# CAUSES OF DELAY IN THE DIAGNOSIS, AND TREATMENT OF PULMONARY TUBERCULOSIS, IN GUJRAT, PAKISTAN

A case of Basic health Unit Joura Jalal Pur and Aziz Bhati Shaheed

Hospital

By

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# LIST OF ACRONYMS

ABSH	Aziz Bhati Shaheed Hospital
AFB	Acid-Fast Bacilli
AIDS	Acquired Immune Deficiency Syndrome
BHU	Basic Health Unit
CNR	Case Notification Rate
DALYs	Disability Adjusted Life Years
DHD	District Health Department
DHQ	District head Quarter
DOH	District Officer Health
DOTS	Directly Observed Treatment Short course
DPIU	District Program Implementation Unit

EDO	Executive District Officer
EMRO	Eastern Mediterranean Regional Organization
EPI	Extended Program of Immunization
FP	Family Planning
FPIU	Federal Program Implementation Unit
GDP	Gross Domestic Product
HCF	Health Care Facility
НСР	Health Care Provider
HEC	Higher Education Commission
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
IMF	International Monetary Fund
IV	Intra Venous
KAP	Knowledge Attitude and Practice
LHS	Lady Health Supervisor
LHV	Lady Health Visitor

LHW	Lady Health Worker
LHWP	Lady Health Worker Program
МСН	Maternal Child Health
MDG	Millennium Developmental Goal
MDR	Multi Drug Resistance
MICS	Multiple Indicators Cluster Survey
MOE	Ministry of Education
МОН	Ministry of Health
NCHD	National Commission for Human Development
NIPS	National Institute of Population Studies
NNS-	New Sputum smear negative
NSS+	New Sputum smear positive
NTP	National Tuberculosis control Program
NWFP	Northern Western Frontier Province
ORT	Oral Rehydration Therapy

РНСЕ	Primary Health Care extension
PPIU	Provincial Program Implementation Unit
РТВ	Pulmonary Tuberculosis
RHC	Rural Health Center
SPSS	Statistical Package for Social Sciences
SRS	Simple Random Sampling
ТВ	Tuberculosis
TBA	Trained Birth Attendant
THQ	Tehsil Head Quarter
UN	United Nation
UNDCP	United Nation Drug Control Program
UNDP	United Nation Development Program
UNESCO	United Nation Education, Scientific, and Cultural Organization
USAID	United Stated Agency for International Development
WB	World Bank
WHO	World Health Organization

#### Abstract

The World Health Organization (WHO) declared a state of global emergency for tuberculosis in 1993, due to the steady increase of the disease worldwide. The DOTS strategy was established to achieve tuberculosis control worldwide in 1995. Pakistan ranks sixth amongst the high burden countries in the world. According to WHO, the estimated incidence of sputum smear positive TB cases in Pakistan was 80/100,000 and for all type of TB cases, it was 177/100,000 per year. The Tuberculosis situation in Pakistan is very alarming because the number of tuberculosis patients is increasing steadily although the treatment success rate is good. This is because there are different causes leading towards an increase in the burden and number of tuberculosis cases. One of the main reasons is the delay in the diagnosis and treatment of tuberculosis due to different causes. The significance of this thesis is to explore the causes which are responsible for the delay in the diagnosis and treatment of tuberculosis.

The research was employed in the form of a cross sectional study with both quantitative and qualitative approaches. It included a semi-structured questionnaire with interviews and observations. Due to the sensitiveness of the topic, a questionnaire was used as a tool to obtain the primary information for the study. The Questionnaire was adopted from previous studies and some adjustments were made to incorporate some new questions to fit the situation of delay in the study areas.. Meanwhile, the secondary data is based upon publications, documents and data available from internet resources. This study was conducted in two settings of District Gujrat, Pakistan. One was the District head quarter hospital (Aziz Bhati Shaheed Hospital) and the other was Basic health unit (Joura Jalal Pur). Therefore the total sample size from these two settings was 50 pulmonary tuberculosis patients who were randomly selected and they were at different phases of their treatment and represent the general population. Also a convenient sample of 13 Lady Health workers at BHU Joura Jalal Pur was also interviewed to find out their role in improving healthcare seeking behavior in pulmonary tuberculosis. Once the respondents were classified according to the geographic and the codes for responses were defined, Statistical Package for Social Science (SPSS) version 17 was used to generate the results from the obtained information.

The results of this study showed after thoroughly examining the findings that there are many factors which are leading to delay in the diagnosis and treatment of pulmonary tuberculosis. These can either be due to patients themselves or by the healthcare providers. Both contribute to diagnostic and treatment delay. The main cause of delay was bad healthcare seeking behavior of the pulmonary tuberculosis patients which caused patients to delay. The results of hypothesis showed and it was concluded from the results obtained by the descriptive and statistical analysis that there was a strong relationship between healthcare seeking behavior and delays. It was observed that if the patients had good healthcare seeking behavior, they got their diagnosis and treatment without any delay and the treatment outcome was good. And the patients who had diagnostic and treatment delays, their healthcare seeking behavior was not good due to different factors which affect the healthcare seeking behavior of the patients. Also it was observed that LHWs play a vital role in improving the healthcare seeking behavior of the patients because they had to identify and refer the TB suspects from the community to the health centers. Their knowledge, awareness and attitude towards the patients is of utmost importance for pulmonary tuberculosis by causing a good healthcare seeking behavior, and avoiding delay in the diagnosis and treatment.

It is highly recommended that media which include television, radio and newspapers etc play a vital role to make people aware more and more about the tuberculosis and its risks. Linkage between private and public health sector should be made stronger so that the patients going to private sector are referred to the public or primary healthcare centers for earlier diagnosis and treatment. Lady health workers should be trained and educated more and more about the tuberculosis to improve their knowledge and awareness about the disease, so they can communicate with the people and make them aware of the disease and in this way healthcare seeking behavior of patients can be improved.

### Chapter 1

#### Introduction

This introductory chapter provides information about the country profile in detail. Then in the next sections global and Pakistan tuberculosis situation will be explained in detail to provide an overview of tuberculosis situation which will help to understand the issue. Then in the final section of this chapter the rational of the study, research objectives, research questions, research hypothesis and research framework will be discussed in detail.

#### **1.1 Introduction to Pakistan**

#### **1.1.1 Location and History**

Islamic republic of Pakistan is situated in south Asia. It has 1064 kilometers of coastline along the Arabian Sea in the south and Afghanistan and Iran in the west, India in the east and china in the north. Pakistan gained independence from the British Empire after a long struggle of almost 100 years on 14<sup>th</sup> august 1947

and this struggle was led by Muhammad Ali Jinnah. Pakistan has four provinces named as, Punjab, Sindh, Baluchistan, and Khyber Pakhtunkhwa. Pakistan's capital is Islamabad and Karachi is the largest city. Urdu and English are official Languages of Pakistan. Recognized regional languages are Punjabi, Balochi, Sindhi, and Pashto. "Pakistan is the sixth most populous country in the world" (Official Pakistani population clock, Retrieved 17 Dec 2010) and has the "second largest Muslim population in the world after Indonesia" (Muslim population, Retrieved 27 March 2007). Pakistan possesses the seventh largest army in the world and the only Muslim country with the possession of nuclear power. Pakistan has 113 districts with several tehsils and union councils.

#### 1.1.2 Geography and Climate

"Pakistan has a total area of 796,095 Square kilometer; it is still debatable due to the disputed territory of Kashmir. Pakistan has a variety of landscapes ranging from planes to deserts and mountains. Karakoram Mountains are among the highest mountains in the world and range in the northern part. Pakistan is divided to three major geographical areas: The northern highlands, The Indus river plane and Baluchistan plateau" (About Pakistan, 24 July 2010). The world's second highest peak K2 is in Pakistan.

"There are four distinct seasons in Pakistan; a cool and dry winter from December through February; a hot dry spring from March through May; a summer and rainy season from June through September; and Monsoon period of October and November" (Pakistan climate, Retrieved 28 March 2010).

#### 1.1.3 Demography

"Pakistan has a fast growing population with an estimated population of 170 million in 2010 making it the world's sixth most populous country" (Official Pakistani population clock, Retrieved 17 December 2010). "The population growth rate is now 1.6%" (CIA, The world fact book). Karachi is the most populous city in Pakistan. "About 20% of the population lives below the international poverty line of 1.25\$ a day" (Human development indices, 1 March 2010). "Life expectancy at birth is 63 years for females and 62 years for males as of 2006" (WHO, 2 Jan 2010). "About 97% of Pakistani's are Muslims and approximately 1.6 % of population is Hindu, 1.6% is Christian, and 0.3% belongs to other religions such as Bahaism and Sikhism" (County profile Pakistan, 2005). The Following Table1.1 and figure 1.1 give demographic information about Pakistan.

Demographic Indicators for Pakistan	2010	1995	2005	2015	2025
Population					
Midyear population (in thousands)	184405	134185	169279	199086	228385
Growth rate (percent)	1.6	2.8	1.7	1.5	1.3
Fertility					
Total fertility rate (births per woman)	3.3	5.7	4	2.8	2.2
Crude birth rate (per 1,000 population)	25	38	29	23	19
Births (in thousands)	4665	5155	4941	4495	4380
Mortality					
Life expectancy at birth (years)	66	60	64	67	71
Infant mortality rate (per 1,000 births)	65	96	76	56	40
Under 5 mortality rate (per 1,000 births)	87	137	103	73	51
Crude death rate (per 1,000 population)	7	11	8	6	6
Deaths (in thousands)	1302	1428	1347	1292	1368
Migration					
Net migration rate (per 1,000 population)	-2	0	-4	-2	-0
Net number of migrants (in thousands)	-435	32	-635	-307	-98

Table 1.1 Demographic indicators of Pakistan

Source: US census bureau (Retrieved 22 Nov 2010)



Figure 1.1 Pakistan population pyramids 2010

"Pakistan's fast growing population has a substantial proportion of youth. In 2004, 40.2% of the population was aged 14 or younger, 55.7% was 15-64 years of age and only 4.1% of the population was above 65 and older" (Country profile Pakistan, 2005).

#### 1.1.4 Economy

Pakistan economy suffered throughout 1990's but from 2002 to 2004 the economy recovered due to changes in government policies. "Recently wide ranging

Source: US census Bureau (Retrieved 22 Nov 2010)

economic reforms have resulted in stronger economic outlook and accelerating growth especially in manufacturing and financial service sectors" (Economy, Pakistan, 8 Mar 2009) "The 2005 foreign debt was close to US \$40 billion. However this has decreased during the recent years due to assistance from IMF and significant debt relief by USA. Pakistan's gross domestic product as measured by purchasing power is estimated to be US \$ 475.4 billion (IMF, 8 Oct 2007) while its per capita income stands at US \$ 2,942" (IMF, 8 Oct 2007). "The poverty rate in Pakistan is estimated to be between 23% and 28%" (WB, UNDP, 20 Jun 2006).



Figure 1.2 Pakistan GDP growth rate 1951-2009

Source: Federal bureau of statistics, Govt. of Pakistan

"Pakistan's GDP is US \$167 billion, which makes it the 48<sup>th</sup> largest economy in the world and second largest economy in South Asia" (Pakistan Economy, Bloomberg, 28 Sep 2009). Pakistan's economy was previously based mainly on agriculture but now it is semi-industrialized. "Foreign investments in different sectors of Pakistan have been made like in Telecommunication, Energy and in constructions. Others industries are mainly chemical, pharmaceuticals, steel, textile which are contributing to the country's economy to a bigger extent. "Pakistan is a rapidly developing country"(Gulf Research Center, 3 Jan 2007). In the previous economic crises Pakistan was also effected which made Pakistan to seek more aid from IMF and USA, however "it is projected that in 2010 Pakistan economy would grow at least 4% and could grow more with international economic recovery" (Associated press of Pakistan, 2010).

#### 1.1.5 Education and Literacy

Education in Pakistan has been underfunded for several decades and has low indicators of education attainment. Free primary education is a fundamental and constitutional right of every Pakistani in each province. Pakistan has only one university at the time of independence named as Punjab University which was founded in 1882 in Lahore. "Pakistan now has 133 universities in which 73 are public universities and 60 are private universities" (HEC, Pakistan) "Education in Pakistan is divided into five levels: primary (grade one through five), middle (grade six through eight), high (grade nine through tenth leading to secondary school certificate), and intermediate (grades eleven and twelve leading to a higher secondary school certificate), and university programs leading to graduate and advances degrees" (MoE Pakistan, 2008). "There are currently 730 vocational and technical institutes in Pakistan" (MoE, Pakistan, 2008). "During 1980's and 1990's total expenditure on education in Pakistan was 2.5% of the total GDP but fell to less than 2% of the GDP in 1998" (Country profile Pakistan, 2005). Through various reforms Ministry of education is trying to have 100% enrollment level amongst "the primary school aged children and a literacy rate of 86% amongst people of aged over 10" (MoE Pakistan, 2008). "Literacy rate was only 57% during the year 2009 amongst adult Pakistani's, the male literacy rate was 69%, while female literacy rate was 45%"(UNESCO, 2009). "Literacy rate varies according to the region and particularly by sex, the literacy rate in females of tribal areas is only 3%" (New York time, 2010).



Figure 1.3 Literacy rate in Pakistan

Source: Wikipedia, Pakistan, UNESCO

#### 1.2 The Global situation of tuberculosis

According to WHO "Tuberculosis or TB is an infectious bacterial disease caused by mycobacterium tuberculosis, which most commonly affects the lungs. It is transmitted from person to person via droplets from throat and lungs of people with the active respiratory disease." (WHO, 2010)

"According to World Health Organization's Global Burden of Disease project, in 2000 it was the eighth highest cause of death, and the tenth highest cause of disability adjusted life years (DALYs)" (Mathers, 2002). "Unlike most others major diseases, with the notable exception of HIV/AIDS, its burden is spread across all age groups and is responsible for the deaths of many productive individuals in the core 15 to 44 age groups" (Murray, 1993).

The second commonest cause of death in the world is tuberculosis killing almost two million people each year. Eight million new TB cases are estimated to occur each year in which more than 95% of the cases occur in the developing world. Prevalence of TB globally is about 16-20 million. "*Almost 80% of the cases occur in economically productive age group 15-59 years*" (MoH, Pakistan).
"More than two billion people, equal to one third of the world population are infected with TB bacilli, and one in ten people infected with TB bacilli become sick with active TB in life" (WHO, 2009). TB disproportionately affects people in poor settings, particularly in Asia and Africa. "More than 90% of new TB cases and deaths occur in developing countries" (WHO, 2009). "There were 9.4 million new TB cases in 2008 (3.6 million of whom were women), 1.8 million People died of TB in 2008 in which 500,000 people were having HIV-equal to 4,500 deaths a day" (WHO, 2009). Twenty two countries are declared as high burdened countries (HBC) with TB, most such Countries are in Africa and Asia, India, China, South Africa, Nigeria and Indonesia have the highest number of TB cases in the world. "Global TB incidence rate was 139 per 100,000 Population in 2008, and Global TB prevalence rate is 164 per 100,000"(US Global Health policy, 2010). "There were 5.7 million TB case notifications in 2008, and 36 million were cured in DOTS programs (between 1995 and 2008) with as many as 8 million deaths averted through DOTS" (WHO, 2008).





Source: Kaiser family foundation, 2009.

Figure 2: TB Incidence, Prevalence and Deaths by Region, 2008 <sup>3,4</sup>								
	Incidenc	e	Prevalence		Deaths			
WHO Region <sup>6</sup> (# of HBCs)	No. in thousands (%)	Per 100,000 Pop	No. in thousands Pop		No. in thousands	Per 100,000 Pop		
Global Total (22)	9,369 (100%)	139	11,096	164	1,324	20		
Africa (9)	2,828 (30%)	351	3,810	473	385	48		
Americas (1)	282 (3%)	31	221	24	29	3.2		
E. Mediterranean (2)	675 (7%)	115	929	159	115	20		
Europe (1)	425 (5%)	48	322	36	56	6.3		
South-East Asia (5)	3,213 (34%)	183	3,806	216	478	27		
Western Pacific (4)	1,946 (21%)	109	2,008	112	262	15		

Figure 1.5 TB Incidence, Prevalence and Deaths by Region

Source: US Global Health Policy, 2010

#### 1.3 Tuberculosis situation in Pakistan

In 1993 World Health Organization (WHO) declared a state of global emergency for tuberculosis, because of the steady increase of the disease worldwide. DOTS strategy was established to achieve tuberculosis control worldwide in 1995. "The global targets of this strategy are to achieve 70% case detection and 85% cure rates by 2005" (WHO report, 2002). "In 2003, DOTS programs successfully treated 84% of all registered new smear-positive patients, but detected only 28% of the estimated tuberculosis cases in the world" (WHO report. 2003). "Out of the 22 countries of Eastern Mediterranean Region of WHO, Pakistan ranks first with 61% of tuberculosis cases" (WHO, EMRO, epidemiology, tuberculosis). "And Pakistan ranks sixth amongst the high burden Countries (HBCs) in the world" (National TB control program Pakistan, 2006).



Figure 1.6 Tuberculosis burden in the Eastern Mediterranean Region in 2008

Source: WHO, Global TB report, an update of 2009

"Approximately 1.5 million people have been infected with TB and an annual incidence of around 300,000 new TB cases with Pakistan" (National TB Control Program Pakistan, 2006). "According to WHO, the estimated incidence of sputum smear positive (SS+ve) TB cases in Pakistan was 80/100,000 and for all type of TB cases, it was 177/100,000 per year" (National TB Control Program Pakistan, 2006). "TB was responsible for 5.1 percent of the total national disease burden" (National TB Control Program Pakistan, 2006) "To further complicate the situation, Pakistan

has an extremely high default rate for the completion of TB treatment ranging from 79% in 1997 to 45% in 1999" (Directorate TB Control Sindh, 1999). "It is universally accepted that a partially treated TB patient is worse than an untreated one as the chronic cases are the ones who excrete multi drug resistant organisms and increase the community burden of TB" (Grzybowski, 1988).

"Pakistan adopted the WHO recommended Directly Observed Treatment Short Course (DOTS) strategy in 1995 for the better control of TB but its expansion did not begin until 2000, when the National TB Program was reactivated, which resulted in doubling of the DOTS detection rate" (EMRO DOTS, 2003). "Despite the increase in DOTS population coverage, from 24% in 2001 to nearly 63% in 2003, the smear positive case detection rate remained low up to 17% in 2003" (WHO report, 2003). "In 2005 DOTS coverage was 100% in public sector in the country" (National TB Control Program Pakistan, 2006). "Like other developing counties in Pakistan high risk groups may include people with human immunodeficiency virus/AIDS, people with diabetes or cancer, the malnourish, those living with someone who has tuberculosis, poor indigent people, occupants of homeless shelters and present or former prisoners" (Long: Njoo: Hershfield, 1999).

#### 1.3.1 Indicators of the National Tuberculosis Control Program in Pakistan

According to NTP performance indicators of the first quarter of 2008 in Pakistan, the proportion of new smear sputum positive (NSS+), case notification rate of NSS+ patients, and treatment success rates in all the provinces are as follows:

- In Punjab the proportion of NSS+ was 43%, case notification of NSS+ was 64 while treatment success rate was 92%.
- 2- In Baluchistan the proportion of NSS+ was 63%, case notification of NSS+ was 41, and treatment success rate was 80%.
- 3- In Sindh the proportion of NSS+ was 58%, case notification of NSS+ was 57, and treatment success rate was 87%.
- 4- In NWFP or newly called as Kheber Pakhtoonkha the proportion of NSS+ was 59%, case notification of NSS+ was 38 and treatment success rate was 90%.



Figure 1.7 Overview of performance indicators of NTP in Pakistan

Source: National tuberculosis control program Pakistan, 2008.

#### 1.3.1.1 Absolute Number of TB cases

According to NTP, there is an increase in the trend of all types of TB patients throughout the Pakistan. This overall increases the burden of TB in Pakistan. In 2009 the total number of NSS+ patient was 101,887; while the number of new sputum smear negative (NSS-) patients was 112,948. Extra pulmonary TB patients was 43,416, relapse patients was 5,997, while treatment after default patients was 1,781 and treatment after failure patients was 1,422 (NTP Pakistan, 2009).

#### 1.3.1.2 Age Distribution of Total cases

According to NTP, a large number of TB patients were in their working age group 15-54, and this number is increasing every year affecting the overall productivity of Pakistan. In 2009 there were 76,715 patients in this age group, while 3,644 patients were in age group 0-14, and 21,312 patients were in age group more the 55 years (NTP Pakistan, 2009).





Source: NTP, Pakistan, 2009

#### **1.3.1.3 Age Distribution of females**

According to NTP, Pakistan in 2009 a large number of female patients

was in the age group 15-54, a total of 37,963 female patients were registered in

Pakistan, while 1,052 were in age group 0-14 and 13,034 female patients were in age

group more than 55 years (NTP Pakistan, 2009).



Figure 1.9 Age Distribution of female patient in Pakistan

Source: NTP Pakistan, 2009

#### **1.3.1.4 Age Distribution of Males**

According to NTP, Pakistan in 2009 there is an estimated 37,963 TB patients in age group 15-54. An interesting situation is that males predominantly have TB more in their later age than females, While female having TB more in their early age group 0-14. In 2009 there were 1,052 Tb cases in age group 0-14 and 13,034 in age group more than 55 years (NTP Pakistan, 2009).



Figure 1.10 Age Distribution of male patients in Pakistan

Source: NTP, Pakistan, 2009

## 1.3.1.5 Case Detection rate of all types and Case detection rate of NSS+

The definition of Case detection rate is that "it is calculated as a number of new smear positive cases notified divided by the number of new smear positive cases estimated for that year expressed in percentage" (WHO, Retrieved 12 Feb 2011). According to NTP, Pakistan the case detection rate of all types of TB and the case detection rate of NSS+ is increasing steadily throughout the years in Pakistan and was 90% and 75% respectively in 2009.



Figure 1.11 Case Detection Rate of all types of TB in Pakistan

Source: NTP Pakistan, 2009

Figure 1.12 Case Detection Rate of NSS+ in Pakistan



Source: NTP Pakistan, 2009

#### 1.3.1.6 Case notification rate of all types per 100,000 Population

Case notification rate is new sputum smear positive pulmonary TB cases, defined as "Number of new sputum smear positive pulmonary TB cases reported in a year divided by total population in the specified geographic area (x 100,000)" (NTP Pakistan, 2010)

According to NTP, Pakistan the case notification rate of all types of TB cases and case notification of NSS+ is increasing steadily throughout the years. In 2009 the case notification rate (CNR) of all types was 160/100,000 and case notification rate of NSS+ was 61/100,000 population (NTP Pakistan, 2009).

