which refers to how well research captures and describes a range of different realities.

In this thesis, I have employed the criteria of trustworthiness. In order to assess trustworthiness, I have used two main strategies suggested in the literature, namely reflexivity and triangulations (Patton, 2002; Creswell, 1998). In the following sections, I will illustrate how the procedures of reflexivity and triangulations were applied in my own research by discussing practical and theoretical challenges and opportunities encountered during fieldwork.

**Reflexivity**

Reflexivity refers to how knowledge is shaped by the researcher and how this is accounted for in the research process (Angen, 2000). In qualitative inquiry, the researcher gets involved, and uses his or her interview skills, creativity and empathic ability to collect data in the field. The researcher as “the instrument” calls for attention to biases, but these biases become problematic only if the researcher is oblivious to them (Malterud, 2001). Here it is of critical importance that the qualitative researcher should clarify his/her position and reflect critically on it, rather than striving for objectivity and neutrality. Therefore, being aware of class, gender, race, ethnicity, and how these factors shape the process of your research project is a fundamental principle in qualitative research (Angrosino & Mays de Pérez, 2003).

**Being an outsider (and changing over time)**

During my stays in India I wrote memos and field notes including personal reflections, feelings and interpretations of what I observed and experienced. My initial role as a researcher very much resembled that of a “child” or “student” asking thousands of questions about the most basic things (Agar, 1980). To some extent I remained in that role throughout the work on my thesis, although my field notes revealed a change in my perceptions and attitudes over time. My initial feelings of frustration and critical thoughts were gradually transformed into analytical reflections and contextual considerations. More specifically, I started to “sympathize” with the doctors. These changes are reflected in my findings, especially in the qualitative papers. In my second paper, I took a rather critical stance towards the health care providers’ attitudes and behaviours. Increasing insights into their professional lives and work conditions during my subsequent observations and interviews (papers III and IV) put me in a more
humble position and urged me to look at broader structures shaping their perceptions and behaviours. Such changes may be understood as a result of my involvement in the field where I increasingly started to identify myself with the participants’ feelings and experiences (Fangen, 2005).

**Being a female nurse**

My background as a young female nurse was double-edged. Although I was primarily a “researcher” in the field, I was also viewed from the perspective of a gendered professional hierarchy. I was often met by such comments as “oh, you’re a nurse and not a medical doctor?” Occasionally I struggled not to internalize dominant views of “only” being a nurse with “less” medical knowledge, especially in the encounters with qualified doctors. I feared that doctors might exclude me from their world, as they did not find it necessary or worthwhile discussing their concerns about diagnosis and medical decisions with me. At the same time, I might have appeared as less threatening to them. I often gained rich information from doctors, both qualified and unqualified, who wanted to teach me and make sure I understood what they did. This allowed me to ask naïve questions in order to explore taken-for-granted behaviours and perceptions.

**Being an observer**

The observations were clearly defined in time and place (during opening hours in the clinics), and initially I adopted the role of a non-participant observer. However, I often found myself moving between the roles of a complete observer and an observer–as–participant (Angrosino & Mays de Pérez, 2003), in the sense that I became an active conversation partner to the doctors. The patients inevitably noted me in the room, and some patients and relatives addressed me with some questions. However, the majority of patients did not pay any particular attention to me. This was especially true when it was crowded with patients waiting for the doctors both inside and outside the consultation room.

**Triangulation of methods, sources and perspectives**

Triangulation of methods, sources and perspectives is regarded as a pivotal strategy in obtaining authenticity (Angen, 2000). In line with the qualitative assumptions of “multiple realities”, I have viewed triangulation as offering completeness and ways of shedding light on the study phenomenon from different angles. For example, differences between men and women did not prove to be significantly associated with health care seeking in study I, whereas studies II and III describe gender as an influencing factor. The differences can be explained by the fact that the studies focused on different aspects of health care seeking (utilization in study I as compared with processes and interactions in the other two studies), and may thus generate different findings.

**Triangulation of methods and sources**

Triangulation of methods and sources involve comparing data from different methods, and comparing the perspectives of people from different point of views (Patton, 2002). Combining qualitative and quantitative methods was one way of triangulating data in this thesis. Within the qualitative approach, interviews and observations were used as complementary methods in my fieldwork. Observations of events, behaviours and
interactions led to questions on how people experienced things; and conversely, experiences and perceptions were situated in observed behaviours and events.

The health care providers were chosen to reflect different aspects of the health care system in terms of private–public, qualifications, sex, and location (rural–urban). The emphasis was on out-patient practices, since they serve as people’s first contact with the health care services, and are crucial for early detection and prompt treatment of TB. However, I recognize that while focusing on these health care providers, I exclude other health care facilities and personnel that are important actors in the provision of TB care. For example, nurses and village health workers working within primary care would have contributed to illuminating the research questions from another angle. Similarly, practitioners specialized in other medical systems such as Ayurveda would have added to the understanding of the ‘healing relationships’ mentioned earlier (Nichter & Nichter, 1996b).

It should also be pointed out that I have mainly focused on the health care provider perspective in the medical encounters. In paper II, I studied the medical encounter as experienced by health care providers, and in paper IV the patient perspective is only indirectly described through observations and their communication with the doctor. In paper III, I included the perspectives of both health care providers and patients, but I acknowledge the need to further explore patients’ experiences in order to capture more fully the complexities involved in medical encounters.

