

**DELAY IN CARE SEEKING AND TREATMENT INITIATION AMONG
PEDIATRIC TUBERCULOSIS PATIENTS IN DELHI**

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DECLARATION

I hereby declare that this dissertation titled “**Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi**” is the bonafide record of my original field research. It has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

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CERTIFICATE

Certified that the dissertation entitled “**Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi**” is a record of the original research work undertaken by Dr. Aakshi Kalra in partial fulfillment of the requirements for the award of the degree of ‘Master of Public Health’ under my guidance and supervision.

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Glossary of Abbreviations

TB	Tuberculosis
HIV	Human Immunodeficiency Virus
RNTCP	Revised National Tuberculosis Control Programme
WHO	World Health Organization
NTCP	National Tuberculosis Control Project
BCG	Bacillus Calmette–Guérin
NSP	New smear-positive
DOTS	Directly observed treatment – short course
PPS	Probability proportional to size
AYUSH	Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homoeopathy
IBM SPSS	International Business Machines Corporation, Statistical Package for the Social Sciences

ABSTRACT

Background:

Delay in diagnosis and treatment initiation of tuberculosis (TB) exacerbates morbidity and accelerates mortality among children. There is paucity of evidence on the extent of delay in treatment seeking behaviour of pediatric TB patients in India. The study aims to examine extent of delay in health care seeking among pediatric TB patients and identify associated factors.

Methodology:

The study used a mixed method approach. Using multi-stage cluster sampling, 175 parents/guardians of pediatric TB patients in Delhi from 8 selected district TB centers were interviewed for the cross sectional survey. Specific instances of delay were captured through 12 in-depth interviews. Binary logistic regression analysis identified the associated factors.

Result:

Median delay at patient and health system level was 3 (range: 1-300) and 41 (range: 10-397) days respectively. Median total delay was 52 (range: 12-553) days. Those having greater distance to the first facility (OR 2.2, 95% CI 1.18-4.07) were more likely to experience prolonged patient delay compared to their counterparts. Among those who reported self-perceived delay, 64.1 percent thought that the symptoms would subside on their own. For pulmonary cases, sex of patient, age of primary care giver, religion and community were factors associated with patient delay. Child's birthplace and household size were associated with delay in care seeking for extrapulmonary TB. Choice of first provider and number of providers visited until diagnosis were linked with health system delay. Qualitative data supported these findings. Among patients <6 years, 45.5% had contact with a TB patient within the household.

Conclusions:

To reduce the total delay a combination of interventions at both levels are needed. Contact tracing within the RNTCP needs to be strengthened. Greater awareness of TB will have impact on better utilization of qualified health providers while proper examination of children with persistent illness may shorten the health system delay.

CHAPTER 1

INTRODUCTION

1.1 Background

Every pediatric Tuberculosis (TB) case is an indicator of continuing transmission in the community (Swaminathan and Rekha, 2010). TB in children (younger than 15 years of age) is often missed or overlooked due to presentation with non-specific symptoms and difficulties in diagnosis. In 2013, South-East Asia and Western Pacific Regions accounted for more than half of the total nine million estimated TB cases in the world wherein India alone had 24 percent of the total cases (World Health Organization, 2014). In the same period, five percent of the total number of identified TB patients in India was pediatric cases (Directorate General of Health Services, 2014). For children, the most important risk factor is exposure to an adult with TB and this is largely missed in the preventive and promotive efforts by the health system. Pediatric cases are usually smear negative unlike adult cases (Swaminathan and Rekha, 2010). There is risk of progressing swiftly towards disease after infection within span of about a year especially in case of infants and young children. The infection rates are higher for adolescents too (Perez-Velez and Marais, 2012; World Health Organization, 2013).

Of the nine million incident TB cases in the world, 550,000 cases were children in 2013 (World Health Organization, 2014). Having known the fact that most of the deaths due to TB are linked with Human Immunodeficiency Virus (HIV), it has been estimated that around 200 HIV negative children in a day lose their lives due to TB in the world (World Health Organization, 2013). Given that the challenge in diagnosis of pediatric TB is augmented by

an intersection of factors, these figures are likely to be higher if we account for the real disease burden.

India is among those high disease burden countries where reporting of pediatric cases is lesser than expected, indicating that there is under-diagnosis (Perez-Velez and Marais, 2012). Within Delhi, pediatric TB cases were 13 percent (5087 pediatric TB cases) out of total new cases registered under Revised National Tuberculosis Control Programme (RNTCP) in 2013 (Directorate General of Health Services, 2014).

1.2 Rationale

The report by World Health Organization (WHO) on childhood TB documents that improving the detection and management of pediatric TB could have greater influence on children's health than improving detection and treatment of adults with TB as per estimates made using modelling studies (World Health Organization, 2013). In fact, majority of the children who present with TB are indicative of missed opportunities by the health system. Delay in seeking care and treatment initiation can have far reaching consequences on the lives of children. Eleven percent of children discontinued their schooling and an additional eight percent took up employment to help their families. This reflects the impact of TB on children when an adult in household suffers with TB (Rajeswari et al., 1999). When children themselves suffer from TB, its aftereffects will presumably be graver.

Under such prevailing circumstances, it becomes important to overcome the historical neglect faced by pediatric TB patients in terms of prioritization and research. It is likely that understanding the health care seeking pathway and delays that are influenced by patient and health system will provide insights for an effective evidence based TB intervention. Also,

timely detection of children with TB will possibly facilitate detection of TB among adults for further restriction of infection.

1.3. Gaps in research

Adult TB has been in focus more than pediatric TB. A literature search on PubMed for last 20 years (1.1.1994 to 31.12.2014) using key words “pediatric”, “childhood”, “tuberculosis”, “delay” and “paediatric” in different combinations yielded only five studies which addressed delays among children, whereas one could locate 124 studies on adults, even with a restrictive search using the same key words (replacing “pediatric”, “childhood” and “paediatric” with “adult”) for the past 10 years. No study which looked at delay among pediatric TB patients in India was identified in this literature search.

It has been seen that among infants and young children, progression from primary infection to disseminated form is likely to occur, and this needs attention. Delay in diagnosis and treatment initiation can ultimately exacerbate morbidity and accelerate mortality among children. It may also increase financial and care burden upon the family.

1.4 Usefulness to RNTCP

Understanding pathways of health seeking might help in identification of the possible areas of intervention that might facilitate early diagnosis. Early notification of children with TB could aid in identification of adult symptomatic patients and hence limit infection. Such studies will help TB control programs and medical providers to target case finding and manage probable TB cases appropriately and effectively.

Non-specific symptoms have an impact on delay but at the same time; socio-economic factors, ignorance, stigma, shifting between doctors or visiting unqualified practitioners for care also play a major role. In such cases, the health system can work to sensitize people

through various means. It is for these reasons; this study proposes to study care seeking delay among pediatric TB patients.

1.5 Study Objectives

Research question:

What is the delay in health care seeking among pediatric TB patients and what are the factors associated with such delay?

Aim:

The study aims to determine the extent of delay in health care seeking among pediatric TB patients and identify the associated factors.

1.5.1 Major objectives:

- To determine the duration of delay in seeking health care among pediatric TB patients,
- To determine the duration of delay in initiating TB treatment by health care system for pediatric TB, and
- To study the factors associated with delay at patient and health system level

1.5.2 Minor objectives:

- To find out the proportion of pediatric TB patients (aged less than six years) who have had contact with TB patients within the household
- To document the pathways of seeking health care for pediatric TB by patients registered under RNTCP and the reasons thereof

1.6 Chapterisation plan

The first chapter introduces the topic and scenario prevailing around pediatric TB and the relevance of a study on pediatric TB for programme planners. The second chapter includes review of literature relevant to pediatric TB and delay in care seeking and treatment initiation. The third chapter consists of details of the methodology used in the study and the ethical considerations. The fourth chapter describes the quantitative and qualitative findings of the study and the last chapter discusses these findings and their implications.

CHAPTER 2

REVIEW OF LITERATURE

2.1 Introduction:

This chapter summarizes the available literature regarding pediatric TB and related topics. It reviews key articles on delay in care seeking for TB and associated factors. In the light of scant literature available on delay among pediatric TB patients, studies related to delay among adult TB patients have been included. It is possible that care seeking for children with TB may vary from that for adults, but it is likely to be shaped their own perceptions of signs of severity and appropriate health care.

2.1.1 Purpose of Literature review:

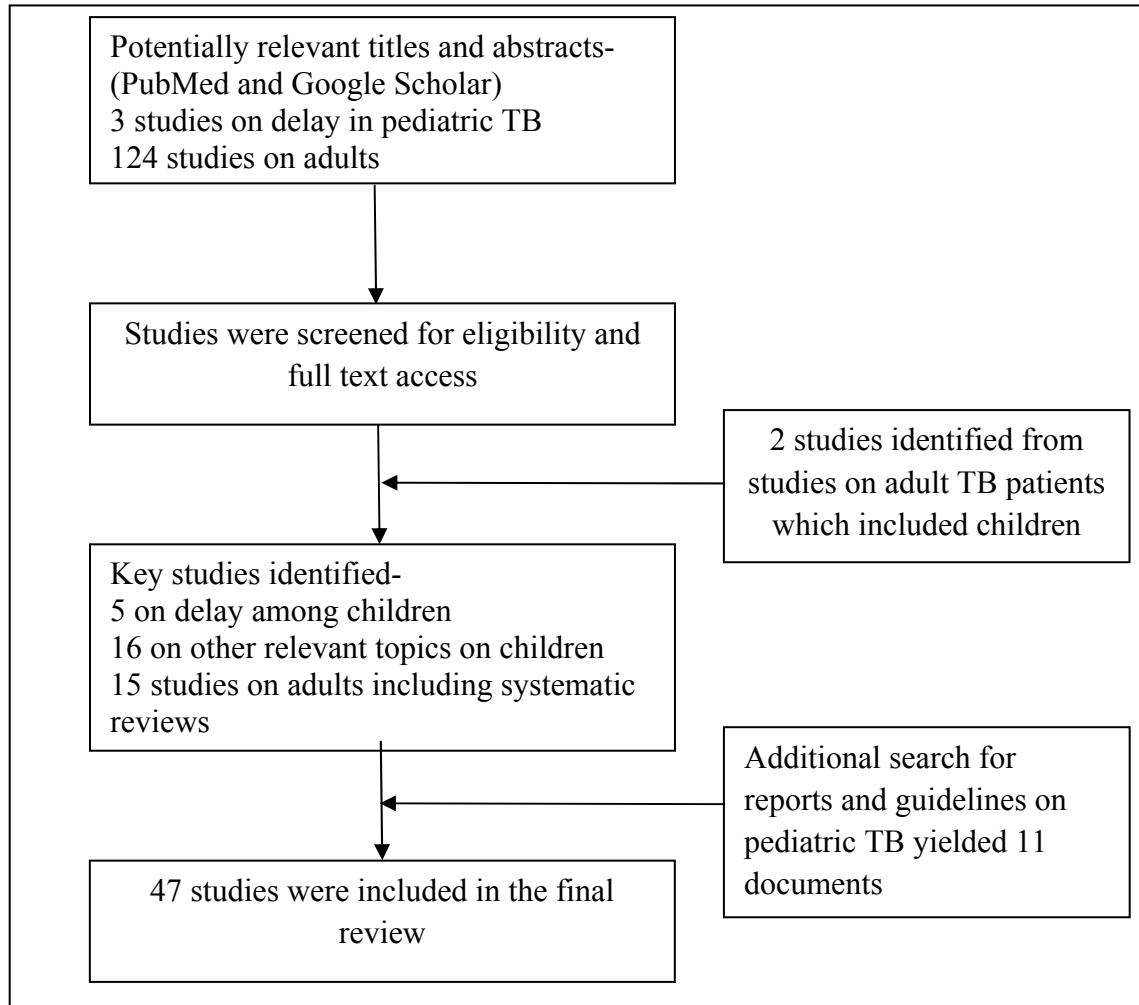
This literature review aims to identify relevant publications in peer reviewed journals, reports and books that address the issue of delay in care among pediatric TB patients. The review proposes to identify the gaps in the available knowledge with specific reference to pediatric TB cases.

2.1.2 Period selected for literature review

A literature search on PubMed and Google Scholar was done for last 20 years (1.1.1994 to 31.12.2014) using key words “pediatric tuberculosis delay”, “pediatric tuberculosis health seeking”, “paediatric tuberculosis delay”, “pediatric tuberculosis health seeking”, “child tuberculosis delay”, “child tuberculosis health seeking”. In the case of adult TB and related topics, similar search for a period of 10 years was defined (1.1.2004 to 31.12.2014). Additionally the bibliography section of each article was looked at in order to identify articles that might have been missed during database search. Search for minor objectives was

done with other relevant keywords such as “contact screening”, “chemoprophylaxis” etc. and search was limited to period of past 10 years.

Figure 2.1: Flowchart of literature review process



2.2 History of TB

TB has been known by many names - phthisis by Hippocrates to consumption in the 18th century, to the white death and the great white plague during the 19th century and many more. The Bhore Committee report mentioned the spread of TB across the country. Till date, this disease continues to take a toll of lives.

In 1948, Bacillus Calmette–Guérin (BCG) vaccination was introduced by Johannes Frimodt-Moller who served as medical superintendent in Madanapalle, Andhra Pradesh which is a sanatorium for TB. Globally anti-tuberculosis drugs were introduced in 1949-1952 and the National Tuberculosis Control Project (NTCP) was launched in India in 1962. The NTCP relied mainly on BCG vaccination and TB treatment. After the advent of complications due to this form of TB treatment, RNTCP was designed in 1993 after WHO declared TB as a global emergency and introduced the directly observed treatment – short course (DOTS). Delhi was one among the pilot sites for RNTCP. The objectives of RNTCP were to achieve at least 85 percent cure rate among the new smear-positive (NSP) cases of pulmonary TB, and a case detection rate of at least 70 percent. The focus was on NSP only and children were usually smear-negative. Hence children were neglected though they were being given DOTS treatment appropriately. By this time, BCG was also proved to be ineffective against TB. Thus in 2003, a workshop on pediatric TB was held by RNTCP and Indian Academy of Pediatrics and recommended (John et al., 2013; Tbcindia.nic.in, 2015):

“Asymptomatic children under 6 years of age, exposed to an adult with infectious (smear positive) tuberculosis, from the same household, will be given 6 months of isoniazid (5 mg per kg daily) chemoprophylaxis”

It was agreed that *“pediatric-focused monitoring may preferably be an integral part of the programme”* and that *“A revision of the RNTCP training modules will be undertaken to include pediatric TB issues”*.

Chemoprophylaxis was the only available resort for prevention of TB.

From history and representations in fiction, including the comprehensive Bhore committee report to Annual TB reports of the programme, pediatric TB had been under represented and

less understood until recently. Before 1950s, only clinical description of pediatric TB used to be studied. Between 1950s and 1980s, research was meagre and focused on existing treatment modalities. In 1990s with the emergence of HIV infection, pediatric TB gained importance due to co-infection and its consequences. In 2003, childhood sub-group was created which started by giving valuable inputs to WHO (World Health Organization, 2013). Recently in January- February 2012, in consultation with Indian Academy Pediatrics, the national guidelines on pediatric TB diagnosis and management were updated using recent evidence and advances in pediatric TB diagnosis and treatment (Kumar et al., 2013).

2.3 Burden of Pediatric TB

Estimates of pediatric TB as aforementioned in chapter one have been discussed in detail in the following sub-sections.

2.3.1. The incidence of pediatric TB

In 2013, out of the reported incident TB cases, around six percent cases were among children and 80,000 deaths from TB were among HIV-negative children in the world (World Health Organization, 2014). In the same year, about five percent of the total cases notified were of pediatric TB in India. In Delhi, pediatric TB cases were 13 percent (5087 pediatric TB cases) out of total new cases registered under RNTCP in the year 2013 (Directorate General of Health Services, 2014).

2.3.2. Measuring burden and its limitations

Measuring accurate burden of pediatric TB is difficult due to many challenges. The first challenge is of diagnosis which is fraught with difficulties because of the non-specific nature of the symptoms, paucibacillary TB and lack of proper diagnostic tests and their availability. TB remains as unrecognized in children suffering from diseases like pneumonia, malnutrition

and HIV (Detjen et al., 2013; World Health Organization, 2013). The second challenge is posed by the weak surveillance system. The number of cases reported in high endemic countries is less than expected. Many on-treatment children are not registered with national TB programmes owing to poor notification rates. Private providers do not often report cases. Adding to this problem is the fact that the chest X-ray also is difficult to interpret at times for children. Diagnosis relies on history of contact, presented symptoms, clinical investigations, X-ray, tuberculin test and sputum smear microscopy if possible. Among young children, bacteriological confirmation for pulmonary TB is not easy as they are not able to produce sputum. It is highly recommended for older children who are able to produce sputum (World Health Organization, 2008). Induced sputum or gastric lavage is used for culture in case of non-availability of sputum. Clearly defined symptoms have been used as a potential diagnostic tool in countries which have severe resource crunches (Marais et al., 2005). Many clinical diagnostic systems are also there like Kenneth Jones criteria and others which have been developed and used in a few countries for reliable diagnosis (Pearce et al., 2012).

2.4 Pediatric TB and its symptoms

Every pediatric TB case is an indicator of continuing transmission in the community. Majority of cases are due to close contact with adult TB patients (Swaminathan and Rekha, 2010). It has been documented that children can potentially transmit mycobacterium TB to their contacts (Curtis et al., 1999).

Tubercle bacilli enter body through inhalation in aerosolised respiratory droplets causing infection which is in turn dependent on duration, probability and proximity of exposure to an infectious case and on the infectiousness of the source. Usual source is infectious case of pulmonary TB (Newton et al., 2008). Other conditions could also be sources of infection

though less infectious as in case of smear negative and culture-positive patients or from extrapulmonary TB patients (Hamzaoui et al., 2014).

When there is infection, risk of developing disease for children is determined by various factors including age, malnutrition, immune status if deficient like in case of HIV, genetic factors, virulence of the organism, magnitude of initial infection and maturity of immune response. Pediatric cases are usually smear negative unlike adult cases (Newton et al., 2008). There is a risk of progressing swiftly towards disease after infection within span of one year especially in case of infants and young children. Infection rates are high for adolescents compared to age group of 6-10 years (Newton et al., 2008; World Health Organization, 2013). Chances of developing infection are higher when there is close contact although around 90 percent of children with infection do not develop symptoms. Symptoms mark the onset of disease (World Health Organization, 2013).

Overall world statistics for the year 2013 indicated that pulmonary TB is most common in children, with just about 20-30 percent of the cases being the extrapulmonary type (World Health Organization, 2013). A study in Delhi, India in 2010 is suggestive of more cases of extrapulmonary (63%) TB (Satyanarayana et al., 2010) with lymph node disease being most prevalent (Puwar et al., 2012). Contrary to this, a study in Varanasi in 2013 documents pulmonary (66%) as major form of TB in children with more than 70 percent of patients under category I and more than 60 percent of the cases in the age group of 10-14 years (Ruchi and Thakur, 2013).

Clinical presentation: Commonly reported symptoms include failure to thrive, reduced playfulness and less frequently low-grade or intermittent fever (Marais et al., 2006). Pulmonary cases usually present as persistent, non-remitting cough or wheeze which do not

respond to likely alternate diagnosis treatment regimen (Perez-Velez and Marais, 2012b). Major symptoms reported according to a study done in Chennai were history of an “insidious illness”, fever with cough and visible glandular swelling in approximately half of the patients. Other symptom was loss of weight seen in around 41 percent cases. Respiratory signs were less frequently observed (Swaminathan et al., 2008). According to national consensus statement on childhood TB in 2010, “fever and/or cough for more than two weeks, recent contact with an infectious case and/or unexplained loss of weight are the reasons to suspect pulmonary TB in children (Kumar et al., 2013). If a child is symptomatic and has been in contact with person with any form of active TB within two years; it is important to suspect TB and examine the child accordingly. Extrapulmonary TB includes peripheral lymphadenopathy, TB meningitis, skeletal TB, skin TB, gastrointestinal tract and other organ involvement. Superficial lymph nodes are involved commonly and other frequent sites of involvement include the anterior cervical, submandibular, and supraclavicular nodes (Marais et al., 2006). In case of TB lymphadenitis, progressive enlargement of lymph node for more than two weeks, firm, minimally tender or non-tender, fluctuating may develop chronic sinus formation (Amdekar, 2010; Goyal et al., 2010) .

2.5 Delay: concept and type

Delay in receiving appropriate care and treatment among symptomatic children is possible in two ways- one could be from patient side- their own behavior and attitude towards the developing symptoms thus the disease and other from the health system’s side. For the patients, delays can occur during the process of noticing symptoms depending on their awareness, determining severity of illness thus assessing the need for care or alternate sources of management and overcoming barriers like stigma, accessibility, acceptability,

privacy and others (Eastwood and Hill, 2004). The period between onset of symptoms and treatment initiation is critical in terms of spread of infection in case of sputum positive patients (Dhingra et al., 2002) which is indicative of importance of reducing delay in treatment. Even if a child is non-infectious, delay in treatment seeking behaviour can have far reaching consequences on child's overall development. When patient comes in contact with the health system, the major limitation is diagnosis in the midst of non-specific symptoms. Along with it there is spectrum of factors involved including attitude of providers, availability of adequate service, quality of services, accessibility, satisfaction and others.

2.5.1 Measurement of delay

There are differences in reporting of delay as there is no standard definition being followed for patient or health system delay. Delay is measured in number of days or weeks (Sreeramareddy et al., 2009) or sometimes a cut-off is set by some authors (Li et al., 2013) in order to define proportion of patients having delayed more than a specified period. Studies have determined cut-offs using median or mean (Gebeyehu et al., 2014). We were unable to make a determination as to whether these cut-offs were decided due to convention or based upon the normality of data. In most of the studies, we found the median duration being reported as an indicator of delay which is suggestive of the nature of variation in the distribution of delay. Few studies considered just the new sputum positive patients and defined a time period beyond which any lack of care would be considered as delay. As cough for two weeks is suggestive of TB so a period of 14 days treated as a cut-off by some others (Behera et al., 2013). Delay is usually determined by asking patients or their care givers about their health seeking pathways and this can be verified with available medical

records. There is always the potential for recall bias when patients are asked about the date of onset of symptoms or date of visiting provider and this is a limitation with respect to self-reported delay in care seeking.

2.5.2 Frameworks for delay

Few conceptual frameworks have been formulated for studying delay in care seeking. Many of them match with respect to the basic ideology but differ in terminology used (Storla et al., 2008; World Health Organization, 2006). A framework provides a description of delay and its distribution over the journey of seeking care until TB treatment. It also provides information about the factors associated with delay and possible intervention areas. Frameworks tend to start at the onset of symptoms (World Health Organization, 2004; Yang et al., 2014) but leave out the period of infectiousness and exposure. Alternatively a TB care continuum from susceptibility to cure has been proposed and this marks areas of intervention with transition in events (World Health Organization, 2013) but this is not specifically for delay.

2.5.3 Patient delay and related factors for adults

Patient delay has been extensively documented in studies related to adult TB patients. There is no uniform definition of delay in the literature. Moreover, its measurement has also been adapted to suit the purpose of research. Some studies have described delay as the period from onset of symptoms to the first visit to a healthcare provider. Few others have broadened the definition by debut of any symptom or to any pulmonary sign whereas a few other studies have preferred to stick to cough as a major symptom. Similarly, there has been variation in the definition of healthcare provider including only qualified doctor to reaching

TB programme or inclusion of traditional healers and others (Sreeramareddy et al., 2014; Storla et al., 2008).

Duration of patient delay: The average delay in presentation has been reported as 4.9 to 162 days in a systematic review including studies from low and middle and high income countries (Sreeramareddy et al., 2009). Median patient delay in different health seeking pathways was found to be varying from 1 to 44 weeks with median 3.5 weeks in a study done in Delhi (Bhagat et al., 2014).