Figure 1.13 Absolute number of TB cases registered per 100,000 (Population (All types)



Source: NTP Pakistan, 2009



Figure 1.14 Absolute number of TB cases registered per 100,000 Population (NSS+)

Source: NTP Pakistan, 2009

#### 1.3.2 Challenges of Tuberculosis management in Pakistan

As mentioned in the previous section about the indicators of TB in Pakistan, it is obvious that although the WHO DOTS program is running effectively in Pakistan but still the burden of TB is increasing steadily and ministry of health (MoH), Pakistan and NTP is facing so many challenges to combat with this deadly disease throughout the Pakistan. "It took four years to bring DOTS coverage to all the public health facilities and the country remains far behind the global targets of case detection rate of 75% and treatment success rate of 85%" (NTP Pakistan, Retrieved 10 Dec 2010). "There are a total 1,163 diagnostic centers in Pakistan in which 1,056 are in public sector, 100 are in private sector, while 7 are parastatal" (NTP Pakistan Retrieved 10 Dec 2010). Large number (477) diagnostic centers are in Punjab Province. But still there are many challenges for Pakistan. "Among these challenges the most important is lack of community involvement, limited engagement of private sector, increasing number of multidrug resistance (MDR) cases, recent rise in HIV cases among IV drug abusers who are also at much higher risk of TB" (Janjua, 2006), and also a number of causes of delay in the diagnosis and treatment of TB which will be discussed in detail in the next sections.

#### 1.4 Rationale of the study

As mentioned in the previous section "tuberculosis remains a major global public health problem" (WHO report, 2002). Early diagnosis and prompt initiation of treatment are essential for an effective tuberculosis control program. "Delay in the diagnosis may worsen the disease, increase the risk of death and enhance tuberculosis transmission in the community" (Toman, 1979). "Diagnostic delays of longer than two months have been indicated to spread the disease to

domestic contacts" (Riley, 1974) "Delay in the diagnosis is significant with regard to not only disease prognosis at the individual level but also transmission within the community and reproductive rate of the TB epidemic" (Dye, 1999: Bjune, 2005). Tuberculosis situation in Pakistan is very alarming because number of tuberculosis patients is increasing steadily although the treatment success rate is good. This is because there are different causes leading towards increase burden and number of tuberculosis patients. One of the main reasons is the delay in the diagnosis and treatment of tuberculosis due to different causes. This study is an attempt to explore these causes which are responsible for the delay in the diagnosis and treatment of tuberculosis. In this study only pulmonary tuberculosis is focused. Gujrat is amongst the highly burdened cities in Punjab, Pakistan. TB DOTS program in Gujrat was started in 2004, though TB DOTS program is running effectively in the district but still the incidence of pulmonary tuberculosis cases is increasing due to different causes of delay in the diagnosis and treatment. These causes are related to the patient himself during the period of health seeking and to the health providers during the period of diagnosis and commencement of anti tuberculosis treatment. "Several factors have been identified as influencing delay in the diagnosis and treatment, including the individual's perception of disease, socioeconomic level, stigma, extent of awareness about the disease, the severity of the disease, distance between the patient's residence and health services and expertise of health personnel" (WHO EMRO, 2009). Causes which contribute to patient or health system delay are numerous and it is very important to identify and address these causes in order to devise strategies for the national tuberculosis control program (NTP). In district Gujrat, proportion of NSS+ cases is 50%, while CNR of NSS+ is 60% and treatment success rate is 90% (NTP Pakistan, 2009).There are 688 tuberculosis patients in the third quarter of 2010, in which 355 were males and 333 were females, while in these 688 patients 322 were NNS+ pulmonary tuberculosis patients.

Table 1.2 Summary of Tuberculosis patients registered in the 3<sup>rd</sup> quarter of 2010 in Gujrat.

TB case notification in DOTS areas						
Pulmonary Tuberculosis		Extra	Total			
Smear Positive	Smear	Pulmonary				
	Negative	tuberculosis				

New		Rela	pses	Treat	ment	Treat	ment							
cases	8			after		after								
				failur	e	defau	lt							
М	F	М	F	М	F	М	F	М	F	М	F	М	F	Т
169	141	4	6	0	1	1	0	138	139	43	46	355	333	688

Source: National TB Coordinator Office, District Gujrat, Pakistan, 2010

In the past there was no such attempt and study done to assess the problem of delay in the diagnosis and treatment of pulmonary tuberculosis in Gujrat, Pakistan. The aim of the present study was to evaluate the causes of delay in the diagnosis and treatment of pulmonary tuberculosis, identify the major contributors to such delay (whether patient delay or health care system delay) and study its various determinants. The Final goal of this study was to identify causes interfering in the case-finding activities under DOTS and to suggest and recommend possible solutions to increase the case detection in the community and by the NTP. And it is assumed that the information obtained by this study will help these programs in achieving their targets.

#### **1.5 Research Objectives**

It is obvious that there is a considerable delay in the diagnosis and treatment of pulmonary tuberculosis. This is due to many factors which are contributing as a whole which leads to a much worse picture of this increased burden of pulmonary tuberculosis in the region. The latest studies revealed that this phenomenon of delay in the diagnosis and treatment is more in developing countries which is a combination of both patient and health system delay. The author is interested in exploring the causes of delay in the diagnosis and treatment of pulmonary tuberculosis in the region and this is the main objective of this research. Therefore this research aims:

- To determine the causes of delay in the diagnosis and treatment of pulmonary tuberculosis in Gujrat, Pakistan.
- 2- To assess and examine the relationship of health care seeking behavior in pulmonary tuberculosis with delay in the diagnosis and treatment of pulmonary tuberculosis.

- 3- To assess and examine the knowledge, attitude, awareness of Lady Health workers which can influence the healthcare seeking behavior of pulmonary tuberculosis patients and in overall decrease the delay in the diagnosis and treatment of PTB.
- 4- To determine the length of delays in the diagnosis and treatment of pulmonary tuberculosis at different levels.

The latest research done in 2008 revealed that there are many causes which are responsible for the delay in the diagnosis and treatment of tuberculosis. This motivates the researcher to assess and examine the causes and determine whether they are affecting the outcome of pulmonary tuberculosis in the region or not? The findings will be useful for the national tuberculosis program and implementers of polices regarding STOPING TB to have more effective program and to achieve the millennium developmental goal (MDG) for tuberculosis.

#### **1.6 Research Questions**

As mentioned in the previous section the main objective of this research is to assess and determine the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. The following research questions are raised in this study:

- 1- What are the causes of delay in the diagnosis and treatment of pulmonary tuberculosis?
- 2- What is the relation of health care seeking behavior of pulmonary tuberculosis patients with delay in the diagnosis and treatment of pulmonary tuberculosis and how it can lead to decreasing the delay in the diagnosis and treatment of pulmonary tuberculosis?
- 3- How Lady Health workers with the help of their knowledge, awareness, and attitude can contribute to improving the healthcare seeking behavior of the patients to decrease time interval of delay in the diagnosis and treatment of pulmonary tuberculosis and to have a better outcome of the disease?
- 4- What are the possible solutions which can be addressed to avoid the delay in the diagnosis and treatment of pulmonary tuberculosis in the region?

These are the main research questions on which this research is based upon to find out the causes of delay in the diagnosis and treatment of pulmonary tuberculosis and to have a better outcome of the disease.

#### **1.7 Research Hypothesis**

Although there are many studies on delay in the diagnosis and treatment of tuberculosis, these studies tend to describe the overall situation and duration of delays at different levels of health care seeking. There are only some studies which focus on the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. However, there are not many studies aiming to discover the actual causes of delay in the diagnosis and treatment of pulmonary tuberculosis and role of lady health workers to decrease the delay intervals. Thus, this study examines the phenomenon of delay in the diagnosis and treatment of pulmonary tuberculosis during the period of heath care seeking and how lady health workers can contribute to decreasing this delay. Following are the research hypothesis for this study: **Ho:** *Healthcare seeking behavior of pulmonary tuberculosis suspect patients is not associated with the delay in the diagnosis and treatment of pulmonary tuberculosis.* 

**H1:** *Healthcare seeking behavior of pulmonary tuberculosis suspect patients is associated with the delay in the diagnosis and treatment of pulmonary tuberculosis.* 

# **1.8 Research Framework**

The diagram below shows how knowledge, awareness and attitude of lady health workers and pulmonary tuberculosis patients can effectively decrease the delay in the diagnosis and treatment of pulmonary tuberculosis at different levels of health care seeking behavior.

"Patient's alertness, awareness to the symptoms of tuberculosis combined with health workers readiness to diagnose the disease and understanding which factors influence this delay is crucial for controlling the spread of infection within a community" (Auer, 2000: Demissie, 2002: Pronyk, 2001: WHO, 2004). Following figure shows the research framework.



Improvement in the knowledge, attitude, awareness, and communication skills of Lady health workers and improvement of the knowledge, attitude, and awareness of pulmonary tuberculosis patients along with their mutual understanding of the situation result in the improvement of health care seeking behavior of the pulmonary tuberculosis patients. Lady health workers may play a vital role in the community involvement and if community is involved in the health sessions, the overall health care seeking behavior of the patients can be improved. If the pulmonary tuberculosis suspect patients have improved health care seeking behavior they go to primary health care facilities for consultation and if they have pulmonary tuberculosis symptoms they can be diagnosed early and their anti tuberculosis treatment can be started on time. This leads to a decrease in the infectivity of the pulmonary tuberculosis patients in the community and causes a better treatment outcome in the end and decrease the burden of the disease in the region. So to decrease the delay in the diagnosis and treatment, lady health workers and health care providers they must involve the community in health sessions held at community level; this will improve the knowledge and awareness of the patients and they will have a better health care

seeking behavior. And this will affect the overall goal to avoid the delays and to have a better outcome of the disease.

#### **1.9 Research Methodology**

The research was employed with a cross sectional study with both quantitative and qualitative approaches. It included a semi-structured questionnaire with interview and observation. A Quantitative research approach was used in the study in order to prove the relations between variables. On the other hand, qualitative analysis was used to obtain detailed information about knowledge, awareness attitude, causes and issues related to delay in the diagnosis and treatment of pulmonary tuberculosis. The interviews with pulmonary tuberculosis patients at Aziz Bhati Shaheed hospital and basic health unit Joura Jalalpur Gujrat, Pakistan provided the actual picture of causes of delay in the diagnosis and treatment of pulmonary tuberculosis in these study areas.

In order to obtain the information for the study, both primary and secondary data were used. A Questionnaire was adapted from previous studies and some adjustments were made to incorporate some new questions to fit the situation of delay in the study areas. Due to the sensitiveness of the topic, a questionnaire was used as the tool to obtain the primary information for the study. Meanwhile, the secondary data is based on publications and documents and data available internet resources and from TB coordinator office from Gujrat. In searching for secondary data, the following key-words were often used: Delay in the diagnosis and treatment of tuberculosis, Knowledge, attitude and awareness about tuberculosis, Burden of tuberculosis, health care system in Pakistan. Then the data was processed by using Statistical Package for Social Sciences (SPSS).

#### **1.10 Limitation and Constrains**

As the study is cross-sectional, it may not capture all human behavioral changes over time. In addition, due to constraints in financial resources and time, this study covered a small sample size which was randomly selected and represented the general population. Therefore the result might not be used to generalize the situation in the whole country. This study did not cover the whole population in Gujrat, However the results of this study are still useful for policy implications and are comparable with previous studies conducted in this region. There are some constraints related to the social context within the targeted respondents *pulmonary tuberculosis patients*.

The number of pulmonary tuberculosis patients coming to both health facilities for their monthly visits to get drugs for pulmonary tuberculosis was a few in numbers, "two to three patients" a day. This is because the patients were registered and were at different phases of their treatment. So it causes difficulty to wait for the patients and to conduct interview with them. Some time the researcher managed to interview only one patient in a day and sometimes up to five and six patients. The reason behind waiting for the patients to come and interview was that these patients came from a very huge population and it was very difficult to get their addresses and visit them at their homes. The lack of privacy at both these health facilities may result in loss of some fact-reflected responses which could be provided by interviews. It is unavoidable to suffer from some bias in doing research. Unintentional bias might happen due to language translation from "Urdu" to "English". In addition, the questionnaires are simplified to fix or adjust to the local language of patients and community and their levels of understanding. Despite the above limitations and constraints, the information reported in this study is rich in its content which is useful for this research. It does capture different perspectives from a heterogeneous sample.

#### 1.11 Organization of Thesis

This research has been organized into 7 main chapters as follows:

**Chapter 1-** It provided an introduction to Pakistan, Global and Pakistan tuberculosis situation, research background, research objectives, research questions, research hypothesis, research framework, research methodology.

**Chapter 2-** It will explain the Primary health care system in Pakistan along with important health indicators in Pakistan. This chapter also provides information about the Lady health worker's program in Pakistan, activities of Lady health workers and referral system of tuberculosis patients in primary healthcare system in Pakistan. This chapter is important because tuberculosis is controlled by primary health care system in Pakistan. **Chapter 3-** This chapter provides the overview of the previous literature on the issue of diagnostic and treatment delay. It will explain the results of previous studies and overview of the previous studies done on this topic in Pakistan.

**Chapter 4-** This chapter will explain the characteristics of the study area; its population, demographic features etc. It will also explain the study setting where this research was conducted.

**Chapter 5-** This chapter will illustrate the research methodology by introducing the procedure of data collection, data processing and analyzing. The details of field work activities and how the interviews were conducted are presented in this chapter.

**Chapter 6-** This finding and results of research will be presented in this chapter including descriptive, statistical analysis. Then discussion will be done on findings of this research.

**Chapter 7-** The conclusion of this research will be presented in the last chapter along with recommendation about how to avoid delay in the diagnosis and treatment of pulmonary tuberculosis.

# Chapter 2

# Primary Health Care System and Lady Health Workers program in Pakistan

Primary health care is defined as "essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-determination" (WHO Alma Ata, 1978).

"In Pakistan, 3.1% of the gross domestic product is spent on economic, social, and community services; 43% is spent on debt servicing" (Ministry of Finance Pakistan, 2000). "About 0.8% is spent on healthcare, which is lower than in Bangladesh (1.2%) and Sri Lanka (1.4%)" (World Bank, 1998-1999). "In 2005 and 2006, less than 17\$ was spent on each Pakistani's health, which is low based on international standards" (Poullier, 2003). "The healthcare system in Pakistan has both public and private health facilities. Healthcare workers include 91,823 physicians, 37,623 nurses, 4,175 dentists, 22,528 paramedics, and 5,619 female health workers" (Khurshid, 2009). "There are 796 hospitals, 93,907 hospital beds, 5,171 basic health units, 531 rural health centers, and 856 maternity and child health centers" (World Bank, 1998: MoH Pakistan, 2001: Shariff, 2001: Khurshid, 2009). "Basic-level healthcare dispensaries (n = 4,635) offer primary healthcare" (Islam, 2002).

#### 2.1 Health Indicators of Pakistan

Health indicators are the set of parameters used to measure and access the status of a country. The main health indicators can be divided into four main parts in Pakistan.

#### 2.1.1 Major health indicators

"These include the life expectancy (years) of males and females which are 64 and 66 year respectively in Pakistan" (Federal bureau of statistics, 1999). "Percentage of disabled population excluding Quetta is 2.6" (Pakistan census organization, 1998) "Only 65% of the population has access to essential drugs" (Mehboob-ul-haq, 2001)"Almost 1.5 million of the population is addicted with heroin" (UNDCP, 2000).

Table 2.1 Health indicators of Pakistan

Major health Indicators						
Life expectancy (years)						
Males	64					
Females	66					
Percentage of disabled population except (Quetta)	2.6					
% of population with access to essential drugs	65					
Estimated population with heroin addiction	1.5 million					
Child health Indicators						
Neo-natal mortality rate (per 1000)	51.0					
Post neo-natal mortality rate (per 1000)	30.5					
Infant mortality rate (per 1000)	80.5					
% of children age 12-23 months that received full immunization	49					
% of children suffering from diarrhea(under 5 years in last 30 years	12					
Family planning Indicators						
Contraceptive prevalence rate	27.8					
% knowledge of any method of family planning	96					
% unmet need of family planning	33					

Women's health indicators					
Maternal mortality ratio (per 100,000)	300-550				
Total fertility rate	4.8				
% of women who received no antenatal care during last pregnancy	48.9				
% of women who had their last delivery at home	76.7				
% of women who received no postnatal care after their last delivery	72.4				
Infertility (Married women 2 or more years age 20 or more)	4.7				

Source: (Federal bureau of statistics, Pakistan census organization: Mehboob-ul-haq:

#### NIPS: UNDCP)

#### **2.1.2 Child Health indicators**

"In Pakistan neo-natal mortality rate per 1,000 is 51.0, and post neo-natal mortality rate per 1,000 is 30.5, while infant mortality rate per 1,000 is 81.5. Only 49% of children age 12-23 months received full immunization and 12% of the children have been suffering from diarrhea under the age of 5 years in the last 30 years" (Federal bureau of statistics, 1999).

#### 2.1.3 Family Planning indicators

According to National institute of population studies (NIPS), "contraceptive use prevalence in Pakistan is 27.8, and percentage knowledge of any type of family planning method is 96, while percentage of unmet need for family planning services is 33" (NIPS, 2000-2001).

#### 2.1.4 Women's health indicators

According to NIPS, "maternal mortality rate per 100,000 is 300-550 in Pakistan, Total fertility rate is 4.8, and only 48.9% of women received no antenatal care during the last pregnancy; 76.7% of women had their last pregnancy at home, 72.4% of women received no postnatal care after their last delivery, while infertility of women 2 or more years age 20 or more is 4.7" (NIPS, 2000-2001).

#### 2.2 Primary health care services in Pakistan

The primary health care system in Pakistan is facing many problems such as lack of resources, structural fragmentation, insufficiency and lack of functional specificity, inaccessibility, and gender insensitivity. "For 66% of those living in the rural part of the country, poverty, illiteracy and inadequately organized healthcare compound already is slowing down progress in health indicators" (World Bank, 2002). "The government of Pakistan has been spending 0.6 to 1.19% of its

GDP and 5.1 to 11.6% of its development expenditure on health over the last 10 years. Besides, more than 45% of this meager budget would be consumed by curative services, mostly at tertiary hospitals" (Nishtar, 2006). The Primary health care services which are provided to the people include, TB case detection with the help of community lady health workers, school health program to improve the health status of school going children which include their personal hygiene, dental care, Polio eradication program, Sanitation program, Maternal and child health care, Measles control program, Family planning services, and control of communicable diseases. The implementation of all these programs is very challenging for the Ministry of health and primary health care providers. The provision of these primary health care facilities is the responsibility of basic health units which are present in almost every union council. In Pakistan, Basic Health Units (BHUs) are seeing an average of 65-75 patients per day. "Recent surveys indicate that, nationally, not more than 20% of the people used the first level public sector network for their health care needs" (NIPS, 2008).

## 2.3 Primary health care system

According to USAID there are four major components of primary health care system in Pakistan. These are as follows (USAID, 2009):

- (1) Outreach and community based activities, which focus on immunization, malaria control, maternal and child health (MCH) and family planning (FP), and the LHWs program.
- (2) PHC facilities mainly for outpatient care.
- (3) Tehsil headquarters (THQ) and district headquarters (DHQ) hospitals for basic inpatient as well as outpatient care.
- (4) Tertiary care hospitals located in the major cities, and in the case of medical colleges, teaching hospitals for more specialized care. Primary care facilities (BHUs and RHCs) are usually managed by a medical officer, except for MCH centers, which are managed by a lady health visitor (LHV).

Source: USAID, 2009
# 2.4 Structure of Primary health care at District level

According to UDAID, "The Executive district officer (EDO) of health is the overall in-charge of the district health care system". The primary health care system at district level has three following tires; (USAID, 2009)

(1) First-level care facilities, i.e. Basic health units (BHU) and rural health centers (RHC), which are to provide outpatient and limited inpatient services. Each BHU is located in a union council and serves 10,000-15,000 people, while each RHC provides PHC coverage to a population of 50,000-60,000.

- (2) THQ hospitals with 60-70 beds and DHQ hospitals with 200 or more beds provide secondary health care services to a population of over 2 million people. They also offer first- and second-level referral services.
- (3) Teaching hospitals located at provincial headquarters or in big cities are attached to medical colleges and well equipped for all kinds of health services at the tertiary care level.

Source: USAID, 2009

"These tires are not well inter-linked with each other, the reason that first and second level facilities are under-utilized while tertiary facilities are over-utilized. There are also MCH centers and civil dispensaries, which provide MCH and FP services. The services also are supported by several vertical programs" (USAID, 2009).

The integrated management of primary health care system starts from the Ministry of Health which is responsible for the policy developments, monitoring and provision of training and administrative materials to the provincial health secretariat. Provincial health secretariat deals with the planning and allocation of finances to the district health departments. The health department at district level consists of DHQs, RHCs and BHUs, and THQs deal with the administrative control and implementation and improvement of health indicators. The district health mainly consists of several basic health units and they are responsible for the provision of basic health facilities at community levels. The basic health units have several lady health workers who are working at the community level and have health houses inside the community to give basic information and knowledge to the community people regarding health. The basic health unit serves as the recruitment for the LHWs from the community around

the basic health unit.

Figure 2.1 Integrated management of Primary health care system



Source: Author

# 2.5 Lady Health Workers program in Pakistan

"Community health workers are the backbone of the primary health care"(Alma Ata, 1978). "In our country, community health workers are known as Lady Health Workers (LHW) and are working under the National Program for Family Planning and Primary Health Care that was launched in Pakistan in 1994" (Majumdar, 1997: Afsar, 2005). The main purpose of this program is to provide health services to the community at their doorsteps. It addresses the primary health care problems in the community. "The importance of LHWs in the field of health cannot be overlooked because they are the solitary means of house-to-house access of health system for the provision of basic health care" (Butt, 2006: Douth waite, 2005). This program was set out to select, train and deploy 100,000 female Lady Health workers throughout the country by 2005. These LHWs are each responsible for an average of 1,000 people.

According to (Oxford policy management report, 2002) the main goals of this program was to establish a primary health care service:

- (1) Providing accessible, preventive, curative and rehabilitative services to the entire population
- (2) Bringing about community participation.
- (3) Improving the utilization of health facilities.

(4) "Expanding availability of family planning services in urban slums and rural areas of Pakistan, and gradually integrating existing health care delivery programs like EPI, Malaria control, Nutrition, MCH within the program" (MoH Pakistan, 1995).

# 2.6 Management structure of Lady Health workers program

The Lady Health workers program (LHWP) was designed to have a management and implementation structure linked to the Ministry of Health (MoH). "These units include the Federal Program Implementation Unit (FPIU) attached to the Federal MoH; the Provincial Program Implementation Units (PPIUs) attached to the Provincial Departments of Health (DoH); and the District Program Implementation Unit (DPIU) that is attached to the District Health Office (DHO)" (Oxford policy Management Report, 2002). The LHWP is embedded in both Ministry and Departments of health, and budget and expenditures are controlled by Ministry staff on deputation and still the accounting and information systems are separate from the MoH and DOH. First it was established that LHWs will get their training from the

first health care facilities, but eighteen months after the program began it was decided to have separate employees as the Lady Health supervisors (LHSs) would be responsible for the training, supervision and monitoring of LHWs and report monthly to DPIU. The LHWs at their house where they live are required to designate a room which is called as "Health House". The following figure shows the management structure of LHWP.





