PATIENTS WITH PULMONARY TUBERCULOSIS : FACTORS ASSOCIATED WITH TIME AT DIAGNOSIS, AND WITH DELAY IN PRESENTATION TO HEALTH SYSTEM

Mohammed Shamsul Alam

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DECLARATION

I, Mohammed Shamsul Alam, hereby declare that this report is my own work. It is being submitted for the degree of Master of Family Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

M.S. ALAM

28 May 1999

DEDICATION

To my wife, Ashu, and my sons, Hasib and Saif, who received less attention than they deserved.

ABSTRACT

The morbidity and mortality from tuberculosis may be influenced by the delay from the onset of symptoms until diagnosis. This study was performed to investigate patient and health services delays in the diagnosis of pulmonary tuberculosis, and the patients' explanations for these delays.

A retrospective questionnaire survey of 100 adults with active pulmonary tuberculosis was conducted. The mean total delay in diagnosis was 69.2 days (median 60 days) comprising patient delay of 45.2 days (median 30 days) and health services delay of 24.0 days (median 22 days). In-patients had longer delays than out-patients. Half the patients utilised hospital services. Thirty nine (39%) patients visited private GP's first, and 22% visited traditional healers. The mean total number of visits per patient before diagnosis was 6.6. (median 5).

Reasons given for late presentation included ignorance of the symptoms of tuberculosis (36%), negative perceptions of tuberculosis (36%), economic burden (33%), fears of being tested for HIV (15%), non-cooperative employers (12%) and prolonged waiting time (11%). The health services were accused of not caring (18%) and were blamed for not performing chest radiographs (26%).

The public should be educated about the symptoms of tuberculosis. Sputum must be examined in patients with prolonged cough. Dialogue with traditional healers should be encouraged.

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CHAPTER 1

INTRODUCTION

1.1 Introduction

Tuberculosis (TB) is an ancient infection. It appears to be as old as humanity itself. German skeletons dating back to 8000BC, and Egyptian skeletons dating from 2500 to 1000 BC have revealed evidence of TB.[1]

More than a hundred years ago, in 1882, Robert Koch discovered the tubercle bacillus. TB has been the subject of extensive research ever since. Koch's discovery did not end the centuries-long saga of TB however; it was but one major step in the ongoing struggle to understand and combat this disease.

TB is very much with us today. It is a major health problem in human society. In the words of a World Health Organisation (WHO) report: 'TB is the most important specific communicable disease in the world'. The infection still remains the cause of a higher morbidity and mortality than any other infection.[2] TB is a global problem. For 400 years or so the world has been in the grip of the TB epidemic.[3] Approximately 1,7 billion people were infected with TB in 1990, which was about one third of the world's population.[4] In 1993, the world Health Assembly declared TB a global emergency. The estimated global annual incidence of TB is 8 - 10 million. Five million people are highly infectious. The mortality is approximately 3 million annually. At least 80% of deaths occur in people living in developing countries in

South Asia, Africa and Latin America.[3] TB is on the rise again in industrialized nations, such as the United States of America.[5]

TB is a time-bomb in Africa. TB is associated with deprivation, poverty and Human Immunodeficiency Virus (HIV) infection.[6] Poverty, malnutrition, over-crowding, alcoholism, measles and HIV infection are all common in Africa, and may trigger clinical disease in the millions of people infected with Mycobacterium tuberculosis. [1]

TB ranks as one of South Africa's major public health problems.[7] The high TB notification rates, the increasing HIV seroprevalence in TB patients, the emergence of multi-drug resistance, and the failure of an annual R500 million expenditure to control TB reflect the seriousness of the tuberculosis epidemic in South Africa.[8] The incidence of TB in this country is among the highest in the world at approximately 310 cases per 100,000 population in 1997 [7], compared to the reported incidence of clinical disease in the USA of 9.5/100,000 population in 1989. The TB incidence in South Africa has been increasing over the last few years and continues to increase for two main reasons - the high incidence of HIV infection which predisposes to disease and an adequate DOTS (directly observed therapy) strategy has not yet developed. [8]

Although the causative organism, Mycobacterium tuberculosis, was recognized over 100 years ago and we are living in the era of effective chemotherapy, TB control programmes are still struggling to control one of the world's most infectious diseases. South Africa is categorized by the WHO as one of 16 countries hampering global efforts to control TB. [9] For the healthy well-being of society and economic development we have to control TB, as it has a significant economic impact due to the fact that it frequently affects a productive segment of society. [10]

One key foundation of TB control is case finding, namely the early and aggressive identification of active TB cases and the prompt initiation of effective anti-tuberculosis therapy. [11] The chronic and insidious nature of TB results in a long period of infectivity and high mortality rates. Delays in diagnosis of TB may result in increased patient morbidity and in further spread of the disease.[12] Late presentation is a major factor for in-hospital death.[13] Early diagnosis is vital for good clinical management and improving public health generally.[14]

Delays in presentation and diagnosis represent one of the most significant obstacles to effective tuberculosis control programmes. Little is known about the extent and the reasons for delays among TB patients in South Africa, or about what the roots of the delay might be. This study was designed to find out the average length of the delays and the patients' perceptions of what factors contributed to delays in presentation and diagnosis of TB.