Patient delay is largely determined by the health-seeking behaviour of patients and perceived severity of symptoms (World Health Organization, 2006).

Factors associated with delay among adult TB patients

Perception related to severity of symptoms: Patients tend to treat symptoms related to TB as of usual seasonal illnesses like common cold (Tobgay et al., 2006). Many studies have reported lack of knowledge/awareness about TB as one of the major factors causing delay in seeking care (Goel et al., 2011; World Health Organization, 2006). Attitudes, belief and knowledge have an impact on delay as per a few systematic review of studies on delay (Eastwood and Hill, 2004; Storla et al., 2008; Yang et al., 2014). Another systematic review done in 2014 suggests that self-medication is one of the risk factors for patient delay (Sreeramareddy et al., 2014).

Time constraints: Occupation and domestic work related responsibilities are often prioritized and thus it has been seen that individuals delay seeking timely care (Goel et al., 2011).

Dependency on smoking and alcohol: Smoking, substance abuse or alcohol dependence especially have been seen linked to patient delay (Kiwuwa et al., 2005; Storla et al., 2008; Tobgay et al., 2006).

Season related issues: Factors related to the weather, with patients preferring to wait for rainy season to get over have been documented to cause delay (Goel et al., 2011).

Socio-demographic characteristics: Older aged, married and those with larger family size were found to access TB treatment less frequently when compared to their counterparts. Lower caste women seemed to have more delay (Storla et al., 2008; World Health Organization, 2006; Yang et al., 2014).

Financial constraints: Financial issues due to poverty (Storla et al., 2008) limit ability to seek care. Direct and indirect costs of seeking care do pose financial barriers (Yang et al., 2014). Inability to pay was also reported in a systematic review for pulmonary TB patients (Sreeramareddy et al., 2014).

Place of residence: Patients who lived in rural areas tend to have more delay as compared to those staying in urban areas (Storla et al., 2008).

Stigma: Fear of social exclusion if diagnosed with TB deters seeking health care on time and this results in delay according to the results of a WHO Mediterranean study. On the other hand, stigma in Somalia prompted patients to seek care (World Health Organization., 2006) and it was found to be more among women (Eastwood and Hill, 2004; Yang et al., 2014). In a multi-country study, it was found that overall stigma index was highest among women in India as compared to Malawi and Bangladesh (Somma et al., 2008).

Sex differences: There have been reports of hesitation in seeking care or starting treatment for young girls because of the stigma associated with visits to the TB centre (World Health

Organization, 2006). Studies done in Ethiopia in 2014 among pulmonary TB patients do not show significantly different results between males and females for delays (Asefa and Teshome, 2014; Kiwuwa et al., 2005). Another systematic review on the contrary describes symptomatic women were more likely to delay seeking care than symptomatic men. (Yang et al., 2014).

Physical reasons: These include geographical accessibility to health care facilities including access to transport to reach the health care facility which resulted in a delay in care seeking (Storla et al., 2008; Yang et al., 2014). Delay in care seeking has also been related to the health centre being far from the residence for 16 percent patients (Tobgay et al., 2006).

Choice of first provider: More than one-fifth of the patients who experienced prolonged delay in care seeking had gone to traditional healers as the first point of contact. Clearly, seeking care within other systems of medicine as the first option for care results in delay (Tobgay et al., 2006).

Few studies reported literacy level, hospitalization/outpatient and means of livelihood to be associated with patient delay (Kiwuwa et al., 2005).

2.5.4 Patient delay and related factors for children

There is paucity of literature on delay among children with TB. For children with pulmonary TB, delay was longer for diagnosis than for the first time presentation to the health care provider. Delay duration was analyzed under four categories based on urban and rural though non-significant ranging from one to four weeks by Beyers et al in 1994. However, children from rural farming communities had the longest duration of median delay in presentation of four weeks (Beyers et al., 1994). Another study done in Hong Kong included both adults and children (age group: 0-19 years) found that patient delay was 11 days and it

was of least duration in comparison to adults of different age groups (Leung et al., 2007). There was patient delay of 12 days among enrolled pediatric patients which was least when compared to those in other age groups (Saldana et al., 2013). Delay from debut of symptoms to diagnosis was 37 days (Inter quartile range (IQR) of 12–89) in a study done in England. For miliary TB, it was 15 days (IQR 5–50) whereas for bone TB, it was 90 days (IQR 48–249). It is important to note that among patients who died, a median delay of 50 days (IQR 31–207) between symptom onset and diagnosis was reported as compared to 33 days (IQR 11–77) among those who completed treatment suggestive of a plausible link which needs exploration.

None of these studies mentioned specific factors associated with delay among children. A qualitative study in Peru among parents of pediatric TB patients receiving treatment, brought out reasons behind delay (Paz-Soldan et al., 2014) which were:

Lack of awareness: Lack of knowledge about TB resulted in confusion about symptoms and this led parents to not seek health care for around two weeks.

Time constraints: There were time related issues like long waiting time and priority for some other work that was responsible for patient delay. Notably, parents who had TB themselves delayed care seeking owing to previous experience of long waiting time.

Stigma: There was a fear of social exclusion of their child by the neighbours, school friends and staff if TB status was revealed.

2.5.5 Health care system delay and related factors for adults

Similar to patient delay, different definitions have been used in literature for endpoint of health system delay. Some studies mention date when diagnosis was made or referral date to TB programme, treatment starting date or both (Sreeramareddy et al., 2014; Storla et al.,

2008) as the starting point for system delay. Health system delay is attributed to delayed diagnosis as compared to delayed treatment initiation (range: 1.2-4.5 days) among adult TB patients. Majority of the symptomatic patients prefer visiting a private practitioner especially general practitioner working in the neighbourhood according to a multi-country study of Eastern Mediterranean region which included Egypt, Islamic Republic of Iran, Iraq, Pakistan, Somalia, Syrian Arab Republic and Yemen. A patient assumed to be having TB is suspected by cough symptom initially hence it can be presumed that more 'missed' cases occur among those who present with other symptoms (World Health Organization, 2006).

Duration of health care system delay: The period of first presentation to diagnosis through referral ranged from 2 to 39 weeks with median 4.5 weeks in study conducted in Delhi (Bhagat et al., 2014). With a similar definition, delay was in a range of 2 to 87 days in a systematic review (Sreeramareddy et al., 2009).

Factors related to health care system delay in adults

Co-morbidities: Existence of multiple morbidities such as chronic cough, other lung diseases, etc. delayed the detection of TB within the health system (Storla et al., 2008).

Non-specific symptoms: Sometimes the lack of visible symptoms or perceived severity of manifested symptoms like absence of haemoptysis also leads to delay in diagnosis (Kiwuwa et al., 2005; Storla et al., 2008).

Type of TB: Patients with extrapulmonary TB have longer duration of delay when compared to pulmonary patients (Farah et al., 2006; Lewis et al., 2003; Storla et al., 2008).

Health infrastructure: Poor health care infrastructure at times restricts early detection and treatment for TB (Storla et al., 2008).

Choice of health provider: Longer delay is caused by seeking care from informal providers like traditional or private practitioners or when the care sought at the government sector has been inconclusive. A systematic review on pulmonary adult patients reported that 48 percent (median) first visited private/informal provider for care and discussed this factor under patient delay (Sreeramareddy et al., 2014). Few studies have mentioned seeking care from government sector as a reason for longer patient delay (Tobgay et al., 2006). On the contrary, delay was nine days when government was the care provider and 50 days when the care provider was from the private sector in a study based in Tamil Nadu (Selvam et al., 2007). There has been reporting of weak referral links between the private health care providers and the health system in few countries (World Health Organization, 2006) which could have led to delay.

Financial constraints: Economic/financial concerns can be a potential reason for delayed care. One of the reasons for provider shopping is when patients visit to private practitioners first and when they are not able to afford further care, they consult other doctors before reaching TB programme (World Health Organization, 2006). Medical expenses restricted patients from undergoing treatment also when multiple visits per month to a doctor were needed (Kiwuwa et al., 2005).

Number of providers consulted until diagnosis: Visiting multiple doctors for seeking care can result in prolonged delay (World Health Organization, 2006). Women looked for care from more sources like traditional healers and pharmacies when compared to men in Africa but this variation in care sought did not contribute to longer delay (Eastwood and Hill, 2004; Yang et al., 2014). In a systematic review, it has been found that number of health care

providers visited before diagnosis was 2.7 (median) in case of pulmonary TB (Sreeramareddy et al., 2014).

Health provider's degree of suspicion of TB: Private provider's degree of suspicion for TB and their not adhering to the guidelines for diagnosis (World Health Organization, 2006; Yang et al., 2014) have been documented as reasons for extended delay.

Patients having tertiary level education, females and patients living in houses with higher family size (≥ 3.6 persons per room) had less total delay in initiating treatment as compared to their counterparts according to an Ethiopian study (Asefa and Teshome, 2014). Patient satisfaction with TB services (Yang et al., 2014) has been documented as a possible reason for extended delay.

2.5.6 Health care system delay and related factors for children

Duration of health care system delay: In South Africa study, median delay was found to be four weeks from first visit to doctor until diagnosis. There was no significant difference between rural and urban for duration of delay or delay from diagnosis to treatment initiation. It shows that once diagnosed then treatment initiation takes lesser time (Beyers et al., 1994). Another study reported delay to be 11 days which was least of the other age groups but here age group selected was 0-19 years (Leung et al., 2007) whereas 24 days of health care delay was reported in United Kingdom which also included subjects of Indian origin (Saldana et al., 2013). This study showed that out of all age groups, pediatric TB patients had the least duration of delay.

Some of the factors which affected health care system delay were non-availability of proper equipment and tests for accurate diagnosis which made parents visit multiple centres,

misdiagnosis; children were being looked after by parents suffering from TB themselves which compromised effective care (Paz-Soldan et al., 2014).

2.6 Contact with known household TB patient

Children living with sputum positive patients have increased risk of mortality compared to their counterparts (Gomes et al., 2011). TB infection was found to be common among children having household TB contact according to a systematic review in 2011 (Triasih et al., 2011). Children less than six years of age are given chemoprophylaxis if they are in contact sputum positive TB patient as they are at higher risk of getting infection (Nelson and Wells, 2004). WHO recommended household contact screening of index case in order to control transmission and enable prompt care and treatment if required (World Health Organization, 2011, 2012). There was limited information on the implementation of contact screening activities in the field in India although a few reported suboptimal effort in this direction (Pothukuchi et al., 2011). It also becomes important to relate this to the time lag in presentation to health provider as the behaviour might differ when compared to others having no contacts.

CHAPTER 3

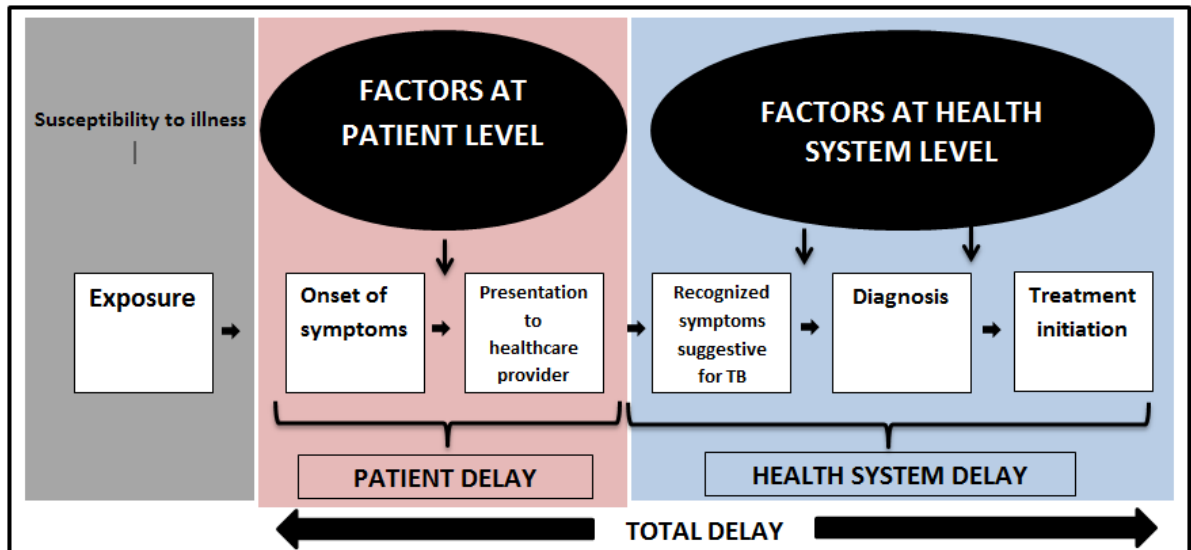
METHODOLOGY

This chapter has been divided into sub-sections which include the conceptual framework, the detailed methodology adopted to conduct this study and the ethical considerations.

3.1 Conceptual framework

A conceptual framework was used to describe the continuum from exposure to the treatment initiation which could be influenced by multitude of factors. It has been modified and adapted from a review published in 2014 to identify the barriers and delay in treatment for TB focusing on gender related differences (Yang et al., 2014) and draws inputs from the reviewed literature. It illustrates the sequence of events which occur till the treatment initiation which was used to define delay. It provides indication for the areas of intervention to reduce the duration of delay.

Fig. 3.1 Conceptual framework for patient and health system delay (modified and adopted from study by Yang et. al in 2014)



The interview schedule for the cross sectional survey and the guidelines for the in-depth interviews were based on this modified framework.

3.2 Study design

A mixed methods research- *embedded design*, combining both quantitative cross-sectional survey and qualitative in-depth interviews was undertaken. In this embedded design, a supplemental quantitative or qualitative strand is added when a single research methodology is not adequate to answer the research questions (Creswell and Plano Clark, 2011). For the present study, using a single study design, either quantitative or qualitative, would have only elucidated a portion of the picture of delay and its implications. While the quantitative component would well describe the duration and associated factors causing delay, it would not explain extreme instances of health care seeking at both ends. A mixed methods research was considered the most suitable here to answer the research question and to capture the overall picture of delay in a systematic manner.

The quantitative component was planned as cross sectional survey among parents/guardians of pediatric TB patients to measure extent of delay and its determinants. The qualitative component documented the specific instances of delay using in-depth interviews, both prompt health care seeking and extreme cases of delay.

Integration of quantitative and qualitative data occurred at two points. One was during data collection, while selecting the in-depth interview informants based on the preliminary findings of the cross sectional survey and second was while reporting the findings so as to have a holistic overview of delay.

3.3 Study setting

The study was conducted in Delhi, the national capital territory of India with a population of 16,787,941 and density of 11,320 people per square kilometers. Out of the total population

of Delhi, 97.5 percent people live in urban regions and rest in rural. In the urban and rural regions of Delhi, there were 12.0 percent and 13.5 percent children in the age group of 0-6 years respectively (Census of India, 2011). In 2013, there were 5087 pediatric TB cases reported in Delhi accounting for 13.0 percent of the total new cases registered under RNTCP which is higher than the national level of five percent (Directorate General of Health Services, 2014).

RNTCP started in Delhi as pilot in October 1993. Delhi is covered through a network of around 551 DOTS centres under 25 district TB centres. These 25 district TB centres have 38 TB units for diagnosis and treatment of TB (Directorate General of Health Services, 2015). In order to avail treatment services, patients can directly visit these centres to seek care or can be referred by any of the health care providers. In addition to the government DOTS centres, there are non-governmental organizations, community DOTS providers and private providers engaged in treatment delivery effectively to the patients in almost all parts of Delhi.

3.4 Time frame

Data were collected from the period of 18th June, 2015 to 24th August, 2015.

3.5 Study population

Target population: Pediatric TB patients registered under RNTCP in Delhi

Source population: Pediatric TB patients registered under RNTCP in Delhi within two months from the date of survey (beginning from 18th June, 2015 to 24th August, 2015)

Study population: The study included parents or guardians of pediatric TB patients providing formal consent for participating through health care provider in RNTCP and satisfying the preset inclusion criteria.

3.6 Sample size estimation

Sample size was estimated using OpenEpi 3.0.3. A cross-sectional design was best suited here considering the exploratory nature of the study. A pilot study was done as there were no previous studies giving an estimate of the proportion of pediatric TB cases. A study among adult TB patients, considered a time interval of 14 days after the onset of symptoms to seeking care as patient delay (Behera et al., 2013). This particular study was chosen as it was conducted in north India and the time lag described by the study was based upon the RNTCP guidelines. Thus a cut-off of 14 days was taken for patient delay in the pilot study which was conducted telephonically amongst 30 parents/guardians of known pediatric TB patients living in Delhi. The proportion of patients with delay was estimated to be 53.3 percent. The sample size was then calculated using this proportion of 53.3 percent with 95 percent confidence interval a precision of ten percent and an assumed design effect of two since cluster sampling was being planned. The estimated sample size was 173. The calculated sample size was rounded off to 175. All those who declined to participate were replaced by the next eligible patient in the list as per the TB register at the district level.

3.7 Inclusion and Exclusion Criteria

3.7.1 Inclusion criteria

Parents of pediatric TB patients were considered as respondents if satisfying following criteria:

- a) Pediatric TB patients registered under RNTCP within 2 months of the date of survey of the participant (period of two months was chosen so as to manage recall bias and to track patients. Patients under intensive phase of treatment (usually first two months)

visit DOTS centres three times a week whereas continuous phase patients visit only once a week hence could have been difficult to trace)

b) Pediatric TB patients under the category I (Category I includes new smear positive, smear negative and extrapulmonary TB patients)

c) Parents consenting and willing to participate in the study through health provider

Throughout the study, the parents/guardians of the pediatric TB patients who participated in the study have been referred to as respondents.

For the in-depth interviews, only the chosen informants who consented for audio recording of the interviews were included. Throughout the study those who were included in the qualitative component have been referred to as informants.

3.7.2 Exclusion criteria

a) Pediatric TB patients who were not alive

b) Pediatric TB patients who had ‘transferred out’ to other centres (a ‘transferred out’ patient is one who registered in a TB centre and who has been transferred to another centre for any reason. This is because such persons will not be easy to trace within the system).

3.8 Sampling strategy

3.8.1 Quantitative sampling:

The sample was selected using multistage cluster sampling strategy. Probability proportional to size (PPS) cluster sampling was adopted since within Delhi the pediatric TB population is not evenly distributed within the centres. Out of the total 25 district TB centres in Delhi, eight district TB centres were chosen through a random process. Sample districts were selected through PPS of the number of patients reported in each district TB centre. The total

cumulative population was divided by the total clusters/district TB centres planned for the study (N=8) to get 'Sampling Interval' of 12.5. The cluster/district TB centre was identified as the first centre when the cumulative population was greater than or equal to this interval. Subsequently the sampling interval was added to identify eight centres.

From within the selected centre, one TB unit was randomly chosen. From each TB unit, a minimum of five DOTS centres were included in the study to achieve the required number of cases from that TB unit. Five DOTS centres were selected from each district as this was the minimum number of DOTS centres in a district.

3.8.2 Qualitative sampling:

Informants for the in-depth interviews were chosen from among the survey respondents. Patients with extreme delay and those prompt in seeking care were identified throughout the survey. They were contacted for their consent for in-depth interview and audio recording. The final choice of the respondents was purposively made by the investigator based on the survey. Six respondents in each of the two domains of health seeking pathway were interviewed aiming for saturation of information.

3.9 Replacements and plan for non-respondent analysis

Parents or guardians who did not consent were recorded. In such a case, the respondent was replaced by the next pediatric TB patient satisfying the inclusion criteria. Basic information and reason(s) for non-participation was sought from all those who were contacted to be part of the study. A record of all such replacements was maintained and documented using a checklist.

3.10 Operational definitions

Operational definitions of delay used as part of research (World Health Organization, 2006):

Patient delay: defined as the duration in days from the reported onset of symptoms to the first visit to a health provider*.

Health provider delay: defined as the duration in days between the first visit to a health provider and the initiation of treatment.

Total delay: is the sum of patient and healthcare system delay.

*Health provider includes but is not restricted to qualified specialist, primary physician, private practitioner and traditional healer. Self-medication of any form was also considered as the first step towards managing the emerging symptoms.

3.11 Study tools

The cross sectional survey was conducted using an interview schedule which was developed for this study based on the conceptual framework, reviewed literature and the exploratory study conducted in December 2014. The interview schedule was developed in English, then translated into Hindi and was back translated into English by a member belonging to the local community. Both English and Hindi interview schedules were used during the study. The interview schedule had seven sections broadly focusing on general background information of patient and primary care giver, health seeking pathway, knowledge and stigma. A tabulated checklist was used to keep record of all participants including those who were not available or refused.

The in-depth interview guidelines were also developed for this study based on the conceptual framework and reviewed literature. Modifications were made during the survey based on the new findings; for instance recording perception of symptoms. Consent form for survey and

in-depth interview were developed in both English and Hindi. The format of the checklist, consent form for survey and in-depth interviews, interview schedule and the in-depth interview guidelines are provided in Annexure I to IX.

3.12 Data collection

Data collection was done by the investigator. Adult primary care givers (parent/guardian) of pediatric TB patients were the respondents who were interviewed. First, the respondents were approached by the health provider for their consent to participate. If they agreed, the investigator met the selected respondent. Written informed consent for participation was taken thereafter. Of the respondents who did not consent for the study, a few basic responses were sought. The data about the pediatric TB patient as well as about the primary care giver himself/herself was collected from the concerned respondent. A separate non-respondent analysis was done among those who declined to participate. For the respondents who were not present at the time of the visit to the DOTS centre, permission was sought to contact them over phone through health care provider. If they were not willing, their data was marked as 'declined'.

During the survey, possible informants for the in-depth interviews were identified and the permission was taken to contact them again for the interview. A time was chosen based on their convenience. A total of 12 in-depth interviews were conducted to achieve information saturation, only after written informed consent for the interviews. Permission was also sought to re-contact for clarifications or for any other information.

3.13 Data entry

Data were entered into Epi Data software, version 2.0.2.13. Analysis was undertaken with SPSS software, version 21 (IBM) for analysis. Only unique ID was used and the name,

address or any other personal identification of the subject were removed. Therefore it cannot be linked directly to any child. Design effect was calculated using STATA version 11.2.

3.14 Data analysis

The data was analysed for the delay measured in number of days. Simple frequencies and cross tabulations with the dependent variable of delay (in terms of its occurrence/duration) was done to identify important factors that are associated with delay. Further bivariate and multivariate analysis were done to determine the association between factors influencing the delay among pediatric TB patients with IBM SPSS using non-parametric tests since the data was positively skewed. Binary logistic regression was done to arrive at final model by dividing delay by median. Sub group analyses were done for minor objective and wherever judged to be necessary.

Open source Weft Qualitative Data Analysis software was used to analyse qualitative data. We sought to explore instances of ‘no delay’ where seeking care and/or treatment initiation was prompt. The second category was to identify those children who had ‘extreme delay’ in any way- patient or the health system level. These two categories were identified as requiring detailed exploration as they might offer plausible explanations for the markers or determinants of prompt care and delay.

The broad codes were decided by reading through the interviews extensively in both domain of ‘no delay’ and ‘extreme delay’. The coding was deductive in nature based on the nature of delay and preliminary analysis of quantitative data. The codes were then collapsed into broader themes and linkages between the themes were identified.

3.15 Data storage

The interview schedules, consent forms, audio recordings and transcripts have been kept with the investigator who also bears complete responsibility for confidentiality. Data would be preserved for a minimum of three years following completion of the study.

3.16 Ethical considerations

Written informed consent was taken from all participants and details about the investigator were given to each participant. Participation was completely voluntary. In case of illiterate study participants, research subject information sheet was explained before taking their thumb impressions and the same was witnessed by another literate person who also signed the consent form.