## 2.7 Activities of Lady Health workers

According to (Oxford policy management report 2002) and (World health organization) "the LHW is the key for all the activities of primary health care programs and serves to provide the basic primary health care facilities at the doorsteps of community people". The activities of LHWs include:

- (1) The LHWs organize the community by developing women groups and health committees in their area, which is a very important aspect of primary health care approach.
- (2) LHWs register all the population of their catchment's area for provision of services focusing on the priority age groups i.e. children under five and eligible couples (married women 15-49 years of age) for motivation and counseling of family planning.
- (3) LHWs act as liaison between formal health system and community.
- (4) LHWs give health education regarding hygiene and sanitation to the community.

- (5) LHWs discuss with community issues related with better health, hygiene, nutrition, sanitation, family planning emphasizing their better benefits toward an improved quality of life.
- (6) LHWs provide essential drugs for the treatment of minor illnesses like diarrhea, malaria, acute respiratory tract infection, intestinal worms and contraceptives to eligible couples.
- (7) LHWs strengthen the EPI program to improve the vaccination status of the women and children.
- (8) LHWs identify tuberculosis suspects from the community and refer them to basic health units for their check up and initial diagnosis.
- (9) LHWs provide motivation and referral services to mothers for safe motherhood including antenatal, safe delivery and postnatal care. LHWs achieve this by close coordination with the nearest basic health units, traditional birth attendant (TBAs) and skilled birth attendants including midwives and lady health visitors (LHVs).

#### 2.8 Impact of LHWs on Health

The activities done by the LHWs as mentioned in the previous section have an impact on the primary health care system in Pakistan. These health interventions have proven clinical efficacy in reducing morbidity, mortality and on fertility. The impact by LHWs on the primary health includes improvement in the vaccination of children, to whom this vaccination is provided at their doorsteps. A large and very healthy impact is the use of contraceptive methods by the eligible couples which are made available by the LHWs. The antenatal care has improved with the help of LHWs, and there is an increased uptake of these antenatal services by pregnant women. Postnatal care has also improved due to the regular monitoring and follow-ups of the child growth. There are evidences for a lower rate of diarrhea among the children of five year age group. There is also a very good impact on the tuberculosis case detection rate. The advantage of LHWs is mainly in the rural area where the population has better health indicators due to the presence of LHWs. There is a significant improvement in the health indicators in population served by LHWs due to the provision of health knowledge, provision of family planning, antenatal and

postnatal services and also due to the referral to the first level health care facilities. LHWs also promote the use of health services and improve health behavior. Households where LHWs perform their activities usually have substantially better outcome measures.

# 2.9 Referral of tuberculosis patients in Primary health care system with the help of LHWs

Lady Health workers play a very important role in case detection of tuberculosis in the primary health care system. As LHWs live very close to the community people they can identify tuberculosis suspects and refer them to the first level care facilities for diagnosis and treatment. LHWs are equipped with awareness, knowledge, about the disease and they can communicate easily with the community people and can find tuberculosis suspects through their daily visits to the households. The LHWs are frequently trained about the knowledge and general aspects of the tuberculosis and how to communicate and refer the tuberculosis suspects to the first level health care facility from the community. When a LHW visit a household she picks up a tuberculosis suspect if he/she is having cough more than three weeks with fever, and weight loss and other symptoms related to tuberculosis. Then LHW discusses this with the suspect and tries to convince him for the check up in the first level health care facility and makes a referral slip for him and refers him to the health facility for the checkup. This first level health care facility serves as a treatment center for the diagnosed tuberculosis patients. When a TB suspect reaches at the first level health care facility the medical officer examines him thoroughly and if he confirms that the patient might have tuberculosis he refers him for the diagnosis to the diagnostic center which may be a tertiary head quarter (THQ), district head quarter hospital (DHQ) or rural health center (RHC). After reaching there and being diagnosed as tuberculosis, the patient is sent back to the first level health care facility for his treatment because the patient belongs to the catchment area of that health care facility. The LHW who referred this patient is appointed to take care of his treatment and timely drug intake. There is a continuous feedback after each month from the first level health care facility to the diagnostic center which is usually a THQ, DHQ

or RHC. The following figure shows the referral system of TB patients with the help of LHW.

Figure 2.3 Referral of TB patients in primary health care system



# 2.10 Chapter Summary

This chapter explained the overview of primary health care system and lady health worker program in Pakistan. First it explained health indicators in Pakistan. Then it explained the primary health care services, system and structure in Pakistan. Then in the second section lady health workers program, its structure, activities and impact of lady health workers on primary health care system were discussed. And in the final section referral of tuberculosis suspect patients in the primary health care system with the help of lady health workers was discussed in detail.

# **Chapter 3**

# **Literature Review**

This chapter will thoroughly analyze and review the previous literature on delay in the diagnosis and treatment of tuberculosis. It firstly describes the concepts of delay intervals in diagnosis and treatment of tuberculosis. Then the next section will explain the overview of delay in the diagnosis and treatment of tuberculosis. Finally results of previous studies and factors associated with delay in the diagnosis and treatment of tuberculosis will be discussed. This chapter reviews relevant literature on delay in the diagnosis and treatment of tuberculosis in Pakistan and other countries to reveal the causes of delay.

# 3.1 Definitions and concept of delay in the diagnosis and treatment of tuberculosis

According to Dimissie, the following time intervals and delays were determined for each respondent: "The patient interval was the time interval between the appearance of major pulmonary symptoms and the first medical consultation. Intervals longer than the median were considered indicative of a patient delay" (Demissie, 2002).

According to Laim, the diagnosis interval was regarded as "*the time from the first medical consultation until the date of diagnosis*" (Laim, 1997). A diagnosis interval longer than the median was indicative of a diagnostic delay.

According to Loh, "the treatment interval was the time from diagnosis to initiation of treatment" (Loh, 2005). Intervals of longer than the median are considered indicative of treatment delay. According to a WHO study other definitions of different types of delay intervals in tuberculosis are as follows:

"The total delay is the time interval from the onset of illness until the initiation of anti-tuberculosis drugs" (WHO EMRO, 2003-2004). It is the sum of two time intervals: diagnostic delay and treatment delay. These are defined as follows:

1- Diagnostic delay: "Time interval between the onset of symptoms and labeling the patient as a tuberculosis patient (tuberculosis diagnosis)" (WHO EMRO, 2003-2004) 2- **Treatment delay:** "Time interval between tuberculosis diagnosis and initiation of anti-tuberculosis drugs" (WHO EMRO, 2003-2004)

"The total delay is also the sum of patient and health care system delay" (WHO EMRO, 2003-2004) and these are defined as follows:

- 1- **Patient delay:** "Time interval between onset of symptoms and presentation to a health care provider" (WHO EMRO, 2003-2004).
- 2- **Health care system delay:** "Time interval between the date of health care seeking behavior at a health care provider and the initiation of anti-tuberculosis treatment" (WHO EMRO, 2003-2004).

The following figure explains the concept of delay intervals in tuberculosis.

Diagnos	Treatment delay						
Onset of symptoms		Date	e of diagnosis				
1 <sup>st</sup> health seeking encounter			Date of treatment				
Patient delay	Hea	Health system delay					
Total delay							
Source: WHO EMRO, Report or	n diagnostic and trea	tment delay, 20	003-2004				

Figure 3.1 Different delay intervals contributing to the total delay in tuberculosis

### 3.2 Overview of delay in the diagnosis and treatment of tuberculosis

Tuberculosis control can be achieved if patients with disease receive adequate and timely treatment. "The main factors that determines the risk of becoming exposed to tubercle bacilli include the number of incident infectious cases in the community, the duration of their infectiousness and the number and nature of the interactions between a case and a susceptible contact" (WHO EMRO, report, 2003-2004). Therefore the duration of infectiousness is very important in tuberculosis spread. The proportion of smear positive tuberculosis cases remains high in the community if they are not detected at a very early stage. Early case detection is very important in reducing the number of incidence cases in the community. It is assumed that the most important and challenging task for the National tuberculosis control program is the early case detection for timely diagnosis and treatment. But unfortunately this is not happening around the world especially in the developing world where there is a considerable delay in the diagnosis and treatment of tuberculosis due to so many factors related to patients themselves and the health care system.

There are few studies around the world which are focused on this important issue of delay in the diagnosis and treatment of tuberculosis. According to these studies delay in the diagnosis and treatment of tuberculosis can result in a significant patient morbidity. "In addition, untreated cases of tuberculosis constitute an important reservoir for the transmission of disease in the community"(Laim, 1997). "Public health responses have focused on interpreting the chain of transmission by treating active cases that present for care, tracing their contacts and chemoprophylaxis" (CDC, 1992: Comstock, G.W, 1994). If such efforts miss symptomatic TB patients, these patients may not suspect their diagnosis and may therefore delay seeking care long enough to spread the disease. "Delay of more than two month has been shown to spread the disease to domestic contacts" (Riley, 1974). "Moreover delays in diagnosis may also worsen the course of the disease and even increase the case fatality rate"(Katz, 1985: Enarson, 1978: Kramer, 1990). "More general studies of access to care and delay in care-seeking among patients without TB confirm that a self-perceived need for care and physician ratings of the severity of symptoms are strong predictors of prompt care-seeking" (Weissman, 1990:

Battistella, 1971). Aday and Andersen concluded that "more equitable access to care occurs when need for care or severity of illness predicts utilization better than potential access barriers (e.g., ethnicity, income, insurance status, appointment waiting time)" (Aday: Anderson, 1981). *A number of studies on delays in TB diagnosis have reported long delays due to both patient delay in seeking healthcare and healthcare provider`s delay in correctly diagnosing TB* (Franco, 1996: Caminero, 1995).

Delay in the diagnosis is significant with regard to not only disease prognosis at the individual level but also transmission in the community and the reproductive rate of the TB epidemic (Dye, 1999: Bjune, 2005). Most of the transmission occurs between the appearance of cough and initiation of treatment. According to Modeblo the patients become more contagious as the delay progresses; the longest delays are associated with the highest bacillary numbers on sputum smears (Modeblo, 1999). Patient's alertness to the symptoms of tuberculosis combined with health worker's readiness to diagnose the disease and understanding which factors influence this delay are crucial for controlling the spread of the infection within a community (Demissie, 2002). The following table will shows the

median diagnostic delay for pulmonary tuberculosis in 58 studies:

Country	Year	First author	DD Pat	DD HCP	DD total
Tanzania	2000	Wandwalo	15	120	136
United Kingdom	2003	Lewis	63	35	126
Burkina Faso	2006	Ouedraogo	*	*	120
Ethiopia	1999	Madebo	*	*	120
Ghana	1998	Lawn	28	56	120
Malawi	1988	Nkhoma	*	*	120
Thailand	1991	Tesana	*	*	120
Thailand	1993	Pungrassami	*	*	120
Romania	1989	Anastasatu	69.	34 🐟	107*
Iran	2002	Masjedi	13.		93 🔶
Vietnam	1999	Long	54.	29 🔶	93 🔶
Pakistan	2006	WHO	9	87	91
Malaysia	1994	Hool	15	35	90
United States	2005	Golub	32	26	89
Iran	2006	WHO	24	42	88
Malaysia	1997	Liam	14	49	88
Botswana	1998	Steen	21	35	84
New Zealand	2000	Calder	7	49	84
Uganda	2005	Kiwuwa	14	63	84
Spain	2003	Altet Gomez	43.	39 🔶	82 🔶
Ethiopia	2005	Yimer	15	61	80
Nepal	2001	Yamasaki-Nakagawa	23	29	79
Japan	1990	Niijima	*	*	78†
Mongolia	1996	Enkhbat	29	35	78
Nigeria	2004	Odusanya	56	7	70
South Africa	2001	Pronyk	28	7	70
Australia	2001	Ward	30		66
Thailand	2006	Rojpibulstit	31	20	66
China	2004	Bai	30	24	65
Italy	2006	Gagliotti	7	36	65
Spain	1996	Franco	23	32	64
Turkey	2004	Güneylioglu	184	13.	64 🔶
Ethiopia	2002	Demissie	60	6	64
Norway	2006	Farah	28	33	63
United States	1998	Asch			60
India	2002	Rajeswari	20	23	60
Rorea	1992	Chause	54.	14*	60 *
The Cambia	2001	Linghandt	*	*	60
The Gambia	2001	Needbarn	*	*	60
Cambadia	2001	Sala	*	10	50
Somalia	2006	WHO	53	7	50
Malawi	2000	Salaninoni	*	*	56
Svela	2006	WHO	31	15	55
China	2005	Xu	10	39	50
Turkey	2006	Okur	30	19	49
United Kingdom	2007	Rodger	*	*	49
Australia	1996	Pirkis	*	*	44
Talwan	2005	Chlang	7	23	44
Egypt	2004	WHO	12	18	42
Japan	2002	Sasaki	21	7	42
Iraq	2004	WHO	31	2	36
United States	1999	Sherman	21	6	35
Yemen	2004	WHO	28	4	35
China	2006	Deng	19	5	31
France	1996	Gulbaran			30 🔶
Thailand	2001	Ngamvithayapong	11	8	*
Pakistan	2001	Sadiq			21€

Figure 3.2 Median diagnostic delays of pulmonary tuberculosis patients in 58 studies

Table continued

DD Pat (Diagnostic Delay by the Patients): Time from debut of symptoms to first visit to health care provider DD HCP (Diagnostic Delay by the Health Care Providers): Time from first visit to a HCP to the making of a proper diagnosis DD Total (Total Diagnostic Delay): Time from debut of symptoms to the making of a proper diagnosis \* Data not obtainable † Average calculated by the reviewers from separate numbers for female and male Mean 80% percentile € 77% percentile

Source: (Dag Gunderson Strola, 2008)

## 3.3 Results of previous studies in the World

There have been a few studies on diagnostic and treatment delay throughout the world especially in the developing countries. The researcher was able to find quite a number of studies on this issue but few studies were specifically focused on diagnostic and treatment delays. The articles were obtained on this issue of delay in the diagnosis and treatment of tuberculosis from 1995-2010. In this section results of these studies were discussed to assess the seriousness of this issue and to find the causes of delay in the diagnosis and treatment of tuberculosis especially pulmonary tuberculosis.

One of the studies was done in 2008, which was "A systemic review of delay in the diagnosis and treatment of tuberculosis" by Dag Gundersen Strola,

Solomon and Gunnar Bjune. 58 studies were systemically reviewed to know the issue of delay in the diagnosis and treatment of tuberculosis. In this study it was observed that the main factors for diagnostic delay were coexistence of chronic cough, negative sputum smear, rural residence, low access, initial visitation of a government low-level healthcare facility, extra-pulmonary TB, human immunodeficiency (HIV) virus, seeking help from a private practitioner or traditional healer, old age, poverty, alcoholism and substance abuse, female sex, history of immigration, low educational level, low awareness of TB, incomprehensive beliefs, self-treatment, and stigma and other lung diseases. The core problem in delay of diagnosis and treatment seemed to be a vicious cycle of repeated visits at the same healthcare level, but failure to access specialized TB services (Dag Gunderson, 2008).

Another systemic review of literature on "*Time delay in diagnosis of pulmonary tuberculosis*" was done by Chandrashekhar, Kishore, Jorismenten and J Van den Ende in 2009. In this study a systemic review of literature was done. Literature search was done from EMBASE and Medline from 1990 to 2008. 419 studies were identified and only 52 were qualified for the review. The range of total delay was 25-185 days, patients delay was 4.9-162 days and health system delay was 2-87 days for both high income and low income countries. Patient delay in low income countries was 31.7 days and health system delay was 28.5 days. It was almost similar to those of high income countries where patient's delay was 25.8 days and health system delay was 21.5 days. It was observed and concluded that a high treatment success rate of DOTS may be supplemented by measures to shorten the diagnostic delay (Chandrashekhar, 2009).

A study was done in Ethiopia by Solomon Yimer, Gunnar Bjune and GetuAlene in 2005; the title of this research was "*Diagnostic and treatment delay among pulmonary tuberculosis patients in Ethiopia: a cross sectional study*". This study was conducted in Tuberculosis management units which were randomly selected in Amhara Region. In this study a total of 384 new smear positive pulmonary tuberculosis patients were selected. The median total delay was 80 days. The median patient delay was 30 days while median health system delay was 21 days and median health seeking period and health provider`s delays were 15 and 61 days respectively. It was observed that 48% of the delay was more than one month. With a P- Value of 0.0001 it was noted that patient's delays were strongly associated with first visit to non-formal healthcare providers and self-medication. With a P-value of 0.0001 there was a strong association between prior attendance to health clinic and increased health system delays. According to the conclusion of this study the delay in the diagnosis and treatment of pulmonary tuberculosis (PTB) is unacceptably high in Amhara region. Healthcare system and heath provider's delay contribute to the major portion of the total delay (Soloman, 2005).

A study "Longer *delays in tuberculosis diagnosis among women in Vietnam*" was conducted in 1998 by N.H. Long, E. Johasoon, K. Lonnroth, B. Eriksson, A Winkvist, V.K. Diwan. This study was done in 23 randomly selected districts in four provinces of Vietnam. A sample size of 1,027 patients who were in their age group 15-49 were selected during the 1996 and interviewed. All these respondents were new smear positive patients. The mean total delay was observed as 13.3 weeks for women and 11.4 weeks for men. This included a patient's delay of 7.9 weeks and 7.6 weeks for women and men respectively. Health care provider's delay was longer among women as (5.4 weeks and 3.8 weeks for men). In this study it was observed that women visited more HCPs than men. The conclusion of this study was that patient's delay was unacceptably long for both women and men. Men got their diagnosis earlier than women (Long, 1998)

Another study was done at Maryland Department of Health and Mental Hygiene from 1 June 2000 to 30 November 2001. The study was done by J. E. Golub, S. Bur, W.A. Cronin, S. Gange, N. Baruch, G.W. Comstock, R.E. Chaisson. The title of this study was "Patient and health care system delays in pulmonary tuberculosis diagnosis in a low-incidence state". This was a prospective study and in this study for 158 patients it was observed that the median patient delay was 32 days, while median health system delay was 26 days and median total delay was 89 days. It was also observed that less educated and non-white patients had longer patient delay while English speaking patients had longer health system delay. Also the patients presented to the private physician had health system delays of 51 days while patients presented to emergency room had delays of 18 days and for public clinic 10 days of delay was observed. A rapid diagnosis of TB was observed in this study when chest X-rays and AFB culture were done. According to this increased awareness of the current epidemiology of TB and better use of available diagnostic tools will reduce delays and may reduce TB transmission; also education of the patients about TB symptoms might reduce delays (Golub, 2000)

A study in Malaysia was done in 2007 by Chang and Esterman with a title of "Diagnostic delay among pulmonary tuberculosis patients in Sarawak, Malaysia: a cross sectional study". A cross sectional study was conducted in 10 tuberculosis clinics in Sarawak from June 2003 to May 2004. A semi-structured questionnaire was designed and interviews were conducted on diagnosis or within the admission period. A total of 316 new smear-positive pulmonary tuberculosis patients were included in this study. The median patient delay was 30 days while the median diagnostic delay was 22 days. It was observed by the health-care provider where patients first sought their consultation, that action taken by the HCP and respondent's income were associated with diagnostic delay. The median treatment delay was 0 days. It was also observed that females appeared to have a longer delay. Also it was concluded that both patients and health care providers played a role in delay in the diagnosis and treatment (Chang, 2007).

Olumuyiwa, and Joseph did a research in Nigeria on "Patterns of delay amongst pulmonary tuberculosis patients in Lagos, Nigeria" in 2004. In this study 141 patients were included. 63% were males and 37% were females. 82% of the patients had positive smears. Healthcare seeking from a health facility was observed by 83% of patients and delay was longer than one month after the onset of symptoms. The median health system delay was 1 week while the median patient delay was 8 weeks and median total delay was 10 weeks. Health care provider delay was recorded in 13% of patients. Patients delay was the most significant in this study and was the major contributor in total delay. Patient's socio-demographic characteristics were strongly associated with patient delay. It was concluded in this study that patients delayed by themselves and did not present to the centers in time and served as reservoirs of infection in the community. Patient's education and awareness should be improved to avoid diagnostic delay (Olumuyiwa, 2004).

Another study in Malaysia was done by Laim, and Tang in 1997 on "Delay in the diagnosis and treatment of pulmonary tuberculosis in patients attending a university teaching hospital". In this study a total of 97 respondents who were newly

diagnosed of pulmonary tuberculosis were included. This study was conducted to find out the diagnostic and treatment delays in pulmonary tuberculosis. In this study it was observed that 36 cases were sputum smear-positive while 61 were smear-negative. Tuberculosis was confirmed in 32 of the smear-negative cases. The median patient delay was 2 weeks while health care provider delay was 7 weeks and total delay was 12.5 weeks. It was believed that the majority of the patients consulted private practitioners rather than visiting public health care facilities. Because the patients visited private consultants and they rarely suspected tuberculosis on diagnosis, both X-ray chest and sputum examination were underutilized. It was concluded in this study that education and awareness to the patients should be provided to decrease the delay in the diagnosis and treatment and private general practitioners should be more alert to the diagnostic possibilities of tuberculosis (Laim, 1997).

A study was done in Yemen at National Tuberculosis Institute in Sana's in December 2001 to March 2002 by J.Date and K.Okita. This study was focused on people living in the mountainous area of Yemen. The title of this study was "Gender and literacy: factors related to diagnostic delay and unsuccessful treatment of *tuberculosis in the mountainous area of Yemen*". Patients were interviewed and data was collected from 74 smear-positive pulmonary tuberculosis patients. In this study it was observed that illiterate patients had a longer diagnostic delay than literate patients with a P-value of 0.006. Patients did not know about the tuberculosis properly, they had their own views about that. Females completed treatment more properly than males with a P-value of 0.046. Female's lack of education did not hinder them from receiving TB diagnosis and treatment. The thinking that tuberculosis is a traditional illness however causes longer diagnostic and treatment delay among the un-educated patients (Date, 2002).