Triangulations of researchers and perspectives
Malterud (2001) points out that “multiple researchers might strengthen the design of a study – not for the purpose of consensus or identical readings, but to supplement and contest each others’ statements” (p 484). My approach in this thesis was in line with this view. The triangulation of researchers included different professions (two medical doctors, a social scientist, and nurse), ages, and cultural backgrounds (Indian and Swedish). While I was responsible for the actual coding and categorization, the emerging categories and themes were frequently discussed in the research team, recognizing different perspectives and views. In addition to the co-authors’ role to “supplement” and “contest” my findings, they also engaged in a process of auditing to ensure that the analysis was logical and clearly documented (Creswell, 1998).

My close collaboration with my Indian co-author and research colleague, a female medical doctor trained in community medicine, was characterized by the interplay between insider and outsider perspectives. The outsider’s perspective is typically described as the researchers’ analytical explanations and descriptions, whereas the insider perspective represents the understanding and interpretations made by people within a culture (Bartunek & Louis, 1996). During my stays in Ujjain, my colleague also became a “key informant” in the sense that she contributed with her knowledge as a medical doctor and her experience of working in the same context as the doctors that I interviewed and observed. Thus, my observations and interpretations were continuously compared with her understanding as an “insider”. However, coming from the same cultural setting does not necessarily mean that a person has an insider’s view in all respects. This became particularly evident in the interviews with patients when she was perceived as an “outsider” in terms of her urban educated middle-class
background. Although we were both perceived as outsiders to varying degrees, being women in this context facilitated our interviews with female patients because of norms guiding communication and interaction between men and women.

The challenge of translations and analysis of translated text

The language barrier, especially in the encounters with patients, had implications both for establishing relationships with participants, and for the subsequent analysis. Obviously, qualitative material works best when analysed in the original language since discrepancies between original and translated text often occur, and it is sometimes difficult to find equivalence of meanings and words. In the transcription and translation of interviews and tape-recorded consultations in Hindi I worked closely with my Indian colleague. This allowed us to discuss language problems and cultural meanings inherent in words and phrases that were not easily translated into English. All final transcripts were read through while listening to the tape-recordings and any missing sentence or words were added to the transcripts.

An alternative and frequently used analysis method of medical encounters is discourse analysis (Silverman, 2001). While it comprises a variety of approaches, the main focus is on the properties and structures of language use in a social context, and how the study of language can provide insights into social structures and power relations within a society (Traynor, 2006). Since I worked with translated text I did not consider this method to be feasible or applicable to my material.

Transferability and Generalizability

The villages in study I were selected from three development blocks based on their proximity to a rural health care centre. This is not a representative sample of a larger rural population, and any generalization must be made with caution.

There is a substantial difference between transferability in qualitative inquiry and the concept of generalizability. Since individual subjective meaning is central for qualitative inquiry, findings are not seen as facts that are applicable to a population at large, but rather as analytical descriptions or theories that can be applied within a specified setting and can enhance our understanding of a certain phenomenon (Sandelowski, 1986; Patton, 2002). From this perspective, the experiences and observations accounted for in this thesis need to be understood against the background of the study setting. Rural poverty is still a major challenge in the district, and the public health care infrastructure remains poorly developed compared with other states in India. The vast number of private providers in rural areas and the lack of public health care facilities obviously shape health care seeking and the way in which the medical encounters are perceived in this study setting.

DISCUSSION OF FINDINGS

In the following section, I will discuss my findings in relation to two priority settings in the development of TB care and control strategies in India and globally, namely the empowerment of patients and communities, and the engagement of all health care
providers (WHO, 2007). These two aspects are considered from different angles in the discussion sections of all four papers, and I will re-visit them here.

**Patient centeredness in TB control**

Strategies for empowerment in TB control show great variety in terms of conceptual and operational definitions, intervention activities and evaluation methods. In a recent review, these interventions and experiences were defined as falling into four broad areas: enablement of patients to take more responsibility of their health and treatment; organization of TB patients through meeting forums; patient-centred strategies in delivery of health care; and involvement of patients in decision-making processes and organization of health care (Macq, Theobald, Dick et al., 2007). The findings in this study relate to the area of empowerment through patient-centred care, and the question is how this can be understood in the context of medical encounters in TB control?

Shared responsibility between patients and health care professionals, one central aspect of patient-centred care (Mead & Bower, 2000), is currently being promoted in the International Standards for Tuberculosis Care (Hopewell, Pai, Maher et al., 2006) and in the ‘patient charter’ developed by NGOs and patient activists (Case, 2006). However, as is shown in the qualitative studies (II, IV), the question of responsibility can be problematic in the encounters. At the DTC, the TB doctors’ accounts sometimes implied that patient-related shortcomings, rather than the programme or other structural factors, were responsible for problems in diagnosis or treatment. In study II, the interviewed health care providers considered that they had fulfilled their responsibilities after giving instructions, and the outcome of treatment was dependent on patients’ motivation to follow the doctors’ instructions. Patient characteristics such as ignorance or “irresponsible” behaviour were often put forward as the main obstacles.