The study was approved by the Institutional Ethics Committee, SCTIMST before the commencement of the study (Reference number:SCT/IEC/754/JUNE-2015)

3.17 Study variables

The study variables are listed:-

Outcome variables:

1. Patient delay:- measured in days from the day of onset of symptoms to visiting provider for the first time or till first action taken for managing the symptoms.
2. Health system delay:- measured in days from the first action taken to the day of treatment initiation. It was calculated by summing up the time period between the consultations or action taken for health of the child including gap between any two actions and time lapsed when treatment was stopped, if done.

Predictor variables:

The predictor variables were grouped into a number of categories, for example religion was grouped as Hindu, Muslim, Christian, Sikh and others. During analysis these were regrouped into two categories as Hindu and others because highest percentage of the participants were Hindu and very few were from the other groups. Similar regrouping was done for many other predictor variables.

1. Profile of the patient – This included information on age, sex, education status and place of birth.
2. Profile of the primary care giver – It included data on relation with the patient, literacy level, age, sex, work status, BPL card holder, monthly income, community, religion, household size and ownership of the place of current stay.
3. Information regarding exposure/contact with TB patient in the household – In this, pediatric TB patient's relation with the TB patient in the house and period of such exposure. This information was captured to address the minor objective of finding proportion of children having TB contact at house.
4. Health seeking pathway – symptoms experienced (both prompted and unprompted responses), symptoms for which care was sought and actions taken from onset of symptoms to treatment initiation. Actions included information on type of provider and facility visited, diagnosis made and reasons for going to the provider. It also helped in calculating health system delay.
5. Distance from the first facility – it was measured in kilometres as reported by the participant. It was validated by DOTS provider whenever possible.

6. Primary care giver's knowledge on TB - There were eight questions and scoring was done based on mean thus dividing into two groups – participants with high and poor knowledge. Responses were recorded as 'correct', 'wrong' and 'don't know'.
7. Stigma - there were 14 questions included to assess stigma perceived by the participants. High and low stigma groups were formed based on mean of the responses. Responses were recorded as 'never', 'sometimes' and 'ever' to statements which tried to assess stigma levels.

Knowledge and stigma scales have been adopted and modified to suit the pediatric TB population from WHO study on delay among adult TB patients (World Health Organization, 2006). Since these scales have not been validated for children before, they would be applicable to sample population only. Cronbach alpha was calculated for this to measure internal consistency of the scales.

3.18 Dissemination of results:

Results of the study shall be disseminated by publishing in relevant journals and presenting in conferences. A copy of the findings would be submitted to the Tuberculosis Association of India as they provided partial financial support for undertaking the study.

CHAPTER 4

RESULTS

This section consists of findings of the study. It includes the profile of the sample population- both pediatric TB patients and their primary care givers and the description of delay – both patient delay and health system delay. The chapter includes a description of the appropriate bivariate and multivariate analysis carried out against the identified independent variables.

Summary of data collection

There were total of 315 eligible pediatric TB cases registered under selected eight district TB centres. Out of these, 188 were contacted through RNTCP health care provider for participating in the study. Table 4.1 shows the summary of data collection from each of the district TB centers. Thirteen respondents (6.9%) did not consent to participate in the study.

Table 4.1: Summary of the data collection, Delhi

District TB centre	DOTS centers	Number contacted	Number consented	Dropout rate^a(%)
District TB centre 1	5	13	11	15.4
District TB centre 2	5	25	23	8.0
District TB centre 3	5	42	40	4.8
District TB centre 4	5	17	16	5.9
District TB centre 5	17	51	45	11.8
District TB centre 6	5	7	7	0
District TB centre 7	5	16	16	0
District TB centre 8	5	17	17	0
Total	52	188	175	6.9

^aFor each district: (those who declined/number contacted)*100

They were replaced by the next eligible pediatric TB case in the list. Non-respondent analysis shows that respondents who refused were distributed across the eight district centres. The most common reasons given for non-response were ‘do not wish to disclose information about the child’ followed by ‘shortage of time’. Figure 4.1 in the annexure XI shows flow

chart of patients who met inclusion criteria for the study population. The final sample had 175 pediatric TB patients. The design effect was computed to be one.

4.1 Characteristics of the sample population

This section has been divided into three parts, including the profile of pediatric TB patients, profile of the primary care givers and a description of delay.

Data were collected from 52 DOTS centres across Delhi of which a majority were government health facilities (81.1%) followed by non-governmental organizations (13.7%) and a few community volunteers and private practitioners. More than half (64.6%) of the DOTS centres were located in urban areas.

The health seeking pathway and delay in care seeking was determined using records of previous treatment with the patients. Majority (95.4%) of the respondents had retained a few or all documents of previous health related experiences of their children/wards.

4.1.1 Profile of the pediatric TB patients

The mean age of the pediatric TB patients was 9.2 ± 3.6 years. Since increased susceptibility for TB has been reported in young pre-school (below age six) and above 10 years of children (Marais, 2008), the sample was divided into three age groups. Majority of the children were above the age of six years (81.1%). Two children were HIV positive (1.4%) out of 144 children who had undergone HIV testing. The representation of extrapulmonary TB (69.7%) in the sample was more than that of pulmonary TB. Out of the pulmonary TB cases, 46.8 percent were sputum positive. Peripheral lymph nodes (47.5%) were the most common site of extrapulmonary TB with specific involvement of cervical lymph nodes. This was followed by abdominal TB (23.8%), pleural effusion (13.1%) and other forms viz.,

meningitis, hilaradenopathy, TB involving spine, bone and skin. A detailed profile of the patients is presented in table 4.2.

Table 4.2: Profile of the sample population of pediatric TB patients, Delhi (N=175)

Characteristics		n (%)
Age of child (years) ^a	0-5	33 (18.9)
	6-10	65 (37.1)
	11-14	77 (44.0)
Sex of child	Male	79 (45.1)
	Female	96 (54.9)
Type of TB	Smear negative pulmonary TB	25 (14.3)
	Smear positive pulmonary TB	22 (12.6)
	Extrapulmonary TB	122 (69.7)
	Both pulmonary and extrapulmonary TB	6 (3.4)
Place of birth of child	Delhi	119 (68.0)
	Outside Delhi	56 (32.0)
Education status (n=165) ^b	Never went to school	11 (6.7)
	Presently studying in school	105 (63.6)
	Was studying and took leave upon diagnosis	38 (23.0)
	Discontinued completely on diagnosis	11 (6.7)
Informed about TB in school (n=154)	Yes	66 (42.9)
	No	88 (57.1)

^abased on literature reviewed- susceptibility to infection

^bFor those who are equal to or above the age of 3 years

There were six cases of both pulmonary and extrapulmonary TB. For the purpose of bivariate analysis based on the type of TB, these cases were counted under pulmonary TB as it was the form that has negative externalities for others. Among 32 percent of the children (n=56) who were not born in Delhi, 16.1 percent of the parents/guardians had shifted to Delhi for treatment of the child. Majority of the children (88%) were going to school at the time of

diagnosis out of which 57.1 percent had not informed the school about TB. The reasons cited for this were ‘fear of discrimination by school staff or peers’ (67.1%), ‘child feels inferior and bad’ (11.4%) followed by no need and time to tell, associated disability, education gets affected, previous experience of others at school, will tell in future and no one is concerned at school.

4.1.2 Profile of the primary care givers of pediatric TB patients

Majority of the primary care givers were parents of the child (80.0%) especially mothers. Since most of the mothers were housewives, there was no or irregular source of income. Work status over past one year of the primary care giver indicated that 58.9 percent had no income source whereas 28 percent had an irregular income as daily wage worker or part-time worker/small businesses at home. A few had a regular source of income. Based on the wide range of household monthly income reported by the respondents, a new category cut at quartiles was formed so as to observe the distribution. Whenever respondents reported range for income, mean value was noted. More than 50 percent of the respondents had household income equal to or more than Rs.7500 per month. There were 30.3 percent of respondents who were BPL card holders. Majority of the respondents belonged to Hindu religion (75.4%) and were having household size of more than four (80.0%). More than half of the families (58.3%) lived in a one roomed house. There were 48 percent of the households which had at least one child under the age of six years. More than 90 percent of the households had at least one child between the age group of six to fourteen years.

Table 4.3 shows the details of the primary care giver and associated variables. There were 46.3 percent primary care givers who took leave from work for treatment of their child out of which 81.9 percent reported that it affected their income.

Table 4.3: Profile of the primary care givers of pediatric TB patients, Delhi

Characteristics		n (%)
Relation with pediatric TB Patient	Mother	103 (58.9)
	Father	37 (21.1)
	Siblings	14 (8.0)
	Grandparents	11 (6.3)
	Other relatives ^a	10 (5.7)
Age (in years)	Less than equal to 35	118 (67.4)
	More than 35	57 (32.6)
Sex	Male	51 (29.1)
	Female	124 (70.9)
Literacy level	No formal education	69 (39.4)
	Primary school completed	56 (32.0)
	Secondary school completed	40 (22.9)
	Graduate level and above	10 (5.7)
Monthly income (in INR) (n=173) ^b	Upto 5500	34 (19.7)
	5500-7500	49 (28.3)
	7500-10000	42 (24.3)
	10000 and above	48 (27.7)
Religion	Hindu	132 (75.4)
	Muslim	42 (24.0)
	Christian	1 (0.6)
Community	General	73 (41.7)
	Scheduled caste	47 (26.9)
	Scheduled tribe	4 (2.3)
	Other backward classes	31 (17.7)
	Do not know	20 (11.4)
Household size	Less than equal to four	35 (20.0)
	More than four	140 (80.0)
Ownership of the house (n=174) ^c	Staying on rent	89 (51.1)
	Own the house	80 (46.0)
	Staying with relative	5 (2.9)

^aOthers: maternal/paternal siblings, cousins

^bTwo did not disclose monthly income and mean of the range (if provided) of monthly income was taken

^cOne did not provide information

At the onset of symptoms, only 18.9 percent of respondents perceived symptoms could be due to TB. The most common cause of TB as reported by 40.6 percent respondents was contact with any TB patient. The source of information about TB was a health care provider (47.4%) followed by someone known to have TB (21.7%) and others including media/display boards, friends and relatives. There were 45.7% of respondents who reported high stigma associated with TB whereas there were 53.1 percent who had good knowledge about TB. The Cronbach alpha for knowledge and stigma score measure was 0.429 and 0.757 respectively.

4.1.3 Description of the outcome variable - delay

Median patient and health system delay was 3 (range: 1-300) and 41 (range: 10-397) days respectively. Median total delay was 52 (range: 12-553) days with mean of 64.98 days. Range seemed to be a more appropriate measure to reflect spread than interquartile range as the data is positively skewed. Mean with standard deviation for patient and health system delay was 12.24 ± 28.65 and 52.57 ± 45.91 days respectively. Thus quantum of delay is important.

Based on the frequency distribution the mean and median did not fit as the apt measure for measuring the duration of delay. Mean is particularly susceptible to outliers or the values at extreme ends. Since data is not normally distributed, the median was a better measure of central tendency than mean. But as meaningful delay would be those beyond the third quartile, the median would have represented delay, but it would not represent a point which calls for interventions. For instance, children with patient delay of four days and 300 days (extreme) would be in the same category and this could be very unfair to those with extreme delay, which forms the focus of this study.

A delay of four days cannot be treated as delay considering that nature of TB which develops over a period of time. Any form of categorization combined with the inherent skew in the distribution of delay would result in information loss. It is not merely a statistical problem but a clinical one as well because for children and from public health perspective too, it was better to describe delay rather than categorizing delay into two groups for description. Thus the intrinsic nature of the outcome (taking as continuous variable) was retained at the level of describing the delay and its distribution.

Measuring patient and health system delay

Table 4.4 presents patient and health system delay using quartiles. Delay was divided at quartiles- lowest below quartile one (Q1), from quartile one to quartile two (Q1-Q2), quartile two to quartile three (Q2-Q3) and quartile three and above (Q3-maximum). The mean delay in days was calculated within these groups. Within each group, there seemed to be consistency but when compared with sample mean of 12.24 and 52.57 days there is noticeable difference in the last group with mean of 38.6 and 105.6 days for patient and health system delay respectively.

Table 4.4: Delay among pediatric TB patients, Delhi (N=175)

Quartiles	Group 1	Group 2	Group 3	Group 4
Category	(upto 2)	(2-3)	(3-12)	(12-300)
Patient delay (in days)	Mean (n)			
Within group mean	1.0 (32)	2.0 (49)	5.6 (49)	38.6 (45)
S.E of mean within group mean	0.00	0.00	0.37	7.11
Cumulated mean	1.0 (32)	1.6 (81)	3.1 (130)	12.2 (175)
Health system delay (in days)	(upto 27)	(27-41)	(41-64)	(64-397)
Within group mean	19.0 (43)	33.1 (43)	51.5 (45)	105.6 (44)
S.E of mean within group mean	0.69	0.53	1.06	9.61
Cumulated mean	19.0 (43)	26.1 (86)	34.8 (131)	52.6 (175)

The cumulative mean showed how consistent the mean within quartiles is. Last groups of both types of delay had 45 and 44 pediatric TB cases respectively which account for considerable proportion out of the total patients in sample. Distribution of patient and health system delay seemed to differ by type of TB. Boxplots of patient and health system delay are presented as figure 4.2 and 4.3 respectively. Boxplots show median (central line), interquartile range (box) and range (whiskers) with outliers and extreme values. There was median (range) patient delay of 2 (1-120) in pulmonary TB cases as opposed to 3 (1-300) days in extrapulmonary cases. For pulmonary and extrapulmonary TB cases, there was health system delay of 37 (11-153) and 44 (10-397) days respectively. Once the patient reaches RNTCP, time lag was shorter and treatment was started within a maximum period of seven days at respective DOTS centres.

Figure 4.2: Boxplot of patient delay based on nature of TB

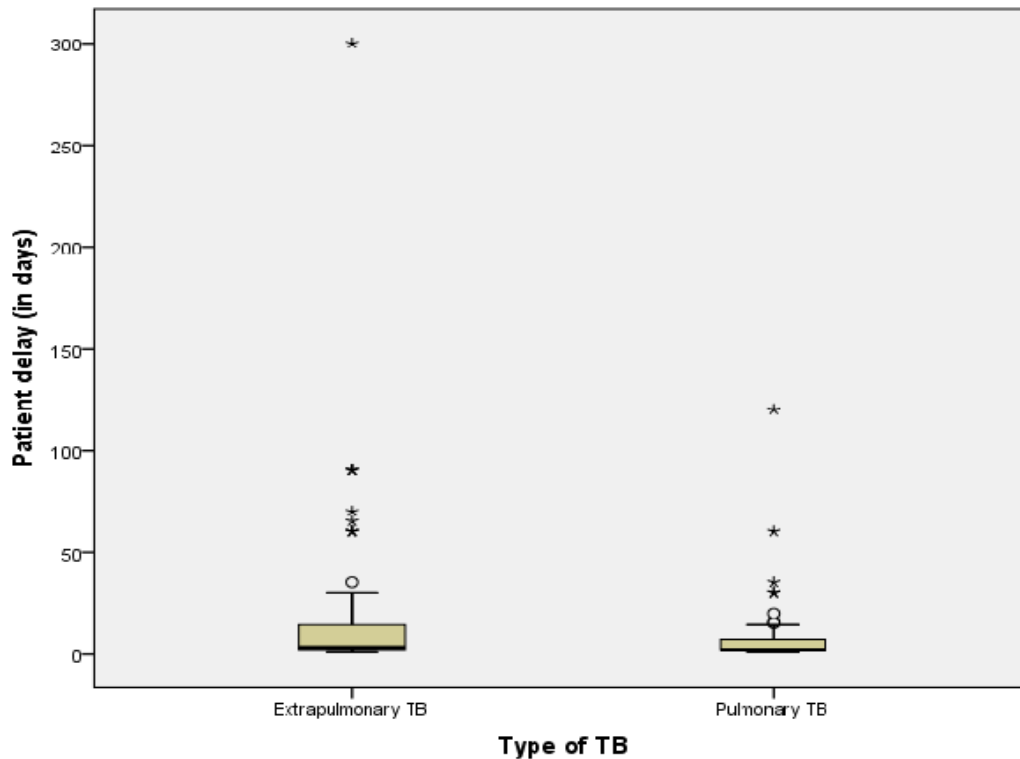
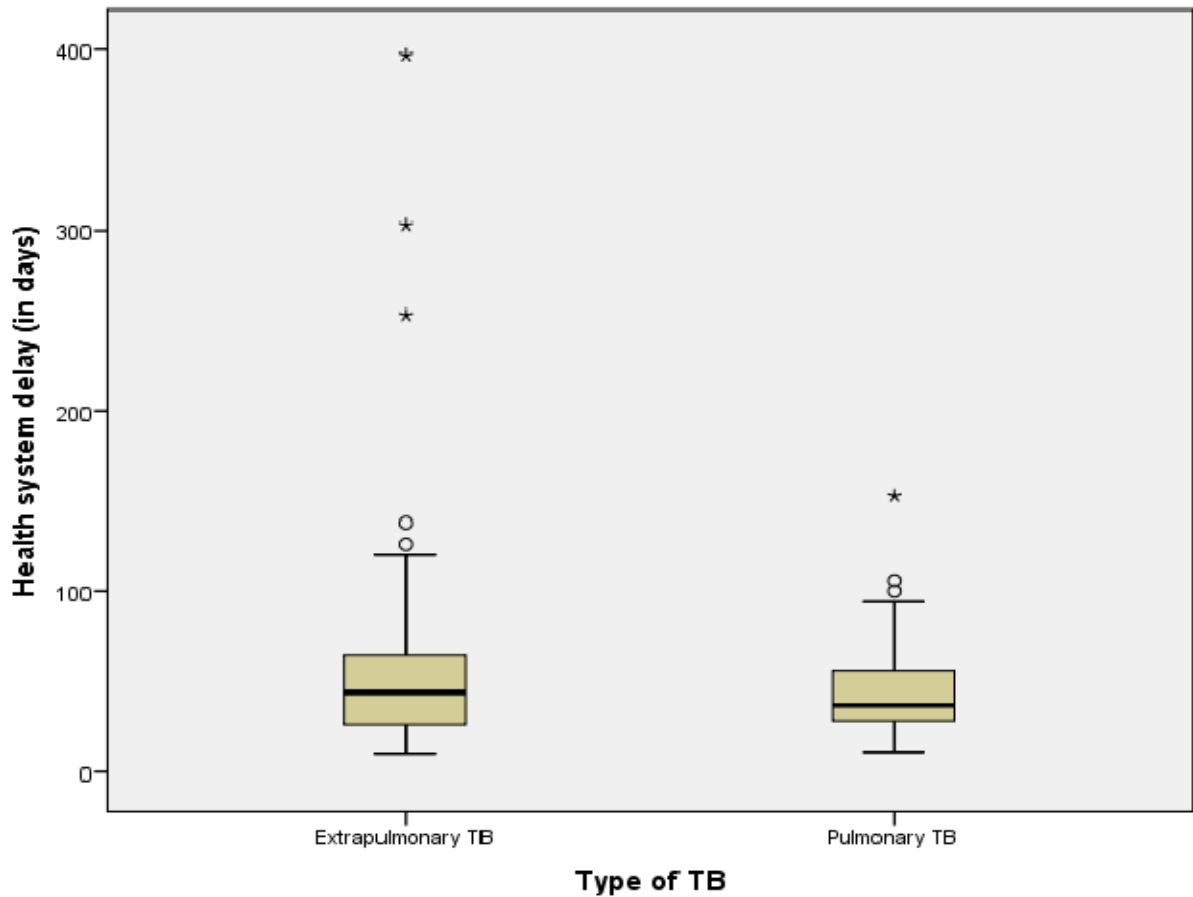


Figure 4.3: Boxplot of health system delay based on nature of TB



4.2 Pediatric TB patients with household TB contacts

Out of 33 pediatric TB cases who were under the age of six years, 45.5 percent had contact with TB case within household. More than half of the children (60.0%) had exposure within a period of one year. Parents (53.3%) were the most commonly reported source of contact. Table 4.5 shows the details of the children with household contacts. Sub-analysis of this group for delay revealed that median health system and total delay were 55 and 60 days respectively which is relatively higher than the sample median. Patient delay was lesser comparatively with median of two days.

Table 4.5: Pediatric TB patients less than six years (n=33) in contact with TB patient, Delhi

Category		n (%)
Contact with TB patient	Yes	15 (45.5)
Period of contact (n=15)	Within one year	9 (60.0)
	Within one-two years	1 (6.7)
	Two-three years	2 (13.3)
	Three-four years	1 (6.7)
	More than four years	2 (13.3)
Relation with TB contact (n=15)	Mother	5 (33.3)
	Father	3 (20.0)
	Grandparents	2 (13.3)
	Siblings	2 (13.3)
	Others ^a	3 (20.0)

^aOthers include parental sibling and neighbours

4.3 Health seeking pathway

4.3.1 Reported symptoms

Symptoms were recorded in two forms, prompted and unprompted. Then respondents were asked for the symptoms for which they sought care. Fever (54.3%) and weight loss (41.1%) were the most commonly reported unprompted and prompted symptoms respectively. Around half of the respondents sought care for fever followed by swelling (25.7%), pain (22.3%) and others. Table 4.6 shows tabulation for reported symptoms. Among pulmonary TB cases, around 77.4 percent of the respondents reported fever as the major worrying symptom for which they sought care followed by cough (18.9%). In extra-pulmonary TB cases, nodular swelling (36.1%) followed by fever (35.3%) caused respondents to seek health care for children.

Table 4.6: Symptoms reported by primary care givers, Delhi (N=175)

Characteristics	Symptoms^a		
	Unprompted	Prompted	Sought care
Cough	31 (17.7)	21 (12.0)	13 (7.4)
Fever	95 (54.3)	37 (21.1)	84 (48.0)
Weight loss	14 (8.0)	72 (41.1)	8 (4.6)
Swelling	48 (27.4)	12 (6.9)	45 (25.7)
Pain	52 (29.7)	22 (12.6)	39 (22.3)
Others ^b	18 (10.3)	2 (1.1)	13 (7.4)

^aPercentages do not add to 100 due to multiple responses

^bOthers include:- vomiting with/without blood, weakness, loss of consciousness, fits, rashes over the body, loose motion, dental problem and loss of hunger

4.3.2 Health seeking behaviour

Table 4.7 presents first action taken by respondents for seeking care. The most preferred health care provider after the onset of symptoms was the private provider (34.9%) followed by unqualified practitioner (25.1%) and to a lesser extent – the government provider (19.4%). Distance to the first facility consulted was reported to be greater than or equal to one kilometer for 56.3 percent of the respondents.