1.2 Literature Review

1.2.1 The National Tuberculosis Control Programme (NTBCP) in South Africa.

Although the NTBCP is in it's fourth year, the documents to be used for reporting and evaluation have not yet been finalised. In 1995, a revised NTBCP based on the DOTS strategy was established.[8] The control of TB continues to be a major challenge in

South Africa. In an attempt to reform the approach to TB control the Department of Health implemented a revised TB policy during 1996.[15] The policy was based on the WHO strategy defined by five key elements.[16] They are (a) Government commitment to a national TB programme as a specific health system activity, integrated into comprehensive primary care, and supported technically at a national level, (b) standardized, directly observed, short course treatment (DOTS), prioritizing sputum positive patients, (c) passive case finding, (d) an ensured supply of essential anti-TB drugs, and (e) effective monitoring.

During 1997, 108,382 cases of TB were reported to the National Department of Health. Only 60% of the positive sputum smear patients diagnosed were reported as 'cured' at the end of their treatment period. The treatment interruption rate of patients was 18%.[17] These findings indicate that all is not well in the NTBCP. A lack of a comprehensive district health system, the economic recession and health care workers with poor morale are the main obstacles to rapid progress in the NTBCP.[15]

1.2.2 Patient Characteristics

According to a WHO report, the global prevalence of infection with Mycobacterium tuberculosis is similar in males and females until adolescence, after which it is higher in males.[18] In recent studies from developing countries including South Africa, the mean age has varied from 32 to 45 years, the male to female ratio from 1.4:1 to 2.2:1, and the unemployment rates among TB patients from 25 to 47%. [6, 10, 13, 19, 20,]

The frequency, duration and severity of symptoms vary in TB patients. In a Korean study in 1993, almost all patients had fatigue followed by cough.[21] In a Malaysian

study in 1994/5, the first symptom was cough in 63% of 97 patients,[20] and in a Johannesburg study the mean duration of symptoms was 102 days among in-patients.[13] The symptoms of patients in studies from Ghana and Botswana are shown in Table 1.

Table 1

Presenting symptoms of TB in studies of delay in diagnosis

	City / Country Years / Number	
	Kumasi / Ghana[6] 1995 / 100	**Kweneng / Botswana[19] 1993-94 / 212**
Presenting Symptoms	**%**	**%**
Cough (%)	94	93
Haemoptysis	26	5
Fever	78	5
Chest pain	74	-
Weight loss / Anorexia	54/21	5/7
Night sweats	-	8
Dyspnoea / Headache	-	13/5

In a Ghanaian study, 26% of patients had haemoptysis, 78% fever and 54% weight loss compared to only 5% with each of similar symptoms in a Botswanaian study. We do not know the reasons for these differences. Nothing was mentioned regarding night sweats, dyspnoea and headache in the Ghanaian study, and about chest pain in the Botswanaian study. We do not know whether these symptoms were absent or not recorded in one or other study.

1.2.3 Delays in Presentation and Diagnosis

The extent of delays found in several published studies are shown in Table 2.

Table 2

The mean/median patient and doctor delays in the diagnosis of TB in published studies

City/Country/Year	Number (n)	Patient Delay (days)	Doctor Delay (days)	Total Delay (days)
Cape Town/RSA/1991 (children)[22]	172	30.1 (mean)	35 mean)	65.1 (mean)
Kweneng/Botswana/1993-94 (adults)[19]	212	35.7 (mean) 21 (median)	85.4 (mean) 35 (median)	121.1 (mean) 84 (median)
Kumasi/Ghana/1995 (adults)[6]	100	89.6 (mean) 28 (median)	126.7 (mean) 56 (median)	231 (mean) 120 (median)
Korea/1993 (adults)[21]	630	54 (median)	14 (median)	
Kuala Lumpur / Malaysia / 1994-95 (adults)[20]	97	14 (median)	49.0 (median)	87.5 (median)
California/USA/1993 (adults)[5]	248	74.0 (mean)	-	-

(NB: all delays have been converted to days for comparative purposes)

In Kuala Lumpur, 82% of patients first consulted private GP's, only 6.2% of these consulted GP's suspected TB, and the mean number of doctor consultations before diagnosis was 5 (range 1-35).[20] In Ghana, in a study of 100 patients, 85% of patients sought help from a conventional medical practitioner (government or private), 9% consulted traditional healers in urban areas and 62.5% in rural areas, and the mean number of doctor consultations before diagnosis was 4.2.[6]

1.2.4 Reasons for Delay

Numerous reasons for delay have been advanced in studies performed in different countries. These are mostly cultural or local factors including social stigma, economic pressures, the rural-urban divide, low rates of suspicion for TB, prolonged waiting room time, visiting traditional healers and poor quality of health services.[19,5,6,10,12,22,23.]