These findings suggest that treatment difficulties tend to be viewed by the doctors as a patient-related responsibility. Some critical considerations of the notion of patient-centeredness have drawn attention to how its inherent message of greater patient control holds the opportunity for doctors to blame patients for their ill health or non-adherent treatment (Salmon & Hall, 2003). Another consideration relates to how the emphasis on patient responsibility may result in neglect of structural factors in the encounters over which patients have little control. However, in view of the findings from study IV, the real concern is perhaps how a patient-centred approach, including shared responsibility, can be achieved if the encounters are embedded in a context where not only the patient but also the doctor faces structural factors that are considered beyond personal or professional control. Clearly, the standardized diagnostic procedures and treatment within a resource constrained organization left both patients and the doctor with limited options, and resulted in little communication and sometimes unsolved tension and scolding of the patients.

While improvement of interpersonal skills and communication is regarded as one important strategy to increase patient-centeredness (Macq et al., 2007), the question is how such programmes should be implemented in a resource-constrained setting. Evaluations of patient-centred interventions in TB clinics as well as in other clinical contexts show inconclusive results (Lewin, Skea, Entwistle et al., 2001; Rangan, Ambe,
While there are some studies indicating that communication skills can improve satisfaction and adherence among TB patients (Munro, Lewin, Swart et al., 2007), improved communication or interpersonal skills alone do not seem sufficient. Findings from the DTC indicated that the TB doctor’s work situation was characterized by a diversity of responsibilities, including both clinical and administration work, which had to be balanced against several organizational shortcomings within the programme. Focusing solely on interpersonal skills in a situation like this may divert attention from the “real” structural problems that need to be addressed at a central management level.

Intervention studies aiming at patient-centred care in South African TB clinics illustrate this well (Dick, Lewin, Rose et al., 2004; Lewin, Dick, Zwarenstein et al., 2005). Lack of desired outcomes in these studies indicated that structural barriers may limit the effect of such interventions. Health care providers were more concerned with their own work conditions rather than with the experiences of patients (Dick et al., 2004), and they did not see themselves as having the agency to initiate workplace change (Lewin et al., 2005). One of the important insights from study IV is the close connection that seems to exist between the structural limitations perceived by the doctor and how patients were received in the consultation room.

Hence, improving the quality of medical encounters in TB control requires attention and interventions at several levels. Improving interpersonal skills and communication is important, but may not be effective unless other barriers to clinical and organizational changes are removed. Strengthening of the RNTCP organization by ensuring adequate numbers of trained staff, more time allocated to each patient and a supportive management therefore seems crucial. I think it is also important to note that in efforts to improve medical encounters, patient-centeredness should not merely be seen as a tool to reach a specific end such as adherence, but it should also be viewed as being worth striving for in its own right to ensure reasonable work conditions for health care providers and dignified care for patients.

The interplay between gender, social class and caste

Power imbalances originating from social orders created by gender and class, as demonstrated in this study, may be considered an intrinsic part of the doctor–patient relationship, and therefore difficult to eliminate (Waitzkin, 1989). The social class discrepancy, especially between qualified doctors and patients, seemed to contribute to stereotyped perceptions of the “ignorant patient”, which, in turn, tended to inhibit communication and discourage doctors from providing information to the patients. In these circumstances, doctors cannot be expected to eliminate or “solve” social discrepancies, but they can be given support and tools to bridge gaps and to become aware of how their own attitudes and biases may affect the interaction and the outcome of the medical encounter. Indeed, health care providers’ accounts also revealed an awareness of how tension between layperson and biomedical understandings, as well as structural factors (illiteracy, social status), created communication gaps between themselves and their patients. Their insights into the causes of communication barriers should be recognized as an important starting point in programmes to improve communication and interpersonal skills (Stewart, 2003).
The doctors’ interactions with female patients were often restricted by social structures outside the immediate doctor–patient relationship. This became particularly evident when the consultations included family members and in the doctors’ accounts of young married women living with their husbands’ families. Many women practised body concealment and seclusion (purdah) in relation to their husbands’ senior relatives, and the expected behaviour of the women would be to keep silent and let her attendant talk to the doctor. Breaking these customs in the consultations was described by the doctors as difficult. This draws attention to the way in which women’s health, care seeking and encounter with health care providers is situated in a socio-cultural context. Currie & Wiesenberg (2003) write that “those who are relatively powerless – such as women in patriarchal settings – are likely to view both the cause and outcome of their illness as beyond their control” (p 884). From that perspective, health care providers are faced with a delicate balance between paying attention to female patients’ own illness experiences and involving family members who often act as guardians and decision-makers. A culturally sensitive approach suggested by one of the female doctors in this study was to use one’s “authority” as a doctor to ask family members to wait outside during history taking and examination, and then involve them towards the end of the consultation.

A related area concerns whether gender congruence (i.e. when patient and doctor are of the same sex) may lead to better interactions, and, in turn, better consultation outcomes in terms of satisfaction, information-giving and adherence to treatment (Johansson & Winkvist, 2002; Street, 2002). Findings in this thesis suggest that female patients may feel greater freedom to assert their needs and preferences with female providers. At the same time, female doctors, especially qualified ones, are rare in rural parts of India. The staffing of the DTC and related TB units in the study setting reflected an organization predominantly staffed by men. In particular, decision-making and supervision positions were employed by men, whereas nurses were exclusively women. Ensuring appropriate levels of female staffing in TB activities is thus important for the delivery of gender-sensitive care.

In these efforts, it should be noted that the health system often reflects a hierarchy where professional status and gender are closely related to each other. For example, a recent review of human resources in health shows that men tend to have more favourable positions in the health system hierarchy than women in terms of decision-making positions, employment terms, career choices and opportunities (George, 2007). In the absence of a female doctor, women may feel more comfortable talking to a nurse or the equivalent, but if this group of staff has little or no influence in the delivery of care, women’s expressed needs and wishes can be difficult to realize.