Table 4.7: First action for seeking care after onset of symptoms by respondents, Delhi (N=175)

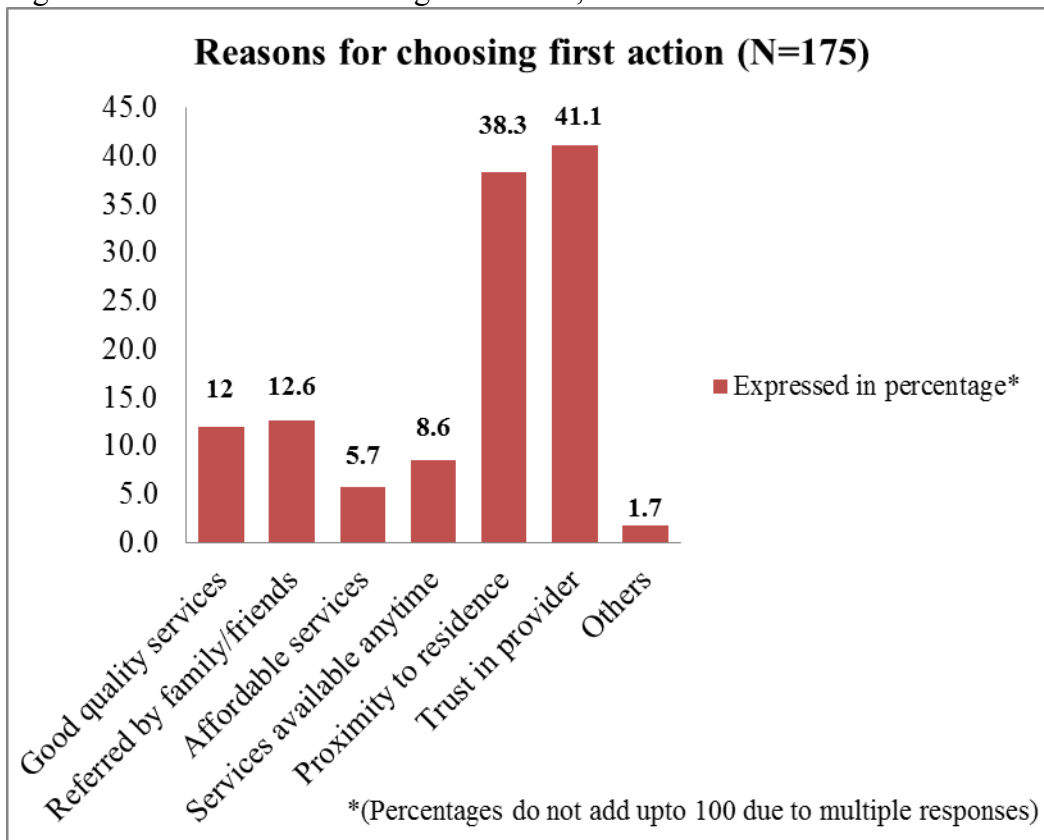
Category	n (%)
Private provider	61 (34.9)
Government provider	34 (19.4)
Unqualified practitioner ^a	44 (25.1)
Pharmacist	13 (7.4)
Self-medication	12 (6.9)
AYUSH	11 (6.3)

^aincludes traditional healers, “Bengali doctors”, “Jholla chap doctors” and rural medical practitioners

Major reasons cited for preferring one provider or action over the other were faith or trust in provider (41.1%) and proximity to residence (38.3%). Figure 4.4 shows the reasons for choosing first health seeking action.

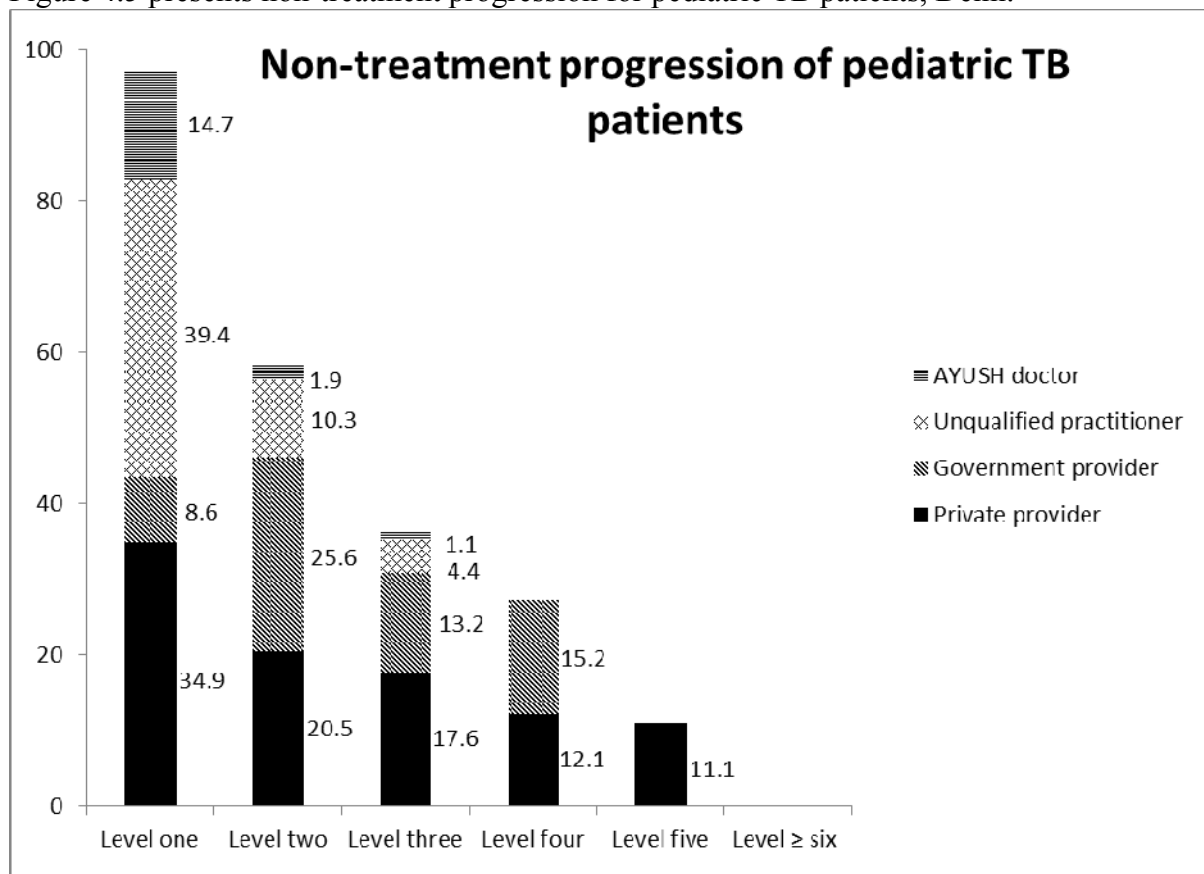
Respondents mentioned getting a confirmed TB diagnosis in the range of first action (level 1) up to diagnosis from the seventh provider (level 7). Only 11.4 percent of children were diagnosed with TB at level one whereas the highest cases (40.6%) were diagnosed at level two. By level three further 33.1 percent were identified with TB followed by last 14.9 percent at level four or more. It becomes clear from figure 4.5 which shows the percentage of children who remained un-diagnosed and the type of provider consulted at each level. All cases at level one were diagnosed by government providers. No child was identified with TB by unqualified practitioner or AYUSH doctors at any level. It seems that even at a government facility, children remained undiagnosed but higher proportions of children were diagnosed in the government facility at every level.

Figure 4.4: Reasons for choosing first action, Delhi



There were 49.1 percent respondents who perceived that there was no time lag between onset of symptoms and first action taken. Among the rest, 64.1 percent of the respondents and their families thought that symptoms would subside on their own followed by monetary concerns (14.6%), scared of the diagnosis (12.4%) and others including no time from work, no good facility around and long waiting time in government hospitals.

Figure 4.5 presents non-treatment progression for pediatric TB patients, Delhi.



4.4 Factors associated with delay

4.4.1. Results of bivariate analysis

Since data were not normally distributed, non-parametric analysis using Mann-Whitney U test (nonparametric independent t test) and Kruskal-Wallis H test (non-parametric oneway ANOVA) was done to examine the possible association of predictor variables and outcome variables.

The outcome variables considered were patient and health system delay. As the consequences of pulmonary and extra-pulmonary TB are quite different as was the nature of delay, all further analysis was carried separately for these two groups.

Tables 4.8 and 4.9 present the results of bivariate analysis to determine the factors affecting delay. For pulmonary cases, it was found that sex of the child, age of primary care giver, religion, community and distance to first facility were factors associated with patient delay. Among these, male pediatric TB patient, distance to first facility equal to or more than one kilometer and primary care giver's age being more than 35 years, belonging to Hindu religion and general category in terms of caste were found to be having longer patient delay than their respective counterparts. Similarly in cases where household size was more than four persons and children were born outside Delhi, patient delay was statistically significantly longer than cases with smaller household size and child's birthplace being Delhi.

Kruskal-Wallis H test showed that there were statistically significant differences in health system delay between the different categories of number of providers consulted until diagnosis and choice of first provider. It holds true for both types of TB. Mean rank of health system delay for number of providers was highest for four or more providers consulted and then in decreasing order whereas for choice of providers, unqualified practitioners had the highest mean rank of followed by private practitioners.

Children having extrapulmonary TB whose primary care giver reported distance to first facility equal to greater than one kilometer had statistically significant longer health system delay than their counterparts.

Table 4.8 Patient delay and predictor variables, Delhi (N=175)

	Pulmonary TB (N= 53)			Extrapulmonary TB (N=122)		
	N	Median (Range)	p value	n	Median (Range)	p value
Sex of child [§]						
Male	18	3 (2-60)	0.073*	61	4 (1-300)	0.750
Female	35	2 (1-120)		61	3 (1-90)	
Place of birth of child [§]						
Delhi	38	2 (1-60)	0.562	81	3 (1-90)	0.016*
Outside	15	3 (1-120)		41	6 (1-300)	
Age of primary care giver (in years) [§]						
35 or less	31	2 (1-120)	0.048*	87	3 (1-300)	0.982
More than 35	22	3.5 (1-60)		35	4 (1-65)	
Religion [§]						
Hindu	43	3 (1-120)	0.075*	89	4 (1-300)	0.257
Others	10	2 (1-7)		33	2 (1-30)	
Community [¶]						
General	17	4 (1-120)	0.008*	56	5 (1-90)	0.502
SC/ST	15	2 (1-60)		36	2.5 (1-90)	
OBC	14	2 (1-10)		17	3 (1-300)	
Household size [§]						
≤4 persons	10	2.5 (2-30)	0.761	25	2 (1-90)	0.071*
>4 persons	43	2 (1-120)		97	4 (1-300)	
Distance to first health Facility (in kms) [§] -174						
< 1	30	2 (1-120)	0.004*	46	2 (1-300)	0.464
≥ 1	23	7 (1-60)		75	4 (1-90)	

[§]Mann-Whitney U test

[¶]Kruskal Wallis test

*Shows the statistically significant differences with p < 0.1

Patient delay was not found to be associated with age of child, literacy level of care giver, monthly household income, knowledge and stigma associated with TB. On the other hand, sex and place of birth of child, knowledge about TB, associated stigma, household size and literacy level of primary care giver were not related with health system delay.

Table 4.9 Health system delay and predictor variables, Delhi (N=175)

	Pulmonary TB (N= 53)			Extrapulmonary TB (N=122)		
	N	Median (Range)	p value	n	Median (Range)	p value
Number of providers until diagnosis ^ψ						
One	5	14 (11-33)	0.002*	15	22 (10-78)	0.001*
Two	23	37 (15-85)		48	44.5 (15-119)	
Three	16	45.5 (16-100)		42	41 (13-253)	
Four or more	9	56 (24-153)		17	70 (16-397)	
Choice of first provider						
Private	20	37 (15-153)	0.038	41	46 (15-138)	0.060
Government	8	23 (11-53)		26	31 (10-126)	
Unqualified	21	51 (16-106)		48	47 (13-397)	
AYUSH	4	37 (18-100)		7	45 (16-93)	
Distance to first health Facility (in kms) [§] n=174						
< 1	30	37.5 (15-106)	0.747	46	47.5 (13-303)	0.087*
≥ 1	23	37 (11-153)		75	35 (10-397)	

[§]Mann-Whitney U test

^ψKruskal Wallis test

*Shows the statistically significant differences with p <0.1

4.4.2. Results of multivariate analysis

It was not possible to undertake multivariate analysis based on the findings of non-parametric tests. Multiple classification analysis (MCA) was envisaged but it assumes normality within groups and requires a minimum of 30 observations in each cell. The present study did not have sufficient number of cases nor could the assumption of normality hold. For this reason, the outcome variables were divided into two categories by median for the multivariate models. Chi square tests determined the associations. Qualitative findings also resonate with the identified factors from Chi-square analysis. Binary logistic regression analysis was done to arrive at final model and the results are given in table 4.10. Variables with p-value < 0.1 in bivariate analysis were considered for multiple logistic regression analysis. The outcome variables considered for this analysis were patient delay and health system delay. Independent variables were checked for collinearity prior to use in the model.

Table 4.10 Predictors of patient delay: Results of binary logistic regression analysis, Delhi (N=175)

Variable	Patient delay		OR (95% CI)
	No (<3 days) n (%)	Yes (≥3 days) n (%)	
Distance to first facility (in kms)			
< 1	44 (57.9)	32 (42.1)	1
≥ 1	37 (37.8)	61 (62.2)	2.19 (1.18-4.07)
Place of birth			
Delhi	61 (51.3)	58 (48.7)	1
Outside Delhi	20 (35.7)	36 (64.3)	1.83 (0.94-3.57)

CI: confidence interval

Cut off of 3 days for patient delay is applicable to this sample only based on division by median

Respondents who reported distance to first facility equal to or more than one kilometer were two times more likely to have patient delay of equal to or greater than three days than their counterpart respondent's children. So as to avoid overestimation, in cases where respondents who reported distance in range lower limit of range was recorded for analysis. Place of birth was not found to be significant in the model.

Median delay at health system level for this sample was 41 days. It was not possible to plan multivariate analysis for health system delay in spite of having two predictor variables significant through chi square results- choice of first provider and number of providers consulted until diagnosis. This was because under each variable there were more than two categories and these could not be meaningfully reduced further. Any analysis with the limited number of cases in each cell would yield spurious results.

4.5 Analysis of the in-depth interviews

In order to capture the specific instances of seeking care both in terms of ‘prompt health seeking or no delay’ and ‘extreme delay’, a qualitative approach was thought of as the most appropriate methodology. This was to understand the health seeking pathway and its determinants as part of the minor objective of this study. A total of 12 in-depth interviews were conducted, six in each of the two categories. Purposive sampling was done to select the informants for in-depth interviews who have had unique health seeking behaviour within each category. This was determined through the preliminary analysis of the quantitative component of this study.

A selection of interviews in both categories that were thought to provide maximum information were read carefully to determine a set of codes with respect to delay. All the interviews were read and blocks of meaning units were selected and coded according to whether they fitted into the pre-identified codes. However, not all the sections of the interview could be accommodated within the set of identified codes. There were portions which remained distinct; these were usually descriptions of settings with situations. The analysis which follows describes the findings under 11 broad codes that were identified. In each description of code, extreme delay cases have been contrasted against no delay cases so as to find plausible explanations for the differences in the two scenarios. Following analysis is an attempt to examine the health seeking pathway from emergence of symptoms to the DOTS treatment initiation. The names of the hospitals or providers taken by informants during the interview have been removed or replaced by alphabets to maintain confidentiality. Additional information required has been provided in brackets wherever necessary.

4.5.1 Experience of symptoms

Extreme delay:

The most frequently observed symptom that prompted care was an unnatural and persistent swelling or a nodule that increased in size over a period of time or tended to recur. This was referred to as “*ganth*”, “*gilti*” or “*dana*”. Sometimes intermittent fever that accompanied the appearance of such swellings was also a matter of concern. Parents or the caregivers also tended to take note of alarming symptoms like vomiting with or without blood and pain but weight loss alone was not taken as seriously unless accompanied by any of the other symptoms. In fact, weight loss was a prompted response among the observed symptoms. None of the informants had thought of the nodule or lump as of TB.

“He got swelling and we thought it was “galu bibi” in the neck (indicated towards the neck of the child) so I distributed prasad (gave offering to the God) and “phoda pichak gaya” (swelling subsided). After that no fever and cough, my child had no problem. He again got “gilti” (nodular swelling) over neck after 4-5 months of first “gilti”. The size of this swelling was like an egg”

- *Father of two years old TB patient*

Prompt health seeking:

The most commonly reported symptoms were fever and pain. Weight loss seemed to worry the care givers. In few cases, informants mentioned “*ganth*” but in this case, it was the accompanying symptoms made them seek care promptly.

“First of all, he was not able to move neck. Pain was there. I told my husband to take him for bathing. He saw a very big ganth. Another small ganth nearby...”

- *Mother of five years old TB patient*

4.5.2 Perception of symptoms

Extreme delay:

Varying perceptions regarding the experienced symptoms were observed. These perceptions were locally referred as “galubibi” which is “curse of goddess that usually happens near the neck region” as explained by informant, “gilti” (nodular swelling), “bishmail” (snake bite), “dadood phul rahe hain” and “kanphade” (some kind of swelling emerging over the body). Sometimes, it was also perceived by the primary care giver him/herself and known people around that it could be due to black magic. As explained by a primary care giver:

“As many men sit in the village, they guide and say show here or there to find out what bad has happened to child so believing and agreeing to their thought we showed to the person who sits in temple in village. He has “manyata” (highly recognized person). He is an old person. He tells people and they get fine usually. I thought that same would happen but my daughter didn’t become fine. We all were thinking it is some “upari hawa” (black magic/witchcraft) that is why all this happened”

- Mother of 12 years old TB patient

These were based on the belief that children can easily contract these ailments from other adults and that it would subside on its own or by offering prayers and performing rituals. There was a strong indication that such perceptions were based on the similar experiences of the adult members in the house, neighbourhood or by the children themselves.

“My husband also had this. Earlier my husband’s neck used to swell up in the rainy season then I had done “thali bajana” in village. It is since that day, it didn’t happen. My husband is doing fine”.

- Mother of 11 years old patient

There was a perception that persistent fever was typhoid and that TB was indicative of untreated or inadequately treated typhoid. This was inferred from the traditional healers. An

informant took her child to a “*baba*” (local traditional healer) who told her why fever was persisting:

“It was in village where we got to know that “moti jhara” (typhoid) had worsened. Before that we had no idea it was typhoid”

- *Mother of 12 years old TB patient*

Prompt health seeking:

The perception regarding observed symptoms was based upon the pre-existing illness, if any or common thoughts that of any injury due to fall or an insect bite. None of the informants described these symptoms to be linked with any of the cultural beliefs. Quoting a line said by father of child who was HIV positive:

“We thought those symptoms were side effects of HIV. My child usually has diarrhea, fever and cough...”

- *Father of six years old TB patient*

Another informant described a unique experience of his child where he was not aware of the emerging swelling and went for seeking care for other symptoms and found TB by chance due to the prompt suspicion of the treating doctor. However it is important to note that the health care seeking for visible symptoms was prompt.

“All this began around March this year when my grand-daughter developed pain. Her stomach was aching on and off. Yes, she had fever on and off. She was losing weight also. We were thinking that it is seasonal as winters were going to end. We had not noticed the swelling which she had in the armpit which has caused TB. It only came into notice when doctor at XYZ hospital (government hospital) told us after her examination”.

- *Grandfather of seven years old TB patient*

4.5.3 Perception regarding time lag

Extreme delay:

Since the symptoms were not perceived as of TB, care givers seemed to be under the impression that the symptoms were not severe and would subside with time. Care givers tended to relate TB with cough.

“I thought it will subside on its own. But after a period of three months and a half, I got scared that it is not subsiding and increasing so I should do something. I thought nerve would have got compressed or some swelling happened like that”.

- *Father of two years old TB patient*

Another informant waited for a period of 10 months before taking any action presuming that child would be fine on his/her own. Perceived severity and other notions influenced the decision to seek care:

“It took me around 10 months to actually look for doctor for the very first time. We thought it will be fine on its own”.

- *Father of six year old TB patient*

Also sometimes care givers use their child’s past health related experiences to decide whether they should even attempt at seeking care in Delhi:

“In childhood when she was 2-3 years old, she was bitten by a dog then the doctor had said that “garmi ho sakti hai kabhi bhi” (changes in body which may produce heat and some reactions). We were thinking it is because of that she is not eating and there are on and off symptoms. This is why we delayed”.

- *Mother of 12 years old TB patient*

Prompt health seeking:

Symptoms those were not consistent in their appearance caused people to relax. Persistence of any symptom prompted immediate care. Sometimes, experience of pain and recurrence led the care givers into deciding that the condition was severe.

“Fever and pain subsided but as soon as we stopped medication after 3 days, fever again came in 2 days. Then we decided to move to XYZ (government hospital)...”

- Grandfather of seven years old of TB patient

4.5.4 Choice of health provider

Extreme delay:

The analysis shows three major categories of health providers who cater to the needs of the children and the informants. One is the public sector specifically doctors in government hospital, the other is the private sector doctors and the final one is unqualified practitioners who could be pharmacists, traditional healers or self-medication practiced by caregivers themselves. Based on the perception and previous experiences, informants prioritize their preference for the provider. The private sector and unqualified practitioners were the first preferred provider. In fact, even when the informant visited the public sector, they take recourse to other form of providers eventually.

“I went to my relative near my house from where this “bishmail” story started. She scared me after I visited government hospital saying that “Are you not worried about your child? She is having “bishmail” only. If it spreads, your child will die. Go to the village” so we went immediately next day for village”.

- Mother of 11 years old TB patient

Summary of a patient having extreme delay- A mother described the journey of her child from the day fever emerged. Since the symptoms were on and off, perception of severity of symptoms decreased. Prior health experiences masked the need for treatment. After a period of about 4 months, they sought care from pharmacist followed by traditional healer in village who told them typhoid had worsened and advised abstinence for 8-10 days along with performing a ritual using coconut, incense stick and tying a thread to “peepal” (Holy Hindu tree) tree. They presumed it to be black magic and preferred an old recognized man in village for treatment than health provider. Due to financial constraints, they returned to Delhi and performed rituals again. Since the situation did not improve, they went to a government hospital where they were given medicines. TB was diagnosed on subsequent visits through various tests.

Unqualified practitioners have been referred by the informants with different names as “baba”, “temporary doctors”, “jholla chap doctors” and “Bengali doctors”. Care givers choose providers by their accessibility and prior experience.

Prompt health seeking:

Choice of health provider was based on the previous experience and trust in the provider. The type of providers who provided services was government sector hospitals, private practitioners (patients reported them as qualified doctors but DOTS provider confirmed that many among these are unqualified practitioners). Even if the first resort was not qualified provider, the reoccurrence or persistence of symptoms sent them to a government facility.

“We went to XYZ (government) hospital only as there was no relief from that ganth”.
- Mother of an adolescent TB patient

4.5.5 Treatment considered until diagnosis

Extreme delay:

Firstly, the type of treatment considered among extreme delay cases has a certain pattern. The informants had visited their native villages in between to seek care. They religiously followed what local community members or the traditional healers said. One informant said he did to the best of his/her abilities to cure child in pain:

“I went to village and performed “thali bajwayi” (locally prevailing ritual to manage the symptoms). Everyone said that it was bishmail only. They were scaring me. I took her to temple so that she gets blessings by “tilak lagana” (putting holy powder over her forehead). People and women around had been telling that this is bishmail so I took her to village to do the rituals when bishmail is there. It took us a month there approximately. Till that time, this “ganth” had begun to subside as pus had started coming out. In “thali bajana”, we did “kirtan” (offer prayers when few people gather and chant holy songs) and performed rituals like taking bath in Ganges, giving food to young (pre-puberty) girls called “kanjake”. They gave “jhada” (give pat on her

head and back with neem leaves) frequently till the time we were there. We had to pay some money to the ladies who did these prayers for us".

- Mother of 11 years old TB patient

In this case, since the pus was oozing out, the swelling reduced in size. This was attributed to the success of the ritual considered. This led them to continue this treatment when the swelling recurred thus enhancing the time lag to diagnosis.

If care givers consider the symptoms as severe or alarming, they follow all possible treatment options they are aware of or get to know. Lack of improvement through prescribed treatment by the provider makes them change providers. This is how one informant described his health seeking pathway until diagnosis of TB:

"We went to a "Bengali doctor" that "jholla chap" nearby from whom we took medication for a day only... after that we visited homeopathic doctor as people say that with homeopathic medicine... such "ganth" subsides and all becomes well. That "Bengali doctor" had also said take homeopathic medicine. We took treatment for approximately 6 months from there. After that I stopped... there was no improvement at all. We had visited Dr. XYZ (private practitioner) after 2 months since the last time we went to homeopathic doctor. He asked me to get a few tests done. Since it is costly to get tests done anywhere I went to ABC (government hospital) at ____ chowk (a place). There, the rate of tests are subsidized hence we get discount of around 50 per cent. I paid 370 Rs. for the tests. Reports of tests revealed TB... "ganth" TB. Since government facility is there for TB near our place so I came here".