A multi-country study was done in 2003-2004 on "*Diagnostic and treatment delay Tuberculosis in 7 countries of the Eastern Mediterranean Region*" by a number of authors. This study was focused on the core issue of diagnostic and treatment delay of Tuberculosis and its determinants. This study was done in Pakistan, Iran, Iraq, Egypt, Syria Arab republic, Somalia, Yemen. This study was conducted among 5053 newly diagnosed smear-positive pulmonary tuberculosis. Respondents were interviewed with preformed structured questionnaire to know the factors influencing delay in the diagnosis and treatment. The mean duration of delay from the onset of symptoms to the start of anti-tuberculosis treatment ranged from 1.5 to 4 months in different countries. Patient delay ranged from mean of 9.9 days in Pakistan, and 69 days in Somalia. Health system delay was 5 days in Iraq and 90.7 days in Pakistan. It was observed that most of the patients went to private sector to seek healthcare which was the first choice for more than two thirds of the patients. The main determinants of diagnostic and treatment delay were socio-demographic, socio-economic, tuberculosis stigma, tuberculosis knowledge, and more than one health care seeking encounter (WHO EMRO, 2003-2004). The following figure shows the contribution of patient and healthcare system to the total delay in the treatment of patients with tuberculosis in these countries.



Figure 3.3 Contribution of patient or health care system to the total delay

Source: WHO EMRO report, 2006

3.4 Previous studies on diagnostic and treatment delay in Pakistan and their results

In Pakistan there are very few studies focused on the issue of delay in the diagnosis and treatment of tuberculosis. The author was only able to find 3 studies which were done on this topic. One of the studies was mentioned in the previous section which was done in 7 countries of the Eastern Mediterranean Region in 2003-2004. "This study was done in the city of Karachi. Three chest centers where DOTS had been implemented were chosen as a study site. These centers were Nazimabad Chest Clinic, Malir Chest Clinic and Ojha Institute of Chest Diseases. Represented samples of newly diagnosed smear-positive pulmonary tuberculosis cases, 15 years of age and older were consecutively included in the study. A total of 844 cases were selected and interviewed according to the questionnaire developed for this study. In this study the risk factors of patient and healthcare system delay were recorded and identified. Also delay intervals were noted. The following figure will show the delay intervals which were recorded in this study" (WHO EMRO, 2003-2004). The highlighted portion in this figure shows different delay intervals in Pakistan.

	Egypt	Iran, Islamic Republic of	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
Type of Delay	(n = 802),	(n = 800),	(n = 400),	(n = 844),	(n = 809),	(n = 800),	(n = 598),
Type of Delay	n (70)	n (70)	n (70)	<b>n</b> (70)	n (70)	n (70)	n (70)
Patient delay, d	24.2 (27.2)	51 (74.4)	20.05 (20.0)	00 (0 1)	(0. (7(.08)	52 7 ((2.1)	20 (50 2)
Mean (SD)	24.3 (37.2)	51 (74.4)	39.96 (20.6)	<u>9.9 (9.4)</u>	69 (76.98)	52.7 (62.1)	39 (50.3)
Median	12	24	31	9	53	31	28
Range	0-365	1-393	3-103	0-74	0-779	0-426	0-502
Health system							
delay, d							
Mean (SD)	33.6 (44.5)	75 (7.05)	5 (7.05)	90.7 (33.5)	19.5 (41.6)	27.6 (39.6)	19.98 (37.2)
Median	18	42	2	87	7	15	4
Range	0-384	1-583	0-34	10-265	0-785	1-372	0-244
Diagnostic							
delay, d							
Mean (SD)	55.9 (52.0)	124 (114.0)	43.96 (22.8)	96.3 (.33.9.)	76.6 (75.8)	77.6 (78.6)	57.4 (62.3)
Median	42	88	36	<mark>9</mark> 1	58	55	35
Range	0-364	3-728	3-114	21-256	0-786	2-698	0-720
Treatment							
delay, d							
Mean (SD)	1.2 (2.7)	3.1 (5.5)	2 (6.6)	4.2 (4.7)	4.5 (9.8)	2.9 (5.6)	1.7 (7.4)
Median	0	1	0	2	2	1	0
Range	0-42	0-66	0-8	0-43	0-123	0-89	0-92
Total delay, d							
Mean (SD)	57 (52)	127 (114.0)	45.96 (23.69)	100.7 (.34.2.)	79.5 (75.1)	80.4 (79.0)	59.2 (63.94)
Median	44	91	37.5	97	60	57	35
Range	0-364	5-728	3-114	23-267	0-786	2-702	0-720

Figure 3.4 Different types of delay for patients with tuberculosis

Source: WHO EMRO, 2005

The second study in Pakistan was done by Samera, Odd Morkve, and Tehmina Mustafa in May-July 2006. This title of this study was "*Patient and health system delay: healthcare seeking behavior among pulmonary tuberculosis patients in Pakistan*". This was a cross-sectional study done in hospital with a pre-structured questionnaire. The study was conducted in two areas, one in Sialkot at Bthania hospital and another was in Multan in Nishtar hospital in the Punjab, Pakistan. This study consisted of all the tuberculosis patients coming to the hospital during that period. The median health system delay was 60 days with a range from 4-365 days. The median patient delay was 33 days with a range from 2-90 days. Only 37% of the patients were aware about the tuberculosis. Only 27% of patients were stigmatized with tuberculosis. Health system delay was the major contributor to the total delay. Tuberculosis awareness was low among the patients (Samera, 2006).

The third study is "*Healthcare seeking behavior of pulmonary tuberculosis patients visiting TB center Rawalpindi*" by Sadiq, and Muynck between 20 November to 21 December 1998. This was a descriptive cross sectional study and conducted by an open-ended questionnaire. Only 160 newly registered TB patients at different TB centers were included in this survey. Before consulting a TB center 96% of the patients had visited many health care providers. Of 154 patients only 48 were diagnosed as tuberculosis and only 29 of them received anti-tuberculosis treatment. Almost 118 patients consulted the healthcare providers within 3 weeks time. Healthcare providers were the main contributors to diagnostic and treatment delay (Sadiq, 1998)

### 3.5 Risk factors associated with different types of delays in Tuberculosis

According to the previous studies there have been different factors which may contribute to delay in the diagnosis and treatment of tuberculosis. These factors are as follows:

# 3.5.1 Risk factors of Patient's Delay

According to (Sherman, 1999) the patient delay was defined as "the period from the onset of symptoms to the first visit to a healthcare provider". The patient delay is contributed by different factors. According to (WHO EMRO,2005) in Syrian Arab Republic the patient delay was significantly associated with inadequate knowledge regarding tuberculosis, seeking health care from a non-specialized individual at onset of symptoms, such as a traditional healer and seeking care from more than one health care provider. In Somalia the risk factor for patient delay was associated with living in suburbs and rural areas and inadequate satisfaction with care, and high degree of stigma. Results from Yemen showed that the risk factors were female sex, and inadequate knowledge regarding the disease. According to

(Date: Okita, 2005) "Illiterate patients had a longer delay than literate patients. The concept of traditional illness however causes a longer delay among illiterate patients". (Laim, and Tang) said "that to shorten the patient delay the public should be educated about the symptoms of tuberculosis and private general practitioners should be more alert. Patient delay also was associated with distance to health care facility". According to previous studies the patient delay is also associated with risk factors like HIV, coexistence of chronic cough, lung diseases, negative sputum smear, extra-pulmonary TB, rural residence, low access to healthcare, initial visit to government low-level health care facilities, initial visit to traditional or unqualified practitioner, initial visit to private practitioners, old age, poverty, female sex, alcoholism or substance use, history of immigration, low educational level and awareness and knowledge about TB.

## 3.5.2 Risk factors of Health care system delay

According to (Sherman, 1999) the health care system delay was defined as "the interval from the date a medical or health care provider was first consulted by the patient to the date the patient was first placed on anti-tuberculosis treatment". According to (WHO EMRO, 2005) "health care system delay was mainly attributed in Egypt, Iran, and Pakistan". The significant risk factors for health care system delay were: old age, obtaining a negative smear results for acid bacilli, a positive history of chronic pulmonary disease, and seeking health care from private sector. Also in cases where private practitioners made the initial diagnosis a longer time of delay was seen. Time to reach health care facility more than half hour, high cost of medical services, seeking care at non-specialized health facility and more than one health care encounter before initial diagnosis were also significant risk factors of health care system delay.

# 3.5.3 Risk factors of total delay

According to Sherman total delay was defined as "the period from the onset of any tuberculosis symptoms or non-symptoms to the start of at least two antituberculosis drugs for suspected or confirmed tuberculosis" (Sherman, 1999). According to WHO the risk factors of total delay in Egypt, Pakistan, Somalia, Syria, and Yemen were; being illiterate (2.76 fold increased risk), time to reach health
facility >1/2 hour and > an hour (1.73 and 1.75 fold increased risk compared to those <1/2 hour, high crowing index (1.2 fold), and more than one health care provider before diagnosis (2.55 fold increased risk) (WHO EMRO, 2005). The risk factors of total delay are: belief that low cost services are inadequate, living in suburbs, being diagnosed by health facility not belonging to national tuberculosis control program, visiting several health care providers before diagnosis, inadequate knowledge and awareness about the disease, poor satisfaction with care, and high degree of stigma is also playing an important role in the total delay in the diagnosis and treatment of tuberculosis.

The causes of delay in the diagnosis and treatment of pulmonary tuberculosis in Gujrat, Pakistan will be discussed in detail in the next chapter as they were revealed in the study. Although the number of risk factors or causes are similar to those discussed in this chapter but still it needs to be discussed as they were assessed in this research.

# **3.6 Chapter Summary**

This chapter has reviewed previous studies for understanding the concept of delay in the diagnosis and treatment of tuberculosis. First in this chapter the concept and definitions of different types of delay in the diagnosis and treatment of tuberculosis were discussed. Secondly an overview of delay in the diagnosis and treatment of tuberculosis was discussed. Thirdly the results of previous studies in the world and in Pakistan were discussed. Finally the risk factors of patient delay, health care system delay and total delay were discussed.

## **Chapter 4**

## Characteristics of study area

This is a short and very important chapter and describes the overview of the study area district Gujrat, Aziz bhati shaheed hospital Gujrat and Basic health unit Joura Jalal Pur Gujrat. First, the information of location, geography, climate and demographic information in the study area will be provided. The key indicators and Gujrat PHC model will be presented in the second part of this chapter. Third, the characteristics of Aziz Bhati Shaheed hospital and Basic Health unit Joura Jalal Pur will be briefly described.

### 4.1 Location

Gujrat is an ancient district of Pakistan situated in Punjab province on the bank of Chenab River, Located about 120 kilometers (75 miles) north of Lahore which is the capital of Punjab province and 150 Kilometers (93 miles) from Islamabad, the capital of Pakistan. Because of its proximity with the rivers the land is good for cultivation with rice and sugar-cane as main crops. It is bounded on the North-East by Jammu and Kashmir, on the North-West by the River Jhelum which separates it from Jhelum district, on the East and South-East by the river Chenab, separating it from the districts of Gujranwala and Sialkot, and on the West by Mandi Bahauddin district. District Gujrat is spread over an area of 3,192 square kilometers (Available on <u>www.itsPakistan.net/pakistan/gujrat.aspx</u> visited on 1 may 2011).

### 4.2 Climate

Gujrat city has a moderate climate; it becomes hot in summer and the temperature rises up to 45 °C (113 °F) during the daytime but hot spells are comparatively shorter due to proximity of Azad Kashmir Mountains."The winter months are very pleasant and the minimum temperature may fall below 2°C" (www.itsPakistan.net/pakistan/gujrat.aspx) *The average rain-fall on the Kashmir border is over 100 cm, at Kharian it is 75 cm, at Gujrat 67 cm and at Dinga 50 cm* (Available on www.world66.com/asia/southasia/pakistan/gujrat visited 1 May 2011)

#### 4.3 Population and Area Information

According to Population and Housing Census, 1998 the total population of Gujrat district is 2,048,000 persons out of which 1,026,000 (50.1%) are males and 1,022,000 (49.9%) are females. Density of population in the district is 642 persons per square kilometer. Percentage break-up of the rural and urban population is 1,480,700 (72.3%) and 567,300 (27.7%) respectively. Area of District Gujrat is 1,232sq. Miles/ 3192 sq. km/ 788757 acres (Population and Housing Census, 1998)

#### 4.4 Key Indicators of District Gujrat

According to Multiple Indicator Cluster Survey (MICS), 2007-2008 done by the government of Punjab planning and development department bureau of statistics, *Punjab MICS is a household survey intended to assist the Government of Pakistan/Punjab in planning and monitoring social service delivery and other indicators of development. The survey fills gaps in essential data, providing recent and relevant information at the provincial, divisional, district and tehsil level. The survey findings will ultimately be fed into government programs for sustainable*  *development and poverty alleviation* (MICS, 2007-2008). The results of indicators are in percentage. According to MICS, 2007-2008 the adult literacy rate 15-24 years in district Gujrat was 90. Gender parity index for primary education was 1.02 and for middle/secondary education was 1.11. Adult health care provided by the lady health workers was 75 and physical access to the health care facilities within half an hour distance was 94. Under 5 mortality rate per 1,000 births was 100 while infant mortality rate per 1,000 births was 70. Use of Oral Rehydration Therapy (ORT) was 54. Prevalence of diarrhea was 6.0. Child disability (2-9 years) of age was 6.9.

## 4.5 Gujrat Primary Health Care Model

According to USAID, 2009 report on the Review and assessment of various Primary health care models in Pakistan, the Gujrat Primary health care model was explained as follows:

The Gujrat PHC model is a partial replica of the primary health care extension (PHCE) project, with some changes in implementation strategy and intervention design. Under the model, the National Commission of Human Development (NCHD) is the direct partner of provincial and district government and implementation of interventions is under the leadership of the District Health Department (DHD) and district government administration. The project is named Restructuring and Strengthening of PHC System, with the goal to ensure access to quality PHC to every individual of Gujrat (USAID report, 2009, p27, p28).

The following figure shows the key strategy and salient features of Gujrat PHC model.

Figure 4.1 Key Strategy and Salient Features of Gujrat PHC model

- 1- Strategy: Strengthen PHC by focusing on the union council as the basic operational unit for effective service delivery and therefore restructuring the BHU through: Determining the community's real health needs; Doing a system's analysis of BHUs and allied services; Aligning service delivery with health needs.
- 2- Process: Restructure the PHC system in a phased approach by:
   Establishing community health needs through a door-to-door baseline health census, doing a comprehensive systems analysis of the BHU, Strengthening

the capacity of BHUs, Redefining of catchment area, Redefining roles and responsibilities to integrate curative and preventive services, Establishing community participation and ownership, establishing a simple referral system.

- 3- Establish community health needs (baseline health census): The district health supervisors, LHWs, LHSs, and health officers are trained on data collection and registration of households and population. The data are processed by data assistants at each BHU. This establishes the benchmarks on key health indicators.
- 4- Establish the current state of health care delivery system: A system analysis of management of BHUs and outreach services at the district and union council level was done to identify the type and nature of services, BHU utilization rate, staff competencies, infrastructure/ logistics support systems, HMIS utilization in decision making, and community involvement in BHU management.

5- **Restructure the BHU:** This was considered through redefining the catchment area of BHUs and aligning health services with community needs. Other components included:

- Training of DHD and health officers
- Redefine roles and responsibilities of health officers (medical officer BHU), who is the team leader and responsible for ensuring health care services for the catchment population
- Redefine roles and responsibilities of vaccinator and LHWs
- Rationalize LHS-LHW ratio to 1:8 (current 1>20)
- Strengthen outreach services through robust monitoring support
- Set BHU-specific targets
- Set performance-based incentives and accountability
- Institutionalize training need assessment and periodic training
- 6- Establish community governance structure: One of the core interventionsis sensitizing communities on actual health needs and mobilizing communitiesto support the public health sector initiatives. This is done by bringing

communities and health department together, Training communities in health service management, establishing a representative Community Governance Structure comprising communities and DHD.

- 7- Strengthen HMIS: The project established a database at each BHU for its catchment population and considered integration with the existing national HMIS, to get a holistic health picture of the district.
- 8- **Strengthen referral system:** Effective linkages from household to BHU/RHC and secondary-level health facilities are established.

Source: USAID report, 2009

## 4.6 Aziz Bhati Shaheed Hospital Gujrat

Aziz Bhatti Shaheed Hospital (ABSH) is the government health care facility in Gujrat and covers almost 2.5 million people of Gujrat. *ABSH has been attached with the Nawaz Sharif Medical College as the teaching hospital. The District Head-quarter (DHQ) Hospital Gujrat was established in 1963 and renamed in 1966 as Aziz Bhatti Shaheed DHQ Hospital, Gujrat. The hospital has 400 beds. It* 

is not only providing the health care needs for local people, but also of the people neighbouring districts and towns such as Bhimber, Mandi Bahauddin and Wazirabad. This hospital is also providing routine care services to the prisoners of District Jail, Gujrat. The hospital currently has the departments of Emergency, ENT, Gynaecology, Medicine, Obstetrics, Ophthalmology, Orthopaedics, Surgery, Paediatrics, TB/Chest Cardiology and Urology. It serves as a diagnostic and tuberculosis (UOG, available treatment centre of in Gujrat on www.uog.edu.pk/Academic Programme/NSMC/Teaching Hospital.htm visited 1 May 2011).

## 4.7 Basic Health Unit Joura Jalal Pur Gujrat

In district Gujrat there are 92 Basic health units and BHU Joura Jalal Pur is one of them. It is situated 12 kilometers from the main city in Joura Jalal pur village in Union Council Khokhar. This is a small basic health facility responsible for providing basic health care facilities to the community which comes under its catchment area. It covers a total of almost 21,000 people living in the Union council Khokhar. This BHU has facilities to provide maternal and child health care, safe delivery, family planning services, vaccination, basic medical and emergency facilities; it also serves as a treatment center for tuberculosis patients living in the catchment area of this BHU. Aziz Bhati Shaheed Hospital serves as a diagnostic center of tuberculosis for this BHU.

Figure 4.2 District Gujrat Map



Source: Unknown (Internet)

# 4.8 Chapter Summary

In this chapter a brief overview of the study area was presented. Many important features of study area such as location, Climate and Population and area were discussed in the first section. Then a very important part the key indicators of district Gujrat were described. Gujrat Primary health care model was also described in this chapter which shows and explains the overall structure and salient features of Gujrat`s Primary health care. In addition a very brief introduction to Aziz Bhati Shaheed Hospital and Basic health unit Joura Jalal Pur was made. Finaly the map of study area was shown in the last part.

# Chapter 5

## **Research Methodology**

This chapter explains in detail the procedures and methods used for data collection and data analysis. Firstly, it describes the characteristics of study design along with procedures of selecting respondents. The primary data collection mainly focuses on semi-structure questionnaire with pulmonary tuberculosis patients who are in different phases of their treatment in the study area; this is presented in second part. This part will also explain secondary data collection. The last parts consist of the procedure of data processing and analyzing by using different statistical procedures and methods.

## 5.1 Research design

This study comprises of a cross sectional study design with characteristics of both quantitative and qualitative analysis in order to get high quality results. Statistical testing is used to examine association between the dependent and

independent variables which is the subject of hypothesis testing. To find out this relation or association, doing a statistical test is important as it justifies whether the relation on association is true or not. According to the other researchers a statistical test permits analysis to determine whether or not some observed phenomenon is likely to be true (Riley, 2000, p198). A quantitative analysis method will bring out the most common co-variation among variables and the subject to be studied in an extensive pattern among many cases (Riley, 2000). While a qualitative analysis method focuses on gathering non-numeric information using focus groups, interviews, document analysis, and product analysis (Riley, 2000). In addition to this examination more details about the behavior of the respondents, participatory observation is used during the field work. These methods were used to get the answers from the respondents to know the causes of delay in the diagnosis and treatment of pulmonary tuberculosis.

#### **5.2 Sampling Methods**

There are two main sampling techniques in social science which are as follows:

- 1- "The non probability sampling is defined as any technique in which samples are selected in some way not suggested by probability theory" (Babbie, 2005).
  The basic examples of non probability sampling methods are purposive (judgmental) sampling, snowball and quota sampling, and convenience sampling.
- 2- While, "the probability sampling is a general term for samples selected in accordance with probability theory. It typically involves some random selection mechanism" (Babbie, 2005). The probability sampling methods are simple random sampling (SRS), systematic sampling, and stratify sampling etc.

In this study two sampling methods for two different groups of samples were used:

1- The SRS was used for pulmonary tuberculosis patients because of the following reasons: "The SRS is a probability sampling which can reduce the bias of sample selection by its statistical representative of population. The SRS can ensure that each respondent has an equal chance to be selected for the study which is a way to minimize the bias of selection"

2- The convenience sampling method which is a type of non-probability sampling was used for the other sample of lady health workers because of the following reason. "In convenient sampling as the name implies, the sample is selected because they are convenient". The LHWs were convenient to the researcher because they are working in the same health facility and community where the first sample of pulmonary tuberculosis patient was taken and these LHWs were well aware of the patients and situation.

In general, the objective of social research is to generalize the result from sample to the large population and avoid bias. Therefore, the presentation of the population and precise statistical estimates are very important. "When the researchers want precise, statistical descriptions of large population they turn to probability sampling" (Babbie, 2005)

The interviewer (Researcher) went to the study setting, The Aziz Bhati shaheed hospital (ABSH) and used the simple random sampling method to interview the respondents (Pulmonary tuberculosis patients) who came to hospital at different phases of their treatment or who came for the first time for the diagnosis. Random samples of patients were also interviewed at the other health facility, The Basic Health unit Joura Jalalpur to find out the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. Therefore the total sample size from these two settings was 50 pulmonary tuberculosis patients who were at different phases of their treatment and represented the general population.

Also a convenient sample of Lady Health workers at BHU Joura Jalalpur was also interviewed to find out their knowledge, attitude and awareness towards pulmonary tuberculosis patients and to find out their comments about the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. Therefore this sample size was 13 LHWs who were working at basic health unit Joura Jalal pur, Gujrat and represented the community in which they were appointed.

### **5.3 Data Collection Methods**

The data collection comprised of both primary data collection and secondary data collection. They are both described in this section.

This primary data collection consists of observations and field work done by using questionnaire and interviews with the patients and health care providers. And the secondary data collection was done from the previous studies, journals, internet resources, and health department.

The following are the main contents of primary data collection.

## 5.3.1 Questionnaire Design

This study is based upon the fact that there are numerous causes of delay in the diagnosis and treatment of pulmonary tuberculosis and LHWs may play a vital role to interact with pulmonary tuberculosis patients to decrease the delay intervals. For this study two questionnaires were designed one of them was for pulmonary tuberculosis patients and the other was for Lady Health Workers. The characteristics of these two questionnaires are described as follows:

### 5.3.1.1 Pulmonary Tuberculosis Patient Questionnaire

This questionnaire was designed based on previous study which was conducted for a multi-country study in order to obtain reliable information about the extent of diagnostic and treatment delay and factors implicated in the Eastern Mediterranean Region. This study was conducted during the period 2003-2004. Also other studies related to the diagnostic and treatment delay were observed to find relevant questions to include in this study. The questionnaire included information about socio-demographic characteristics, risk factors of pulmonary tuberculosis and health seeking behavior. The patients were also asked questions regarding the elements that might influence their health seeking behavior, tuberculosis stigma, knowledge about the disease, and satisfaction with care, etc. These sections and characteristics of the questionnaire are described in detail as follows:

- 1- **Socio-demographic status:** The socio-demographic status was obtained by using the following variables: age, residence, education, occupation, civil status, income.
- 2- **Risk Factors:** This included the questions about the possible risk factors like: history of smoking, duration of smoking, previous exposure to TB patients.
- 3- **History of current illness:** The history of current illness was obtained by asking questions about the chief symptoms and dates when patient

experienced them. These included history of cough, fever, weight loss, haemoptysis, chest pain, loss of appetite. This section also included about the symptom which made the patient to seek healthcare.