However, gender-sensitive communication skills should not be seen as an inherent female trait. For example, the tendency of both male and female patients to be more open with female doctors has been attributed to their rapport-building skills (e.g. positive feedback, showing interest in patients’ concerns about non-medical issues) in the consultations (Hall & Roter, 2002; Roter, Hall, & Aoki, 2002). This evidence may suggest that patients’ openness is a result of good interpersonal skills, which can be learned and applied in the consultations irrespective of the doctor’s sex, rather than the
sex of the doctor per se. Considerable research has been carried out in high-income settings on the effect of doctors’ communicative behaviour on male and female patients (Street, 2002), but these questions remain unexplored in low-income settings and warrant further in-depth studies. A question that needs to be explored, for instance, is to what extent doctors can bridge communication barriers with female patients by adopting interpersonal and communication skills that specifically address gendered norms of communication.

While social class and gender emerged as important aspects in the qualitative studies, the participants’ accounts of caste were more ambiguous (field notes). In patients’ narratives of village life, social and ritual rules rooted in the caste system were very much part of their daily lives. However, caste was perceived as less relevant in their choice of health care provider. In a similar way, the doctors said that they never considered caste in the actual encounter; their job was to provide treatment irrespective of caste identity. Traditionally, the medical profession used to be the occupation of higher castes, but changes in the education system and society at large, made the participants reflect on the doctors’ profession as cross-cutting the caste boundaries, and the fact that a person belonging to a “lower” caste can be a doctor these days. The patients’ accounts further suggested that the acquired social position of a doctor, manifested in educational credentials or “abilities to heal”, was the decisive factor, not the caste to which he or she belonged. This view was reflected in the pragmatic stance several patients took on the question of caste. They simply highlighted their purpose in seeking care, namely to get treatment.

These findings may be understood in terms of processes of change in Indian society. The caste system has historically worked as a social discriminator in Indian society, but research demonstrates that with the expansion of the market economy, class is becoming increasingly important for the acquisition of social status and as a means of negotiating social positions previously determined by caste (Gupta, 2004; Kapadia, 2002a). It should be emphasized, however, that class and caste remain highly correlated in rural areas (Shah et al., 2006), and discrimination due to social class may also imply or conceal specific caste inequities or biases.

**The consumerist approach: empowering or abusive?**

Our findings showed how consumerism in health care created both opportunities and vulnerabilities in patients’ health care seeking and interactions with doctors. In papers I and III, patients’ health care seeking indicated that the numerous private health care providers offer choices and access to care in rural areas. In papers II and III, the consumerist approach in the medical encounters includes a provider orientation towards patients’ choices, preferences and satisfaction. As shown in paper III, this approach offered opportunities for patients to negotiate fees based on their evaluations of the providers’ capacity to treat and cure specific symptoms and diseases. The health care providers, especially in the informal sector, responded to this by adjusting their fees according to patients’ requests and ability to pay. These features of consumerism are well in line with some of the inherent values of patient empowerment. The patient is seen as an active agent with choices and opportunities to make requests, resist medical
dominance, and take an active part in decisions concerning their own health (Lupton, 1997).

However, the very aspects that created opportunities in a consumerist environment also created vulnerabilities. As pointed out in study II, private health care providers were also driven by economic interests, and patients seemed to be referred to governmental facilities only after being assessed for their ability to pay for private care. This practice was also evident in study III, suggesting that doctors had to find out not only who could pay, but also what patients were prepared to pay for. These findings indicate that while ‘financial’ support was provided to the poor in private practice, it also entailed a selection and assessment of patients based on their ability to pay for private health care services. Nichter (1996a) defined the propensity to help poor patients in an Indian rural setting as a ‘Robin Hood’ mentality among private practitioners. To compensate for fee losses by treating poor patients for free or on credit, they tried to charge higher fees from more affluent patients.

From this perspective, the negotiable features of what patients could afford, and the preparedness to pay if the disease was perceived to be serious, may feed negatively into existing exploitive features of the private health care sector such as the commission system mentioned by doctors in study III. The impoverishing effects of TB treatment have been well documented in studies showing the relatively large proportion of health care expenditure in relation to total expenditures in poor households (Rajeswari, Balasubramanian, Muniyandi et al., 1999). Also, as is shown in article I, the probability of receiving a sputum smear examination is significantly less if the patient seeks care from a private provider. Inadequate diagnostic practices among private providers have been reported from other studies in India (Prasad, Nautiyal, Mukherji et al., 2003), and delays in diagnosis have consequently been related to the health system when private or unqualified providers were consulted first (Rajeswari et al., 2002; Selvam et al., 2007).

Women’s accounts in paper III revealed considerable financial and social insecurity in their lives because of TB and the costs of treatment. Such accounts can be understood in the context of family and community-based power structures in rural Ujjain (and elsewhere in India) which fosters female seclusion and subordination (in varying degrees), and anchors women’s financial and social security to marriage. When a woman gets married, she belongs to her husband’s family. This system incorporates values of women being inferior to men, and promotes cultural imperatives to invest in sons and men for both material and spiritual reasons. By tradition, women have also been viewed as financial liabilities in their natal families because of the practice of dowry (Banerjee, 2004). As commercialization of health becomes embedded in this cultural context, distinct financial and social structures of vulnerabilities seem to arise for women in households in which they have little autonomy and decision-making power.