- Father of nine years old TB patient

Prompt health seeking:

Summary of patient having prompt health seeking: A child develops swelling over the neck. The mother of eight years old child rushed to a government hospital. She chose this facility as she had heard that they provide good quality services although it was not near to her house. Prompt decision for seeking care was related to a suspicion that this might have been some injury due to previous fall from tree. Doctors could not find anything so other tests were done. So as to avoid waiting period in government hospital, mother of child got X-ray done in private clinic. Child was diagnosed with TB subsequently. She then visited private provider to re-confirm the diagnosis and then started treatment.

The source of diagnosis was usually a government facility. Private practitioners who had tied up with RNTCP sent potential or confirmed TB cases to the nearby district TB centre. Even children diagnosed by private providers visited government hospital for confirmation. Severity of symptoms and emergency care including hospitalization reduce delay in diagnosis. Doctor's suspicion for TB also reflects in earlier diagnosis. It could be based on predisposing conditions such as HIV.

“We went to a private doctor (no MBBS doctor in that area as per DOTS provider but I have written as patient said). She used to give medication every time we went. First that lady doctor had detected typhoid. She gave medication for 10 days. There was no improvement. Then that lady doctor suggested us to get x-ray done and few blood tests. She said that x-ray is showing TB. There is water in my child's lungs and abdomen. You should go to some hospital. We went to XYZ hospital (government hospital) then they gave medication for 3-5 days but his swelling was increasing over his abdomen so the doctors at the hospital had admitted my child. After few days, they discharged him and in between they did many tests. Finally they told us that he has TB. Then they referred us to this DOTS centre for medication. Since then medication is going on regularly”.

- *Father of nine years old TB patient*

4.5.6 Consequences of TB treatment

Extreme delay:

Consequences have been directly linked with improvement seen in child after undertaking a particular treatment modality. Expectations regarding improvement were rooted in previous experiences and perceived severity of symptoms. Previous experiences with a provider did not figure in the reasons for persisting with a provider if results were not visible.

“I told you (referring to interviewer) that we were doing dressing at intervals. We were taking medication as prescribed earlier. We thought it will be fine but that didn't happen in those eight months. Gradually my child lost weight. It looked like I

will lose her. She had stopped eating food... no food or water. Then we rushed to XYZ (government hospital)”.

- Mother of 13 years old TB patient

Prompt health seeking:

If elimination or reduction of symptoms were not visible by following a particular health action then care givers opted for the nearest known government hospital. Distance to the facility consulted was an important factor.

“My son-in-law usually goes to this XYZ (private) doctor plus it is very near to our place. Hardly 100 meters.... it is at the end of my lane... since it didn’t subside we went to ABC (government) hospital as it is affordable and the nearest hospital to our house.

- Grandfather of seven years old TB patient

4.5.7 Reasons for shifting between different health providers

Extreme delay:

As the primary action to manage symptoms, informants prefer one provider over the other owing to the distance from the house, usual household practice of visiting the provider for any ailment and perceived affordability.

“We usually approach him for the illness in family. We get fine with his medicine. Like there is some problem we go to him. He works like a doctor. He treats patients also. His shop is near our house. Every chemist gives medicine this way”.

- Mother of 12 years old TB patient

For persons who move between village and Delhi particularly if symptoms occur while they are in village then they seem to be performing rituals instead of visiting health provider. If they have faith in that activity then they either perform ritual in current place of living or even prefer to migrate between places to perform the ritual.

“We thought it was only “galu bibi” (curse of God in neck region) so we offered “prasad”(offering to God) for Rs. 1.25 to the God and gave food to cow and moved

little Prasad around the head of my child so that god/goddess who were angry calm down and my child gets fine"

- *Father of two years old TB patient*

Prompt health seeking:

Reasons for shifting between doctors was nearness of centre to house, experience of others, affordability, good quality hospital and referral by friends and family. This is what an informant said about his visit to a particular government hospital for seeking care:

"Neighbours told us about this hospital. They said show before this worsens or becomes any other disease. It is not very near to my home. Since it is good, we went".

- *Mother of eight years old TB patient*

4.5.8 Perception of TB treatment

Extreme delay:

As mentioned earlier, TB has been associated with cough and phlegm. Informants also believed that TB makes a person looks weak. It was difficult for them to believe that the disease was TB, particularly extrapulmonary TB. One informant explained in his way that TB is an infectious disease but his understanding was different:

"We were quite shocked that my child has TB. No one at home has TB. I could have got too. By nature, he got TB. It is a god given disease. Anyone can have this disease. There was little tension how he got but treatment is there".

- *Father of two years old TB patient*

Another informant described his/her dilemma:

"Few people do not believe me as they are saying that her body doesn't look like of a TB patient. She looks fine. A TB patient is usually weak and feeble. She is not that weak".

- *Mother of 11 years old TB patient*

Informants were hesitant regarding treatment for extrapulmonary TB, particularly because of the fear of scars for girls.

“It is a matter of girl child and her neck was having this scar. I was scared for future”.

- Mother of 11 years old TB patient

Care givers immediately started treatment and seemed to be content with it except for the number of tablets a child needs to take which at times were an irritant.

Prompt health seeking:

Perception about TB treatment has been built upon the ideas gathered from past experiences and non-specificity of symptoms especially in case of extrapulmonary TB where it depends on the site affected. Informants could connect TB with cough and phlegm only.

“If TB is there then it is there. Treatment is required. TB is not new to our family. My daughter I mean her mother had TB around 10-12 years back. That time she was in Bihar. leela’s (name changed) younger brother also had TB. He died recently around 5-6 months back during his treatment in XYZ (government) hospital. He was being treated for chest TB there and doctors had recently found that his TB was in brain but within 2-3 days of diagnosis, he died. That’s how life is”.

- Grandfather of seven years old TB patient

4.5.9 Associated stigma and discrimination

Extreme delay:

Stigma has been described at two levels – what the informant felt about his/her child having TB; and at another level, what the child felt. The emergence of TB brought fear of being discriminated in minds of care giver and child as well. Parents do not disclose the TB status of the child to others. Care givers within home also tend to separate utensils and clothes and we found similar results from quantitative analysis. They are not comfortable doing it but they wish to safeguard other children:

“We feel sad sometimes I cry also. Don’t know how it happened. I haven’t shared this news with many. I don’t know how people can react with they get to know about

TB. One never knows. Very close relatives are aware of it. We try to keep child away especially from other younger kids. I don't even give same plate to eat. His plate and utensil are separate. I don't want others to get it".

- *Mother of eight years old TB patient*

Children found it difficult to tell their friends about their TB status. An informant mentioned that her daughter chose not to tell her school friends. She fears that others might behave badly and isolate her and that might make her feel bad.

Prompt health seeking:

Stigma was reported at two levels- patient and care giver. Some informants did tell others that their child has TB with a notion that it is not right to restrict child in any manner and as the TB was not infectious. Others chose to keep the child's illness hidden. They feared discrimination especially for girl child and fear of being thrown out of rented house. Few had seen neighbours in the same DOTS centres. Their explanation for not revealing the child's TB status took the form of - 'they did not tell us, why should we?' Father of the HIV positive child described his feelings about stigma he and his child face due to TB and HIV:

"A few are aware of it. There is no need to share with the rest. TB and HIV are not very acceptable diseases... people run away once they hear about it... few neighbours and relatives do object when my child stands with their children. I always try to be around my child so that such things don't happen but what to do after all he is just a six years old boy. I take my child to playgrounds etc. in evening".

- *Father of six years old patient*

Stigma was not limited to what happens in and around house but it affects social life of child at school. A child does fear the consequences of sharing the diagnosis with friends.

"TB is such a disease that people do discriminate. They are not comfortable when my child is around. I can't help on that. We haven't told in school as he (referring to child having TB) feels bad. He is scared that how will my friends react. School staff might also discriminate so we didn't tell. He goes out to play. His friends in colony

are not aware of TB. We will not tell anyone. He goes to tuition and school with them”.

- Father of nine years old TB patient

4.5.10 Knowledge about TB

Extreme delay:

Awareness and knowledge about TB varied. In spite of their child being diagnosed with TB care givers were not aware of the cause and symptoms. An informant who was complying with the DOTS treatment asked me if she could give additional treatment to the child as she had heard about it from her family and friends:

“People say that eating tortoise meat helps in curing TB. In fact people also mentioned about eating pigeons. Shall I give it to my child also?”

- Mother of 11 years old TB patient

There were notions regarding the BCG vaccine which were identified through quantitative analysis as well. It was being related as the cause of TB.

“My wife had mentioned about TB vaccine to me that our elder son has vaccine mark but younger doesn’t have. Actually that mark is the sign that TB has been thrown out of body so may be TB happened because of that. Doctor had told me that TB has spread to my child through some source. As in my case, if 2-4 children play together or like my friends who sit at workplace, they used to take my child in their lap or give food and sometimes kiss my child so that’s why my child got TB. No one in the house has TB but outside like in my workplace someone has spread TB to my child”

- Father of two years old TB patient

Informants have also linked TB with source of infection outside home and prevailing unsanitary conditions.

Prompt health seeking:

Informants were aware of the form of TB which is transmissible and seemed to be wary about extrapulmonary TB as it does not match with the symptoms they normally link with TB.

“My daughter has been playing with second floor lady’s daughter, the one who has similar symptoms. Who knows from where she got TB. May be from her...”

- Mother of four years old TB patient

4.5.11 Experience at DOTS centre

Extreme delay:

When broadly asked about their experience, they described about nearness to DOTS centre, improvement seen in child and attitude of the DOTS provider. Informants seemed to be rather content with the services and facilities. There was hardly any mention of the number of medicines being taken, even though that is thought to be a contentious issue:

“My experience has been good so far. There has been little improvement in her. My girl, who was not even able to drink water, has started eating and drinking a little now. Sometimes, time becomes an issue for daily wage workers like us but then I come in afternoon sometimes for medicine. That is also important. It is okay”.

- Mother of 12 years old TB patient

Informants were also asked what they would do if they came across any other child with similar symptoms in neighbourhood. Everybody confirmed that they would refer the child to the facility where their child was diagnosed with TB.

Prompt health seeking:

Distance and timing especially functioning evening clinics of the DOTS centre seems to facilitate the treatment process. Experience is also directly influenced with improvement seen in child. Informants seem to be content with services being provided and were willing to refer any child in whom they see similar symptoms.

“Experience is good so far. She misses school to get medicine at times. My child is recovering and taking treatment regularly. Her swelling is subsiding as well. She has few complaints – one is back pain and other is she doesn’t eat properly. We are consulting doctor at XYZ (government) hospital for this”.

- Grandfather of seven years old TB patient

CHAPTER 5

DISCUSSION AND CONCLUSIONS

The present study provides insights into the extent of patient and health system delay among pediatric TB patients in Delhi and the factors associated with such delay. It also documents the health seeking pathway prior to initiation of DOTS.

Conventionally, data on delay is divided by mean or median as there is no consensus on cut-off for different types of delay among different populations. For this study, some of the analysis has used the median as a cut-off and at other times used other count based measures of delay. The distribution of delay was not normal and it was skewed to the right. For this reason, the bivariate analysis used non-parametric tests. Such analytical strategies have been adopted in other studies among adult TB patients (Aldhubhani et al., 2013; Trigueiro et al., 2014). The data on delay was categorized based on nature of TB as there were marked differences in the duration of delay among pulmonary and extrapulmonary cases.

5.1 Patient and health system delay and associated factors

The study showed that the median health system delay was longer than the median patient delay but treatment initiation was prompt once the patient reached the RNTCP system. This finding is similar to a study from South Africa which reported median patient delay of one day and health system delay of four weeks with treatment initiation period of 0.1 week after diagnosis (Beyers et al., 1994). For both pulmonary and extrapulmonary TB cases, health system delay was more than the patient delay. Children with extrapulmonary TB faced longer duration of both types of delay when compared to pulmonary TB patients. This could be due to non-specificity of symptoms experienced by children with extrapulmonary TB and higher representation of such cases in the sample. This is in concordance with a study

reporting longer delay for different types of extrapulmonary TB (Abubakar et al., 2008) compared to pulmonary TB. On an average, it took 65 days for a child to start TB treatment after the onset of symptoms. The median delay was 52 days which was twice the reported delay in a similar study (Saldana et al., 2013). This difference could be due to the low representation of children in that study and the variation due to difference in the study setting. Delay could have been longer among children who died indicative of survivorship bias; the present study did not include TB cases who had died.

The median patient delay (three days) was short when compared to delay reported in the literature of 11 days (Leung et al., 2007) or 12 days in a study which included participants of Indian origin (Saldana et al., 2013). A possible explanation can be the positive skew in the data and variation in the definition of delay. A median delay of one day has been reported among pulmonary TB cases alone in South Africa (Beyers et al., 1994). Distance to the first facility was significantly associated with longer duration of patient delay and with health system delay for children with extrapulmonary TB. The greater distance to the first facility could be related to the practice of visiting traditional healers in rural villages by parents/care givers of children with TB. It could also be related to preferences for specific government hospitals which were at some distance from their residences. The resultant is patients travelling longer distances travelled to reach them. Among pulmonary TB cases, children whose primary care giver was Hindu and belonged to general category (that is, did not belong to Scheduled Caste/Tribe or other backward groups) had longer delay. A higher representation of Hindus and general category persons in the sample may have contributed to this. The qualitative findings also suggest that a majority of the participants who performed rituals to cure child were Hindus. Comparatively, in case of pulmonary TB, primary care

giver delayed care for male child more than the female child although range of delay was extended for the female child. Older the care giver longer the patient delay for children with pulmonary TB. Either excessive financial and care burden of the family or age related reasons especially in cases where care givers were grandparents may be the reason. Those who perceived a time lag in seeking care thought that the symptoms would subside. This is a reflection of the lack of awareness about TB which is in resonance with a qualitative study done in Peru (Paz-Soldan et al., 2014). Another major reason reported for time lag was financial concerns.

Overall, number of providers consulted until diagnosis and choice of the first provider were significantly associated with health system delay. Longer duration of delay can be deducted for those consulting multiple providers until diagnosis which has been reported in previous study (Paz-Soldan et al., 2014) and choosing a less than qualified provider or a private sector provider as first provider.

5.2 Pediatric TB patients with household TB contacts

According to RNTCP guidelines, all household contacts of sputum smear positive pulmonary TB patients should be screened for TB disease. Contacts aged less than six years are eligible for chemoprophylaxis if not having active form of disease. Household TB contacts of pediatric TB patients were parents and the exposure with within the span of a year. It was beyond the scope of the study to determine the nature of TB the household contact had. Since children were less than six years, they may have been in contact with members of the household though it cannot be said with assurance that the source of the child's TB was the household contact only. Nevertheless, it indicates missed opportunities for diagnosis within

the programme. There was longer duration of health system delay in such cases than the extent of delay observed in the total sample population.

5.3 Health seeking pathway for pediatric TB patients

Primary care givers sought care for prolonged fever more often than cough for pulmonary TB patients. Majority of the studies conducted among adult TB patients suggest cough as the chief complaint (Osei et al., 2015; Storla et al., 2008). This suggests that persistent or recurring fever could be markers for early diagnosis of TB. For extrapulmonary TB patients, the most worrying symptom was reported to be nodular swelling. Children with extra pulmonary TB usually present with symptoms which mimic other common childhood diseases. At times, finding diagnosis of TB is fortuitous. This is supported by qualitative results.

There seemed to be a preference for private providers followed by unqualified practitioners for the first presentation to health system. This provides a potential intervention area to catch-up with patients for early diagnosis. Even in studies among adult TB patients in Delhi, unqualified and private practitioners were the most sought providers for first level of care (Bhagat et al., 2014; Kapoor et al., 2012). Proximity to residence and faith in provider make primary care giver seek care from a particular provider for the first action which is in keeping with the qualitative study's findings. Another reason for seeking care from a particular provider was affordability. Less than one-fifth of the sample population suspected symptoms to be of TB. The maximum number of providers consulted until confirmed TB diagnosis was seven. Our study draws attention towards the need to create awareness regarding TB in the community. No patient was diagnosed with TB at any level of care by unqualified practitioner or AYUSH provider. It also calls for proper examination and suspicion of TB

for a child presenting with persisting illness. In majority of the cases, patients had been diagnosed at a government facility. The care givers' prior experiences with other childhood illnesses lead to discounting the severity of observed symptoms for children.

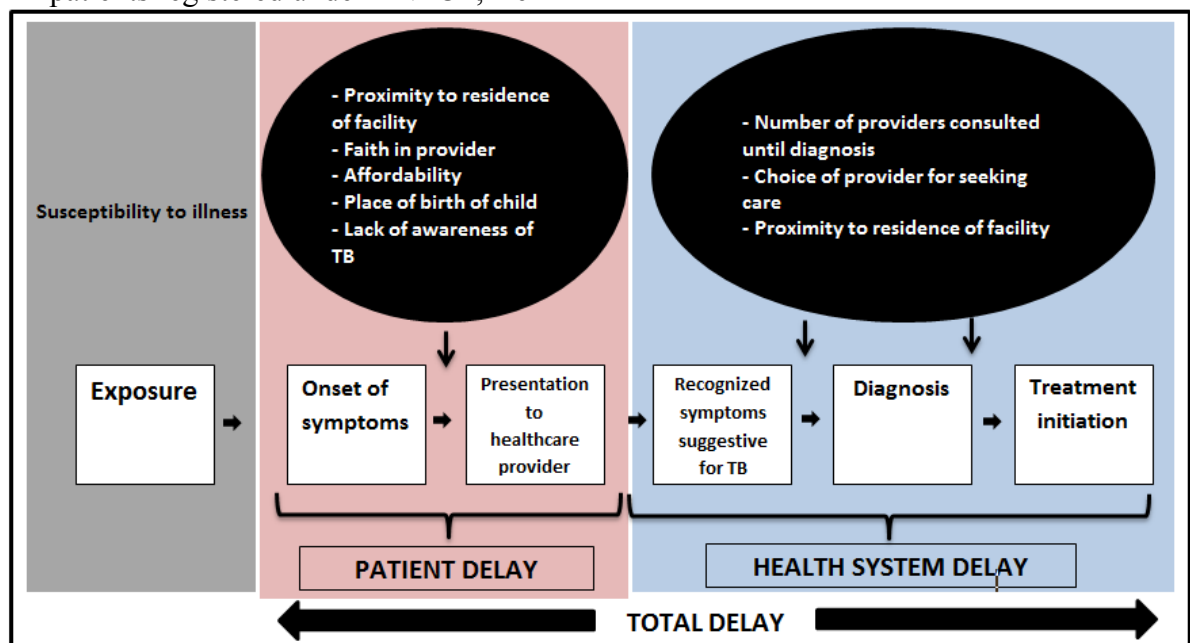
Most of the cases of extreme delay were related to extrapulmonary TB. The symptoms were non-specific and often diagnosis in the health system is differential. Therefore, it is not surprising that mere appearance of symptoms like swelling tends to be ignored unless accompanied by fever. Care givers with high burden of care tended to see these symptoms as part of everyday life rather than symptom of a disease. Results of cross-sectional survey did not find knowledge and stigma to be associated with delay contrary to qualitative findings. Primary care givers reported children have fear of being isolated by their peers if TB status is revealed. Questions related to stigma were indirect in nature so as to facilitate accurate responses rather than socially acceptable ones. Internal consistency of stigma scale was high while the knowledge scale was not. This inconsistency in the knowledge scale could be related to the poor knowledge of TB among respondents or the inappropriateness of the scale for knowledge of pediatric TB.

5.4 Emerging conceptual framework from the study

The conceptual framework proposed in chapter three was modified to arrive at a final framework. The modifications have been made based on the integrated results of quantitative and qualitative components of the study. Decision to seek care for the child is influenced by multiple factors at different levels of care. The emerging factors which seemed to affect patient and health system delay were added to the framework. It provides possible areas which can be explored for effective interventions to reduce the duration of delay from the onset of symptoms to the initiation of treatment.

The most decisive factor for seeking care after the onset of symptoms was proximity to the first facility. Faith or belief in the services of the provider which were dependent either on personal or other’s experience and affordability lead to delay in care. Patients thought that the symptoms would subside on their own which is indicative of the lack of awareness about TB. On the other hand, number of providers consulted and choice of first provider seemed to influence health system delay.

Figure 5.1: Emerging conceptual framework for patient and health system delay for pediatric TB patients registered under RNTCP, Delhi



5.5 Strengths of the study

This study used a mixed methods design which offered a holistic picture of the overall delay in Delhi for patients registered under RNTCP. The conceptual framework is based on findings and this can aid further research and possible intervention. The study focused on childhood TB, an important component of TB transmission. The dropout percent was low (6.9%). The study was conducted by a single investigator to avoid inter-observer bias.

Design effect was calculated to be one in contrast to anticipated value of two which indicates that sample size was larger than needed to ensure variability. PPS was used to ensure proper representation of the distribution of cases across Delhi. Information collected from the participants was cross checked with DOTS provider to enhance validity of the data recorded. In the light of scant literature, this study can prove to be a modest contribution to the evidence base.

5.6 Limitations of the study

Results may not be generalizable to pediatric TB patients not registered under RNTCP or for re-treatment cases. There could have been issue of recall bias although attempt was made to minimize the bias by verifying through records. There were 95.4 percent participants who had few or all documents of previous health care encounters. Differences could be seen by nature of TB but since sample size was small, it was difficult to find the peculiarities in detail.

5.7 Conclusions

A significant proportion of pediatric TB cases below age six had adult household contacts and yet experienced longer duration of delay when compared to all children. This points to the urgent need to strengthen contact screening within the programme. Children at extreme end of delay indicate a yearlong failure to thrive, malnourishment and other added burden of visiting unqualified practitioners, monetary and education concerns; adding to this is the smear positive status of the TB patient, which denotes infectiousness. To reduce the total delay a combination of interventions at both levels are needed. Greater awareness of TB among the community members will have an impact on early notification after onset of symptoms and better access to qualified health provider thus reducing patient delay. Non-

specificity of TB symptoms and paucibacillary nature points to the need for proper examination of children and this could contribute to reducing the health system delay. Providers need to be trained to recognize the possibility of TB in children with any persistent illness, particularly if they are also not thriving. Such training will contribute to reducing delay for extra-pulmonary cases.

5.8 Policy implications

All adult TB patients should be followed up for household contacts, especially children and the children to be offered chemoprophylaxis more stringently to reduce the burden of pediatric TB. All identified pediatric TB cases should be accompanied with contact tracing to identify possible adult contacts who may be sources of infection. Routine examination of children for other ailments should cover presence of any swelling and test for possible TB. This might increase the burden of care providing at system level, but serve to reduce the burden of untreated extrapulmonary TB among vulnerable children. There is a need to bring all forms of providers; both qualified and unqualified within the ambit of the TB programmes in order to reach out to a wider clientele that seems to utilize alternative systems of care. Caregivers of treated children are willing to recommend appropriate care for others and this is an important entry point for the programme.

References

Abubakar I, Laundry MT, French CE, et al. (2008) Epidemiology and treatment outcome of childhood tuberculosis in England and Wales: 1999-2006. *Archives of Disease in Childhood* 93(12): 1017–1021.

Aldhubhani AHN, Izham MIM, Pazilah I, et al. (2013) Effect of delay in diagnosis on the rate of tuberculosis among close contacts of tuberculosis patients. *Eastern Mediterranean Health Journal* 19(10): 837–842.