Healthcare seeking behavior: This section of questionnaire was very 4important and covered the healthcare seeking behavior of pulmonary tuberculosis patients. The attitude with the onset of symptoms before initial diagnosis included how patient get their checkup and the cost of that checkup. This also included the date at which patient was first seen by health care provider (HCP). Questions regarding the facility and specialty of HCP to whom patient first sought his consultation were included. The health facilities were coded and noted after the patient answered. Healthcare seeking behavior also contained questions about the reasons of first consultation of health facility with the onset of symptoms and reasons for non-consultation of health facility with the onset of symptoms. This also included perceived causes of delay in health seeking behavior and the number of health care seeking encounters by the patients.

- 5- **Satisfaction with care:** This included variables measuring satisfaction with care at the healthcare facility and was recorded on a 4-point Likert scale in which 0 is best and 3 are worst. These variables were: availability of services in healthcare facility, prompt action taken, and adequacy of equipment, free medication, health facility workload and waiting time.
- 6- Tuberculosis Stigma: This included variables measuring tuberculosis stigma and was recorded on a 5 point Likert scale in which 0 is the highest and 5 is the lowest level of stigma. These variables include: Feeling ashamed of having tuberculosis, having to hide tuberculosis from others after diagnosis, isolation due to tuberculosis, relation with others, cost of TB due to long duration of the disease, effect on work performance, effect on marital relation, and effect on family responsibilities, chances of marriage due to TB, affect on family relations. The degrees of stigma were recorded.
- 7- Accessibility to reach Primary Health care Facility (PHC): This included the questions related to time and distance from home of the patient to the nearest public health care facility.

- 8- Patient knowledge and Correctness of information: This section included variables measuring knowledge and correctness of information of TB by the patient and was recorded on a 3 point Likert scale. These variables included: previous knowledge of tuberculosis, source of information, kind of disease, its causes, curability, vaccination, duration of treatment of TB, and whether TB is hereditary or not. Overall knowledge was recorded as good or bad.
- 9- Date of diagnosis and treatment: This included the date of initial diagnosis and date of treatment. This was recorded to find out the duration of delays in the diagnosis and treatment of pulmonary tuberculosis.

### 5.3.1.2 Lady Health Worker Questionnaire

This questionnaire was designed by using previous studies based on the knowledge, attitude, and perception (KAP) of tuberculosis by the health care providers. This questionnaire was designed for the LHWs to assess their knowledge, awareness and attitude towards pulmonary tuberculosis. This questionnaire included information about the socio-economic status, awareness about the general aspects of

tuberculosis, knowledge and attitude about tuberculosis. The characteristics of this questionnaire are described in detail as follow:

- 1- Socio-economic status: The socio-economic status of LHWs was recorded by using following variables: age, education, residence, civil status, income, and the number of household she visited every day.
- 2- Awareness about the general aspects of tuberculosis: This included the variables which measure all the general aspects of tuberculosis like: Is TB communicable, hereditary, caused by germ, spread of TB, curable?, skipping of TB drugs, death by TB, TB spread by contact, overcrowding, smoking, and inadequate diet. These questions were answered in YES or NO by lady health workers.
- 3- **Knowledge about tuberculosis:** This included variables which measure knowledge about tuberculosis. These are as follow: causes of TB, is TB contagious?, mode of TB spread, most common symptoms of TB, most effective test for TB diagnosis, how many sputum samples required for TB diagnosis, duration of treatment, type of TB drugs, correct way of taking TB

drugs, factors assessing treatment outcome, and consequences of incomplete or inappropriate TB treatment. All these variables were recorded by open ended questions to LHWs.

- 4- Attitude towards pulmonary tuberculosis patient: It includes variables which show the attitude of LHW's towards PTB patients. These variables were recorded as follows: Whether PTB patients should be isolated from family or not?, sharing food with PTB patients should be avoided or not?, patient should quit job or not, affected mother should breast feed baby or not, baby should be separated from affected mother or not, marriage to affected patient should be avoided or not, and should PTB patients be prohibited from visiting public places like, markets, mosques etc. The answer to all these questions shows the attitude of LHWs towards the PTB patients.
- 5- Suggestions and comments by LHWs: This section included the valuable suggestions and comments by the LHWs about the causes of delay in the diagnosis and treatment of pulmonary tuberculosis and how to avoid these delays to have a better outcome of disease. LHWs live very close to the

community people and their role is very important regarding the healthcare seeking behavior of pulmonary tuberculosis patients.

Construction of the questionnaire is the most challenging phase in data collection process. The purpose of this pilot study was to test the questionnaires, for instance, how long it takes for conducting the interview, and whether or not the wordings in the questionnaire are understandable for respondents and so on. The purpose of this pilot study was not only to modify the questionnaires but also to learn and pre-examine what would happen in the actual process of interview in the field. The pilot study was conducted in the first week of September 2010. This questionnaire testing was conducted with the help of colleagues who were working in the study areas. Some patients and some health care providers were interviewed. After the pilot study was conducted, the questionnaire was modified to make the wordings simple, to edit some options of answers and to change the order of some questions.

The process of self administered questionnaire was conducted from September 12 to October 30, 2010. In addition, before starting this field work, permission for this field work was taken at the District Officer Health (DoH), Gujrat. Then orientation of the objectives of the research and guidance to questionnaires using were conducted at basic health unit Joura Jalal pur for lady health workers. The researcher explained all the aspects of this study to the LHWs and to the other healthcare providers and asked for their cooperation to make this study successful.

#### 5.3.2 Interview Process

### 5.3.2.1 The Interview with Pulmonary tuberculosis patients

In this study, interview was used to obtain the information from respondents. It was decided to use the interview as the method of data collection based on a few reasons. First of all, there was a limitation in knowledge of respondents to fill up the questionnaires. Majority of patients in Gujrat especially in rural areas have low literacy rate and sometimes they had received only a few years of education. Therefore, the interview was the best way to get useful information. Secondly, interview was used to ensure a high respondent rate. Due to the limitation of time and resources, the researchers had to be flexible to maintain the respondent rate. Interview method was favored to clarify the questions with respondents in order to obtain a better quality of answers. Finally, the interview process allowed the interviewer to observe directly the behavior of respondents during answering the questions.

To interview with the pulmonary tuberculosis patients the interviewer chose the study settings randomly such that some days the patients were interviewed at BHU Joura Jalal pur and sometimes at Aziz Bhati Shaheed Hospital. In the beginning of the interview, the researcher introduced himself, informed the duration of the interview that might take for filling up the questionnaires and informed the respondents about the purpose and the topic of the study. The pulmonary tuberculosis patients were made aware that they had the right to choose not to answer any questions at anytime during the process if they did not want to answer. These respondents were those pulmonary tuberculosis patients who were at different phases of their treatment and came to the health facilities for their medicine and if new pulmonary tuberculosis patient he/she came for initial diagnosis. After the self introduction and showing the purpose of the study, the pulmonary tuberculosis patients were selected to be the sample of the study if they agreed to fill up the questionnaires administered by the interviewer. Each interview took about 20 minutes. However, the interview duration took a longer time with some respondents who had a low educational background. Therefore, the interviews were conducted just a few hours close to lunch time. For example, from 9am to 1pm. The answers to all the questions in the questionnaire were recorded very carefully keeping in mind that nothing should be missed. After each interview the respondent was thanked for his/her cooperation and wished for good health.

### 5.3.2.2 The interview with Lady Health Workers

To interview with the lady health workers interviewer chose the study setting at the basic health unit Joura Jalal pur, Gujrat because they work and were assigned for the community which is in the catchment area of BHU. Before the interview process the lady health workers were briefed and made aware of the purpose of this study and importance of their role to decrease the delay intervals of diagnosis and treatment. After self introduction and purpose of the study the interview process was done and LHWs were made sure that they had the right not to answer the question which they did not want to. Each interview with the lady health workers took about 20 minutes. The answer to every question was noted very carefully. After interview process LHWs were thanked for their participation and cooperation.

#### 5.3.3 Data processing and analysis

After questionnaires were completed, they were coded according to where and how the interviews were conducted. Once the respondents were classified according to the geographic and the codes for responses were defined, Statistical Package for Social Science (SPSS) version 17 was used to generate the result from the obtained information.

There are three main methods of data analysis used in this study. Along with the demographic characteristics of pulmonary tuberculosis patients and lady health workers the first method used in study which is simple but very useful was a descriptive analysis and done for both PTB patients and lady health workers. In the second method for statistical analysis, the Chi- square test was used to see if there is any relationship between dependent and independent variables and to test the hypothesis and to test the significance of the study. Finally correlation analysis and logistical regression was done to see the relations between dependent and independent variables.

#### **5.3.3.1 Descriptive Analysis**

Though descriptive analysis is simple, it is useful for basic information such as percentage, frequency, mean, maximum, minimum, standard deviation, etc. Descriptive statistics provides important information by comparing data from different groups of the variables. In this study descriptive statistics was mainly used for finding the causes of delay in the diagnosis and treatment of pulmonary tuberculosis by the patients and health care providers. Also the descriptive statistics was done to assess the level of lady health workers to see whether they could contribute in decreasing the delay intervals in the diagnosis and treatment of pulmonary tuberculosis.

### 5.3.3.2 Chi-Square test of Independence

According to studies a Chi-Square test of independence is a test to see the relationship between categorical variables. It was used in this study to prove the null hypothesis and to check whether there was a relationship between the health care seeking behavior of pulmonary tuberculosis patients with the diagnostic delay, treatment delay and no delay. The health care seeking behavior in this study is either good or bad, which depends on many factors which were also examined for association between healthcare seeking behavior and delays. They will be discussed in the next chapter.

# **5.4 Chapter Summary**

This chapter provided the detailed procedure and explanation of how this survey was conducted. It described the three stages of field work, i.e. the process before the field work, during and after the field work. For example how the questionnaires were designed and the pilot study performed. The sampling methods and the activities during the interview process with the target people were included in this chapter. Finally the important statistical methods and process of data analysis were elaborated in this chapter.

# **Chapter 6**

## **Findings and Discussion**

The results and the data interpretation are presented in this chapter. This chapter is divided into pulmonary tuberculosis patient findings and lady health workers findings. First, the demographic characteristics of respondents are described for pulmonary tuberculosis patients and lady health workers in separate sections. The descriptive statistics of the study are shown in separate sections for pulmonary tuberculosis patients and lady health workers. Next, the results of statistical analysis which aims to examine the hypothesis of the study are highlighted. Then the results of logistical regression will be described. The Final part contains the discussion on finding and results.

### 6.1 Pulmonary tuberculosis patient's findings and results

### 6.1.1 Socio-demographic Characteristics of Respondents

It is very useful to understand the socio-demographic characteristics of the respondents in order to examine the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. The main socio-demographical variables of pulmonary tuberculosis patients: are; age, sex, marital status, education level, occupation, residence, and number of house hold members. Here in this section all these demographic characteristics are described in detail as follows:

## 6.1.1.1 Distribution of Respondents by Age group

To find out the causes of delay in the diagnosis and treatment of pulmonary tuberculosis in Gujrat, 50 respondents were interviewed at Aziz Bhati Shaheed hospital and BHU Joura Jalal Pur respectively. Patients from different age groups were interviewed and categorized accordingly. Due to sensitivity of study only pulmonary tuberculosis patients at different phases of their treatment were selected. (In total 50 patients), the highest percentage of respondent was aged 15-35 years which accounted for 76%. The number of respondents in 35-50 years accounted for 16%. The number of respondent pulmonary tuberculosis patients below 15 years of age and above 50 years of age shared the same percentage of 4 % respectively. The

majority of patients were from the productive age group. The following figure shows the percentage of respondents by age group.



Figure 6.1 Distribution of respondents by age group

## 6.1.1.2 Distribution of Respondents by Gender

Females have less access to the health care facilities due to cultural and family restrictions. In a male dominating society females have less chance to go and have their health checkups. Males work outside and run the family so they have easy access to the outside world and health care facilities. In Pakistan women specially living in rural community have to take permission from their husband or family head
to go outside and have checkup with the health care providers. In total of 50 patients, 56% were males and 44% were females respectively. The following figure shows the percentage of respondents by gender.



Figure 6.2 Distribution of respondents by gender

## 6.1.1.3 Distribution of Respondents by Residence status

People living in urban areas have easy access to health care facilities as compared to people living in rural areas. Patients living in rural areas have to travel a long distance to reach the health care facilities for their checkup. This is why the patients hesitate to have their checkup on time for any health condition and especially if they have pulmonary tuberculosis symptoms. Also the healthcare facilities are not good in rural areas as compared to urban areas. In this study 60% of the pulmonary tuberculosis patients belonged to rural areas and 40% to urban areas.



Figure 6.3 Distribution of Respondents by Residence status

## 6.1.1.4 Distribution of Respondents by Civil status

To find the causes of delay in the diagnosis and treatment of pulmonary tuberculosis, the civil status of the respondents are important because especially if the female is married she has to take permission from her husband to have a checkup for any symptom. There is a taboo so that most of the husbands do not allow their wives to go alone and have their checkups. On the other hand if female is divorced, separated or widow she face a lot of problems in the community and cannot take her decisions independently. In a total of 50 respondents, 62% were married, 38% were single and there were no respondent who was divorced, separated, or widow respectively. The following figure shows the distribution of respondents by their civil or marital status.



Figure 6.4 Distributions of Respondent by Civil Status

## 6.1.1.5 Distribution of Respondents by Education level

Education is important for the awareness and knowledge of a disease in a community. One of the causes of delay in the diagnosis and treatment of pulmonary tuberculosis could be the low level of education and awareness among the pulmonary tuberculosis patients. Patients with low education level tend to have longer delay intervals than the patients having good knowledge. Education level by categories range from illiterate/no school, primary school education, middle school education, higher secondary school education, and university level education. The majority of respondents had completed primary school (44%). About 22% and 2% of them finished middle school and higher secondary school respectively. Just only 2% of the respondents entered or finished a higher degree of education which is at university level. A large number of respondents, about 30%, were illiterate or did not go to school ever in their life. The following figure shows the percentage of respondents by education level.



Figure 6.5 Distribution of Respondents by Education level

#### 6.1.1.6 Distribution of Respondents by Occupation

Most of the respondents were workers which accounted for 32%; they were ordinary workers such as farmers, vendors, shop owners etc. About 38% of the women were house-wives. About 8% of the respondents were professionals which included persons with skills and working in some factory or work in offices etc. Students accounted for 4% of these respondents. About 18% of these respondents were unemployed and they did nothing. The following figure shows the percentage of respondents by occupation.



Figure 6.6 Distribution of respondents by Occupation

#### 6.1.1.7 Distribution of Respondents by Number of Household

The number of household members is important especially in the case of pulmonary tuberculosis. The more is the number of household members the more is the chance to get infected because they live in close contact. In total of 50 respondents, 50% of them had 5-8 household members and 26% of them had 9-12

household members. 14% of them had 1-4 while 10% of the respondents had more than 12 household members. These households lived in close contact with each other as the respondents had the same living places usually consisting of 2-3 rooms. So the chance of infectivity with mycobacterium tuberculosis was very high. The households of these respondents therefore need proper screening for tuberculosis because if they do not have their proper screening and awareness about the symptoms, they might get pulmonary tuberculosis and if they do not know there will be delay in the diagnosis and treatment of pulmonary tuberculosis. The following figure shows the percentage of respondents by household.



Figure 6.7 Distribution of Respondents by number of Household

Characteristics	N=50	(%)
Age(years)		
>15	2	4%
15-35	38	76%
36-50	8	16%
<50	2	4%
Gender		
Male	28	56%
female	22	44%
Residence		
Urban	20	40%
Rural	30	60%
Civil status		
Married	31	62%
Single	19	38%
Divorced/separated	0	0%
Widow	0	0%
Education		
No School/illiterate	15	30%
Primary	22	44%
Secondary	11	22%
Higher	1	2%
University	1	2%
Occupation		
Workers	16	32%
House wife	19	38%
Student	2	4%
Professional	4	8%
Unemployed	9	18%
Number of Household		
1 to 4	7	14%
5 to 8	25	50%
9 to 12	13	26%
>12	5	10%

Table 6.1 Socio-demographic characteristics of pulmonary tuberculosis patients

#### 6.1.1.8 Interpretations from socio-demographic characteristic of respondents

In this study which was focused on causes of delay in the diagnosis and treatment of pulmonary tuberculosis, the socio-demographic characteristics were very important. Most of the pulmonary tuberculosis patients who were interviewed were in their middle age group which is the reproductive age group i.e. 15-35 years. Males predominantly suffer from pulmonary tuberculosis because they are in close contact with the outside environment and have their interaction with other people while females usually stay at home and could not go outside without getting permission from their husbands or family heads. Education is very important for early detection of tuberculosis. In this study the majority of patients only finished their primary school and a large number of patients did not go to school in their entire life and they could only read and write their name. A large number of patients were workers while some of the patients were unemployed. The majority of the patients who were interviewed live in crowded environment because they had only one or two rooms at their living place. They also lived in close contact with a large number of household members because most of the respondents had more than eight household members. All these characteristics may lead to a delay in the diagnosis and treatment of pulmonary tuberculosis and cause an increase in the infectivity in the community.

## 6.1.2 Results of Descriptive Statistical Analysis

Descriptive statistical analysis provides important information by comparing data from different groups of variables. In this study the descriptive statistical analysis was mainly used for information of respondents, the frequency and percentage of different variables to find the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. Descriptive statistical analysis was used for pulmonary tuberculosis to see "Whether health care seeking behavior of pulmonary tuberculosis suspect patients was associated with the delay in the diagnosis and treatment of pulmonary tuberculosis or not"

"A healthcare seeking behavior refers to all the things humans do to prevent and detect the disease" (Sara Mackain, 2003). In this type of study two approaches were mainly used to explain the healthcare seeking behavior of pulmonary tuberculosis to prevent a delay in the diagnosis and treatment. One was healthcare seeking behavior in response to illness and second was healthcare seeking behavior and utilization of health care system and facilities. A good healthcare seeking behavior of a pulmonary tuberculosis patient or suspect is very important for earlier diagnosis and treatment. To find out the causes of diagnostic and treatment delay it is very important to find the healthcare seeking behavior of pulmonary tuberculosis patients. Healthcare seeking behavior is a broad term and contains all those factors which lead to the diagnosis and treatment of PTB.

To find out the healthcare seeking behavior of pulmonary tuberculosis it is very important to assess the following factors: correctness of information on tuberculosis knowledge, tuberculosis stigma, frequency of risk factors for pulmonary tuberculosis among patients, symptoms of patients with pulmonary tuberculosis, gender differences, patients attitude with the onset of symptoms, facility of the health care provider from whom patient first sought his consultation, reasons of first consultation of the HCF with the onset of symptoms, reasons for non-consultation of PHC facility with the onset of symptoms, number of visits to the HCP before diagnosis, facility of the HCP who made the initial diagnosis, accessibility to the public health facility, satisfaction with care, source of tuberculosis information, perceived causes of delay in health care seeking, specialty of the HCP who made the initial diagnosis, investigations performed for pulmonary tuberculosis patients, and the diagnostic and treatment delay intervals.

All these factors contribute to the healthcare seeking behavior of pulmonary tuberculosis patients and influence the delay in the diagnosis and treatment of pulmonary tuberculosis patients. In the next section descriptive analysis of all these factors will be done to prove the hypothesis and to find the diagnostic and treatment delays in pulmonary tuberculosis.

## 6.1.2.1 Correctness of patient's Knowledge about tuberculosis

The percentage of patients whose knowledge about the disease was correct is shown in the following table.

			Not	Total
Knowledge Items	Yes	No	known	(%)
Is tuberculosis contagious?	58%	14%	28%	100%
What kind of disease do you have?	50%	16%	34%	100%
Is tuberculosis hereditary?	56%	14%	30%	100%
Is tuberculosis curable?	88%	0%	12%	100%
Is there a vaccine for TB?	2%	8%	90%	100%
Duration of anti-tuberculosis treatment	70%	4%	26%	100%

Table 6.2 Correctness of Patient's information on tuberculosis knowledge

According to the table in this study among the total number of patients only 58% knew that tuberculosis is a contagious disease, while 14% believed that it is not a contagious disease and could not spread from one another, while 28% of the patients did not know whether TB is contagious or not. 50% of the patients knew the kind of disease they had, while 16% did not know the kind of disease they had, and 34% of the patients did not know the answer. Among the total number of patients 56% of them said that it was a hereditary disease while 14% believed that was not a hereditary disease and 30% of them did not know the answer. Only 88% of the patients knew that TB is a curable disease, while 12% did not know the answer. 2% of the patients said that there is a vaccine available for TB, while 8% said that there is no vaccine and 90% of the patients did not know the answer. 70% of the patients knew the exact duration of the anti-tuberculosis treatment, while 4% did not know the

duration and 26% did not knew the answer. Correctness of patient's knowledge about tuberculosis is an important tool to assess the healthcare seeking behavior of the patients and to find the causes of delay in the diagnosis and treatment. If patients are well aware and have knowledge about the diseases they can access the healthcare facilities in time to avoid the complications of the disease and in this way they can avoid delay in the diagnosis and treatment. Overall, Tuberculosis knowledge was assessed as good "1", average "2", and bad "3". Only 20% patients had a good knowledge and information of tuberculosis.

#### 6.1.2.2 Perceived Stigma related to tuberculosis

Interestingly both males and females had the same perceptions regarding the social stigma related to tuberculosis. Assessing stigma in patients is important to know about their healthcare seeking behavior and their perception about the disease. The degree of stigma was high in this study for most of the pulmonary tuberculosis patients. Some 50% of the total patients felt ashamed that they had developed tuberculosis and 40% of them tried to hide the disease from others. Some 26% of the

patients believed that their relation with others affected with the other after diagnosis of pulmonary tuberculosis. Only 16% of the patients felt that this disease is costly due to long duration of the treatment, while 48% of the patients did not agree with this. Only 30% of the patients preferred to live isolated after being diagnosed by tuberculosis, while 38% of the patients did not agree with this statement. Some 48% of the patients believed that tuberculosis affected their work performance. More than 58% of patients agreed that this disease affected their marital relation. Also more than 60% of the patients felt that their family responsibilities were affected by this disease after being diagnosed. 70% of the patients strongly agreed that chances of marriage were less if a person has tuberculosis. Family relations were also affected in some 70% of the patients. Therefore overall degree of tuberculosis stigma was almost 75%. Table 6.3 shows percentage of stigma related to tuberculosis.