Attention to possible barriers to health care for men is also required in such a diversified health care setting. While we found no clear differences between health care utilization and access to TB investigations between men and women, other findings from India indicate that women utilized public health care to a larger extent than men, and were thus more likely to be notified within the RNTCP (Balasubramanian, Garg,
These studies are from South India where the public health care infrastructure is more developed, which may benefit women’s access to health care in particular. The general low access to TB investigations (i.e. CXR and sputum investigations) in Ujjain district may also explain why no differences were observed between men and women for these outcome variables.

In paper II, male patients were perceived as more demanding in the medical encounters, since they adopted a more active role by asking more questions, challenging advice or requesting specific treatment. It can be argued that this may benefit men in terms of getting a prompt diagnosis and treatment, but as indicated in studies II and III the doctor’s attempts to meet patients’ requests also contributed to clinical practice that was not necessarily perceived as “correct” by the doctors. Evidence suggests that when health care providers’ income is dependent on patients’ willingness and/or ability to pay, doctors tend to act in accordance with patients’ demands, even though they know that the requested treatment is incorrect (Lönnroth, 2000). The extent to which negotiations in medical encounters may affect men and women differently, in terms of getting a TB diagnosis and treatment in the private health care sector, needs to be explored in more detail, especially with regard to the outcome of the consultation in terms of suggested treatment, prescriptions and advice.

The studies in this thesis did not address the actual performance of health care providers (e.g. knowledge or prescription practices), but tension between the knowledge of what they should do and what they were actually able to do was often articulated by the private doctors. This suggests that adequate knowledge and training alone may not be effective when ‘market forces’ such as purchasing power tend to determine the outcome of a consultation. A study from Pakistan addressed this know–do gap, and showed that private providers had adequate knowledge of diagnostic and treatment procedures but this knowledge was not translated into actual practice while treating patients (Thaver, Harpham, McPake et al., 1998). This has also been reported by a study from Mumbai on the management of malaria cases, where private providers explained their suboptimal practice as due to demands for quick remedies from patients who could not afford the appropriate diagnostic tests or treatment (Kamat, 2001). Arguably, medically ‘irrational’ practices can be understood as ‘rational’, given the social and economic context in which private providers work.

The role of doctors in the consumerist approach involved vulnerability, as illustrated by their fears of losing their reputation or of being sued. Perceptions of patients as consumers with legal protection and claims are illustrated in the Indian Consumer Protection Act, under which health care providers who offer fee-for-services can be sued for malpractice and negligence. Bhat (1999) found that the awareness of this act among private providers is high compared with other acts regulating the medical profession, indicating that the legal rights of patients influence the practices of private providers.
The Public–Private Mix

In line with previous findings from India and other countries where private care constitutes a significant share of health care delivery (Lonnroth et al., 2001; Uplekar, Pathania, & Raviglione, 2001a), studies I and III indicated a strong preference for the private health care sector among cough symptomatics and TB patients. The shift from public to private health services after the first health visit, observed in study I, provides some new insight into health care utilization patterns, as it suggests that public health care services fail not only to attract patients but also to keep them. The reason for this was not clear from the first study, but previous studies regarding public health care services have depicted problems in connection with travel distance to the facilities, inconvenient opening hours, long waiting times and poor reception by staff (Jaiswal et al., 2003; Sudha, Nirupa et al., 2003). In study III, however, we recognized a blurred distinction between the private and the public.

According to RNTCP guidelines, governmental institutions should provide free TB treatment, but in practice, free services included several “hidden” costs such as medicines prescribed and bought from private pharmacies, referral to the private sector for investigations or treatment, and informal payments. Similar findings have been found in other low-income settings where provision of public care is reportedly poor (Russell & Gilson, 1997), and marginal differences in health care expenditures between private and public practitioners have been demonstrated in an Indian study (Bhatia & Cleland, 2001). As shown in this study, free TB treatment gave rise to ambivalent feelings: it was associated with poverty, but was nevertheless stated as one of the main benefits of public care. Clearly, if these expected benefits were removed, the availability of an informal support system in the private sector made it not only ‘socially’ desirable but also financially attractive to patients.

Practitioners in India are known for being engaged in both sectors; government doctors engage in private practice, and private doctors utilize public hospital services to serve their private patients (Yesudian, 1994). For example, in paper III the public TB doctor suggested that patients should come to his private clinic for consultations. This referral behaviour can be seen as a response to the structural problems encountered in the public health care system (e.g. lack of drugs), but it could also be argued that there is an inherent patient-centred approach in this practice. With this in mind, Kamat (1995) observed a “privatization of public sphere”, referring to a primary health care centre in Maharashtra, South India, which had gained popularity by letting patients choose between private and public care at their convenience.

The integration of private health care providers into TB control activities seems particularly important in a setting where the private health care sector accounts for the greater part of health care delivery and expenditures, and where the private and public spheres already overlap through informal processes. The findings in this thesis suggest that there are a number of informal referral channels, financial support mechanisms as well as market-driven interests that need to be considered in the public–private collaboration strategies that are being emphasized and pursued as a major goal for TB control in India (RNTCP, 2007). A recent review from public–private collaboration projects implemented in India showed promising results, with improved case
notification while maintaining high treatment success rates (Dewan, Lal, Lonnroth et al., 2006). Economic analysis further suggests that such collaborations are cost-effective interventions (Floyd, Arora, Murthy et al., 2006). So far, these projects have only been implemented on a small-scale basis. Challenges remain in terms of distrust between private and public providers (De Costa, Johansson, & Diwan, 2007; Vyas, Small, & DeRiemer, 2003), lack of training and information, as well as poor incentives and regulatory mechanisms (Uplekar et al., 2001a).