Amdekar YK (2010) Consensus statement on childhood tuberculosis. *Indian pediatrics* 47(1): 41-55.

Asefa A, Teshome W (2014) Total delay in treatment among smear positive pulmonary tuberculosis patients in five primary health centers, southern Ethiopia: a cross sectional study. *PloS One* 9(7): e102884.

Behera BK, Jain RB, Gupta KB, et al. (2013) Extent of Delay in Diagnosis in New Smear Positive Patients of Pulmonary Tuberculosis Attending Tertiary Care Hospital. *International Journal of Preventive Medicine* 4(12): 1480–1485.

Beyers N, Gie RP, Schaaf HS, et al. (1994) Delay in the diagnosis, notification and initiation of treatment and compliance in children with tuberculosis. *Tubercle and Lung Disease* 75(4): 260–265.

Bhagat N, Grover M, Sharma N, et al. (2014) Treatment pathways of extrapulmonary patients diagnosed at a tertiary care hospital in Delhi, India. *Lung India* 31(1): 16.

Census 2011. (2015) *Delhi Population Census data 2011*. Available from: <http://www.census2011.co.in/census/state/delhi.html> (Accessed 26 March 2015)

Creswell JW, Clark VLP (2011) Choosing a Mixed Methods Design. In: Creswell JW and Clark VLP (eds.) *Designing and Conducting Mixed Methods Research*. California: SAGE publications, Inc.

Curtis AB, Ridzon R, Vogel R, et al. (1999) Extensive transmission of Mycobacterium tuberculosis from a child. *The New England Journal of Medicine* 341(20): 1491–1495.

Detjen A, Gnanashanmugam D, Talens A (2013) *A Framework for Integrating Childhood Tuberculosis into Community-based Child Health Care*. Washington, D.C: CORE Group, International Union Against Tuberculosis and Lung Disease.

Dhingra VK, Rajpal S, Taneja DK, et al. (2002) Health care seeking pattern of tuberculosis patients attending an urban TB clinic in Delhi. *The Journal of Communicable Diseases* 34(3): 185–192.

Directorate General of Health Services (2014) *TB India 2014 Reach the Unreached Find, Treat, Cure TB, Save Lives*. New Delhi: Central TB Division.

Directorate General of Health Services (2015) *TB India 2015 RNTCP Annual status report REACH TREAT CURE TB*. New Delhi: Central TB Division.

Eastwood SV, Hill PC (2004) A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *The International Journal of Tuberculosis and Lung Disease* 8(1): 70–75.

Gebeyehu E, Azage M, Abeje G (2014) Factors Associated with Patient's Delay in Tuberculosis Treatment in Bahir Dar City Administration, Northwest Ethiopia. *BioMed Research International* 2014.

Goel K, Kondagunta N, SoansSJ, et al. (2011) Reasons for patient delays & health system delays for tuberculosis in South India. *Indian Journal of Community Health* 23(2): 87–89.

Gomes VF, Andersen A, Wejse C, et al. (2011) Impact of tuberculosis exposure at home on mortality in children under 5 years of age in Guinea-Bissau. *Thorax* 66(2): 163–167.

Goyal JP, Shah VB, Kukkar SR (2010) Consensus statement on childhood tuberculosis. *Indian Pediatrics* 47(6): 539–540; author reply.

Hamzaoui A, Yaalaoui S, Cherif FT, et al. (2014) Childhood tuberculosis: a concern of the modern world. *European Respiratory Review* 23(133): 278–291.

John TJ, Vashishtha VM, John SM (2013) 50 years of tuberculosis control in India: progress, pitfalls and the way forward. *Indian Pediatrics* 50(1): 93–98.

Kapoor SK, Raman AV, Sachdeva KS, et al. (2012) How did the TB patients reach DOTS services in Delhi? A study of patient treatment seeking behavior. *PloS One* 7(8): e42458.

Kiwuwa MS, Charles K, Harriet MK (2005) Patient and health service delay in pulmonary tuberculosis patients attending a referral hospital: a cross-sectional study. *BMC public health* 5: 122.

Kumar A, Gupta D, Nagaraja SB, et al. (2013) Updated national guidelines for pediatric tuberculosis in India, 2012. *Indian Pediatrics* 50(3): 301–306.

Leung ECC, Leung CC, Tam CM (2007) Delayed presentation and treatment of newly diagnosed pulmonary tuberculosis patients in Hong Kong. *Hong Kong Medical Journal* 13(3): 221–227.

Marais BJ (2008) Tuberculosis in children. *Pediatric Pulmonology* 43(4): 322–329.

- Marais BJ, Gie RP, Hesselning AC, et al. (2006) A refined symptom-based approach to diagnose pulmonary tuberculosis in children. *Pediatrics* 118(5): e1350–1359.
- Marais BJ, Obihara CC, Warren RM, et al. (2005) The burden of childhood tuberculosis: a public health perspective. *The International Journal of Tuberculosis and Lung Disease* 9(12): 1305–1313.
- Nelson LJ, Wells CD (2004) Global epidemiology of childhood tuberculosis. *The International Journal of Tuberculosis and Lung Disease* 8(5): 636–647.
- Newton SM, Brent AJ, Anderson S, et al. (2008) Paediatric tuberculosis. *The Lancet Infectious Diseases* 8(8): 498–510.
- Osei E, Akweongo P, Binka F (2015) Factors associated with DELAY in diagnosis among tuberculosis patients in Hohoe Municipality, Ghana. *BMC public health* 15: 721.
- Paz-Soldan VA, Alban RE, Dimos Jones C, et al. (2014) Patient Reported Delays in Seeking Treatment for Tuberculosis among Adult and Pediatric TB Patients and TB Patients Co-Infected with HIV in Lima, Peru: A Qualitative Study. *Frontiers in Public Health* 2: 281.
- Pearce EC, Woodward JF, Nyandiko WM, et al. (2012) A systematic review of clinical diagnostic systems used in the diagnosis of tuberculosis in children. *AIDS research and treatment* 2012: 401896.
- Perez-Velez CM and Marais BJ (2012) Tuberculosis in Children. *New England Journal of Medicine* 367(4): 348–361.
- Pothukuchi M, Nagaraja SB, Kelamane S, et al. (2011) Tuberculosis Contact Screening and Isoniazid Preventive Therapy in a South Indian District: Operational Issues for Programmatic Consideration. *PLoS One* 6(7): e22500.
- Puwar B, Patel V, Puwar T (2012) A record based study on paediatric tuberculosis in Ahmedabad city, India. *National Journal of Community Medicine* 3(1): 153-156.
- Rajeswari R, Balasubramanian R, Muniyandi M, et al. (1999) Socio-economic impact of tuberculosis on patients and family in India. *The International Journal of Tuberculosis and Lung Disease: The Official Journal of the International Union Against Tuberculosis and Lung Disease* 3(10): 869–877.
- Ruchi, Thakur HP (2013) Characteristics of childhood tuberculosis patients registered under RNTCP in Varanasi, Uttar Pradesh. *Indian Journal of Public Health* 57(1): 36–39.
- Saldana L, Abid M, McCarthy N, et al. (2013) Factors affecting delay in initiation of treatment of tuberculosis in the Thames Valley, UK. *Public Health* 127(2): 171–177.
- Satyanarayana S, Shivashankar R, Vashist RP, et al. (2010) Characteristics and programme-defined treatment outcomes among childhood tuberculosis (TB) patients under the national TB programme in Delhi. *PloS One* 5(10): e13338.

- Selvam JM, Wares F, Perumal M, et al. (2007) Health-seeking behaviour of new smear-positive TB patients under a DOTS programme in Tamil Nadu, India, 2003. *The International Journal of Tuberculosis and Lung Disease* 11(2): 161–167.
- Somma D, Thomas BE, Karim F, et al. (2008) Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *The International Journal of Tuberculosis and Lung Disease* 12(7): 856–866.
- Sreeramareddy CT, Panduru KV, Menten J, et al. (2009) Time delays in diagnosis of pulmonary tuberculosis: a systematic review of literature. *BMC infectious diseases* 9: 91.
- Sreeramareddy CT, Qin ZZ, Satyanarayana S, et al. (2014) Delays in diagnosis and treatment of pulmonary tuberculosis in India: a systematic review. *The international journal of tuberculosis and lung disease* 18(3): 255–266.
- Storla DG, Yimer S, Bjune GA (2008) A systematic review of delay in the diagnosis and treatment of tuberculosis. *BMC public health* 8: 15.
- Swaminathan S, Datta M, Radhamani MP, et al. (2008) A profile of bacteriologically confirmed pulmonary tuberculosis in children. *Indian Pediatrics* 45(9): 743–747.
- Swaminathan S, Rekha B (2010) Pediatric tuberculosis: global overview and challenges. *Clinical Infectious Diseases* 50(Suppl 3): S184–194.
- TBC India. (2015) *History of TB Control*. Available from: <http://www.tbindia.nic.in/history.html> (Accessed 28 March 2015)
- Tobgay KJ, Sarma PS, Thankappan KR (2006) Predictors of treatment delays for tuberculosis in Sikkim. *The National Medical Journal of India* 19(2): 60–63.
- Triasih R, Rutherford M, Lestari T, et al. (2011) Contact Investigation of Children Exposed to Tuberculosis in South East Asia: A Systematic Review, Contact Investigation of Children Exposed to Tuberculosis in South East Asia: A Systematic Review. *Journal of Tropical Medicine, Journal of Tropical Medicine* 2012: e301808.
- Trigueiro DRSG, Nogueira J de A, Sá LD de, et al. (2014) The influence of individual determinants in the delay of the tuberculosis diagnosis. *Texto & Contexto - Enfermagem* 23(4): 1022–1031.
- World Health Organization. (2004) *Gender in Tuberculosis Research*. Geneva: WHO.
- World Health Organization (2006) *Diagnostic and treatment delay in tuberculosis -An in-depth analysis of the health-seeking behaviour of patients and health system response in seven countries of the Eastern Mediterranean Region*. Cairo: WHO.
- World Health Organization (2008) *Implementing the WHO Stop TB Strategy: a handbook for national TB control programmes*. Geneva: World Health Organization.

World Health Organization (2011) *Early detection of tuberculosis- An overview of approaches, guidelines and tools*. Geneva: WHO.

World Health Organization (2012) *Recommendations for investigating contacts of persons with infectious tuberculosis in low- and middle-Income countries*. Geneva: WHO.

World Health Organization (2013) *Roadmap for childhood tuberculosis: towards zero deaths*. Geneva: WHO.

World Health Organization (2014) *Global tuberculosis report 2014*. Geneva: World Health Organization.

Yang WT, Gounder CR, Akande T, et al. (2014) Barriers and Delays in Tuberculosis Diagnosis and Treatment Services: Does Gender Matter? *Tuberculosis Research and Treatment* 2014.

ANNEXURE II

Interview schedule

**Delay in care seeking and treatment initiation among pediatric TB patients in
Delhi**

Achutha Menon Centre for Health Science Studies,
Sree Chitra Tirunal Institute for Medical Sciences & Technology,
Thiruvananthapuram, Kerala, 695011

*All information obtained from this interview will remain confidential and will be used for research purposes only.
Individual information will not be disclosed to anyone under any circumstances.*

Serial number:

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District code

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 DOTS center code

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Relation of informant with pediatric TB patient:-

Section 1: Checklist (Fill checklist before proceeding)

Section 2: General information

Location and date		Response	Instructions								
2.1	Participant's unique identification (UID) Number	<table border="1" style="width: 100%; text-align: center;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table> <p style="text-align: center; margin-top: 5px;">District code DOTS center Patient ID</p>									
2.2	Date of interview	<table border="1" style="width: 100%; text-align: center;"> <tr> <td style="width: 30px; height: 20px;">DD</td> <td style="width: 30px; height: 20px;">MM</td> <td style="width: 30px; height: 20px;">YYYY</td> </tr> </table>	DD	MM	YYYY						
DD	MM	YYYY									
2.3	Start time	<table border="1" style="width: 100%; text-align: center;"> <tr> <td style="width: 20px; height: 20px;">HH</td> <td style="width: 20px; height: 20px;">MM</td> <td style="width: 20px; height: 20px;">AM</td> <td style="width: 20px; height: 20px;">PM</td> </tr> </table>	HH	MM	AM	PM					
HH	MM	AM	PM								
2.4	End time	<table border="1" style="width: 100%; text-align: center;"> <tr> <td style="width: 20px; height: 20px;">HH</td> <td style="width: 20px; height: 20px;">MM</td> <td style="width: 20px; height: 20px;">AM</td> <td style="width: 20px; height: 20px;">PM</td> </tr> </table>	HH	MM	AM	PM					
HH	MM	AM	PM								
2.5	No. of visit (s) made to complete interview										
2.6	T.B. Registration number		From records								
2.7	TB Unit										
2.8	Type of DOTS center	<table border="1" style="width: 100%;"> <tr> <td style="width: 20px; text-align: center;">1</td> <td>Government health facility</td> </tr> <tr> <td style="text-align: center;">2</td> <td>Community Volunteer</td> </tr> <tr> <td style="text-align: center;">3</td> <td>Non-Governmental Organization</td> </tr> <tr> <td style="text-align: center;">4</td> <td>Private practitioner</td> </tr> </table>	1	Government health facility	2	Community Volunteer	3	Non-Governmental Organization	4	Private practitioner	
1	Government health facility										
2	Community Volunteer										
3	Non-Governmental Organization										
4	Private practitioner										

2.9	DOTS center location	1 2	Urban Rural	
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Section 3: Background characteristics

Sl. No.	Questions		Response	Instructions
3.1	How old was your child on last birthday? (in years)			
3.2	Residence			
3.3	Who looks after the child's health care needs most of the times? (This means during the last three times when the child was ill, who looked after the child?)	1 2 3 4 5	Mother Father Grandparents Other family members within same household Others (specify)	
3.4	MOTHER			
3.5	Age in completed years		_____	
	Literacy	1 2 3 4 5 99	No formal education Primary school completed Secondary school completed Graduate level completed Post Graduate and above Refused	
3.6	Which of the following best describes your main work status over the past 12 months?	1 2 3	Regular income Irregular income No income- Unemployed	
3.7	FATHER			
3.8	Age in completed years		_____	
	Literacy	1 2 3 4 5 99	No formal education Primary school completed Secondary school completed Graduate level completed Post Graduate and above Refused	
3.9	Which of the following best describes your main work status over the past 12 months?	1 2	Regular income Irregular income	

		3	No income- Unemployed											
3.10	PRIMARY CARE GIVER (applicable only if different from parents) Age in completed years			If coded 1 or 2 in 3.3 then skip 3.10, 3.11, 3.12										
3.11	Literacy	1 2 3 4 5 99	No formal education Primary school completed Secondary school completed Graduate level completed Post Graduate and above Refused											
3.12	Which of the following best describes your main work status over the past 12 months?	1 2 3	Regular income Irregular income No income- Unemployed											
3.13	Are you a BPL card holder?	1 2 99	Yes No Can't say											
3.14	Monthly income of the household (in Rs.)													
3.15	Religion of the head of the household	1 2 3 4 5 99	Hindu Muslim Christian Sikh Other Can't say											
3.16	To which community do you belong?	1 2 3 4 5 99	General Scheduled caste Scheduled Tribe Other backward classes Don't know Can't say											
3.17	How many people, including yourself, live in your household?		<table border="1"> <thead> <tr> <th>Category</th> <th>Number</th> </tr> </thead> <tbody> <tr> <td>Younger children (0 to 5 years)</td> <td></td> </tr> <tr> <td>Older children (6 to 14 years)</td> <td></td> </tr> <tr> <td>Above 14 years</td> <td></td> </tr> <tr> <td>Total</td> <td></td> </tr> </tbody> </table>	Category	Number	Younger children (0 to 5 years)		Older children (6 to 14 years)		Above 14 years		Total		
Category	Number													
Younger children (0 to 5 years)														
Older children (6 to 14 years)														
Above 14 years														
Total														
3.18	How many rooms are there in your house?													

3.19	Owner of house where you stay currently	1 2 3 99	Staying on rent Own the house Staying with relative Can't say	
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Section 4: Patient characteristics

Pediatric TB patient characteristics		Response		Instructions
4.1	Place of birth of child	1 2 3 99	Delhi Outside Delhi Don't know Can't say	
4.2	Reason for staying in Delhi			Answer this only if coded 2 for 4.1
4.3	Educational status of the child	1 2 3 4 99	Never went to school Presently studying in school Was studying and taken leave for treatment Discontinued completely upon diagnosis Not applicable	"Not applicable" if child is under the age of 3 years. If coded 1 or 99, then skip Q 4.4 and 4.5
4.4	Have you informed school authorities/teachers about TB diagnosis?	1 2 99	Yes No Can't say	
4.5	If No for Q4.4, then please state the reason for not informing in school			
4.6	Has your child ever been in contact with anyone having continuous cough for more than a month or having TB? <i>Question only for <6 years child</i>	1 2 3 4 5 6 7	No contact If Yes then within 1 year within 1- 2 years 2-3 years 3 -4 years, more than 4years Don't know	If coded 1 then skip Q4.7
4.7	What was/is the relation of child with person/persons suffering from TB? <i>Question only for <6 years child</i>	1 2 3 4 5 6	Mother Father Grandparents Siblings Neighbours Others(specify)	
4.8	What were the symptoms experienced by your child (regard to TB)?	1 2	Mentioned unprompted Cough Fever	Mentioned after prompting 1- Cough 2- Fever

		3	Loss of Weight	3- Loss of Weight	
		4	Swelling	4- Swelling	
		5	Pain (chest, abdomen etc.)	5- Pain (chest, abdomen etc.)	
		6	Others (specify)	6- Others (specify)	
4.9	Which of these symptom(s) were worrying enough for you to go to a health care provider? (multiple response possible)	1	Cough		
		2	Fever		
		3	Loss of Weight		
		4	Swelling		
		5	Pain (chest, abdomen etc.)		
		6	Others (as specified in previous Q4.8)		
4.10	After how many days of onset of symptoms did you go to health care provider?				
4.11	Number of health providers consulted till reaching RNTCP for treatment? (Excluding RNTCP)				

Section 5: Health care seeking pathway

	Category	Provider consulted:	Health facility	Approximate gap between two actions? (in days) Record date if available	Was there any break or stoppage in treatment? If yes, then for how long (in days)?	Diagnosis made, if any: (as reported by Patient)	Reason for going to the provider
			1-Not applicable			1-TB	1-Confidentiality
	Action taken	1-Private Doctor	2-Pharmacy			2-Other (specify)	2-Good quality services
		2-Government doctor	3-TB Centre/Chest Hospital				3-Referred by family/friends
		3-Vaidya	4-Public Hospital				4-Affordable/free services
		4-Pharmacist	5-Private Practice (Hospital or Clinic)				5-Services available anytime
		5-Self-medication	6-Others (specify)				6-Near to house
		6-Others (specify)					7-Faith & belief /confidence in getting cured
							8-Did not get better
5.1	1 st action						9-Referred by doctor
5.2	2 nd action						10-Others (specify)
5.3	3 rd action						

5.4	4 th action						
5.5	5 th action						
5.6	6 th or more actions till diagnosis						

Questions		Response		Instructions
5.7	Date first seen by HCP for the current illness		DD/MM/YYYY	
5.8	Who took the decision to seek care for the first time?	1 2 3 4 5 6	Mother Father Both parents Family members Neighbours Others (specify)	
5.9	Self-perceived reasons for time lag between onset of symptoms and visiting the doctor (multiple responses possible)	1 2 3 4 5 6 7 8 9	No time lag Fear of what would be found on diagnosis Hoped that symptoms would go away on their own No health facility around Money constraints Poor quality of health services Long waiting hours at health facility Busy with work Others (specify)	
5.10	Distance (in km) from home to the health facility where you went first			
5.11	Did you take leave from work for treatment purpose?	1 2 3	Yes No Don't remember	Skip 5.12 if coded 2 or 3.
5.12	If yes, did this affect your job?	1 2	Yes No	
5.13	Date of diagnosis of TB		DD/MM/YYYY	Confirm from records
5.14	Date of starting DOTS		DD/MM/YYYY	Confirm from records
5.15	Who provides DOTS treatment tablets to the child?	1 2 3 4	Mother Father Other family member DOTS provider	

Section 6: Informant's knowledge on TB

Informant's knowledge on TB		Response	Instructions
6.1	Before your child was diagnosed with TB, had you heard of any other child having TB?	1 2	Yes No
6.2	Before you came to _____ TB Centre, what did you think this illness that your child had was?	1 2	TB Others (specify)
6.3	What do you think about the causes of TB? (multiple responses possible)	1 2 3 4 5 6 7	Bacteria Malnutrition Contact with other TB patient Sin Witchcraft Don't know Others (specify)
6.4	Source of information on TB	1 2 3 4 5	TV/Radio/Newspaper From health provider Friends/relatives Someone known having TB disease Others (specify)
<p>[Yes/right, 1] [No/wrong, 2] [not known, 3]</p> <p>I am going to read a series things that I have heard about TB. Can you tell me whether these statements are correct? In case you do not know whether it is correct, you can also tell me that you do not know the answer.</p>			
6.5	TB is hereditary	1 2 3	
6.6	TB is contagious, that is it is spread from person to person.	1 2 3	
6.7	There is a treatment for TB	1 2 3	
6.8	There is a vaccine for TB	1 2 3	
6.9	The approximate duration of treatment for TB is 6 months	1 2 3	
6.10	TB treatment is available free of cost	1 2 3	
6.11	TB affects lungs	1 2 3	
6.12	TB affects other body parts/organs like bones, abdomen etc.	1 2 3	

Section 7: Stigma

I am trying to find out whether or not there is some form of discrimination against people who have TB still prevailing in our society. I am asking you to respond to a set of statements and say if this ever happens.

	Stigma	Response		
		Never	Sometimes	Ever Always
7.1	Parents are ashamed if their children have TB			
7.2	The diagnosis of TB in a child is kept hidden from others.			
7.3	Family members keep the child with TB isolated from family gatherings/festivals			
7.4	Neighbours treat a child differently if they come to know that the child has TB			
7.5	Family members will treat a child differently if they come to know that the child has TB			
7.6	A child with TB is not allowed to play with others			
7.7	TB treatment for a girl will be delayed			
7.8	TB Treatment for a boy will be delayed			
7.9	The dishes used by a child with TB will be kept and washed separately			
7.10	The clothes worn by a child with TB will be kept and washed separately			
7.11	The education of a girl child is likely to suffer after having TB disease			
7.12	The education of a boy child is likely to suffer after having TB disease			
7.13	Parents are likely to hide past TB experience of a girl child during time of her marriage			
7.14	Parents are likely to hide past TB experience of a boy child during time of his marriage			

Thank you for your time!

From records:-

1	Type of TB which the child is suffering from	1 2 3	Smear-Negative Pulmonary TB Smear-Positive Pulmonary TB Extra Pulmonary TB																									
2	If child has extrapulmonary TB, then site of TB	1 2 3 4 5 6 7	Peripheral Lymph nodes Abdomen Pleural effusion Hilar Adenopathy Bones/Joints Brain/meninges Other (Specify)																									
3	HIV status of the child (from records/treatment card)	1 2 3	Positive Negative Not recorded																									
4	Investigations done		<table border="1"> <thead> <tr> <th></th> <th>Date</th> <th>Result</th> </tr> </thead> <tbody> <tr> <td>1- Sputum examination</td> <td></td> <td></td> </tr> <tr> <td>2- X-ray</td> <td></td> <td></td> </tr> <tr> <td>3- Mantoux test</td> <td></td> <td></td> </tr> <tr> <td>4- FNAC</td> <td></td> <td></td> </tr> <tr> <td>5- Biopsy</td> <td></td> <td></td> </tr> <tr> <td>6- Gastric Lavage/Induced Sputum</td> <td></td> <td></td> </tr> <tr> <td>7- Others (specify)</td> <td></td> <td></td> </tr> </tbody> </table>		Date	Result	1- Sputum examination			2- X-ray			3- Mantoux test			4- FNAC			5- Biopsy			6- Gastric Lavage/Induced Sputum			7- Others (specify)			
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6- Gastric Lavage/Induced Sputum																												
7- Others (specify)																												

Interview Guide

Thank you very much for agreeing to talk to me about your child's illness. I am trying to find out all the things you did to help find treatment for your child.