1.2.5 Economic Impact of TB on the patient

TB has a significant economic impact on patients as it effects the productive segments of society.[2,10] A study in Zambia found that 44% of TB patients were the main source of household income, and in seeking diagnosis, patients incurred a mean total cost equivalent to 127% of their mean monthly income and direct expenditures represented 60% of this cost. The immediate lost income and potential job loss incurred from time off work also created an economic barrier for patients seeking care.[10]

In Uganda, patients bear more than 60% of the total burden of TB and furthermore, half of the monetary costs and the majority of time lost from work are incurred before diagnosis. [24]

1.2.6 Spread of TB

An untreated sputum smear-positive person can infect 10 to 14 others in a year.[25] Patients with active TB remains contagious for at least 2 weeks after the initiation of therapy. Patients with smear-positive disease are likely to be contagious much

longer.[26] A study at a Blantyre hospital in Malawi found 14% of nurses working in the medical ward developed TB between 1993 and 1994.[27] Delay in diagnosis is the major factor responsible for the spread of TB among co-workers.[28]

1.2.10 **Mortality of TB**

TB is projected to cause 30 million deaths for this decade.[29] Delayed diagnosis carries high mortality.[30] Female sex, lower admission haemoglobin level and lower body weight were associated with in-hospital fatalities in a study in Johannesburg.[13] TB kills more adults every year than AIDS, malaria and tropical diseases combined.[2]

1.2.10 **TB in Women**

Globally it is estimated that 766,000 girls and women died from TB in 1990. As the leading infectious killer of youths and adults, TB kills more women than all causes of maternal mortality combined.[2] Lower notification rates are reported among women compared to men living in low-income countries.[31]

The stigma of TB in women is potentially harsh. In Pakistan, women with TB are likely to be divorced, and husbands often take a second wife. Unmarried women with TB are likely to have more difficulty finding a marriage partner than those without TB.[32] Barriers to early detection and treatment of TB vary, and are probably greater for women than for men. When women are ill they wait longer to report their illness than men.[33]

1.2.9 HIV Infection and TB

The prevalence of HIV infection among adults diagnosed with TB is on the increase. It was 36% in 1993 and 59% in 1995 in Hlabisa, Kwazulu Natal.[7]

Individuals who are HIV-positive have a relative risk of developing TB following infection of between 2 and 100 times higher than those who are HIV-negative.[34] The estimated annual risk of tuberculosis in individuals with HIV and TB co-infection is 5 - 8%, with a lifetime risk as high as 50% or greater.[35,36] HIV infection is not a significant clinical predictor of early mortality from TB.[13] There is no association between HIV positivity and delays.[19]

1.2.10 Multidrug Resistant TB (MDR-TB)

MDR-TB is thought to be highly prevalent because of a breakdown in the health infrastructure, inappropriate prescription, lack of drug availability and poor patient compliance.[37]

In South Africa, the incidence is above 2%. One-third of the National TB budget is spent on the management of MDR-TB.[15] In USA, 3,5% of strains are resistant to Isoniazid and Rifampicin.[37] The HIV-infected patients showed, in a study in South Africa, less drug resistance than HIV-negative patients, and MDR was not a significant clinical predictor of early mortality from TB.[13]

1.3 Motivation for the Study

Control of TB relies primarily on the early and aggressive identification and treatment of cases of active TB.[11] But delays in presentation and diagnosis of TB, as demonstrated in the literature review, occur and are associated with a higher mortality, increased morbidity and greater spread. Untreated smear positive patients are the main sources of spread of TB in the community. Late presentation may be associated with more advanced disease and more complications. As TB affects mainly young wage earners in the developing world, it has a significant economic impact on patients. HIV infection which is on the increase among patients diagnosed with TB, causes more rapid progression of TB.

These delays represent a significant problem in TB control programmes. Rapid diagnosis is important from the patients' perspective too. How can we improve this? We need to know the extent and the reasons for these delays in South Africa.

1.4 Aim of the Study

The aim was to determine and explore the factors associated with the time of diagnosis, and delay in presentation to the health system by patients with pulmonary tuberculosis admitted to the Sizwe Tropical Disease Hospital and those attending Hoek Street Clinic as out-patients

1.5 Objectives of the Study

The objectives of the study were to:

i) Find out some of the demographic factors which might have contributed to any delay in diagnosis of TB.

ii) Describe the symptoms and the duration of illness.

iii) Collect details of health seeking behaviour i.e. previous medical consultations for the same problem.

iv) Determine the time from onset of symptoms to presentation and the patients' reasons for any delay (patient delay and reasons for delay).

v) Find out the time from presentation to diagnosis and the patients' view of factors associated with any delay (health services delay and reasons for delay).

vi) Determine total delay (patient delay + health services delay).

vii) Find out the patients' perspective on problems in seeking and getting help from health services.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 Ethical Issues

i) Prior to undertaking the study, the protocol was submitted to and approved by the Committee for Research on Human Subjects (medical) of the University of the Witwatersrand, Johannesburg.

ii) Gaining access to research sites - The Superintendent of Sizwe Tropical Disease (previously Rietfontein) Hospital and the Chief Executive Officer of Hoek Street TB Clinic granted written permission to interview patients and to use their files.

iii) Gaining access to patients - Written informed consent was obtained from all the patients participating in the study. The patients were handed an information sheet (Annexure A) regarding the study. The contents were verbally explained to those who could not read. The patients were assured about anonymity. It was voluntary for the patients to participate in the study.