The question of equity has received increasing attention in the assessment of public–private collaborations (Malmborg, Mann, Thomson et al., 2006; Sheikh, Porter, Kielmann et al., 2006). In view of the findings in this thesis, there are several important questions that need attention. First, how might the negotiable features of affordability influence private and public doctors’ decisions to offer TB patients free care? Patients were evidently prepared to go to great lengths to pay for private health care, even when they did not have cash available. Health care providers, on the other hand, may calculate benefits and losses carefully before referring patients or offering them free services. Indeed, tendencies to keep patients who are willing to pay for private care have been reported from areas where public–private collaborations are being implemented (Greaves, Ouyang, Pefole et al., 2007; Murthy, Frieden, Yazdani et al., 2001). Also, the propensity to only refer the very poor patients to public health care facilities, sometimes referred to as “dumping” (Sheikh et al., 2006), may contribute to reinforcing the poverty stigma attached to public health care facilities. From this point of view, attempts in bridging the gaps between private and public may in reality further encourage a two-tier system.

Another issue is how successful these programmes will be in including those who are economically vulnerable. Poor access to qualified doctors in the rural settings of Ujjain and Madhya Pradesh can be seen as evidence of deep-rooted discrimination against the rural poor. Arguably, increasing coverage of TB services by involving unqualified doctors in rural areas could have a positive effect on equity. There is some evidence that collaboration benefits women’s access to health care in particular (Uplekar et al., 2001a). However, a related concern is how to improve access while ensuring adequate diagnosis and treatment in a context where ‘irrational’ practice has emerged from the interactions between patients’ preferences and doctors’ attempts to attract and retain patients in a competitive market.
7 CONCLUSIONS

The findings of this thesis highlight important aspects of health care seeking and medical encounters in the context of TB care in a rural district of India characterized by a diversified health system.

The majority of individuals with a cough consulted a private provider first. There was little utilization of public health care, and a shift from public to private health services after the first health visit was observed, suggesting that public health care services fail, not only in attracting patients but also in keeping them. The consumerist approach identified in this study sheds light on possible reasons for patients’ strong preference for the private health care sector. A provider orientation towards patients’ satisfaction meant opportunities for patients to negotiate treatment and fees according to their evaluations of the providers’ capacity to treat and cure specific symptoms and diseases. There was also an important social impetus underlying these negotiations, since being able to afford private health care conveyed messages about one’s social status, and provided opportunities to escape the stigma of poverty attached to public health care.

While these features suggested that patients were active agents in the medical encounters, they were also in a vulnerable position during these encounters, since their ability to pay was assessed by health care providers before treatment and investigations were prescribed. Moreover, there was no clear demarcation between the consumerist and the authoritarian approaches, suggesting that different approaches towards patients might coexist in the medical encounters.

A discrepancy between layperson and biomedical understanding was encapsulated in health care providers’ views of ‘the ignorant patient’, and was identified as creating communication barriers in medical encounters in both the public and private health care sectors. While young women in particular were perceived as reluctant to participate or incapable of talking to health care providers, they were also restricted in the consultations because of gendered norms for interactions that were embedded in family relationships that are typical in rural settings of India. For this reason, the role of family members, in terms of both support and limitations, needs to be taken into consideration in the development of gender-sensitive strategies in TB care.

Within the RNTCP, an authoritarian approach towards patients was more tangible than in the private sector. However, a doctor’s dilemma of conflicting accountabilities was observed due to tension between programme requirements and patients’ needs and preferences. There seemed to be a close connection between structural limitations and how the doctor interacted with patients. The finding highlights the need to improve communication in medical encounters within the RNTCP, but the behaviour of doctors or patients may not change unless the constraints of the organizational context are simultaneously attended to. With regard to future research, an important message from this study is that interventions aiming at improving interpersonal skills in medical encounters also need to consider structural factors that may inhibit or facilitate changes.
Finally, the boundaries between the public and the private health care sectors were blurred by a number of informal processes and overlapping practice among health care providers. One such process relates to how an informal support system in the private sector and the illusion of free public TB care challenged the “official” notions of private and public health care expenditures. The integration of private health care providers into TB control activities therefore seems particularly important in a setting where utilization of the private health care sector is substantial, and where the private and public sectors already overlap through informal links.
8 ACKNOWLEDGEMENTS

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Finally, my Pelle. I’ll just put it very simply: thank you!
9 REFERENCES


10 APPENDIX

Appendix 1 English Version of the questionnaire in study I

<table>
<thead>
<tr>
<th>Block:</th>
<th>Block Code:</th>
<th>Village:</th>
<th>Village Code:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household Number:</td>
<td>Name of Head of Household:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients ID No.:</td>
<td>Name of Patient:</td>
<td>Age:</td>
<td>Years:</td>
</tr>
</tbody>
</table>

1. Duration of cough: Week: -------- Month: -------- Years: ---------

2. Other complaints (do not prompt the symptoms, only tick if mentioned):
   a) Fever       b) Chest Pain       c) Weakness
   d) Breathlessness e) Weight loss f) Blood cough
   g) Nightly sweating h) Others ---------------