	Strongly			Don`t	Don`t agree at	Total (%)
Stigma	agree	Agree	Average	Agree	all	
Feel ashamed of						
having TB	50%	8%	8%	32%	2%	100%
Have to hide TB						
diagnosis	40%	4%	10%	40%	6%	100%
Relation with others	26%	4%	24%	46%	0%	100%
Cost of Tb due to long						
duration	16%	8%	22%	48%	6%	100%
Prefer to live isolated	30%	14%	18%	38%	0%	100%
Affect on work						
performance	26%	22%	18%	14%	0%	100%
Affect on marital						
status	18%	4%	36%	30%	12%	100%
Affect on family						
responsibilities	4%	14%	60%	20%	2%	100%
Chances of marriage	70%	4%	22%	2%	2%	100%
Affect on family						
relations	8%	8%	74%	6%	4%	100%

# Table 6.3 Stigma Related to Tuberculosis

Overall tuberculosis stigma was assessed as "0" for higher, "1" for average and "2"

for low. 48% of the patients have higher while 40% have average tuberculosis stigma.

# 6.1.2.3 Frequency of Risk Factors for PTB among patients

In this study it was important to find out the risk factors involved in the occurrence of tuberculosis. The following table 6.4 shows different risk factors of tuberculosis among the patients.

Characteristics	n=50(%)
Smoking	
Never	64%
Current	10%
Ex-smoking	26%
Daily consumption of cigarettes	
Median	10
Min-Max	1- 60
Smoking duration(Years)	
Median	10
Min-Max	1-40
Previous Exposure to TB patients	54%

Table 6.4 Frequency of Risk factors of Pulmonary Tuberculosis among the patients

In this study smoking, whether current or ex-smoking was reported in pulmonary tuberculosis patients. In a total of 50 patients about 64% patients never smoked in their life while 10% and 26% were current and ex-smokers, respectively. The median number of cigarettes smoked per day was 10 with a minimum of 1 and maximum of 60. And the median duration of smoking was 10 years with a minimum of 1 year and maximum of 40 years. A positive history of previous exposure to a tuberculosis patient was recorded in 54% of the pulmonary tuberculosis patients among a total of 50 patients.

This shows that more than half of the patients in this study had a risk factor for pulmonary tuberculosis either in the form of smoking or previous exposure to the tuberculosis patients. Most of the patients had exposure to someone having tuberculosis in their family and the patients lived in close contact with them unaware of the facts they might get tuberculosis in the future. The following figure also shows the frequency of risk factors.



Figure 6.8 Frequency of risk factors for PTB among the patients

## 6.1.2.4 Symptoms of patients with Pulmonary Tuberculosis

A positive history of various symptoms experienced by pulmonary tuberculosis patient was recorded. Table 6.5 shows the percentage of symptoms of pulmonary tuberculosis.

Characteristics	n=50	(%)
Cough	47	94%
Fever	46	92%
Weight loss	47	94%
Haemoptysis	23	46%
Chest pain	30	60%
Loss of appetite	43	86%

Table 6.5 Symptoms of Patients with PTB

This table shows that cough and weight loss were the main symptoms with 94% frequency among the patients. Fever existed within 92% while chest pain, loss of appetite and haemoptysis was present in 60%, 86% and 46% of the patients respectively. Most the patients presented with cough fever and weight. Almost all the patients presented with more than one symptom at a moment. Cough with or without fever was the main symptom that prompted the patients to seek healthcare. This was one of the major reasons of delay in the diagnosis and treatment of pulmonary tuberculosis that patients were unaware of the symptoms and took them casually. Almost all the patients looked for health care when their symptoms and health condition were in advanced stage. Previous studies showed that patients well aware of symptoms of pulmonary tuberculosis could have their diagnosis and treatment in

time. In this way delay in the diagnosis and treatment can be avoided. Following figure 6.9 also shows the frequency of symptoms for PTB among patients.



Figure 6.9 Frequency of symptoms for PTB among patients

#### 6.1.2.5 Patients Attitude towards the Onset of Symptoms

Patient's attitude with the onset of pulmonary tuberculosis symptoms is one of the important components of the healthcare seeking behavior for the patients. To prove the hypothesis that good healthcare seeking behavior can decrease delay in the diagnosis and treatment of pulmonary tuberculosis, attitude of the patients with the onset of symptoms must be known. In this study nearly 30% of the patients consulted a healthcare provider which mainly included a private practitioner, or healthcare providers at government healthcare facilities. Almost 52% of the patients went to quacks which are unqualified persons doing their mal-practice in the vicinity of the community. Nearly 16% of patients practiced self-medication immediately after the onset of symptoms while 2% of the patients consulted traditional healers and health workers respectively. Table 6.6 and figure 6.10 show patients attitude with the onset of symptoms of pulmonary tuberculosis.

Table 6.6 Attitude of Patients with the onset of symptoms of PTB

First Action	n=50	(%)
Health care provider	15	30%
Self medication	8	16%
Traditional medicine	1	2%
Health worker	1	2%
Drug store	0	0%
Others (Quacks etc)	25	50%

Figure 6.10 Attitude of Patients with the onset of symptoms of PTB



From the findings it is obvious that the majority of the patients consulted for their symptoms for the first time with private practitioners and unqualified persons such as quacks.

# 6.1.2.6 Facility of the Health care provider to whom Patients first sought

## consultation

Table 6.7 shows facility of the health care provider to whom patients first

sought consultation.

Health facility	n=50	(%)
Tuberculosis center	2	4%
Primary health care center	3	6%
Chest hospital	0	0%
Public hospital	1	2%
Private practice(clinic etc)	15	30%
others(Quacks etc)	29	58%

Table 6.7 Facility of the HCP from to Patients first sought consultation

The first healthcare provider consulted by the patients was unqualified quacks working in the community and accounted for almost 58% of the patients. This was not a good health care seeking behavior because this caused delay in the diagnosis and treatment of pulmonary tuberculosis due to mal-practice of these people. About 30% of the patients consulted the healthcare providers in the private sector. Only 6% and 4% of patients went to primary healthcare centers and tuberculosis centers respectively to seek first consultation for their illness. Only 2% of the patients sought consultation from public hospitals. Not a single patient sought consultation from a chest clinic. In this study the case is different because almost 88% of the patients sought consultation from unqualified persons such as quacks or from private clinics. This caused a delay in the diagnosis and treatment of PTB patients due to malpractice or low level of awareness and communication between the patients and HCP in private sector. Figure 6.11 also shows the health facility of the health care provider.



Figure 6.11 Health facility of the HCP from whom patients first sought consultation

# 6.1.2.7 Specialty of the HCP to whom Patient first sought consultation

Following table 6.8 shows the specialty of the HCP to whom patients first sought consultation after the onset of symptoms.

Table 6.8 Specialty of the HCP to whom patients first sought consultation

Specialty of HCP	n=50	(%)
Chest Specialist	5	10%
General Practitioners	22	44%
Others	23	46%

It was seen that only 10% of the patients sought their first consultation after the onset of symptoms from chest specialist while 44% consulted a general practitioner and 46 % went to other sources which included non-qualified persons, quacks, radiologists, surgeons etc. The following figure also shows the specialty of HCP.

Figure 6.12 Specialty of HCP to whom patients first sought consultation



## 6.1.2.8 Reasons of First Consultation of the HCF with the Onset of Symptoms

Health services were consulted chiefly because the clinics or the health care providers were located close to the patient's residence. All the patients had multiple reasons for first consultation. And this was why author had to take each reason separately. Almost 68% of the patients felt that the health facilities were accessible to them. The second and main reason for the consultation was that about 88% felt that they had confidence in getting cured. Almost 72% of the patients were advised by somebody for the consultation. About 10% and 2% believed that services were available anytime and free of cost, respectively. Table 6.9 and figure 6.13 show the reasons of first consultation of the HCF with the onset of symptoms.

Reasons	n=50	(%)
Accessible	34	68%
Confidence in getting cured	44	88%
Services available anytime	5	10%
Referred by previous health service	0	0%
Free services	1	2%
Advised by somebody	36	72%
others	2	4%

Table 6.9 Reasons of first consultation of the HCF with the onset of symptoms



Figure 6.13 Reasons of first consultation of the HCF with the onset of symptoms

### 6.1.2.9 Reasons for not consulting the PHC facility with the onset of symptoms

The reason why almost 80% of the patients did not initially consult a primary healthcare facility or tuberculosis center with the onset of pulmonary tuberculosis symptoms was that they were unaware of the facilities provided at the primary health care centers or tuberculosis centers. This was an important factor for delay in the diagnosis and treatment of pulmonary tuberculosis because patients were not aware of the facilities or they did not know where they should go for the initial diagnosis. In total of 50 patients, 18% of them felt that the PHC facility or TB center

was too far from their home. Another 18% of them felt that they had previous bad experience with the PHC facility or TB center. As compared to the above mentioned reasons, 12% of the total patients felt that these centers were crowded or they would have to wait for a long time in the queue. The following table 6.10 and figure 6.14 show the reasons for not consulting the PHC facility of TB center with the onset of symptoms.

Figure 6.14 Reasons for not consulting the PHC facility or TB center



Table 6.10 Reasons for not consulting the PHC center or TB center

Reasons	n=50	(%)
Too far	9	18%
Too busy/Long waiting time	6	12%
Bad experience	9	18%
Others(Unaware of facilities)	40	80%

6.1.2.10 Number of Visits by the patients to the HCP before an initial diagnosis of PTB

Almost 36% of the patients visited more than 10 times to the HCP before the initial diagnosis. These HCP mostly belonged to private sector. The mean number of healthcare providers visited before diagnosis was recorded as 8 (4.47), and median value was also 8. These visits to the HCP varied from 1 to 15. The following table 6.11 shows the number of visits by the patients to the HCP before an initial diagnosis of PTB.

Table 6.11 Number of visits by the patients to the HCP before initial diagnosis of

PTB

No. of health care seeking encounters before diagnosis	n=50 (%)
Mean (SD)	8 (4.47)
Median	8
Min-Max	0-15

The number of patients visits to the health care providers before the final diagnosis is shown in figure 6.15, which indicates that about 70% of patients paid 4 to more than

10 visits to the healthcare provider before being finally diagnosed with pulmonary tuberculosis.



Figure 6.15 Number of visits of patients to HCP before being finally diagnosed

## 6.1.2.11 Accessibility of Patients to the TB center/PHC centers

The accessibility of the patients to tuberculosis health services varied greatly and is an important tool to find the causes of delay in the diagnosis and treatment of pulmonary tuberculosis and healthcare seeking behavior. It is known that if the healthcare facilities are in access to the patients they can have their health checkups in time and delay can be avoided. In this study it was seen that around 58% of the patients were living within half an hour to an hour reach from health facility. While 40% were living less than half an hour and 12% of them were living more than one hour from health facility. Following table 6.12 and figure 6.16 shows the time taken to reach a TB center or PHC center from their home.

Time to Reach	n=50	(%)
<1/2 hr	20	40%
1/2-1 hr	24	58%
> 1 hr	6	12%

Table 6.12 Time Taken to Reach a TB center/PHC center

Figure	6.1	6	Time	Taken	to	Reach a	TΒ	center/PHC	center
0									



Table 6.13 shows that a TB center or PHC center was located within 1-5 km for 64% of the patients, while 22% of the patients had to travel a distance of 6-10 km before reaching a TB center/PHC center. In some 10% of the cases the nearest TB center/PHC center was as far as 21-15 km or >25 km away. This shows that these centers were not so far from their home.

Distance	n=50	(%)
1 to 5 km	32	64%
6 to 10 km	11	22%
11 to 15 km	2	4%
16 to 20 km	0	0%
21 to 25 km	3	6%
>25 km	2	4%

Table 6.13 Distance to a TB center/PHC for Patients

#### 6.1.2.12 Patient's waiting time at the TB center/PHC center

After the patient reached at the TB center/PHC center either for the initial diagnosis or to get his/her monthly anti-tuberculosis drugs, he had to wait in the healthcare facility. It is important to know the waiting time in the healthcare facility which patients experience. The following table 6.14 shows that 58% of the patients waited for 15 to 30 min, while 32% had waited for less than 15 min for their check up

and treatment. Patients had to wait more than 1 hour for the first visit when they came for the initial diagnosis, while some time they had to wait for more than this. 6% of the patients waited more than 1 hour for their treatment or initial diagnosis.

Table 6.14 Patient's waiting time after reaching the TB center/PHC center

Time	n=50	(%)
<15 min	14	28%
15-30 min	30	60%
>30 min - 1 Hr	3	3%
> 1 hr	3	6%

# 6.1.2.13 Source of Tuberculosis Information

Source of information for a tuberculosis patient is very important to avoid a delay in the diagnosis and treatment and to have a good healthcare seeking behavior. The following table 6.15 shows different sources of tuberculosis information for the patients.

Table 6.15 Source of tuberculosis information

Previously heard of TB	n=50	(%)
Yes	37	74%
No	13	26%
If Yes then Source of information	n=50	(%)
MoH campaign (media)	4	10.81%
Education	5	13.51%
Friends/Relatives	14	37.83%
TB disease in friends/relatives	19	51.35%

It was recorded that only 74% of the total number of patients had previously heard of tuberculosis, while 26% had not heard about tuberculosis previously. The patients who had heard about the tuberculosis previously knew about the disease from different sources. The source of information was one or more than one among these patients. About 51.35% patients knew about the disease because the patients had some friend or relative who was had tuberculosis, while 37.83% heard about the disease from friends or relatives. Only 13.51% and 10.81% of the patients who previously heard of tuberculosis got information about the disease from previous education or knowledge and from Ministry of health campaigns through media. For a good healthcare seeking behavior and to avoid delay in the diagnosis and treatment of pulmonary tuberculosis it is important that patients know about the disease and its consequences. The following figure 6.17 also shows different sources of information about tuberculosis.



Figure 6.17 Different Sources of Tuberculosis Information

## 6.1.2.14 Patient's Satisfaction of Care in TB center/PHC center

When a patient reaches the TB center/PHC center it is very important that patients are satisfied with the facilities provided at these centers. The following table 6.16 shows patient's satisfaction with care after reaching TB center/PHC center for diagnosis or treatment.

	Best	Average	Worst	Total (%)
Availability of services	90%	10%	0%	100%
Prompt action from HCP in PHC	92%	8%	0%	100%
PHC well equipped	92%	8%	0%	100%
PHC giving free medicine	100%	0%	0%	100%
Enough PHC in area	2%	0%	98%	100%
Health facility workload	40%	58%	2%	100%

Table 6.16 Patients Satisfaction with care

In this study it was noted that interestingly patient satisfaction with care was very good after reaching at the TB center/PHC center for the diagnosis or treatment. The satisfaction with care was rated and recorded as Best, Average and Worst. Patient's satisfaction with the availability of services was very good and 90% of the patients believed that it was best while 10% of them said that it was average. 92% of the patients said that prompt action was taken from the HCP at the TB center/PHC center. Also 92% of the patients believed that PHC center/TB center was well equipped with the facilities for TB diagnosis and treatment. 100% of the patients said that medicine was freely available at these centers. Regarding PHC center/TB centers in the area only 2% patients believed that these centers in the area were enough, while 98% believed that these centers in the area were not enough to provide the healthcare facilities. 40% of the patients believed that there was no health facility work load while 58% believed that it to be average and 2% believed that health facility work load was worst.

## 6.1.2.15 Perceived Causes of Delay in Health care seeking by the patients

Patient's perception about the causes of delay is important for the assessment of healthcare seeking behavior of the pulmonary tuberculosis patients. In this study patient's perception about the causes of delay in healthcare seeking was recorded to know the possible causes of delay in the diagnosis and treatment of pulmonary tuberculosis and to find out the healthcare seeking behavior of the patients. Among all the patients 80% of them believed and hoped that their symptoms would go away on their own, which that was why they kept on delaying. 48% of them had fear of what would be found on diagnosis, so they kept on avoiding diagnosis to hide it from others. 10% of the patients feared of social isolation if they got a diagnosis of pulmonary tuberculosis. Only 14% of the patients from the total believed that there was no delay in the diagnosis and treatment. Only 6% of the patients had economic constrains and could not afford the expenses to travel and get diagnosis and
treatment. Table 6.17 shows the perceived causes of delay in healthcare seeking by

the patients.

Table 6.17 Perceived Causes of delay in healthcare seeking

Causes		(%)
No delay	7	14%
Fear of what would be found on diagnosis	24	48%
Hoped their symptoms would go away on their own	40	80%
Fear of social isolation	5	10%
Economic constrains	3	6%
Inadequate staff attitude	1	2%
Poor quality of health services	0	0%
Others	1	2%

### 6.1.2.16 Specialty of the HCP who made the initial diagnosis

Table 6.18 shows that the diagnosis was mainly made by the chest specialists at the tuberculosis centers in primary healthcare centers or at public hospitals though they were the last one to be consulted. This accounts for 80% of the patients. General practitioners mostly at their private clinics were responsible for 14% of the diagnosis while in 6% of the patients the diagnosis was made by the surgeons, radiologist, etc. For a good healthcare seeking it is important for the patients to consult the chest specialist at an earlier stage of the disease at the tuberculosis centers

or at primary healthcare centers when patients feel symptoms of the pulmonary tuberculosis

Table 6.18 Specialty of the HCP who made initial diagnosis of PTB

Health care provider	n=50	(%)
Chest specialist	40	80%
General practitioner (Private clinics)	7	14%
Infectious disease specialist	0	0%
Others(Surgeons, Radiologist etc)	3	6%

Also figure 6.18 shows the specialty of the HCP who made the initial diagnosis for

pulmonary tuberculosis.

Figure 6.18 Specialty of the HCP who made initial diagnosis of PTB



### 6.1.2.17 Investigations Performed by the HCP for Initial Diagnosis of PTB

The patients reached the healthcare providers at tuberculosis center, primary healthcare centers or public hospital and most of them were consulted by the chest specialist. The majority of the patients almost 78% were diagnosed by both sputum smear examination and X-ray. Only 20% of the patients were diagnosed by X-ray only while 48% were diagnosed by complete blood examination, lymph node biopsy along with sputum smear examination and X-ray. None of the patients were referred to the other doctor or hospital after reaching the healthcare provider at TB center or PHC center. Table 6.19 shows the investigations performed by the HCP for initial diagnosis of pulmonary tuberculosis.

Investigations		
Sputum smear examination (only)	0	0%
X-ray (only)	10	20%
Both sputum smear and X-ray	39	78%
Referred to the other doctor/hospital	0	0%
Others (Blood CBC, Lymph node biopsy)	24	48%

Table 6.19 Investigations performed by the HCP for initial diagnosis of PTB

### 6.1.2.18 Delay in the Diagnosis and Treatment

Table 6.20 shows a comparison between the extent of delays recorded in different patients and the different types of delay. The mean duration of total delay between the onset of symptoms and labeling a patient as pulmonary tuberculosis patient to initiation of anti-tuberculosis drugs was 46 days with a range from 19 to 288 days.

Types of delay	n=50(%)
Patient delay (Days)	
Mean (SD)	8.5 (19.27)
Median	0
Range	0-90
Health system delay (Days)	
Mean (SD)	84.1 (57.64)
Median	74
Range	0-244
Diagnostic delay (days)	
Mean (SD)	90.14 (60.40)
Median	73
Range	0-288
Treatment delay (Days)	
Mean (SD)	0.56 (2.80)
Median	0
Range	0-19
Total delay (days)	
Mean (SD)	45.35 (63.34)
Median	36.5
Range	19-288

Table 6.20 Different types of delay for Pulmonary Tuberculosis patients

The variables with regard to delay i.e. diagnostic delay, treatment delay, patient delay and health system delay were taken from the survey by asking the patients about the time of onset of symptoms and time of initial diagnosis and treatment. The time and date were recorded and as the definitions of delays explained in the third chapter the exact length of delays were recorded. The patients were the main factors for the delay when the diagnostic delay occurred and to some extent the health care providers when treatment was delayed for some reasons. Different types of delays were the contributing factors to the total delay in the diagnosis and treatment of pulmonary tuberculosis. In this study the mean duration of patients delay was 9 days with a range from 0-90 days. Health system delay was the time interval between the date of first health seeking encounter at a health care provider and the initiation of anti-tuberculosis treatment. In this study the mean duration of health system delay was 84 days with a range from 0-244 days. The mean duration of diagnostic delay in this study which was the time interval between the onset of symptoms and labeling of the patients as pulmonary tuberculosis patients, was 90 days with a range from 0-288 days. The mean duration of treatment delay in this study, the time interval between

the initial diagnosis and initiation of anti-tuberculosis drugs, was less than a day with a range from 0-19 days. All these findings in this study show that both patients and the health care providers especially in the private sector are the main contributing factors to the delay in the diagnosis and treatment of pulmonary tuberculosis. Patients kept on ignoring their pulmonary tuberculosis symptoms and did not go for the initial diagnosis to a TB center or PHC center; rather they preferred to visit private health care providers which included general practitioners at private clinics, traditional healers, and unqualified persons called quacks. These healthcare providers did not do the diagnosis of pulmonary tuberculosis, and patients experienced delay. This was the major cause of delay along with patient's unawareness, and their healthcare seeking behavior caused the delay in the diagnosis and treatment. However when a patient reached at the Public health care facility or Tuberculosis center, he faced a very little delay in the diagnosis and treatment of pulmonary tuberculosis.

### 6.2.1.19 Distribution of Respondents according to Healthcare seeking behavior

A healthcare seeking behavior is that in which a patient do all the things to detect and prevent the disease. This comprises of healthcare seeking behavior with the onset of illness and healthcare seeking behavior with the utilization of health system. In the previous section all those factors were discussed which contributes for a healthcare seeking behavior of a pulmonary tuberculosis patient. According to this a patient can have a good healthcare seeking behavior which can lead to decrease in the delay intervals or a bad healthcare seeking behavior which can increase the delay intervals. Also the healthcare seeking behavior of males and females can differ. A healthcare seeking behavior of the pulmonary tuberculosis patients depends upon the following:

- 1- Patients socio-demographic characteristics
- 2- Risk factors of Tuberculosis
- 3- Tuberculosis knowledge and awareness
- 4- Tuberculosis stigma
- 5- Source of tuberculosis information
- 6- Duration of tuberculosis symptoms
- 7- Patients attitude with the onset of symptoms
- 8- Facility of the HCP to whom patient first sought the consultation

- 9- Number of healthcare seeking encounters before the initial diagnosis
- 10-Facility of the HCP who made the initial diagnosis
- 11-Specialty of the HCP to whom patient sought first consultation
- 12- Accessibility to the public health care facility
- 13-Patient's satisfaction with care

All these factors were discussed separately in the previous section and were assessed for every patient, if the patient had tuberculosis stigma, poor tuberculosis knowledge, more than two healthcare seeking encounters and if he experienced longer diagnostic and treatment delay due to different causes then the patient was labeled as having bad health seeking behavior and vice versa. Table 6.21 shows the distribution of respondents according to good and bad healthcare seeking behavior. This was assessed by overall assessment of all the above mentioned factors contributing to healthcare seeking behavior.