2.2 Study Design

It was a cross-sectional descriptive study based on interviews with TB patients. Demographic information was collected related to age, sex, occupation, income, number of persons in the household under one roof, distance to the nearest health centre/doctor and the cost of getting there, past history and family history of TB, symptoms and duration of illness and details of past medical attention for this illness.

In addition, data was obtained on the factors stated by patients influencing the time of presentation and diagnosis of TB.

2.3 Settings

The study sample of in-patients was collected from Sizwe Tropical Disease Hospital, a public sector hospital run by the National Health Department. It is a 500-bed hospital, situated in Johannesburg, serving as a referral centre for patients with complicated TB. Most patients at this institution are black.

The study sample of out-patients was selected from Hoek Street TB Clinic, a public sector clinic run by the Johannesburg City Council. It is situated at 18 Hoek Street, close to a taxi rank and the Joubert Park railway station, in the densely populated Johannesburg inner-city. It is a day clinic which provides diagnostic and curative health care for TB patients. Most patients are black.

2.4 Study Population

The population consisted of adult patients with confirmed pulmonary tuberculosis (PTB), both new and retreatment patients, admitted to Sizwe Hospital or attending the Hoek Street Clinic. PTB cases were confirmed by examination of sputum smear and/or culture. Acid-fast facilli (AFB) were detected on direct smear of expectorated samples of sputum by fluorescent microscopy using a phenol-auramime strain, when at least 1-9 AFB/100 field at 500 x magnification were seen (reported as scanty). Doubtful smears (1-2 AFB/300 fields) were checked by the Ziehl-Neelsen staining method. Specimens were processed for culture using a modified Petroff's method. Culture was carried out using both a Lowenstein-Jensen (LJ) agar slope and BACTEC 12B vial.[38]

2.5 Sampling

Systematic random sampling was used for in-patients. The starting point was selected at random. The sampling interval was 3. The population in the hospital was 300 patients. The required sample size for in-patients was 50. The patient beds were not ordered according to any order or cyclical pattern. Some beds were empty. Every third patient was interviewed. If a patient refused to participate, the next patient in the sequence was selected. The patients were interviewed after the routine morning ward round to ensure the least disruption to clinical services. The study was performed from the 3rd to 10th July, 1998. At Hoek Street Clinic (ambulatory service) the starting point was selected at random. The sampling interval was 5. The sample size for out-patients required was 50. If a patient refused to participate, the next patient in the sequence was selected. The study time was the 5th to 14th August, 1998.

2.6 Sample Size

A sample size of 50 in each group, calculated with the assistance of a statistician, was considered sufficient to show a statistically significant difference between the two groups, based on a 5% level of significance and 90% power.

2.7 Pilot Study

A pilot study was done at Hoek Street Clinic to test the questionnaire and the logistics of its administration, the sampling interval and to ensure minimal disruption to both patients and clinical services. Most of the patients wished to return to work immediately after taking their medications (directly observed therapy - DOTS) but the length of the questionnaire did not cause much disruption. The questionnaire did not require any changes to its structure.

2.8 Instrument

Measurements were done by structured interview. The questionnaires (Annexure B) consisted of both open- and close-ended questions. The patients were interviewed by the researcher. The interviewing time was 15-20 minutes per patient.

There were 12 patients (7 in-patients and 5 out-patients) who could not communicate in English. In those cases, a trained, independent, objective and medically oriented nurse helped the researcher to interview the patients.

HIV results were not included since most in-patients did not know their status and most out-patients had not been tested.

2.9 Exclusion Criteria

a) Patients who refused and/or were unable to consent to participation.

b) Patients who had extrapulmonary TB.

c) Patients under the age of 16 years.

2.10 Data Analysis

Data was analysed using frequency, rates and proportions for categorical variables. Groups were compared using Fisher's Exact Test and Chi Square Test where appropriate. Data was described in the report. Probability (p) values were determined from t-tests and Mann-Whitney tests.

2.11 Definition of Terms

a) Patient delay : the time from the onset of symptoms until the patient first sees a conventional medical practitioner or traditional healer.