3. Cause of cough (as perceived by patient):
   a) Change in weather b) Food/ Drinks (cold food/Drink) c) Smoking d) Pollution
   e) Infection f) Asthma g) Tuberculosis h) Cancer
   i) Any other cause j) No information

4. Do you have health insurance? YES / NO? ________________________________

5. Since the onset of the symptoms have you sought health care from any providers or have you received any treatment for your symptoms, including self-medication? Yes/ No

   (IF Question No. 5.1 is YES  Answer Following (5.2 - 5.14)
   (IF Question No 5.1 is NO  Answer Question No. 6)

5.2 Duration after which you sought health care from any provider Day: ____ Month: ____ Yrs: ____

5.3 Reason for delaying treatment (Circle more than one alternative if necessary?)
   A) Inability to pay for medicines / Investigations / Transport
   B) Lack of proper advice for doses and regular treatment
   C) Side effects of drugs not tolerable
   D) Distaste
   E) Forgetfulness
   F) Medicines not available
   G) Health center/ Clinic not opened
   H) Health personnel refused to give medicine
   I) Not willing to pay
   J) Nobody to accompany to the health center/clinic
   K) Family members not supporting
   L) Any other reason specify
<table>
<thead>
<tr>
<th>5.4</th>
<th>Where did you go for treatment / health advice? (Circle the right answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Govt. doctor</td>
</tr>
<tr>
<td>B</td>
<td>Govt. health worker</td>
</tr>
<tr>
<td>C</td>
<td>Qualified private practitioner</td>
</tr>
<tr>
<td>D</td>
<td>Trained private health worker</td>
</tr>
<tr>
<td>E</td>
<td>Unqualified Provider</td>
</tr>
<tr>
<td>F</td>
<td>Any other specify</td>
</tr>
<tr>
<td>G</td>
<td>Pharmacies, self-medication</td>
</tr>
<tr>
<td>H</td>
<td>Any other specify</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.5</th>
<th>Why did you choose this particular provider? (Circle the right answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Close to home</td>
</tr>
<tr>
<td>B</td>
<td>Convenient timings</td>
</tr>
<tr>
<td>C</td>
<td>Cheap prices</td>
</tr>
<tr>
<td>D</td>
<td>Faith</td>
</tr>
<tr>
<td>E</td>
<td>Familiarity</td>
</tr>
<tr>
<td>F</td>
<td>Quality of care</td>
</tr>
<tr>
<td>G</td>
<td>Any other reason</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.6</th>
<th>What kinds of examinations were performed? (Circle the right answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Smear</td>
</tr>
<tr>
<td>B</td>
<td>Chest X-ray</td>
</tr>
<tr>
<td>C</td>
<td>Others, specify:</td>
</tr>
</tbody>
</table>

| 5.7 | What kind of diagnosis did you get? |

<table>
<thead>
<tr>
<th>5.8</th>
<th>What treatment (Medical System) did you choose? (Circle the right answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Allopathic</td>
</tr>
<tr>
<td>B</td>
<td>Ayurvedic</td>
</tr>
<tr>
<td>C</td>
<td>Homeopathic</td>
</tr>
<tr>
<td>D</td>
<td>Home Remedy</td>
</tr>
<tr>
<td>E</td>
<td>Others</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.9</th>
<th>Why did you choose this specific Medical System? (Circle the right answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Easy availability</td>
</tr>
<tr>
<td>B</td>
<td>Affordability</td>
</tr>
<tr>
<td>C</td>
<td>Faith</td>
</tr>
<tr>
<td>D</td>
<td>Any other reason</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.10</th>
<th>What treatment did you get? (Circle the alternatives)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Provider / health care action</td>
<td>A</td>
</tr>
<tr>
<td>2nd Provider / health care action</td>
<td>B</td>
</tr>
<tr>
<td>3rd Provider / health care action</td>
<td>C</td>
</tr>
<tr>
<td>4th Provider / health care action</td>
<td>D</td>
</tr>
<tr>
<td>A</td>
<td>Antibiotics</td>
</tr>
<tr>
<td>B</td>
<td>Anti-TB drugs</td>
</tr>
<tr>
<td>C</td>
<td>Cough medicine</td>
</tr>
<tr>
<td>D</td>
<td>Traditional/Herbal medicine etc.</td>
</tr>
<tr>
<td>E</td>
<td>Other medicines</td>
</tr>
<tr>
<td>F</td>
<td>No treatment</td>
</tr>
<tr>
<td>5.11</td>
<td>Did you take the treatment following the prescription and without any interruptions? Yes= 1 / no= 2</td>
</tr>
<tr>
<td>------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1st Provider / health care action</td>
<td>YES= 1</td>
</tr>
<tr>
<td>If no: What is the reason for irregular treatment (Circle the alternatives)</td>
<td></td>
</tr>
<tr>
<td>A) Inability to pay for medicines / Investigations / Transport</td>
<td>A</td>
</tr>
<tr>
<td>B) Lack of proper advice for doses and regular treatment</td>
<td>B</td>
</tr>
<tr>
<td>C) Side effects of drugs not tolerable</td>
<td>C</td>
</tr>
<tr>
<td>D) Distaste</td>
<td>D</td>
</tr>
<tr>
<td>E) Forgetfulness</td>
<td>E</td>
</tr>
<tr>
<td>F) Medicines not available</td>
<td>F</td>
</tr>
<tr>
<td>G) Health center/ Clinic not opened</td>
<td>G</td>
</tr>
<tr>
<td>H) Health personnel refused to give medicine</td>
<td>H</td>
</tr>
<tr>
<td>I) Nobody to accompany</td>
<td>I</td>
</tr>
<tr>
<td>J) Family members not supporting</td>
<td>J</td>
</tr>
<tr>
<td>K) Any other reason specify</td>
<td>K</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.12</th>
<th>Are you satisfied with the care given? Yes =1  No= 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>YES= 1</td>
</tr>
<tr>
<td>If no, why? (Circle the alternatives)</td>
<td></td>
</tr>
<tr>
<td>A) Not cured</td>
<td>A</td>
</tr>
<tr>
<td>B) Poor quality of care</td>
<td>B</td>
</tr>
<tr>
<td>C) Too expensive</td>
<td>C</td>
</tr>
<tr>
<td>D) Not enough information</td>
<td>D</td>
</tr>
<tr>
<td>E) Poor staff attitude</td>
<td>E</td>
</tr>
<tr>
<td>F) Others, specify</td>
<td>F</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.13</th>
<th>The cost of examination and treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examination:</td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td>Examination:</td>
</tr>
<tr>
<td>Drugs</td>
<td>Examination:</td>
</tr>
<tr>
<td>Doctor Fee</td>
<td>Doctor Fee</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.14</th>
<th>The cost of transportation and accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>Transportation</td>
</tr>
<tr>
<td>Accommodation</td>
<td>Accommodation</td>
</tr>
</tbody>
</table>