1. Can you describe what were the symptoms that your child had and how you went about treating them?
2. What were the symptoms that caused you to go to a health care giver?
3. Whom did you go to and what did they suggest?
 - Did you follow the treatment recommended?
 - Did that treatment work?
 - What were the problems you faced in following the treatment suggested?
 - Why did you go to this provider?
 - What did you do after that? (Or did you seek another health care provider?)

REPEAT FOR EVERY PROVIDER MENTIONED

4. Can you describe everything that you did before coming to the TB Centre?
5. What did you do when you came here and found out that your child has TB?
6. Have you told other members of your family/friends/neighbours about it?
 - What was their reaction?
 - What have you done solve the problems faced because of this?
7. You have been coming to this TB Centre for treatment. What are the problems that you have coming here and taking treatment? Can you describe your experiences within this centre from the time you first came, got your child diagnosed and now taking treatment?
8. What would you do if you came across any parent with a child with symptoms similar to that of your child in your neighbourhood? (probe – would you suggest the TB Centre to them? Or would you not? Why)

MAKE SURE THAT EVERY TREATMENT OPTION HAS BEEN ASKED.

Thank parents for giving time.

Interviewer: Aakshi

Date:

UID:

ANNEXURE IV

Achutha Menon Centre for Health Science Studies
Sree Chitra Tirunal Institute for Medical Sciences & Technology,
Thiruvananthapuram, Kerala-695011

Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi

Research Subject Information Sheet

Namaskar! I am Dr. Aakshi Kalra, currently pursuing Master of Public Health course at Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala. I am doing a study on “Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi” as part of my coursework.

Purpose of study:

The purpose of the research is to find out the duration between the onset of symptoms and starting of DOTS treatment for pediatric tuberculosis (TB) patients and factors which influence such duration gap.

About the study:

In this study, survey in selected DOTS centers and few in-depth interviews will be conducted in Delhi. Total of 175 interviews will be done in Delhi among the primary care givers of pediatric TB patients selected by random selection process. This study is being conducted by me as Principal Investigator (PI) under supervision of Dr. Mala Ramanathan, Additional Professor at Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum.

The State TB office of Revised National Tuberculosis Control Programme in Delhi has granted me permission to undertake this study. The ethics approval for this study has been obtained from Institutional Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology.

What participation will be required from your side?

Participation involves answering some questions regarding your child's health and actions taken by you while seeking care/treatment. If you agree to participate in the study, then I will interview you for about 20-30 minutes. The information given by you will be documented. After the interview you may be contacted again only if it is found that the information documented is either incomplete or any further clarification is needed.

Benefits from the study:

The study will not directly benefit you. There will be no incentive in any form for participating in the study. But the results of the study will be helpful in further research and policy making which may benefit the society as a whole.

Possible harms from the study:

Some of the questions will be of a personal nature which may make you uncomfortable. In such case you are free to take time to answer or if you are not willing to answer, you can ask me to skip the question. If still you are not willing to answer further, you will be free to terminate the interview without any obligation.

Confidentiality of your data:

Whatever information you share will be kept highly confidential and will only be accessible to me and my supervisor. All the information that is being collected will be used solely for research. Your personal details will not be shared with anyone at any stage. The data other than your personal identifiers will be used for analysis of the study. The results of the study will be published and presented in public forums.

Withdrawal from the study:

Your participation in the study will be completely voluntary. You are free and have right to withdraw during the interview at any time. There will be no penalty for withdrawal or not participating in the study.

Is there any query or doubt you want to ask? I will try to clarify it to best of my ability.

Name of the Principal Investigator: Dr. Aakshi Kalra

Signature of Principal Investigator:

Contact No. of Principal Investigator: 0-8301834467

If you have any doubt/query on the authentication of this study, you may contact the SCTIMST Institutional Ethics Committee Secretary - Dr. Mala Ramanathan. Contact No. – 0471-2524234

Are you willing to participate in the study? - Yes / No.

- If yes – please fill up and give signature on the informed consent provided.
- If no – can you please tell the reason for not participating in the study?

Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi

Respondent code:

Informed Consent

I _____, have read/heard and understood all the information provided in the 'Research subject information sheet' and I have clarified all my doubts. By signing/putting thumb impression I confirm my voluntary participation in this study. I agree to be contacted again if any missing information or further clarification is needed. I understand my right to withdraw from the interview anytime without any obligation. I also understand that my identity will not be revealed in any published or released information from this study.

Signature of the respondent or
Thumb impression (if unable to sign): _____.

Date:
Place:

Witness (if needed): I confirm that the Principal Investigator (Dr. Aakshi Kalra) has explained all the information in the Research subject information sheet to Mr./Mrs./Miss _____ and this person has voluntarily agreed to participate in the study.

Signature of the witness: _____.

Name of the witness: _____.

Date:
Place:

Consent obtained: Yes / No

Type of consent: Written / Oral

Signature of the Principal Investigator: _____.

Name of the Principal Investigator: Dr. Aakshi Kalra

Date:
Place:

ANNEXURE V

Achutha Menon Centre for Health Science Studies
Sree Chitra Tirunal Institute for Medical Sciences & Technology,
Thiruvananthapuram, Kerala-695011

Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi

Research Subject Information Sheet

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Purpose of in-depth interview:

I have already asked you questions about the treatment for TB for your child. I have selected you for in-depth interview as your experiences with health care and treatment have been unique. I would like to understand the processes of decision making regarding care seeking for your child. Each stage of treatment that you have experienced offers insights into the problems experienced by parents/guardians of children with TB.

About in-depth interview:

A total of 10-15 interviews will be done among the primary care givers of pediatric TB patients in Delhi. This study is being conducted by me as Principal Investigator under supervision of Dr. Mala Ramanathan, Additional Professor at Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum.

The State TB office of Revised National Tuberculosis Control Programme in Delhi has granted me permission to undertake this study. The ethics approval for this study has been obtained from Institutional Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology.

What participation will be required from your side?

For this reason, I would like to interview you for about 30-40 minutes to understand the problems you have experienced while seeking care and getting treatment for your child. The information given by you will be audio recorded. After the interview you may be contacted again only if it is found that the information documented is either incomplete or any further clarification is needed.

Benefits from the study:

The study will not directly benefit you. There will be no incentive in any form for participating in the study. But the results of the study will be helpful in further research & policy making which may benefit the society as a whole.

Possible harms from the study:

Some of the questions will be of a personal nature which may make you uncomfortable. In such case you are free to take time to answer or if you are not willing to answer, you can ask me to skip the question. If still you are not willing to answer further, you will be free to terminate the interview without any obligation.

Confidentiality of your data:

Whatever information you share will be kept highly confidential and will only be accessible to me and my supervisor. All the information that is being collected will be used solely for research. Your personal details will not be shared with anyone at any stage. The data other than your personal identifiers will be used for analysis of the study. The results of the study will be published and presented in public forums.

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Are you willing to participate in the study? - Yes / No.

- If yes – please fill up and give signature on the informed consent provided.
 - If no – can you please tell the reason for not participating in the study?
-

Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi

Respondent code:

Informed Consent

I _____, have read/heard and understood all the information provided in the 'Research subject information sheet' and I have clarified all my doubts. By signing/putting thumb impression I confirm my voluntary participation in this study. I agree to be contacted again if any missing information or further clarification is needed. I permit the researcher to audio record my interview for research purposes and share recording with supervisor only. I understand my right to withdraw from the interview anytime without any obligation. I also understand that my identity will not be revealed in any published or released information from this study.

Signature of the respondent or
Thumb impression (if unable to sign): _____.

Date:
Place:

Witness (if needed): I confirm that the Principal Investigator (Dr. Aakshi Kalra) has explained all the information in the Research subject information sheet to Mr./Mrs./Miss _____ and this person has voluntarily agreed to participate in the study.

Signature of the witness: _____.

Name of the witness: _____.

Date:
Place:

Consent obtained: Yes / No

Type of consent: Written / Oral

Signature of the Principal Investigator: _____.

Name of the Principal Investigator: Dr. Aakshi Kalra

Date:
Place:

ANNEXURE VI
साक्षात्कार सारणी

दिल्ली में बाल टी.बी.(क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने में विलम्ब

अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र

श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रौद्योगिकी संस्थान, तिरुवनंतपुरम, केरल, 6950011

इस साक्षात्कार द्वारा प्राप्त सभी सूचनाएं गोपनीय रखी जाएंगी और ये सूचनाएं केवल शोध उद्देश्यों के लिए उपयोग की जाएंगी। व्यक्तिगत सूचनाएं किसी को भी किसी भी परिस्थिति में नहीं बतायी जाएगी।

क्रमांक:

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जिला कोड:

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डॉट्स केन्द्र कोड:

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सूचना देने वाले का बाल टी.बी. रोगी से संबंध :-

खण्ड-1: जांच सूची (आगे बढ़ने से पहले जांच सूची भरें।)

खण्ड-2: सामान्य सूचनाएं

स्थान और तिथि	उत्तर	निर्देश								
2.1 सहभागी का विशेष पहचान संख्या	<table border="1" style="width: 100%;"><tr><td style="width: 16.6%; height: 30px;"></td><td style="width: 16.6%;"></td><td style="width: 16.6%;"></td><td style="width: 16.6%;"></td><td style="width: 16.6%;"></td><td style="width: 16.6%;"></td></tr></table> <p style="text-align: center;">जिला कोड डॉट्स केन्द्र रोगी पहचान क्रमांक</p>									
2.2 साक्षात्कार की तिथि	<table border="1" style="width: 100%;"><tr><td style="width: 33%; height: 30px;">तिथि</td><td style="width: 33%;">माह</td><td style="width: 33%;">वर्ष</td></tr></table>	तिथि	माह	वर्ष						
तिथि	माह	वर्ष								
2.3 प्रारम्भ का समय	<table border="1" style="width: 100%;"><tr><td style="width: 16.6%; height: 30px;">घं.</td><td style="width: 16.6%;">मि.</td><td style="width: 33%;">पू./ अ.</td></tr></table>	घं.	मि.	पू./ अ.						
घं.	मि.	पू./ अ.								
2.4 समाप्ति का समय	<table border="1" style="width: 100%;"><tr><td style="width: 16.6%; height: 30px;">घं.</td><td style="width: 16.6%;">मि.</td><td style="width: 33%;">पू./ अ.</td></tr></table>	घं.	मि.	पू./ अ.						
घं.	मि.	पू./ अ.								
2.5 साक्षात्कार पूरा करने के लिए की गई कुल मुलाकात										
2.6 टी.बी. पंजीकरण संख्या		From records								
2.7 टी.बी. युनिट										
2.8 डॉट्स केन्द्र के प्रकार	<table border="1" style="width: 100%;"><tr><td style="width: 5%; text-align: center;">1</td><td>सरकारी स्वास्थ्य केन्द्र</td></tr><tr><td style="text-align: center;">2</td><td>समुदाय स्वयंसेवी</td></tr><tr><td style="text-align: center;">3</td><td>गैर-सरकारी संगठन</td></tr><tr><td style="text-align: center;">4</td><td>निजी चिकित्सक</td></tr></table>	1	सरकारी स्वास्थ्य केन्द्र	2	समुदाय स्वयंसेवी	3	गैर-सरकारी संगठन	4	निजी चिकित्सक	
1	सरकारी स्वास्थ्य केन्द्र									
2	समुदाय स्वयंसेवी									
3	गैर-सरकारी संगठन									
4	निजी चिकित्सक									

2.9	डॉट्स केन्द्र का स्थान	1	शहरी	
		2	ग्रामीण	

खण्ड 3: पृष्ठभूमि की विशिष्टताएं

प्रश्न		उत्तर		
3.1	पिछले जन्मदिन पर आपके बच्चे की उम्र कितनी थी? (वर्षों में)			
3.2	पता			Will be coded as per administrative divisions of Delhi Govt.
3.3	बच्चे के स्वास्थ्य संबंधी ज़रूरतों को अधिकतर कौन देखता है?(अर्थात पिछली तीन बार जब बच्चा बीमार था तो बच्चे की देखभाल किसने की थी?)	1 2 3 4 5	माता पिता दादा-दादी / नाना-नानी परिवार के अन्य सदस्य जो उसी घर में रहते हो अन्य (स्पष्ट किजिए)	
3.4	माता आयु (पूर्ण वर्षों में)		
3.5	शिक्षा	1 2 3 4 5 99	कोई औपचारिक शिक्षा नहीं प्राथमिक स्कूल के स्तर तक माध्यमिक स्कूल के स्तर तक स्नातक स्तर तक परास्नातक या उससे अधिक स्तर तक मना कर दिया	
3.6	पिछले 12 महीनों में आपके मुख्य कार्य स्थिति का उल्लेख निम्नलिखित में से कौन सबसे सही करता है?	1 2 3	नियमित वेतन अनियमित वेतन कोई आमदनी नहीं – बेरोज़गार	

3.7	पिता आयु (पूर्ण वर्षों में)		
3.8	शिक्षा	1 2 3 4 5 99	कोई औपचारिक शिक्षा नहीं प्राथमिक स्कूल के स्तर तक माध्यमिक स्कूल के स्तर तक स्नातक स्तर तक परास्नातक या उससे अधिक स्तर तक मना कर दिया	
3.9	पिछले 12 महीनों में आपके मुख्य कार्य स्थिति का उल्लेख निम्नलिखित में से कौन सबसे सही करता है?	1 2 3	नियमित वेतन अनियमित वेतन कोई आमदनी नहीं – बेरोज़गार	
3.10	मुख्य देखभाल कर्ता (माता-पिता से भिन्न होने की स्थिति में यह सवाल लागू होगा) आयु (पूर्ण वर्षों में)		If coded 1 or 2 in 3.3 then skip 3.10, 3.11, 3.12
3.11	शिक्षा	1 2 3 4 5 99	कोई औपचारिक शिक्षा नहीं प्राथमिक स्कूल के स्तर तक माध्यमिक स्कूल के स्तर तक स्नातक स्तर तक परास्नातक या उससे अधिक स्तर तक मना कर दिया	
3.12	पिछले 12 महीनों में आपके मुख्य कार्य स्थिति का उल्लेख निम्नलिखित में से कौन सबसे सही करता है?	1 2 3	नियमित वेतन अनियमित वेतन कोई आमदनी नहीं – बेरोज़गार	
3.13	क्या आप बी.पी.एल. कार्ड धारक हैं?	1 2 3	हां नहीं कह नहीं सकते	
3.14	घर की मासिक आय (रु. में)			
3.15	घर के मुखिया का धर्म	1 2 3 4 5 99	हिन्दू मुस्लिम ईसाई सिख अन्य कह नहीं सकते	

3.16	आप किस समुदाय से आते हैं?	1 2 3 4 5 99	सामान्य अनुसूचित जाति अनुसूचित जनजाति अन्य पिछड़ा वर्ग नहीं मालूम नहीं बता सकते											
3.17	आपके परिवार में आपके साथ कितने लोग रहते हैं?		<table border="1"> <tr> <td>श्रेणी</td> <td>संख्या</td> </tr> <tr> <td>छोटे बच्चे (0 से 5 वर्ष)</td> <td></td> </tr> <tr> <td>बड़े बच्चे (6 से 14 वर्ष)</td> <td></td> </tr> <tr> <td>14 वर्ष से अधिक</td> <td></td> </tr> <tr> <td>कुल</td> <td></td> </tr> </table>	श्रेणी	संख्या	छोटे बच्चे (0 से 5 वर्ष)		बड़े बच्चे (6 से 14 वर्ष)		14 वर्ष से अधिक		कुल		
श्रेणी	संख्या													
छोटे बच्चे (0 से 5 वर्ष)														
बड़े बच्चे (6 से 14 वर्ष)														
14 वर्ष से अधिक														
कुल														
3.18	आपके मकान में कुल कितने कमरे हैं?													
3.19	वर्तमान में आप जिस मकान में निवास कर रहे हैं उसके मालिक कौन है?	1 2 3 99	किराये का मकान स्वयं का मकान रिश्तेदार के यहां कह नहीं सकते											

खण्ड 4 : रोगी की विशिष्टताएं

बाल टी.बी. रोगी की विशिष्टताएं		उत्तर		
4.1	बच्चे का जन्म स्थान	1 2 3 99	दिल्ली दिल्ली से बाहर मालूम नहीं कह नहीं सकते	
4.2	दिल्ली में रहने का कारण			Answer this only if coded 2 for 4.1
4.3	बच्चे की शैक्षिक स्थिति	1 2 3 4 99	कभी विद्यालय नहीं गया वर्तमान में विद्यालय में पढ़ रहा है पढ़ रहा था और इलाज के लिए अवकाश लिया रोग की पुष्टि होने के बाद पढ़ाई पूरी तरह से बंद कर दी लागू नहीं	“Not applicable” if child is under the age of 3 years. If coded 1 or 99, then skip Q 4.4 and 4.5
4.4	क्या आपने टी.बी. की पुष्टि के बारे में विद्यालय के प्राधिकारियों/शिक्षकों को बताया?	1 2 99	हां नहीं कह नहीं सकते	

4.5	यदि प्रश्न के उत्तर में नहीं हो तो, विद्यालय में नहीं बताने का कारण?			
4.6	क्या कभी आपका बच्चा किसी के सम्पर्क में रहा है जिन्हें लगातार एक महीने से ज्यादा खांसी रही हो या टी.बी. का रोग ? (यह सवाल केवल 6 साल से कम उम्र वाले बच्चों के मुख्य देखभाल कर्ता के लिए है)	1 2 3 4 5 6 7	कोई सम्पर्क नहीं यदि हां तो— 1 वर्ष के भीतर 1 से 2 वर्ष के भीतर 2 से 3 वर्ष के भीतर 3 से 4 वर्ष के भीतर 4 वर्ष से अधिक नहीं मालूम	If coded 1 then skip Q4.7
4.7	टी.बी. से ग्रसित व्यक्ति/व्यक्तियों से बच्चे का क्या सम्बन्ध था/है? (यह सवाल केवल 6 साल से कम उम्र वाले बच्चों के मुख्य देखभाल कर्ता के लिए है)	1 2 3 4 5 6	माता पिता दादा—दादी/नाना—नानी भाई/बहन पड़ोसी अन्य (स्पष्ट कीजिए)	
4.8	आपके बच्चे को कौनसे लक्षण अनुभव हुए थे? (क्षय से जुड़े)	1 2 3 4 5 6	अपने आप बताया खांसी बुखार वजन घटना सूजन दर्द (छाती, पेट अन्यत्र) अन्य (स्पष्ट कीजिए)	पूछने पर बताया 1.खांसी 2.बुखार 3.वजन घटना 4.सूजन 5.दर्द (छाती,पेट अन्यत्र) 6.अन्य (स्पष्ट कीजिए)
4.9	इनमें से कौन से लक्षण(णों) से चिंता होने पर आप स्वास्थ्य सेवा प्रदाता के यहां गये?	1 2 3 4 5 6	खांसी बुखार वजन घटना सूजन दर्द (छाती, पेट अन्यत्र) अन्य (जैसा कि पूर्व के प्रश्न में स्पष्ट है।)	
4.10	इन लक्षणों के प्रकट होने के कितने दिन बाद आप स्वास्थ्य सेवा प्रदाता के यहां गये?			
4.11	आर.एन.टी.सी.पी. में इलाज के लिए आने से पहले तक कितने स्वास्थ्य सेवा प्रदाता से परामर्श किया? (आर.एन.टी.सी.पी. को छोड़ के)			

खण्ड 5 स्वास्थ्य सेवा पाने की कोशिश का मार्ग

	श्रेणी	प्रदाता परामर्श	स्वास्थ्य सुविधा केन्द्र	दो क्रिया के बीच लगभग फासला? (दिनों में); तिथि रिकार्ड करे यदि हो तो	क्या इलाज बीच में रोका या छोड़ा है? अगर हां तो कितने समय के लिए	निदान, यदि कोई किया गया ? (जैसा रोगी द्वारा बताया गया हो)	स्वास्थ्य सेवा प्रदाता के पास जाने के कारण
		1.निजी चिकित्सक	1.लागू नहीं			1. टी.बी.	1.गोपनीयता
की गई क्रिया		2.सरकारी चिकित्सक	2.फार्मसी				2.अच्छी गुणवत्ता युक्त सेवा
		3.वैद्य	3.टी. बी. केन्द्र / चेस्ट अस्पताल				2. अन्य (स्पष्ट कीजिए)
		4. फार्मासिस्ट	4. सार्वजनिक अस्पताल				4.वहन करने योग्य / निःशुल्क सेवाएं
		5.स्वयं इलाज	5.निजी चिकित्सक (अस्पताल या दवाखाना)				
		6.अन्य (स्पष्ट कीजिए)	6.अन्य (स्पष्ट कीजिए)				
5.1	पहली क्रिया						
5.2	दूसरी क्रिया						
5.3	तीसरी क्रिया						
5.4	चौथी क्रिया						
5.5	पांचवी क्रिया						
5.6	छठवीं या उससे अधिक क्रियाएं - निदान के समय तक की गई						

प्रश्न		उत्तर	
5.7	मौजूदा रोग के लिए चिकित्सा सेवा प्रदाता से पहली बार मिलने की तिथि		तिथि/माह/वर्ष
5.8	किसने पहली बार चिकित्सा सेवा के लिए निर्णय लिया?	1 2 3 4 5 6	माता पिता दोनों माता-पिता परिवार के सदस्य पड़ोसी अन्य (स्पष्ट कीजिए)
5.9	आपकी खुद की समझ से लक्षण के दिखने और चिकित्सक के पास जाने के समय में अन्तराल होने के कारण क्या है (कई उत्तर संभव)	1 2 3 4 5 6 7 8 9	कोई समय अन्तराल नहीं निदान पर क्या पाया जाएगा उसका डर लक्षणों की स्वयं ठीक हो जाने की आशा आस-पास में कोई चिकित्सा सुविधा केन्द्र नहीं पैसे की कमी निम्न गुणवत्ता की चिकित्सीय सेवा चिकित्सीय सेवा के लिए लंबा इंतजार काम में व्यस्तता अन्य (स्पष्ट कीजिए)
5.10	स्वास्थ्य सेवा के लिए पहली बार आप जिस स्वास्थ्य केन्द्र गये थे उसकी आपके घर से दूरी (किमी. मे)?		
5.11	क्या आपने इलाज के लिए कार्य स्थल से छुट्टी ली थी?	1 2 3	हां नहीं याद नहीं
5.12	यदि हां तो क्या इससे आपका कार्य प्रभावित हुआ?	1 2	हां नहीं
5.13	टी.बी. के निदान की तिथि		तिथि/माह/वर्ष
5.14	डॉट्स आरम्भ करने की तिथि		तिथि/माह/वर्ष
5.15	बच्चे को डॉट्स उपचार टैबलेट कौन देता है?	1 2 3 4	माता पिता परिवार का अन्य सदस्य डॉट्स प्रदाता