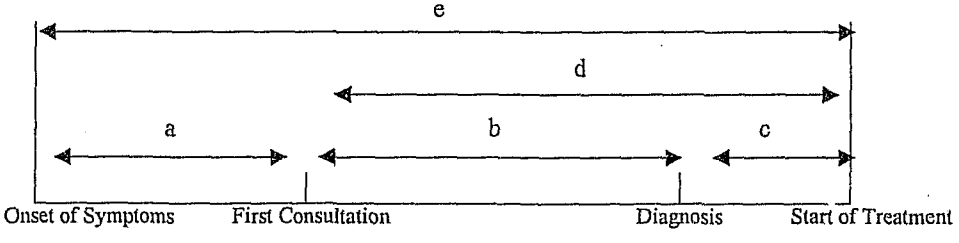
b) Doctor delay : the time from first consultation until diagnosis is made.

c) Treatment delay : the time from diagnosis being made until treatment is started.

d) Health Services delay : doctor delay & treatment delay.

e) Total delay : the time from onset of ·mptoms until treatment is started.

Figure 1 : Delays



a Indicates patient delay; b doctor delay;

c treatment delay; d health services delay;

e total delay;

CHAPTER 3

RESULTS

3.1 Patient Characteristics

a) Demographic information : One hundred patients were included in the study, 50 in-patients and 50 out-patients. One in-patient and 5 out-patients refused to participate. Three in-patients were excluded because of extra-pulmonary TB. No patient was found under 16 years. (Table 3). The mean age was 34 years (median 21, range 16-72 years) and the male to female ratio was 1.4:1. The mean educational standard reached was standard 6 (median 6, range 0-12). The mean walking distance to the nearest health care facility was 24 minutes (median 15, range 5-180 minutes). Thirty seven (37%) were unemployed, 28% held white-collar jobs and 35% had blue-collar jobs. Thirty four had no income and 3 were pensioners. The mean income was R675.00 (median R600.00, range R0.00 - 2300.00). The mean number of persons in a household under one roof was 5 (median 4, range 1-13). There were no statistically significant differences in age, sex, education, distance and transport costs, employment, income, number of persons in household, family and past history of TB, compliance, and knowledge of free TB treatment between in- and out-patients (data not shown).

Table 3 : Patient Characteristics

Patients (n = 100)		
Characteristics		number
Age:	≤ 40 years	76
	> 40 years & < 60 years	20
	≥ 60 years	4
Sex:	Male/Female	58/42
Education:	No formal education	14
	Mean education Std 6	86
Distance:	≤ half an hour (walking)	86
Transport cost:	No cost required	47
	Mean return cost R4.00	53
Family members treated for TB:		27
Retreatment Patients:		30
Retreatment more than once:		6 (6/30, 20%)
Poor compliance (previously):		7 (7/30, 23.3%)
Unaware of free TB treatment:		41

b) Presentation : Sixteen categories of symptoms were noted among one hundred study patients. (Table 4). Cough was the most common and usually the first symptom. Haemoptysis was a reason for urgent medical attention. Fifty three percent of patients had cough, loss of weight and night sweats on first consultation. There were no statistical significance between symptoms of in- and out-patients (data not shown).

Table 4 : Presenting Symptoms of Subjects

Presenting Symptoms	n/% of patients	mean duration (days)	range (days)
Cough	95	88	3-1056
Weight loss	85	77	7-1056
Night sweats	64	66	3-240
Tiredness	43	58	3-180
Fever	37	30	3-240
Loss of appetite	37	36	7-180
Chest pain	35	51	3-180
Joint pain	21	36	7-180
Lymphadenopathy	18	40	7-120
Haemoptysis	6	4	2-7
Others: Nausea, shortness of breath, burning feet, short temper, head ache and confusion	2-9	36	7-180

3.2 Previous Medical Attention for this Illness

Ninety one (91%) patients visited one or more health care facilities - private general practitioners (GP), clinics, hospitals and traditional healers (healer). Eighty seven (87/91, 95.6%) patients were diagnosed with TB. Four (4/91, 4.4%) left the facilities ar d presented themselves to, and were diagnosed by Sizwe Hospital or Hoek Clinic. Nine (9%) did not visit any other health facilities but presented directly to Sizwe Hospital or Hoek Clinic.

The mean total number of visits to health facilities per patient were 6.6 (median 5) excluding healers but including primary health care nurses. The highest mean number of visits were at clinics (2.7) (median 2), and the least at hospital (1.6) (median 1). Sixty five (71.5%) patients made 3 or fewer visits excluding healers before being diagnosed as having TB. Forty seven (47/50, 94%), the highest number, were diagnosed by the hospitals and 16 (16/41, 39%) patients, the least number, by GP's. Forty three patients visited more than one facility excluding healers before being diagnosed, in other words, they left one facility and moved to another. The reasons for leaving given by patients were that there had been no change, expensive, long queues and an uncaring attitude. (Table 5 & Table 6). There were no statistical significance between previous medical attentions of in- and out-patients (data not shown).