Table 6.21 Distribution of Respondents according to healthcare seeki	ıg beha	vior
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Health care seeking behavior	n=50	(%)
Good	7	14%
Bad	43	86%

Here 14% of the patients had a good healthcare seeking behavior in which pulmonary tuberculosis patients experienced no delay in the diagnosis and treatment, while 86% of the patients had a bad healthcare seeking behavior in which patients experienced diagnostic and treatment delay due to their healthcare seeking behavior and other causes.

### 6.1.3 Results of Statistical Analysis

### 6.1.3.1 Chi-Square Test of Independence

This test was used to test the association between the two variables in this study to prove the hypothesis. The variables in this study were good and bad healthcare seeking behaviors and delay intervals. This test was used to prove the null and alternative hypotheses which are as follow:

**Ho:** *Healthcare seeking behavior of pulmonary tuberculosis suspect patients is not associated with the delay in the diagnosis and treatment of pulmonary tuberculosis* 

Ha: Healthcare seeking behavior of pulmonary tuberculosis suspect patients is associated with the delay in the diagnosis and treatment of pulmonary tuberculosis
Following tables shows the results of chi-square test to see the association healthcare seeking behavior of PTB patients with diagnosis delay, treatment delay and no delay.
Table 6.22 Association of healthcare seeking behavior with diagnostic delay, treatment delay and no delay.

	Cases						
	Va	lid	Mis	Missing		Total	
	Ν	Percent	Ν	Percent	N	Percent	
Overall healthcare seeking behavior * Diagnostic delay	50	100.0%	0	.0%	50	100.0%	
Overall healthcare seeking behavior * Treatment delay	50	100.0%	0	.0%	50	100.0%	
Overall healthcare seeking behavior * No Delay	50	100.0%	0	.0%	50	100.0%	

### **Case Processing Summary**

### Healthcare seeking behavior and Diagnostic delay

	-		Diagnostic delay		
			Yes	No	Total
Healthcare seeking behavior Good		Count	0	7	7
		Expected Count	5.6	1.4	7.0
		Count	40	3	43
		Expected Count	34.4	8.6	43.0
Total		Count	40	10	50
		Expected Count	40.0	10.0	50.0

Crosstab

	Value	df	Asymp. Sig. (2- sided)	Exact Sig. (2- sided)	Exact Sig. (1- sided)
Pearson Chi-Square	32.558 <sup>a</sup>	1	.000		
Continuity Correction <sup>b</sup>	27.004	1	.000		
Likelihood Ratio	28.279	1	.000		
Fisher's Exact Test				.000	.000

Linear-by-Linear Association	31.907	1	.000	
N of Valid Cases	50			

### Healthcare seeking behavior and Treatment delay

### Crosstab

	-		Treatment delay		
			Yes	No	Total
Healthcare seeking behavior Good		Count	0	7	7
		Expected Count	.4	6.6	7.0
	Bad	Count	3	40	43
		Expected Count	2.6	40.4	43.0
Total		Count	3	47	50
		Expected Count	3.0	47.0	50.0

	Value	df	Asymp. Sig. (2- sided)	Exact Sig. (2- sided)	Exact Sig. (1- sided)
Pearson Chi-Square	.520 <sup>a</sup>	1	.471		
Continuity Correction <sup>b</sup>	.000	1	1.000		

Likelihood Ratio	.936	1	.333		
Fisher's Exact Test				1.000	.630
Linear-by-Linear Association	.509	1	.476		
N of Valid Cases	50				

### Healthcare seeking behavior and No Delay

		-	No Delay		
			Yes	No	Total
Healthcare seeking behavior	Good	Count	7	0	7
		Expected Count	1.0	6.0	7.0
	Bad	Count	0	43	43
		Expected Count	6.0	37.0	43.0
Total		Count	7	43	50
		Expected Count	7.0	43.0	50.0

Crosstab

	Value	df	Asymp. Sig. (2- sided)	Exact Sig. (2- sided)	Exact Sig. (1- sided)
Pearson Chi-Square	50.000 <sup>a</sup>	1	.000		
Continuity Correction <sup>b</sup>	42.039	1	.000		
Likelihood Ratio	40.496	1	.000		
Fisher's Exact Test				.000	.000
Linear-by-Linear Association	49.000	1	.000		
N of Valid Cases	50				

The above tablets shows the results of Chi-Square test performed between healthcare seeking behaviors of the pulmonary tuberculosis patients with diagnostic delay, treatment delay and the patients with no delay. It was seen that with a Chi-square value of 32.558 and degree of freedom 1 the test is very significant with a value of 0.000. This showed that healthcare seeking behavior of the patients is strongly associated with diagnostic delay i.e. if the healthcare seeking behavior is good the patients had no delay in the diagnosis of pulmonary tuberculosis. But if the healthcare seeking behavior is bad the patients experienced diagnostic delay. Also with a Chi-

Square value of 0.520 and degree of freedom 1 the test is significant at a level of 0.471, which showed that in this study the healthcare seeking behavior of the patients was not strongly associated with treatment delay. In the test it was also seen that with a Chi-Square value of 50.000 and degree of freedom 1 the level of significance is 0.000 which showed that there was a very strong association of healthcare seeking behavior with the patients who had no delay in diagnosis and treatment. Thus it was assumed that the patients, who had good healthcare seeking behavior, experienced no delay in their diagnosis and treatment of pulmonary tuberculosis.

**CONCLUSION:** The above mentioned test rejected the null hypothesis and showed that there is an association between the healthcare seeking behavior of the pulmonary tuberculosis patients and delays.

6.1.3.2 Association of healthcare seeking behavior with the factors affecting the healthcare seeking behavior

1-Association of healthcare seeking behavior with tuberculosis knowledge

The followings tables show the result of the association of healthcare seeking behavior of the pulmonary tuberculosis patients with the tuberculosis knowledge.

Table 6.23 Association of healthcare seeking behavior with tuberculosis knowledge

	Cases						
	Valid		Missing		Total		
	Ν	Percent	Ν	Percent	Ν	Percent	
Healthcare seeking behavior * Tuberculosis Knowledge	50	100.0%	0	.0%	50	100.0%	

### **Case Processing Summary**

Healthcare seeking behavior * Tuber	culosis Knowledge Cross tabulation
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	_		Tuberculosis Knowledge			
			Good	Average	Bad	Total
Healthcare seeking behavior Good		Count	3	0	4	7
		Expected Count	1.4	2.0	3.6	7.0
	Bad	Count	7	14	22	43
		Expected Count	8.6	12.0	22.4	43.0

Total	Count	10	14	26	50
	Expected Count	10.0	14.0	26.0	50.0

	Value	df	Asymp. Sig. (2- sided)
Pearson Chi-Square	4.447 <sup>a</sup>	2	.10
Likelihood Ratio	5.954	2	.05
Linear-by-Linear Association	.405	1	.52
N of Valid Cases	50		

#### **Chi-Square Tests**

The results of Chi-Square test done to see the association of healthcare seeking behavior of the pulmonary tuberculosis patients with tuberculosis showed that with a Chi-Square value of 4.447 and degree of freedom 2, the test is significant at the level of 0.108, which shows that there was a strong association of healthcare seeking behavior with the tuberculosis knowledge. It showed that if the patients were aware and had good knowledge of tuberculosis and its outcome they had good healthcare seeking behavior, which could be responsible to avoid the delay in the diagnosis and treatment of pulmonary tuberculosis.

### 2-Association of Healthcare seeking behavior with tuberculosis stigma

The followings table shows the association of healthcare seeking

behavior of pulmonary tuberculosis patients with tuberculosis stigma.

Table 6.24 Association of healthcare seeking behavior with tuberculosis stigma

	Cases						
	Valid		Missing		Total		
	Ν	Percent	Ν	Percent	Ν	Percent	
Overall healthcare seeking behavior * TB stigma	50	100.0%	0	.0%	50	100.0%	

### **Case Processing Summary**

			Higher	Average	Low	Total
Overall healthcare seeking	Good	Count	1	4	2	7
behavior — B		Expected Count	3.4	2.8	.8	7.0
	Bad	Count	23	16	4	43
		Expected Count	20.6	17.2	5.2	43.0

Total	Count	24	20	6	50
	Expected Count	24.0	20.0	6.0	50.0

	Value	df	Asymp. Sig. (2- sided)
Pearson Chi-Square	4.388 <sup>a</sup>	2	.111
Likelihood Ratio	4.528	2	.104
Linear-by-Linear Association	4.288	1	.038
N of Valid Cases	50		

### **Chi-Square Tests**

The results of the Chi-Square test done to see the association of healthcare seeking behavior of the pulmonary tuberculosis patients showed that with a Chi-Square value of 4.388 and degree of freedom 2, the test was significant at a level of 0.111, which showed that there was a strong association of healthcare seeking behavior with the tuberculosis stigma. It was experienced that the patients who had higher degree of tuberculosis stigma had a bad healthcare seeking behavior which affected their prompt diagnosis and treatment of pulmonary tuberculosis.

# 6.1.3.3 Association of healthcare facility of the HCP to whom patients first sought their consultation with diagnostic delay, treatment delay and no delay

The following tables show the association of healthcare facility of HCP to whom patients first sought their consultation after the onset of pulmonary tuberculosis symptoms with diagnostic delay, treatment delay and no delay.

Table 6.25 Association of healthcare facility of HCP to whom patients first sought consultation with diagnostic delay, treatment delay and no delay

	Cases					
	Va	lid	Mis	sing	Total	
	Ν	Percent	Ν	Percent	Ν	Percent
Health facility of the HCP to whom patient first sought consultation * Diagnostic delay	50	100.0%	0	.0%	50	100.0%
Health facility of the HCP to whom patient first sought consultation * Treatment delay	50	100.0%	0	.0%	50	100.0%
Health facility of the HCP to whom patient first sought consultation * No Delay	50	100.0%	0	.0%	50	100.0%

**Case Processing Summary** 

## Health facility of the HCP to whom patient first sought consultation \* Diagnostic delay

	-		Diagnos	tic delay	
			Yes	No	Total
Health facility of the HCP	TB center	Count	1	1	2
sought consultation		Expected Count	1.6	.4	2.0
	PHC	Count	3	0	3
		Expected Count	2.4	.6	3.0
	Public hospital/OPD	Count	0	1	1
		Expected Count	.8	.2	1.0
	Private Hospital/Clinic	Count	10	5	15
		Expected Count	12.0	3.0	15.0
	Others (Quacks,	Count	26	3	29
	Non-qualified persons)	Expected Count	23.2	5.8	29.0
Total		Count	40	10	50
		Expected Count	40.0	10.0	50.0

### Crosstab

### **Chi-Square Tests**

	Value	df	Asymp. Sig. (2- sided)
Pearson Chi-Square	9.231ª	4	.056
Likelihood Ratio	8.882	4	.064
Linear-by-Linear Association	1.248	1	.264
N of Valid Cases	50		

Health facility of the HCP to whom patient first sought consultation \* Treatment delay

### Crosstab

	-		Treatme	ent delay	
			Yes	No	Total
Health facility of the HCP	TB center	Count	0	2	2
sought consultation		Expected Count	.1	1.9	2.0
	РНС	Count	0	3	3
		Expected Count	.2	2.8	3.0
	Public hospital/OPD	Count	1	0	1
		Expected Count	.1	.9	1.0

	Private Hospital/Clinic	Count	1	14	15
		Expected Count	.9	14.1	15.0
	Others (Quacks,	Count	1	28	29
	Non-qualified persons)	Expected Count	1.7	27.3	29.0
Total		Count	3	47	50
		Expected Count	3.0	47.0	50.0

	Value	df	Asymp. Sig. (2- sided)
Pearson Chi-Square	16.332 <sup>a</sup>	4	.003
Likelihood Ratio	6.649	4	.156
Linear-by-Linear Association	.087	1	.767
N of Valid Cases	50		

### Health facility of the HCP to whom patient first sought consultation \* No Delay

			No E	Delay	
			Yes	No	Total
Health facility of the HCP to whom patient first	TB center	Count	1	1	2
sought consultation		Expected Count	.3	1.7	2.0
	PHC	Count	0	3	3
		Expected Count	.4	2.6	3.0
	Public hospital/OPD	Count	0	1	1
		Expected Count	.1	.9	1.0
	Private Hospital/Clinic	Count	4	11	15
		Expected Count	2.1	12.9	15.0
	Others (Quacks,	Count	2	27	29
	Non-qualified persons)	Expected Count	4.1	24.9	29.0
Total	-	Count	7	43	50
		Expected Count	7.0	43.0	50.0

### Crosstab

	Value	df	Asymp. Sig. (2- sided)
Pearson Chi-Square	6.018 <sup>a</sup>	4	.198
Likelihood Ratio	5.771	4	.217
Linear-by-Linear Association	1.178	1	.278
N of Valid Cases	50		

The results of the above mentioned Chi-Square tests done to see the association of healthcare facility of the HCP to whom patients first sought their consultation after the onset of symptoms of pulmonary tuberculosis showed that with the Chi-Square value of 9.231 and degree of freedom 4, the test was significant at a level of 0.056, which showed that there is a very strong association of healthcare facility of the HCP to whom patients first sought their consultation with the diagnostic delay. The patients who visited non-qualified persons such as quacks experienced a longer delay in the diagnosis of pulmonary tuberculosis than the patients visited tuberculosis centers of public health centers.

For a Chi-Square value of 16.332 and degree of freedom 4 the test was significant at a level of 0.003, which showed that there was a very strong association

between the healthcare facilities of the HCP to whom patients first sought consultation with the treatment delay.

For a Chi-Square value of 6.018 and degree of freedom 4 the test was significant at a level of 0.198, which showed that there was a very strong association between the healthcare facilities of the HCP to whom patients first sought consultation with the patients who experienced no delay in diagnosis and treatment of pulmonary tuberculosis. The test showed that those patients who visited TB centers/PHC with the onset of pulmonary tuberculosis symptoms experienced no delay.

### 6.2 Lady health Workers findings and results

It was assumed that "Lady Health workers with the help of their knowledge, awareness, and attitude may play a vital role for a good healthcare seeking behavior of pulmonary tuberculosis suspect patients to avoid delay in the diagnosis and treatment of pulmonary tuberculosis". It was described in the previous chapters that how and why lady health workers are important and how they can be beneficial for the patients. Lady health workers contribute a major role in the earlier diagnosis and treatment of pulmonary tuberculosis patients in the community resulting in good healthcare seeking behavior with their help. To assess the effectiveness of lady health workers role in good healthcare seeking behavior of pulmonary tuberculosis patients a small sample size of 13 lady health workers were chosen who were working at the basic health unit Joura Jalal Pur that covers a catchment population of about 20,000. The Following sections will describe the findings obtained from the lady health workers.

### 6.2.1 Distribution of LHWs by Age group

Most of the LHWs were in their reproductive age group and working in the community to help the public health programs. 6 of the LHWs were in age group 26-35 years, while 4 were in age group above 45 years. Only 2 were in age group 36-45 years while only 1 belonged to age group 15-25. The following figure shows distribution of LHWs by age group.





### 6.2.2 Distribution of LHWs by their marital status

From the total of 13 LHWs, 10 were married, 2 were single and only 1

was widowed. The following figure shows the distribution of LHWs by their marital status.



Figure 6.20 Distribution of LHWs by their marital status

### 6.2.3 Distribution of LHWs by Education level

Only 1 of the LHWs passed her primary school, while 6 completed their secondary school education and 5 completed high school. And 1 of them completed higher secondary school education. The following figure shows distribution of LHWs by their education level.



Figure 6.21 Distribution of LHWs by Education level

### 6.2.4 Awareness of LHWs about the general aspects of Tuberculosis

Following table shows the awareness of LHWs about the general aspects

of the tuberculosis among total of 13 LHWs (n=13).

Table 6.33 Awareness about the general aspects of tuberculosis

General Aspects of TB	Yes	No
Is TB communicable disease?	12	1
Is TB a hereditary disease?	9	4

Is it caused by germ?	13	0
Is it spread by droplet?	13	0
Is it fully curable?	13	0
Can Anti TB drugs are skipped?	0	13
Can TB causes death?	11	2
Can TB spread by contact?	13	0
Can TB favored by overcrowding etc?	12	1

This table shows that from a total of 13 LHWs, 12 of them answer that TB is a communicable disease. 9 out of 13 said that TB is a hereditary disease while only 4 said that it is not. All the LHWs believed that TB is caused by germ and it is spread by droplets and by contact with the TB patients and TB is fully curable. All the LHWs believed that Anti-tuberculosis drugs should not be skipped. 11 of the total LHWs said that TB can cause death while 12 of them said that TB is favored by overcrowding. Overall awareness of Tuberculosis among LHWs was very good.

### 6.2.5 Attitude of LHWs towards TB patients

The following table shows attitude of LHWs towards tuberculosis patients.

Attitude towards TB patients	Yes	No
TB patient should be isolated from family?	3	10
Sharing food with TB patient should be avoided?	6	7
Quitting job by TB patient?		9
Affected mother should not breast feed?	1	12
Separation of baby from affected mother?	1	12

Table 6.34 Attitude of LHWs towards TB patients

Stopping TB treatment after improvement?	11	2
Avoiding marriage with TB patient?	4	9
Prohibition of TB patient to visit public places?	1	12

This table shows that from the total of 13 LHWs, 3 said that TB patient should be isolated from the family. 6 of them said that sharing food with TB patient should be avoided. Only 4 of them believed that TB patients should quit the job after being diagnosed by Tuberculosis. 1 LHW from the total said that affected mother should not breast feed the baby and only 1 said that baby should be separated from the affected mother. 11 of them said that anti-tuberculosis treatment should be stopped after improvement. 4 of them believed that TB patients should be avoided with the TB patients while only 1 of them thought that TB patients should be prohibited to visit public places like markets etc. It is assumed that the overall attitude of LHWs towards tuberculosis patients is average.

### 6.2.6 Knowledge of LHWs about Tuberculosis

The following table shows the knowledge of LHWs about Tuberculosis.

Table 6.35 Knowledge of LHWs about Tuberculosis

		Not
Knowledge of LHWs about TB	Known	known

What is the cause of TB?	4	9
How does TB spread?	8	5
Who has most risk of contracting TB?	9	4
What are the most common symptoms of TB?	13	0
What is the most effective test for TB?	12	1
How many sputum samples needed for diagnosis?	6	7
How long is the treatment?	12	1
What is the correct way to take TB drugs?	12	1
What are the factors to assess treatment outcome?	13	0
What could be the consequences of incomplete treatment?	9	4
Is Tb contagious?	13	0
Do all people with TB have infection?	8	5

did not know the cause. While 8 of them knew how TB spread and 9 of them knew who had the most risk of contracting TB. All of them knew about the most common symptoms of TB and the factors to assess treatment outcome. 12 of them knew what the most effective test was for TB, how long is the duration of anti-tuberculosis treatment and what the correct way to take TB drugs was. Only 6 of them knew the total number of sputum samples required for TB diagnosis. Only 9 of the LHWs knew the consequences of incomplete treatment while 8 LHWs believed that all the people with TB have infection. From the findings of knowledge of LHW it was seen that LHWs have an average level of knowledge about Tuberculosis.

This table shows that only 4 LHWs from the total knew the exact cause of TB while 9

### 6.3 Discussion

This study focused on the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. It was focused to explore the causes of delay from the onset of symptoms of pulmonary tuberculosis to the start of anti-tuberculosis drugs. The duration of delay ranged from one month to four months or even more and was mainly consist of diagnostic delay which was mainly contributed by the patients themselves.

Detailed analysis of the various causes contributing to the affect of health care seeking behavior of the pulmonary tuberculosis patients and timely diagnosis and treatment showed that they could be categorized into factors contributed by the patients lead to patient delay and factors contributed by the healthcare system lead to health care system delay. Delay by the patients themselves was the main contributor to delay in the diagnosis and treatment of pulmonary tuberculosis. As socio-demographic factors were the main determinants of the health care seeking behavior of the patients which in turn, the main contributor of patient delay, an in- depth analysis was important to provide the information. It showed that tuberculosis patients were the most disadvantaged group in their communities. Most of the patients were in their productive age group i.e. 15-35 years of age, 76% of the patients belonged to this age group. The illiteracy rate was significantly higher than those of general population which was almost 30% and only 44% of the patients completed their primary school. Almost 60% of the patients belonged to rural areas which also contributed mainly to their healthcare seeking behavior. Most of the patients were worker almost 32% and 18% of the patients were unemployed. Most of the patients lived in crowded environment which can cause increase in the infectivity in the community, 50% of the patients have 5-8 household members. Tuberculosis has known association with poverty and labeled as a "disease of poverty". "Hence poverty reduction, one of the United Nation's millennium development goals, would contribute to reduction of tuberculosis burden in endemic countries" (WHO EMRO, 2003-2004).

In most of the countries females were having low socioeconomic status; however their knowledge about the tuberculosis was not so different from the males. "Gender did not seem to affect knowledge and attitude of tuberculosis patients in line with what has been previously reported from the region of Syrian Arab republic" (Bashour, 2003). Due to the male dominating societies females were able to get low chances to go by themselves for the checkup and early detection of the disease. That was why tuberculosis stigma was higher among the females.

### 6.3.1 Healthcare Seeking behavior of pulmonary tuberculosis patients and delay in the diagnosis and treatment

In this study health care seeking behavior was the main contributing factor for the delay in the diagnosis and treatment of pulmonary tuberculosis. A health care seeking behavior refers to all the things a person do to detect and prevent the disease. This health seeking behavior comprised of two main things. One was the healthcare seeking behavior in response to the illness and seconds was the utilization of the health facilities. Many factors contributed to have a good health care seeking behavior for the patient. The healthcare seeking behavior started from the start of illness or pulmonary tuberculosis symptoms. Cough along with fever and weight loss were the main symptoms reported by the patients and prompted them to seek health care. Other symptoms were loss of appetite, haemoptysis, and chest pain. Cough and weight loss was reported by 94% of the patients while 92% reported fever. 86% of the patients presented with loss of appetite and haemoptysis was reported by only 46% of the patients. Risk factors for pulmonary tuberculosis were present in all these patients. 54% of the patients had previous exposure to tuberculosis while the other risk factor was smoking which included current smoking and patients who quitted smoking. Daily consumption was 1-60 cigarettes per day with a median of 10 per day while the smoking duration was 1-40 years with a median of 10 years.