खण्ड 6: सूचना देने वाले का टी.बी. संबंधी ज्ञान

सूचना देने वाले का टी.बी. संबंधी ज्ञान		उत्तर		
6.1	क्या आपने अपने बच्चे के टी.बी. होने की पुष्टिकरण से पहले, किसी अन्य बच्चे को टी.बी. हुआ हो ऐसा सुना था?	1 2	हां नहीं	
6.2	इस _____ (डॉट्स केन्द्र) में आने से पहले, आप अपने बच्चे की बीमारी के बारे में क्या सोचते थे?	1 2	टी.बी. अन्य (स्पष्ट कीजिए)	Response from Q2.8
6.3	आप टी.बी. के कारणों के बारे में क्या सोचते हैं? (कई उत्तर संभव)	1 2 3 4 5 6 7	बैक्टीरिया कुपोषण टी.बी. रोगी से संपर्क पाप जादू-टोना नहीं मालूम अन्य (स्पष्ट कीजिए)	
6.4	टी.बी. के बारे में जानकारी के स्रोत	1 2 3 4 5	टेलीविज़न/रेडियो/सामाचार पत्र स्वास्थ्य सेवा प्रदाता से दोतों/रिश्तेदारों अन्य किसी ज्ञात टी.बी. रोगी से अन्य (स्पष्ट कीजिए)	
<p>(हां/सही, 1) (नहीं/गलत,2) (मालूम नहीं, 3) मैं वाक्यों की एक श्रृंखला को पढ़ने जा रही हूँ जो मैंने टी.बी. के बारे में सुनी है। क्या आप बता सकते हैं कि ये वाक्य सही हैं? अगर आप उत्तर नहीं जानते तो आप मुझे बता सकते हैं।</p>				
6.5	टी.बी. वंशानुगत है	1 2 3		
6.6	टी.बी. छूत की बीमारी है यानि के व्यक्ति से दूसरे व्यक्ति में फैलता है	1 2 3		
6.7	टी.बी. के लिए इलाज है	1 2 3		
6.8	टी.बी. के लिए एक टीका है	1 2 3		
6.9	उपचार के लिए लगभग अवधि 6 महीने की है	1 2 3		

6.10	टी.बी. का उपचार निःशुल्क है	1 2 3		
6.11	टी.बी. फेफड़े को प्रभावित करता है	1 2 3		
6.12	टी.बी. शरीर के अन्य भाग/अंग जैसे हड्डी, पेट आदि को प्रभावित करता है।	1 2 3		

खण्ड 7: कलंक

मैं यह पता लगाने का प्रयास कर रही हूँ कि टी.बी. से ग्रसित व्यक्ति के साथ समाज में किसी तरह का भेदभाव होता है या नहीं। मैं कथनों की एक श्रृंखला पर आपकी प्रतिक्रिया के लिए पूछ रही हूँ तथा बताइए कभी ऐसा होता है तो।

कलंक		उत्तर		
		कभी नहीं	कभी कभी	हमेशा
7.1	माता पिता अपने बच्चे के टी.बी. होने पर शर्मिन्दा होते हैं।			
7.2	बच्चे में टी.बी. की पुष्टि होने पर इसे दूसरों से छिपाकर रखते हैं।			
7.3	परिवार के लोग टी.बी. ग्रसित बच्चे को पारिवारिक समारोह/त्यौहार से दूर रखते हैं।			
7.4	पड़ोसियों को यह पता चलने पर कि बच्चा टीबी से ग्रसित है उसके साथ दूसरी तरह का व्यवहार करते हैं।			
7.5	परिवार के सदस्यों को यह पता चलने पर कि बच्चा टीबी से ग्रसित है उसके साथ दूसरी तरह का व्यवहार करते हैं।			
7.6	टी.बी. से ग्रसित बच्चे को दूसरों के साथ खेलने नहीं दिया जाता।			
7.7	टी.बी. का इलाज लड़की के लिए देरी से होगा।			
7.8	टी.बी. का इलाज लड़के के लिए देरी से होगा।			
7.9	टी.बी. से ग्रसित बच्चे द्वारा इस्तमाल किए जाने वाले बर्तनों को अलग से रखा और धोया जाता है।			
7.10	टी.बी. से ग्रसित बच्चे द्वारा इस्तमाल किए जाने			

ANNEXURE VII

साक्षात्कार गाइड

अपने बच्चे के रोग के बारे में मुझसे बात करने के लिए धन्यवाद। मैं उन सभी चीजों के बारे में जानना चाहती हूँ जिससे आपके बच्चे के इलाज में सहायता मिली।

1. आप बता सकते हैं कि आपके बच्चे में क्या लक्षण दिखाई दिये थे और आपने उसका उपचार कैसे किया था?
2. किस प्रकार के लक्षणों को देखकर आप स्वास्थ्य सेवा प्रदाता के यहां गये?
3. आप किसके पास गये और उन्होंने आपको क्या सलाह दिया?
 - क्या आपने उपचार के लिए दी गई सलाह का पालन किया?
 - क्या उपचार से कोई फायदा हुआ?
 - उपचार के लिए दी गई सलाह का पालन करने में आपने किन कठिनाइयों का सामना किया?
 - आप इस स्वास्थ्य सेवा प्रदाता के पास क्यों गये?
 - आपने इसके बाद क्या किया? (अथवा क्या आपने अन्य किसी स्वास्थ्य सेवा प्रदाता से मदद ली)

उल्लिखित सभी स्वास्थ्य सेवा प्रदाताओं के लिए दोहरायें

4. क्या आप इस टी.बी. सेन्टर पर आने से पहले की गई सभी बातों को बता सकते हैं?
5. जब आप यहां आये और आपको पता चला कि आपके बच्चे को टी.बी. है तो आपने क्या किया?
6. क्या आपने अपने परिवार के सदस्यों/मित्रों/पड़ोसियों को इसके बारे में बताया ?
 - उनकी प्रतिक्रिया क्या थी?
 - यह बताने से उत्पन्न समस्याओं के समाधान के लिये आपने क्या किया?
7. उपचार के लिए आप इस टी.बी. सेन्टर पर आ रहे हैं। यहां आने और इलाज कराने में किस प्रकार की समस्याएं हैं? क्या आप इस केन्द्र में पहली बार आने से

लेकर आपके बच्चे के टी.बी. की पुष्टि और अब चल रहे इलाज के अनुभव के बारे में बता सकते हैं?

8. आप क्या करेंगे यदि आपके पड़ोस में रहने वाले किसी माता-पिता के बच्चे में भी उसी प्रकार के लक्षण मिलते हैं जो आपके बच्चे थे? (आप उन्हें टी.बी. सेन्टर जाने की सलाह देंगे या नहीं? और क्यों?)

निश्चित करे की सभी इलाज विकल्प के बारे में पूछ लिया है ।

माता-पिता को समय देने के लिए धन्यवाद करें ।

ANNEXURE VIII

अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र
श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान,
तिरुवनंतपुरम, केरल, 6950011

दिल्ली मे बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज
शुरू करने मे विलंब

शोध अधीन व्यक्ति सूचना पत्र

नमस्कार! मैं डॉ आक्षी कालरा अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र, श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान तिरुवनंतपुरम, केरल से मास्टर ऑफ पब्लिक हैल्थ की पढ़ाई कर रही हूँ। इस पाठ्यक्रम के तहत मैं "दिल्ली मे बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने मे विलंब" पर शोध कर रही हूँ।

शोध का उद्देश्य:

इस शोध का उद्देश्य टी.बी. के बाल रोगियों में लक्षण प्रकट होने तथा इलाज के लिए डॉट्स शुरू करने के बीच की अवधि का पता लगाना है तथा उन कारकों का भी पता लगाना है जो इस अवधि के अंतर को प्रभावित करते हैं।

शोध का विवरण:

इस शोध में दिल्ली के चुनिंदा डॉट्स केंद्रों में सर्वेक्षण तथा कुछ गहन साक्षात्कार किए जाएंगे। कुल 175 साक्षात्कार दिल्ली में क्रमरहित चयन प्रक्रिया द्वारा चयनित बाल टी.बी. रोगियों के मुख्य देखभाल कर्ता से किए जाएंगे। यह शोध को मैं मुख्य जाँचकर्ता के रूप में डॉ माला रामानाथन, अतिरिक्त प्रोफेसर अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र, श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान तिरुवनंतपुरम, केरल के मार्गदर्शन में कर रही हूँ।

दिल्ली के संशोधित राष्ट्रीय तपेदिक नियंत्रण कार्यक्रम के राज्य टी.बी. कार्यालय से मुझे इस शोध को शुरू करने के लिए अनुमति दी गई है। इस शोध के लिए नैतिकता की

मंजूरी श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान के संस्थागत नैतिकता समिति से ली गयी है।

आपका योगदान:

इस भागेदारी के तहत आपके बच्चे के स्वास्थ्य तथा देखरेख/ इलाज करते समय उठाए गये कदमों के संबंध में आपको कुछ प्रश्नों का उत्तर देना है। यदि आप इस शोध में भाग लेते हैं, तो मैं आपका साक्षात्कार लूँगी जोकि 20 से 30 मिनट तक चलेगा। आपके द्वारा दी जाने वाली जानकारी दर्ज की जाएगी। साक्षात्कार के बाद आप से वापस तभी संपर्क किया जाएगा यदि दर्ज की गयी जानकारी अधूरी रह गयी हो या दी गयी जानकारी में कोई स्पष्टीकरण की ज़रूरत हो।

शोध से फायदे:

इस शोध से आपको सीधे तौर पर कोई लाभ नहीं होगा। इस शोध में भाग लेने के लिए किसी प्रकार का प्रलोभन नहीं दिया जाएगा। परंतु इस शोध से भविष्य में होने वाले शोध में व नीति बनाने में मदद मिलेगी जिससे समाज को समग्र रूप से फायदा होगा।

शोध से संभावित हानि:

कुछ प्रश्न निजी प्रकृति के हो सकते हैं, जिससे आप थोड़ा असहज हो सकते हैं। ऐसी अवस्था में आप ज़वाब देने में समय ले सकते हैं या आप ज़वाब न देना चाहें तो मुझे प्रश्न छोड़ने के लिए कह सकते हैं। अगर आप आगे और ज़वाब नहीं देना चाहें तो आप बिना कोई वादा किए साक्षात्कार खत्म कर सकते हैं।

आपके विवरण की गोपनीयता:

आप जो भी जानकारी देंगे वो बेहद गुप्त रखी जाएगी व सिर्फ मेरे और मेरे सुपरवाइज़र की पहुँच में होगी। आपकी निजी पहचान किसी भी स्थिति में किसी के साथ साझा नहीं

की जाएगी। आपकी निजी पहचान के बिना बाकी जानकारी शोध के विश्लेषण में प्रयोग होगी और इस शोध के परिणाम छपेंगे व सार्वजनिक मंच पर प्रस्तुत किए जाएंगे।

शोध से हटना:

आपका शोध में भाग लेना पूरी तरह से स्वैच्छिक होगा। आप साक्षात्कार के दौरान किसी भी समय हटने के लिए मुक्त हैं व ऐसा अधिकार भी रखते हैं। साक्षात्कार में भाग नहीं लेने पर या बीच में हटने पर कोई जुर्माना नहीं होगा।

क्या आप कोई संदेह या सवाल पूछना चाहते हैं? मैं अपनी तरफ़ से सुलझाने की पूरी कोशिश करूँगी।

मुख्य जाँचकर्ता का नाम :डॉ. आक्षी कालरा

मुख्य जाँचकर्ता के हस्ताक्षर :

मुख्य जाँचकर्ता का मोबाइल न-0 :.8301834467

अगर आपको इस शोध की प्रामाणिकता पर कोई संदेह है, तो आप SCTIMST की संस्थागत नैतिकता समिति की सचिव डॉ .माला रामानाथन से 2524234-0471 पर संपर्क कर सकते हैं।

क्या आप इस शोध में भाग लेना चाहते हैं? - हाँ / नहीं

- यदि हाँ - तो कृपया संलग्न सूचित सहमति पत्र भरें व हस्ताक्षर कर के दें।
 - यदि नहीं - कृपया भाग नहीं लेने का कारण बताएं?
-

दिल्ली मे बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने मे विलंब
प्रतिवादी कोड :

सूचित सहमति

में _____ ने 'शोध अधीन व्यक्ति सूचना पत्र' में दी गयी जानकारी सुनी/पढ़ी और समझ ली है और मैंने अपने सारे संदेह स्पष्ट कर लिए हैं। मैं शोध में अपना/अपनी स्वैच्छिक सहमति से भाग लेने की पुष्टि हस्ताक्षर/अंगूठा निशानी लगा कर करता/करती हूँ। मैं अधूरी जानकारी या स्पष्टीकरण की ज़रूरत पड़ने पर वापस संपर्क करने की सहमति देता/देती हूँ। मैं साक्षात्कार से बिना किसी वादे के हटने के अधिकार को समझता/समझती हूँ।

प्रतिवादी के हस्ताक्षर या

अंगूठा निशानी (हस्ताक्षर न कर पाने पर)

तारीख:

स्थान:

गवाह) आवश्यकता हो तो :(मैं पुष्टि करता हूँ कि मुख्य जाँचकर्ता) डॉ. आक्षी कालरा (ने शोध अधीन व्यक्ति पत्र की सारी जानकारी श्री/श्रीमति/कुमारी _____

_____ को समझा दी है व इस व्यक्ति ने शोध में भाग लेने के लिए स्वैच्छा से सहमति दी है।

गवाह के हस्ताक्षर _____

गवाह का नाम:

तारीख:

स्थान:

सहमति प्राप्त :हाँ / नहीं

सहमति का ज़रिया :लिखित / मुँहबोली

मुख्य जाँचकर्ता के हस्ताक्षर:

मुख्य जाँचकर्ता का नाम: डॉ. आक्षी कालरा

तारीख:

स्थान:

ANNEXURE IX

अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र
श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान,
तिरुवनंतपुरम, केरल, 6950011

दिल्ली में बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने में
विलंब

शोध अधीन व्यक्ति सूचना पत्र

नमस्कार! मैं डॉ आक्षी कालरा अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र, श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान, तिरुवनंतपुरम केरल से मास्टर ऑफ पब्लिक हैल्थ की पढ़ाई कर रही हूँ। इस पाठ्यक्रम के तहत मैं "दिल्ली में बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने में विलंब" पर शोध कर रही हूँ।

गहन साक्षात्कार का उद्देश्य:

मैं पहले से ही आपसे आपके बच्चे के टीबी के इलाज के बारे में सवाल पूछ चुकी हूँ। आपके स्वास्थ्य देखभाल तथा इलाज के अनुभव अनूठे हैं इसलिए मैंने आपको गहन साक्षात्कार के लिए चुना है। मैं आपके बच्चे के स्वास्थ्य सेवा पाने की कोशिश के बारे में लिए गये निर्णयों की प्रक्रियाओं को समझना चाहती हूँ। इलाज का प्रत्येक चरण टी.बी. से ग्रस्त बच्चों के माता-पिता/अभिभावक द्वारा अनुभव की गयी समस्याओं में अंतर्दृष्टि प्रदान करता है।

शोध का विवरण:

दिल्ली में कुल 10-15 साक्षात्कार बाल टी.बी. रोगियों के मुख्य देखभाल कर्ता से किए जाएंगे। यह शोध को मैं मुख्य जाँचकर्ता के रूप में डॉ माला रामानाथन, अतिरिक्त प्रोफेसर अच्युता मेनोन स्वास्थ्य अध्ययन केन्द्र, श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान तिरुवनंतपुरम, केरल के मार्गदर्शन में कर रही हूँ।

दिल्ली के संशोधित राष्ट्रीय तपेदिक नियंत्रण कार्यक्रम के राज्य टी.बी. कार्यालय से मुझे इस शोध को शुरू करने के लिए अनुमति दी गई है। इस शोध के लिए नैतिकता की मंजूरी श्री चित्रा तिरुनाल आयुर्विज्ञान एवं तकनीकी प्रोद्योगिकी संस्थान के संस्थागत नैतिकता समिति से ली गयी है।

आपका योगदान:

आपका साक्षात्कार 30 से 40 मिनट तक चलेगा ताकि मैं आपके द्वारा अनुभव की गयी स्वास्थ्य सेवा पाने की कोशिश और इलाज से संबंधित समस्याओं को समझ सकूँ। आपके द्वारा दी गयी जानकारी को ऑडियो रेकॉर्ड किया जाएगा। साक्षात्कार के बाद आप से वापस तभी संपर्क किया जाएगा यदि दर्ज की गयी जानकारी अधूरी रह गयी हो या दी गयी जानकारी में कोई स्पष्टीकरण की ज़रूरत हो।

शोध से फायदे:

इस शोध से आपको सीधे तौर पर कोई लाभ नहीं होगा। इस शोध में भाग लेने के लिए किसी प्रकार का प्रलोभन नहीं दिया जाएगा। परंतु इस शोध से भविष्य में होने वाले शोध में व नीति बनाने में मदद मिलेगी जिससे समाज को समग्र रूप से फायदा होगा।

शोध से संभावित हानि:

कुछ प्रश्न निजी प्रकृति के हो सकते हैं, जिससे आप थोड़ा असहज हो सकते हैं। ऐसी अवस्था में आप ज़वाब देने में समय ले सकते हैं या आप ज़वाब न देना चाहें तो मुझे प्रश्न छोड़ने के लिए कह सकते हैं। अगर आप आगे और ज़वाब नहीं देना चाहें तो आप बिना कोई वादा किए साक्षात्कार खत्म कर सकते हैं।

आपके विवरण की गोपनीयता:

आप जो भी जानकारी देंगे वो बेहद गुप्त रखी जाएगी व सिर्फ मेरे और मेरे सुपरवाइज़र की पहुँच में होगी। आपकी निजी पहचान किसी भी स्थिति में किसी के साथ साझा नहीं की जाएगी। आपकी निजी पहचान के बिना बाकी जानकारी शोध के विश्लेषण में प्रयोग होगी और इस शोध के परिणाम छपेंगे व सार्वजनिक मंच पर प्रस्तुत किए जाएंगे।

शोध से हटना:

आपका शोध में भाग लेना पूरी तरह से स्वैच्छिक होगा। आप साक्षात्कार के दौरान किसी भी समय हटने के लिए मुक्त हैं व ऐसा अधिकार भी रखते हैं। साक्षात्कार में भाग नहीं लेने पर या बीच में हटने पर कोई जुर्माना नहीं होगा।

क्या आप कोई संदेह या सवाल पूछना चाहते हैं? मैं अपनी तरफ़ से सुलझाने की पूरी कोशिश करूँगी।

मुख्य जाँचकर्ता का नाम- डॉ. आक्षी कालरा

मुख्य जाँचकर्ता के हस्ताक्षर-

मुख्य जाँचकर्ता का मोबाइल 08301834467

अगर आपको इस शोध की प्रामाणिकता पर कोई संदेह है, तो आप SCTIMST की संस्थागत नैतिकता समिति की सचिव डॉ .माला रामानाथन से 2524234-0471 पर संपर्क कर सकते हैं।

क्या आप इस शोध में भाग लेना चाहते हैं? - हाँ / नहीं

- यदि हाँ - तो कृपया संलग्न सूचित सहमति पत्र भरें व हस्ताक्षर कर के दें।
 - यदि नहीं - कृपया भाग नहीं लेने का कारण बताएं?
-

दिल्ली मे बाल टी.बी. (क्षय) रोगियों की स्वास्थ्य सेवा पाने की कोशिश एवं इलाज शुरू करने मे विलंब

प्रतिवादी कोड :

सूचित सहमति

मैं _____ ने 'शोध अधीन व्यक्ति सूचना पत्र' में दी गयी जानकारी सुनी/पढ़ी और समझ ली है। मैं शोध में अपना/अपनी स्वैच्छिक सहमति से भाग लेने की पुष्टि हस्ताक्षर/अंगूठा निशानी लगा कर करता/करती हूँ। मैं अधूरी जानकारी या स्पष्टीकरण की ज़रूरत पड़ने पर वापस संपर्क करने की सहमति देता/देती हूँ। मैं शोध कार्य के लिए अपने साक्षात्कार की ऑडियो रेकॉर्डिंग की अनुमति देता/देती हूँ जिसे सिर्फ़ सूपरवाइज़र के साथ साझा किया जाएगा। मैं साक्षात्कार से बिना किसी वादे के हटने के अधिकार को समझता/समझती हूँ।

प्रतिवादी के हस्ताक्षर या

अंगूठा निशानी (हस्ताक्षर न कर पाने पर)

तारीख:

स्थान:

गवाह) आवश्यकता हो तो :(मैं पुष्टि करता हूँ कि मुख्य जाँचकर्ता) डॉ. आक्षी कालरा (ने शोध अधीन व्यक्ति पत्र की सारी जानकारी श्री/श्रीमति/कुमारी _____

को समझा दी है व इस व्यक्ति ने शोध में भाग लेने के लिए स्वैच्छा से सहमति दी है।

गवाह के हस्ताक्षर _____ :

गवाह का नाम: _____ तारीख:

स्थान:

सहमति प्राप्त :हाँ / नहीं

सहमति का ज़रिया :लिखित / मुँहबोली

मुख्य जाँचकर्ता के हस्ताक्षर: _____

मुख्य जाँचकर्ता का नाम: डॉ. आक्षी कालरा

तारीख:

स्थान:

ANNEXURE X

श्री चित्रा तिरुनाल आयुर्विज्ञान और प्रौद्योगिकी संस्थान

तिरुवनन्तपुरम - 695 011, केरल, भारत

SREE CHITRA TIRUNAL INSTITUTE FOR MEDICAL SCIENCES AND TECHNOLOGY

THIRUVANANTHAPURAM - 695 011, INDIA

(An Institute of National importance under Govt. of India)



Institutional Ethics Committee

(IEC Regn No. ECR/189/Inst/KL/2013)

SCT/IEC/754/JUNE -2015

10-06-2015

Dr. Aakshi Kalra

MPH Scholar, AMCHSS,
SCTIMST, Thiruvananthapuram

Dear Dr. Aakshi Kalra,

The Institutional Ethics Committee reviewed and discussed your application to conduct the study entitled "Delay in care seeking and treatment initiation among pediatric tuberculosis patients in Delhi" (IEC/754) on 2nd June, 2015.

Dr.Mala Ramanathan (guide) recused herself from discussions on the submission from Dr.Aakshi Kalra (Agenda Item Vii).

The following documents were reviewed:

Original submission

1. Covering letter, 2. IEC application form, 3. Curriculum vitae of PI. 4. Interview consent form in English
5. Interview consent form in Hindi, 6. In-depth interview consent form in English
7. In-depth interview consent form in Hindi
8. Interview guide in English
9. Interview guide in Hindi
10. Interview schedule in Hindi
11. Interview schedule in English
12. Checklist
13. TAC approved proposal
14. Permission letter from Revised National Tuberculosis Control Programme
15. Budget
16. TAC Clearance letter

Revised submission

1. Covering letter addressed to the Chairperson, IEC, SCTIMST dated 08.06.2015.
2. Modified Interview schedule in English was submitted.
3. Modified Interview schedule in Hindi was submitted.

Page 1 of 2

The following members of the Ethics Committee were present at the meeting held on 2nd June, 2015 at G. Parthasarathi Board Room, AMCHSS, SCTIMST.

SL. No.	Member Name	Highest Degree	Gender	Scientific /Non Scientific	Affiliation with Institution(s)
1.	Dr. R.V.G. Menon	PhD	Male	Lay Person	No
2.	Smt. Sathi Nair	MA	Female	Lay Person	No
3.	Dr. Kala Kesavan. P	MD	Female	Pharmacologist	No

IEC Decision

The IEC approved the conduct of the study in the present form.

Remarks:

The Institutional Ethics Committee expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

There was no member of the study team /guide who participated in voting / decision making process. The ethics committee is organized and operated according to the requirements of Good Clinical Practice and the requirements of the Indian Council of Medical Research (ICMR).

Sincerely,



Mala Ramanathan
Member Secretary, IEC

ANNEXURE XI

Figure 4.1: Flow chart of patients who met inclusion criteria for study population