Table 5 : Previous medical attention for this illness

Factors related to medical service use and perofmance	Hospital	Private GP	Clinic	Healer	Total
Health facility visited ever n (%)	50 (50/91, 54.9%)	41 (50/91, 45%)	39 (39/91, 42.8%)	20 (20/91, 22%)	91 (91/91, 100%)
Health facility visited first n (%)	30 (30/50, 60%)	39 (39/41, 95%)	22 (22/39, 59.56%)	0 (0%)	91 100%
Mean duration of illness (days) on first visit	64	44	83	32	-
Mean no of visits (range)	1.6 (1-9)	2.2 (1-5)	2.7 (1-15)	1.8	8.4
Facility which diagnosed TB - n (%)	47 (47/50, 94%)	16 (16/41, 39%)	24 (24/39, 61.5%)	0 (0%)	87 (87/91, 95.6%)
Patients seeking second opinion n (%)	3 (3/50, 6%)	25 (25/41, 61%)	15 (15/39, 38.5%)	20 (20/20, 100%)	43 (43/91, 47%)

Twenty (22%) patients visited healers. The mean number of visits were 1.8 (range 1-10) (median 1), and total numbers of visits were 39.6. No one was diagnosed as having TB, and eventually all left the healers. The reasons given by the patients for leaving were that there had been no change in health condition, or diarrhoea, haematuria and headache had developed on treatment.

Table 6 : Number of visits to other health facilities before referral to Sizwe Hospital or Hoek Clinic *

No of visit/s		In-patients (n = 48)	Out-patients (n=43)	Total (n=91)	p Value for t-test
1	visit - n (%)	13 (27.1%)	10 (23.3%)	23 (25.3%)	
2	visits - n (%)	7 (14.6%)	21 (48.8%)	28 (30.8%)	< 0.01 (≤ 2 visits)
3	visits - n (%)	5 (10.4%)	9 (20.9%)	14 (15.4%)	< 0.01 (≤ 3 visits)
4	visits - n (%)	7 (14.6%)	3 (7%)	10 (11%)	
5-15	visits - n (%)	16 (33.4%)	-	16 (18.7%)	

* Excluding healers

3.3 Duration of Illness

The median values for patient, health services and total delays were 30, 22 and 60 days respectively. For in-patients, the median patient and health services delays were the same - 30 days. The median values for patient and health services delays were 30 and 14 days respectively in out-patients. These values do not include delays caused by initial visits to traditional healers. Patients visiting a healer influenced all delay parameters. (Table 7a and 7b). Sixty eight patients had more than one visit excluding healers before being diagnosed as having TB. The mean interval between the first and second visits was 22 days (median 15 days).

Table 7a : Mean duration of illness in days in- and out-patients

			p-value	
Delays	**Out-Patient**	**In-Patient**	**t-test**	**Mann-Whitney test**
Patient delay:				
Excluding healers	39.0	53.5	0.05	0.24
Including healers	26.3	44.0	0.004	0.04
Health Services delay:				
Excluding healers	14.8	36.1	0.09	0.22
Including healers	21.3	83.7	0.006	<0.01
Total Delay:				
Excluding healers	53.8	89.6	0.02	0.06
Including healers	47.6	127.7	0.001	<0.01

Table 7b : Overall mean duration of illness in days

			p-value	
	Including healers	**Excluding healers**	**t-test**	**Mann-Whitney test**
Patient delay	35.2	45.2	0.25	<0.01
Health services delay	52.5	24.0	0.36	0.64
Total delay	87.7	69.2	0.69	-

The patient and health services delays were ≤ 1 month in 64% and 73% of patients respectively excluding healers (Table 8). The number of patients who had patient and health services delays ≤ 1 month were higher among out-patients although it was not statistically significant. Twenty three and 43% of patients were diagnosed within 1 and 2 months respectively among out-patients, and 8% and 22% respectively among in-patients. The health services delay was > 3months (7 - 36 months) in 3 patients who had MDR-TB. Reliable information was not available in these cases. They were diagnosed as having TB, and were on treatment. Although they did not default, they were not responding to treatment. Eventually they were referred to and were diagnosed as MDR-TB by Sizwe Hospital.

Table 8 : No/% of patients who had specific patient and health services delays (excluding healers):

Delays (Patients n = 100)				
	$\leq {}^{2}/_{52}$	$\leq {}^{1}/_{12}$	$\leq {}^{3}/_{12}$	$> {}^{3}/_{12}$
Patient delay n / %	29	64	94	6
Health services delay n / %	52	73	97	3

3.4 Differences Between in- and out-patients

The mean patient delay (p= 0.05/<0.01 excluding/including healers), and total delay (p= 0.02/<0.01), health services delay (p= <0.01 including healers) showed statistically significant differences between in- and out-patients (Table 7a). The number of cases were higher among in-patients than out-patients who had retreatment more than once (6 versus 0, p= 0.02) and visited more than one health care facility (32 versus 11, p= < 0.01).

Although retreatment, treatment defaulters, family history of TB and ignorance of free treatment were higher, and duration of symptoms were longer among in-patients, they failed to reach a statistical significance. Age and sex also failed to reach statistical significance.

3.5 Differences Between the Sexes

There were no statistically significant differences between female and male patients in mean patient, health services and total delays (data not shown). Other variables also failed to find any statistical significance.