With the onset of symptoms patients usually practiced self medication and visited traditional healers. This contributed to 18% of the patients. Almost 50% of the patients visited non-qualified persons which usually included quacks working in the vicinity of the communities where patients belonged. While only 30% of the patients visited healthcare facilities which included private hospitals and public hospitals and TB centers. Almost 88% of the patients visited private hospitals and
non-qualified persons (quacks). This was the main reason for the delay in the diagnosis of pulmonary tuberculosis because these practitioners made the patients visit again and again. Patients visited on average 3-4 health care providers before being finally diagnosed and the number of health care seeking encounters included from 1-15 and even more.

Patients visited the first health care facilities due to many reasons; 88% of the patients had confidence in getting cured that's why they visited the health care provider, while 68% of them thought that it was accessible to them. 72% of the patients were advised by somebody that included friends and relatives to the health facility. Almost 80% of the patients did not visit the primary health care facility because they were not aware of the facilities provided for tuberculosis there.

Stigma also proved to be a major factor that determined the healthcare seeking behavior, where fear of social isolation and fear of what would be found on diagnosis were the main obstacles to timely healthcare seeking behavior. A large number of patients felt ashamed that they developed tuberculosis and had tried to hide it from others. Also most of the patients felt that it affected their family and marital relations and work performance. More females then male said that chances of getting married were less if someone had tuberculosis or were diagnosed by tuberculosis. "The association between the accessibility of health facilities and stigma associated with tuberculosis and healthcare seeking behavior of the population is in agreement with other reports" (Salaniponi, 1991).

All these factors and others contributed to the healthcare seeking behavior of the pulmonary tuberculosis patients which affected the diagnosis and treatment of the patients. In this study healthcare seeking behavior of the patients were not good and was bad which was why patients suffered mainly the diagnostic delay. The mean diagnostic delay was 91 days with a range from 0-288 days while the mean treatment delay was less than a day with a range from 0-19 days. This showed that diagnostic delay was predominant mainly due to bad healthcare seeking behavior of the patients and treatment delay was almost negligible especially because patients visiting the PHC facility were finally being diagnosed with pulmonary tuberculosis and their treatment started on the same day. Only a few patients experienced treatment delay because they were diagnosed in private setting and they could not afford the medicine and then they visited PHC facilities after some time for anti-tuberculosis treatment.

In the next section patients delay and healthcare system delay will be discussed separately.

#### 6.3.2 Patient Delay

Patient delay was the contributor to the total delay in this study. "Patient delays can occur during the process of noticing symptoms, determining if one is ill, assessing the need for professional care, and overcoming social, personal, and physical barriers to obtaining that care" (Eastwood, 2004: Safer, 1979). The mean duration of patient delay from the onset of symptoms to the first healthcare seeking encounter was 8.5 days with a range from 0-90 days. "By comparison a mean patient's delay of 3 weeks was seen in Botswana" (Steen, 1998), "while a mean patient delay of 161.7 days was reported from Tanzania, and contributed to more than 90% of the total delay" (Lawn, 1998). Education levels and awareness about

tuberculosis, tuberculosis stigma, and accessibility to the healthcare facility contributed to long delay.

The significant risk factors for patient delay were living in rural areas, low level of education and awareness about the tuberculosis, a high degree of stigma, and seeking healthcare from non-qualified individuals with the onset of symptoms, and from more than one healthcare. It was observed that patient delay was mainly dependent upon the healthcare seeking behavior of the patients.

#### 6.3.3 Health System Delay

Health system delay was mainly responsible for diagnostic delay rather than treatment delay. The mean duration between the first healthcare seeking encounter to the start of treatment was 84.1 day with a range from 0-244 days. A longer health system delay has been reported in other countries such as Viet Nam, Ghana and Botswana, while in contrast patient delay has been more prominent and a major contributor of delay in United stated and Tanzania.

This study showed that several healthcare seeking encounters by the patients were significantly associated with longer delay. Patients were not satisfied with consultation from one healthcare provider. More than 75% of the patients consulted two or more healthcare providers before being finally referred to a tuberculosis center or primary healthcare facility. Some patients even consulted more than 5 healthcare providers. Patients not only consulted healthcare providers, but they also consulted traditional healers, homeopaths or took advice from drugs stores. In spite of consultation from different healthcare providers, the final diagnosis of pulmonary tuberculosis was made by the primary healthcare facility under the supervision of NTP. More than 90% of patients were finally diagnosed at the PHC while the rest of were diagnosed by others. A study from India showed that tuberculosis patients on an average visited 2.5 doctors before reaching the NTP (Rajeswari, 2002).

Socioeconomic status was an important factor for health system delay because patients consulted private healthcare providers who made them visit again and again and advised investigations which patients could not afford and they consulted other healthcare providers before finally being referred to PHC and diagnosed. Also private healthcare providers tend to avoid referring the patients to PHC facilities or TB centers because there was no proper linkage between the private HCP and NTP facilities. Accessibility to these healthcare providers and to the PHC played an important role in the delay diagnosis and treatment.

Non-qualified persons were a main contributor for the patients and delay in diagnosis and treatment. These persons did their mal-practice in the vicinity of these patients and patients tend to visit them more because patients felt that they were accessible to them and they had confidence in getting cured from them. Also these non-qualified (Quacks) charged a low fee and made patients to visit them again and again which worsened patient's condition and the diagnosis and treatment of tuberculosis was delayed. Also a lack of resources in the private sectors and high price of anti-tuberculosis medicine, long time interval between diagnosis and treatment was observed. Time and distance to reach a PHC facility was also contributing factors for delay. On the other hand when patients reached at the PHC facility after a long interval he/she was diagnosed as early as possible and treatment was provided without any delay. And surprisingly patients satisfaction with care provided at these PHC facility was very high almost 99%. Patients were provided with free diagnosis of pulmonary tuberculosis by doing sputum examination along with X-ray chest and blood examination and also they were provided free antituberculosis drugs for the full duration of treatment. Patients were assigned with a lady health worker and she took care of patient's further treatment and daily intake of anti-tuberculosis drugs under their direct observation.

Overall it was observed that health system delay was mainly due to the fact that private HCP had a low index of tuberculosis suspicion and did not adhere to NTP guidelines in diagnosis and referral of tuberculosis suspects to PHC facilities.

# 6.3.4 Factors affecting healthcare seeking behavior and causes of delay in the diagnosis and treatment of pulmonary tuberculosis

There were a number of factors which affected the healthcare seeking behavior of the pulmonary tuberculosis patients which in return affected the diagnostic and treatment delay. These factors were, patients socio-demographic and socioeconomic status, tuberculosis knowledge and awareness, tuberculosis stigma, source of tuberculosis information, patient's attitude with the onset of symptoms, health facility of the HCP to whom patient first sought his consultation, specialty of the HCP to whom patient first sought his consultation, number of healthcare seeking encounters, accessibility to the PHC facility and satisfaction with care.

On the basis of above mentioned factors these were the following causes of delay in the diagnosis and treatment in this study: (1) Inadequate knowledge and awareness regarding the disease (2) Living in rural areas (3) Higher degree of tuberculosis stigma (4) Male dominating society (5) Seeking healthcare from nonqualified or specialized individuals (6) More than one healthcare seeking encounter (7) Seeking initial healthcare from private sector (8) Time and distance to reach a PHC facility (9) Self medication with the onset of symptoms (10) Unaware of the healthcare facilities provided at PHC (11) Fear of what would be found on diagnosis (12) Belief that low cost services are inadequate at PHCs (13) Reluctance to seek healthcare from PHCs (14) Being diagnosed at health facility not belonging to NTP (15) Self belief that symptoms would cease on their own.

#### 6.3.5 Healthcare seeking behavior of patients and Role of Lady Health workers

As described previously LHWs play an important role in the primary health care system. LHWs work and live in the community and they have direct interaction with the community people. They have to visit a number of households every day so they get an update of every individual in their catchment area. They organize the community people by making health committees, and also they act as liaison between the health system and the community. They identify the tuberculosis suspects and refer them to health centers for their initial checkup and diagnosis. This is why their knowledge, awareness and attitude are very important to have a better healthcare seeking behavior of the patients. If their knowledge, awareness and attitude is good, they can communicate, educate and make patients aware about their illness and they can improve the healthcare seeking behavior of the patients and this affects diagnostic and treatment delay. Patients can have good healthcare seeking behavior with the help of LHWs with early diagnosis and treatment of pulmonary tuberculosis.

#### 6.4 Chapter summary

This chapter presented the findings of the survey conducted for this study. Firstly it described the descriptive statistics of the patient finding, and a statistical analysis was done to prove the hypothesis. It was observed that there is a relationship between health care seeking behavior and delay in the diagnosis and treatment of pulmonary tuberculosis. Secondly correlation analysis and regression analysis was done to see the associations between the variables. Thirdly Lady health worker's findings were described. In the final part a discussion was done to elaborate the overall situation of delay in the diagnosis and treatment of pulmonary tuberculosis.

## Chapter 7

#### **Conclusion and Recommendations**

This chapter provides conclusion of research with summary of the findings described in chapter 6. The summary of the findings are compared with the objectives of the study which were shown in chapter 1. This chapter also attempts to provide recommendations for early diagnosis and treatment of pulmonary tuberculosis and for a good healthcare seeking behavior of patients. Finally, scope of further research will be discussed based upon this research.

#### 7.1 Summary of findings and conclusions

This part describes the summary of findings by comparing the data obtained from the fieldwork with the 4 main objectives of this study.

The Conclusion by comparison between the findings and objectives of this study is explained as follows:

The main objective of this study was to find out the causes of delay in the diagnosis and treatment of pulmonary tuberculosis. The results of this study showed after thoroughly examining the findings that there were many factors which were associated with a delay in the diagnosis and treatment of pulmonary tuberculosis. These can either be due to patients themselves or the healthcare providers. Both may have contributed to diagnostic and treatment delay. Main causes of delay were due to healthcare seeking behavior of the pulmonary tuberculosis patients which kept on patients to delay. All these causes were related to the delay in the diagnosis and treatment of pulmonary tuberculosis. These causes are as follows:

#### 1- Inadequate knowledge and awareness regarding the disease

- 2- Living in rural areas
- 3- Higher degree of tuberculosis stigma
- 4- Male dominating society
- 5- Self medication at the onset of initial symptoms
- 6- Seeking healthcare from a non-specialized individual such as quacks etc
- 7- More than one healthcare seeking encounters

- 8- Seeking initial healthcare from the private sector
- 9- Time and distance to reach a public healthcare facility
- 10-Unawareness of patients with the healthcare facilities provided at the

PHCs

- 11-Fear of what would be found on diagnosis
- 12-Belief that low cost services are inadequate at PHCs
- 13- Reluctance to seek healthcare from PHCs
- 14-Diagnosed in a health facility not belonging to National Tuberculosis Program
- 15-Self belief that symptoms would cease on their own

This second objective in this study was to examine or determine if there was any relationship between healthcare seeking behavior of the patients with diagnostic and treatment delay and also with no delay. The results of hypothesis showed and it is concluded from the results obtained by the descriptive and statistical analysis that there is a strong relationship between healthcare seeking behavior and delays. It was observed that if the patients had good healthcare seeking behavior, they got their diagnosis and treatment without any delay and the treatment outcome was good. It was seen that in patients who had diagnostic and treatment delay, healthcare seeking behavior was not good due to different factors which affected the healthcare seeking behavior of the patients and were discussed in the previous chapters.

The third objective was to determine knowledge, awareness and attitude of the LHWs which can influence the healthcare seeking behavior of the patients to avoid delay in the diagnosis and treatment of pulmonary tuberculosis. Unfortunately not a big sample of LHWs was obtained for this study but from the interviews of few LHWs and observations it appears that LHWs play a vital role in having a good healthcare seeking behavior of the patients because they have to identify and refer the TB suspects from the community to the health centers, their knowledge, awareness and attitude towards the patients is of utmost importance to have a good healthcare seeking behavior and to avoid delay in the diagnosis and treatment of pulmonary tuberculosis. LHWs are the only source to identify the suspect patients from the community. Their knowledge, awareness and attitude are important as that they can communicate, educate and make the people aware of the situation and disease and to have early checkup, diagnosis and treatment if someone has tuberculosis suspicion.

The fourth and final objective of this study was to determine the length of delays in the diagnosis and treatment of pulmonary tuberculosis at different levels. It was seen that there were considerable delays of diagnosis and treatment in this study. Patients had to suffer longer delays especially in diagnosis mainly due to their own healthcare seeking behavior and also due to health care providers which mainly included private sector and non-qualified or specialized persons. The mean diagnostic delay in this study was 90.14 days with a range from 0-288 days, while treatment delay was almost negligible with a mean of 0.56 days with a range from 0-19 days. The mean duration of patient delay was 8.5 days with a range from 0-90 days, while the mean duration of health system delay was 84.1 days with a range from 0-244 days. Total delay was recorded with a mean of 45.35 days with a range from 19-288 days.

#### 7.2 Recommendations

The following recommendation can be given to improve healthcare seeking behavior of the patients and to reduce the delay in the diagnosis and treatment of Tuberculosis:

- 1- Media which include television, radio and newspapers etc can play a vital role to increase people's awareness about the tuberculosis and its risks. Media can also play a role to educate and make people aware not only with the tuberculosis but also with the proper ways they should choose to avoid delays in their treatment. People should be informed that if they have tuberculosis symptoms they should follow the primary health care guidelines and should visit primary healthcare facilities rather going to private sector because health checkup, diagnosis and treatment is free in PHC facilities. People are not aware about the facilities provided at the PHCs, so media should be engaged to provide this information to the people.
- 2- Linkage between private and public health sector should be made stronger so that the patients going to private sector should be referred to the public or

primary healthcare centers to have free checkup along with diagnosis and treatment.

- 3- Lady health workers should be trained and educated more about the tuberculosis to improve their knowledge and awareness about the disease, so they can communicate with the people and make them aware of the disease and in this way healthcare seeking behavior of patients can be improved.
- 4- Health committees which are already working at the community level should be engaged properly and actively with the help of health department and healthcare providers so that they can educate people and make them aware of tuberculosis symptoms and primary healthcare facilities.
- 5- Lady health workers should be engaged actively and should be given more incentives so they can work with interest and visit the households with proper knowledge and awareness to identify tuberculosis suspects and guide them through their diagnosis and treatment.
- 6- Government could improve the diagnostic facilities at the public hospitals and national tuberculosis program guidelines could be improved to have a better

healthcare seeking behavior of the patients and to avoid the diagnostic and treatment delays.

- 7- Tuberculosis stigma should be improved with proper knowledge and awareness about the disease that it's a curable disease and if proper and timely diagnosis and treatment can be done a lot of social problems that a patient can face due to tuberculosis can be avoided.
- 8- Health department could provide the diagnostic facilities at basic health unit so that patients can afford to go to the nearest health unit instead of going to a big public hospital to have their diagnosis.

#### 7.3 Future research

The results of this study contribute to further study on diagnostic and treatment delay. The results provided the basic causes of delay in the diagnosis and treatment of pulmonary tuberculosis in district Gujrat, Pakistan and it reflected the situation in other areas as well. Further studies on diagnostic and treatment delays should be conducted to further clarify the problem especially to know the healthcare seeking behavior of the patients and attitude of the healthcare provider because these were the main reasons for the delay in the diagnosis and treatment. Also studies to clarify the stigmatization of tuberculosis should be conducted. Future studies should be focused more to find out the possible solutions by which diagnostic and treatment delay can be avoided.

Future studies on Lady Health workers should be done with special focus on their role to reduce the diagnostic and treatment delays of tuberculosis. A larger sample of Lady Health workers should be taken to study their knowledge, awareness and attitude towards the tuberculosis. Also a study should be conducted to see linkage of private and public healthcare providers to strengthen the TB DOTS program and to avoid the diagnostic and treatment delays.

The results of this study were generated from a small sample size and also from two settings. There should be a strong suggestion to re-conduct this study with more sample size and more study settings should be included to have a broader view about the problem of diagnostic and treatment delay.

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### Appendix

#### A- Pulmonary Tuberculosis Patient's Questionnaire



## **QUESTIONNAIRE SURVEY FORM**

"Causes of delay in the diagnosis and treatment of Pulmonary Tuberculosis in Gujrat, Pakistan: the case of Basic health unit Joura Jalal Pur and Aziz Bhati Shaheed Hospital"

## Patient's questionnaire

By

#### **Dr.Touseef Ansar**

Public Health Management (PHM) School of Health, Environment, Life Sciences Ritsumeikan Asia Pacific University (APU) Japan Asalam-o-Alaikum! My name is Dr.Touseef Ansar, who is a graduate student at Ritsumeikan Asia Pacific University in Japan. I am pursuing my master degree in the field of International Cooperation Policy (Public Health Management).

Now, I am doing survey on "Causes of delay in the diagnosis and treatment of Pulmonary Tuberculosis in Gujrat, Pakistan: the case of BHU Joura JalalPur and Aziz Bhati Shaheed Hospital. This survey requires for the completion of Master's degree; therefore, I would like to ask your participation for this data collection which takes about 20 minutes for interviewing. Also, I would like to confirm that all your information will be kept in privacy and confidentiality while it only needs to analyze for my academic purpose, so your participation is vitally important to me. Do you agree?

Thank you beforehand.

## I-Socio-demographic characteristics and risk factors:

- 5. Name: -----
- 6. Age (years):-----
- 7. Sex:

#### □ Male

#### □ Female

8. Number of household members:
9. Number of rooms in the house:
10. District:Full address:

11. Educational level:

□ University or higher

□ Primary/Middle/Senior

#### □ Illiterate/read & write

#### 12. Occupation:

 $\Box$  Technical/professional

 $\Box$  Clerical/worker

□ Student

 $\Box$  Unemployed or (house wife)

#### 13. Income:

□ Savings

□ Income=expenses

 $\Box$  In debt

#### 14. Residence:

□ Urban

□ Suburban

□ Rural

- □ Homeless/displaced
- 15. Marital Status:
  - $\Box$  Married

 $\Box$  Single

□ Divorced/separated

□ Widowed

16. History of smoking:

□ Never

 $\Box$  Current smoker

□ Quitted smoking

17. If smoker specify amount of daily consumption (number of cigarettes/day): ------

18. Duration of smoking: years-----; months------;

19. Previous exposure to TB patients:

□ Yes

□ No

20. Nationality: -----

21. Other chronic diseases (e.g. HIV/AIDS, Diabetes, COPD, Disability, etc): ------

## **II-History of current illness:**

Chief symptoms and date of onset of the current illness:

22. Cough:
Date (dd/mm/yy):
23. Fever:
Date (dd/mm/yy):
24. Loss of Weight:
Date (dd/mm/yy):
25. Haemoptysis:
Date (dd/mm/yy):
26. Chest pain:
Date (dd/mm/yy):
27. Others (specify):

Date (dd/mm/yy):-----

28. Which symptom(s) made you seek healthcare: -----

29. Health seeking behavior with onset of symptoms (before initial diagnosis) and cost of one consultation: -----

First action	Code	Date(dd/mm/yy)	Total expenses
НСР	0		
Self medication	1		
Traditional medicine	2		
PHC worker at home	3		
Drug store(pharmacies)	4		
Others (Specify)	5		

30. Date first seen by HCP for the current illness (dd/mm/yy): ------

31. Health facility of the HCP whom you first sought his consultation: ------

Order	Code Of health facility	Date (dd/mm/yy)	Code of Health facility	
1				
2			TB center	0
3			РНС	1
4			Chest Hospital	2
5			Public hospital/OPD	3
32. If pri	vate practice, specify th	e specialty of the HCP	Private Practice(Clinic etc)	4
whom yo	ou first sought his consul	tation:	Others (Specify)	5

□ Chest specialist

#### $\Box$ GP

 $\Box$  Others (specify)

33. Reasons of first consultation of the health facility (mentioned in q.31) with the onset of symptoms

0	Accessible
1	Confidence in getting cured
2	Services available anytime
3	Referred by previous health service
4	Free services
5	Advised by somebody
6	Others (specify)

34. Reasons of non-consultation of health facility (coded 0,1,2 in q.31) with the onset of symptoms (in case he did not consult 0,1,2) (check):

0	Too far
1	Too busy/Long waiting time
2	Bad experience
3	Others (specify)

# **III-Satisfaction with care (score: 0 best, 1 average, 3 worst):**

35. Availability of services in PHC/	TB centers:		
36. Prompt action from HCP in PH	C:		
37. PHC well equipped:			
38. PHC giving free medicine:			
39. There is enough PHC in the area	a:		
40. Health facility workload:			
41. Waiting time ( $0: \le 15$ min,	1: 15-30 min:	2: >30 min-1 hr	3:>1
hr)			

#### 42. Perceived Causes of Delay in Health Seeking Behavior (check): ------

0	No delay
1	Fear of what would be found on diagnosis
2	Hoped their symptoms would go away on their own (denial and concealment
3	Fear of social isolation
4	Economic constraints
5	Inadequate staff attitude
6	Poor quality of health services
7	Others (specify)

43. TB stigma

# Strongly agree=0 Agree=1 Average=2 Do not agree=3 Do not agree at all=4

1. Do you feel ashamed for having TB?
2. Do you have to hide TB diagnosis from the other people?
3. Does TB affect relation with the others?
4. Is TB very costly due to long duration of the disease?
5. Do you prefer to live isolated since you got TB diagnosis?
6. Does TB affect your work performance?
7. Does TB affect marital relation?
8. Does TB affect family responsibilities?

9. Do you think there is less chances of marriage due to TB diagnosis?
10. Does TB affect your family relations?

44. Date of first TB diagnosis (dd/mm/yy): ------45. No of health seeking encounters (HCP) before initial TB diagnosis: -----46. Health facility of the HCP who made the initial TB diagnosis (by code mentioned in q.31)

\_\_\_\_\_

47. Specialty of the HCP who made the initial TB diagnosis:

□ Chest specialist

 $\Box$  GP

 $\Box$  Others (specify)

48. Action taken by HCP who made the initial TB diagnosis: [dd/mm/yy]

- □ Sputum examination
- □ X-ray
- $\Box$  Both
- □ Referral

□ Others (specify) 49. X-ray: 1. Negative ------ 2.positive ------ 3.not performed 50. Date of initiation of treatment (dd/mm/yy): ------

## IV-Accessibility to the public health facility providing

#### treatment:

51. Time to reach from home to the nearest public health facility: 1. <1/2 hr: ----- 2.  $\frac{1}{2}$ -1 hr: ----- 3. > 1hr: ----- 52. Distance (in Km) from home to the nearest health facility providing treatment and diagnosis:

\_\_\_\_\_

# V-Patient's knowledge on TB:

53. Have you previously heard of TB? -----

54. Source of information on TB (select) ------

0	MOH campaign (media)
1	Education
2	Friends/Relatives
3	TB disease in friends/relatives
4	Others (specify)

# **Correctness of information on TB:**

[Yes/right, 0] [No/wrong, 1] [not known, 2]

55. What kind of disease do you have?
56. Is TB hereditary?
57. Is TB contagious?
58. Is TB curable?
59. Do you know if there is a vaccine for TB?
60. Do you know the approximated duration of treatment?
61. Do you know the kind of TB drugs?