6. What was the reason for not seeking health care?
   A) Not serious enough to warrant treatment
   B) Waiting for spontaneous recovery
   C) Lack of money
   D) Lack of time
   E) Lack of awareness about treatment
   F) No health care facility available locally
   G) No transport facility available
   H) Nobody to accompany to the health center/clinic
   I) Family not willing
   J) Any other reason -------------------------------------------------
Appendix 2 Question guides

*Health care providers (Paper II)*

1. Introduction
What kind of experience and training do you have?
What kind of patients do you see?
How often do you see TB patients (or patients with prolonged cough)?

2. Could you please think of a female patient with TB (or with prolonged cough) that you have recently seen?
Follow-up: Could you describe this patient (symptoms, background, personality etc)?
   Did she come alone or with somebody?
   What happened when the patient came to you?
   What did you talk about?
   Questions brought up by the patient?
   What kind of information did you give?
   Did you experience any difficulties with this patient? (Diagnosis, treatment, communication etc)
   Was it a good or a bad experience? What made it a good/bad experience?
   Was it a typical female patient? If not, how would you describe a typical female patient?
   In general, do you perceive any particular difficulties with female patients?
   In general, what do you talk about with female patients?

3. I would now like you to think of a male patient with TB (or with prolonged cough) that you have recently seen. (Continue to ask the same questions as above when necessary.)

4. You have described two encounters, one with a male patient and one with a female patient. If you think about these two encounters, did you experience any differences:
   In the way you behaved or talked to the male and female patient, respectively?
   Between the male and the female patient (e.g. symptoms, communication, (behaviour, education etc)
   In general, do you experience any differences between female and male patients?

5. In general, could you tell me about some challenges/difficulties that you have experienced when seeing TB patients (cough patients)?
Follow-up: Diagnosis?
   Follow-up visits? Treatment interruption? Reasons?
   Communication with patients?
   Payments?
TB patients (Paper III)

1. Can you tell us about what kind of doctors/providers you have visited for your problems (TB)?

2. Could you describe an experience with a doctor/provider that you have recently seen?

   Follow-up: What happened when you came to the clinic?
   How would you describe that doctor?
   What did you talk about?
   Anything you wanted to talk about to the doctor that you didn’t do?
   If yes, could you explain the reason for that?
   Did somebody accompany you to the doctor?
   If yes, what kind of help did you get from your attendants?
   Did you meet any other staff in the clinic (e.g. nurses, etc)?
   If yes, how did they receive you?
   What kind of expectations did you have when you went to the doctor?

3. When you seek health care, how do you make the decision where to go?

   Follow-up: Who makes the decisions?
   In general, how are decisions made in your home?

4. We would like to ask you about payments (Ask about the specific doctor mentioned in question 1 and about doctors/providers in general):

   Follow-up: How did you pay (cash, credit, loan etc)?
   Who paid?
   What is your opinion about paying a doctor?
   How do you feel about paying?
   What is acceptable to pay for?

5. Is there anything else you would like to tell us?
Appendix 3 Diagnostic guidelines within RNTCP

Three consecutive sputum smear samples should be collected for diagnosis (figure). Patients with at least two positive smear results are diagnosed as cases of smear positive TB. For patients with only one sputum smear positive result, chest X-ray should be taken to confirm or dismiss a sputum smear positive TB diagnosis. Patients with negative sputum smear samples should be prescribed symptomatic treatment and broad spectrum antibiotics for 10-14 days. If the symptoms persist, the procedure including three sputum smear examinations and chest X-ray (if necessary) should be repeated. A patient is diagnosed as a case of sputum negative pulmonary, if all three samples are negative but chest X-ray is consistent with pulmonary tuberculosis TB (RNTCP, 2005).