3.6 Demographic and Clinical Factors Related to the Duration of Illness

The out-patients had shorter mean patient, health services and total delays than in-patients (Table 7a). Haemoptysis was the only symptom which had shortened patient delay significantly (p= 0.01). Employment (p=0.96), income (p=0.93), family history of TB (p=0.74), past history of TB (p=0.45), education (p=0.14), level of care (p=0.15) and female sex (p=0.24) were not statistically significant with respect to the duration of the illness.

3.7 Reasons Associated with Time of Presentation to Health Services

The reasons comprised the statements made by the patients. Twenty (20%) patients gave only one reason whereas eighty (80%) patients gave between one and four reasons. (Table 9 a, b, c).

Table 9a

Reasons for early presentation

Patients (n = 29), Patient delay ≤ 14 days

Reasons	n
Thought symptoms were due to TB	10
Worried about haemoptysis, most likely due to TB	6
Thought "bad flu" (influenza or self limiting upper respiratory tract infection) but doctors found TB	11

Table 9b

Reasons for late presentation

Patients (n = 71), Mean Patient delay 37.5 days

Reasons	n	
Thought symptoms were due to simple flu or other self limiting disease, or others (e.g. pregnancy, radiation hazard) but never thought of TB	36	
Thought symptoms could be due to TB but still they did not like to visit a doctor until they were intolerable, because:		
Prolonged anti-TB treatment -	25	
Bad side effects of anti-TB drugs -	6	
Quality of life not improved by treatment -	2	= 36
Sick and tired of TB as they and/or their family members had TB more than once -	3	
Financial problems	33	
Fears of hospitalization, of dying in the hospital beds, and of being tested for HIV	15	
Patients blamed their employers because: they refused to give leave, said no work-no pay, would discriminate or dismiss from jobs if they knew that patients had TB	12	
Prolonged waiting time specially in the clinic and hospital. Health care workers were rude and unfriendly	11	
Social stigma	7	
Busyness, laziness, or no time	7	
Too much violence around, scared to go out (2%), no-one to accompany them (2%), lost hope of future/life because many had died in the family from violence, poverty or disease (2%), advised to go to a healer not to a doctor (1%)	7	

Table 9c

Reasons for health services delay

Patients (n = 37), Mean delay 51.2 days

Reasons	n
Patients blamed their doctors for taking a long time to find out about the disease, because: *(patients thought)* doctors were in a hurry, poor listeners, and did not examine properly (18%), and/or chest radiographs were not done (26%)	33
Patients blamed themselves for poor compliance with the advice given to them by health workers	4

3.8 **Association Between the Severity of the Disease and the Duration of Illness** (see page 34, under Limitations).

CHAPTER 4

DISCUSSION

4.1 Patient Characteristics and Presentation

In this study, the patients interviewed represent a predominantly young urban adult population in Johannesburg. Their mean age and sex ratio were similar to those found in other developing countries.[6, 10, 20] The mean age and male gender were interestingly lower than those found in another study among in-patients in Johannesburg in 1997.[13] It may be due to the influence of rising HIV infection in South Africa.

TB is thought to be a disease of the poor. The study population were mostly uneducated or poorly educated and jobless or from the low income group of society; although there may be sociopolitical reasons for this. Age, education, employment status and income did not influence delays statistically.

The patients had a mean of 5 other people (range 1- 13) sleeping under the same roof and probably had other close contacts with major potential public health implications in terms of infecting close contacts.

Most patients were in close proximity to a health care facility with minimal transport costs. It may be because the study was done in Johannesburg; the scenario in rural South Africa with less easy access to medical care may be different.

High rates of family history (27%) and past history (30%) of TB possibly demonstrate the extent of active TB infection in this population.

The mean patient delay was longer, though it was not statistically significant, among patients who had a family and/or past history of TB. This implies that these patients possibly had not learned from past experience. Many of them (36%) had negative perceptions about TB. One can say that probably they were not properly educated by health care workers during previous episodes of TB, or they had undergone unpleasant experiences. The reasons were not explored.

Six percent (6) of patients in this study had haemoptysis compared to 26% in Ghana.[6] The reason may be the longer mean patient delay (12.8 weeks) in Ghana. Other symptoms were similar to those found in Ghana[6] and Botswana.[19] Fifty three (53%) patients had chronic cough, weight loss and night sweats on first consultation. So all of these should have been investigated for AFB on first visit but less than half (25%) of these 53% of patients were suspected of having TB on that first visit. It means, many health workers were unaware of or not alert to the high rates and symptoms of TB.

4.2 Previous Medical Attention for this Illness

As many as half (50) of the patients had been seen at hospitals previously, of whom 47 (94%) were diagnosed as having TB at that time. This compares to the 80 patients who visited primary health care facilities which included GP's (41) and clinics (39). In these facilities only 50% (40) were suspected of or diagnosed with TB. Thirty nine

patients consulted GP's first and most of them (25) left for the public sector mainly because of financial problems. GP's made the diagnosis in only 16 patients.

The mean total number of visits was 8.4 (median 6) including healers and 6.6 (median 5) excluding healers which is higher than those found in similar studies.[6, 19, 20] Twenty six percent of patients made more than three visits before being diagnosed as having TB which represents a high percentage of missed diagnosis in patients with chronic cough.

The government has placed great emphasis on the primary health care system. Ideally most TB patients should start at a primary health care facility and be diagnosed there, not at a secondary or tertiary care hospital. The above findings suggest that many health workers were not alert to TB symptoms. GP's were poor at diagnosing TB. The deficiency among GP's could be due to their low level of awareness of the disease and their poor diagnostic skills. It must be admitted that the information on whether the patients were told that TB was suspected or not depended entirely on the patients' recall in most of the cases and the actual percentage of GP's who considered the diagnosis of TB could have been higher. GP's probably did not send sputum samples to private laboratories due to the patients financial constraints, and instead referred them to hospitals and not to public sector clinics. The reasons were not explored. If GP's are trained and they have access to free sputum microscopy for TB, their contribution will increase.

Twenty (22%) patients visited traditional healers compared to 34 in Botswana,[19] and 9% and 62.5% in urban and rural Ghana.[6] In rural South Africa, it may be higher. Such a visit influenced health services delay significantly in this study. No one was diagnosed with TB and all left because of adverse side effects of traditional drugs

(muti). We can say that at least those TB patients did not get help from them. Treatment by a healer may, once started, take considerable time.[39] We need to enter into a dialogue with healers. If they find any patients with TB symptoms, they should refer them to a primary health care center for work up.

4.3 Delays and Reasons

This study highlights the prolonged delay from the onset of the patients' symptoms until a diagnosis was made, though it was somewhat shorter than those found in other similar studies.[5,6,19] Some authors feel that TB should be diagnosed within 30 days of symptom onset, while others consider a period of less than two months as desirable.[40,41] In this study, 31% and 65% of patients were diagnosed within 1 and 2 months respectively.

The mean patient delay was shorter than those in Botswana[5] and Ghana[6] but longer than that in Malaysia.[7] This shorter delay may be because this largely urban study population in Johannesburg had easy access to health facilities. This delay may be longer in rural South Africa.

Many patients blamed economic barriers for late presentation. But many (39) preferred to consult a private GP first where they needed to pay. Most of those who left the GP did so for financial reasons. So the economic barriers were really a significant problem. The TB epidemic is the result of a network of interlinking factors, one of them being poor socio-economic status. Socio-economic conditions and the physical environment of the community must be improved. Economic barriers should be reduced through decreasing the number of health encounters, decentralization of

health services and free sputum microscopy. The patient's employer should be contacted with the consent of the patient and his co-operation requested. Follow-up discussion with the employer at regular intervals will help to ensure completion of treatment. The patient's negative perceptions about TB can be addressed by proper health education and reinforcement through media campaigns. Many patients presented late for fear of HIV testing. HIV infection still carries a social stigma. Random HIV testing is not recommended in the NTBCP. If it is really necessary, proper counselling should be done, and informed consent should be obtained. Full staffing of clinic, making appointments, decentralization of services and total commitment of health workers may be able to reduce the waiting time. Social and political stability with reduction of violence will help to strengthen the NTBCP.

The mean health services delay was shorter than the mean patient delay when healers were excluded. (Table 7a). Seventy three (73%) had a health services delay ≤ 1 month compared to 64% with a similar patient delay. The median patient delay exceeded that of health services delay, indicating that major contribution to delay can be attributed to patient related factors. The doctor delay exceeded the patient delay (the doctor's fault) in Cape Town (children), Botswana,[19] Ghana,[6] and Malaysia.[20] (See page 6).

How can we reduce health services delay further? Chest x-rays are not included in the NTBCP as an essential tool for TB diagnosis. In the Border region of South Africa, a median health services delay of 1.5 weeks was found for PTB in 1983. X-rays were used quite extensively on patients who were clinically suspicious of PTB, and only 75% of the patients were smear-positive.[42] In a study in Botswana, 45% of those who had symptoms of PTB X-rayed at first visit had negative results.[19] In a Japanese study, the median health services delay was

13 days for patients who had a chest X-ray at first visit versus 50 days for the rest.[31] X-rays are expensive and routine X-rays are not indicated at a first visit. There is a case for more liberal utilization of chest X-rays in repeat visitors with negative AFB results or with a prolonged dry cough of more than 3 weeks.

For patients who made more than one visit, the median interval between the first and second visits was 15 days (mean 22 days) compared to 21 days (median) in Botswana.[19] It was a long period. Many of them visited healers during that time. So patients should be encouraged to return if symptoms persist. We do not know how many health workers advised that.

Thirteen (13%) patients presented themselves to Sizwe Hospital or Hoek Street Clinic, despite the fact that four of them had previously seen one or more health facilities during the course of their illness. So it commends the open door policy at these TB hospitals and clinics, and shows that the patients had confidence in their services.

The public including TB patients should be educated about the symptoms of TB, and the right health seeking behaviour. Both the patient and doctor delays will be shortened if they present to a TB hospital or clinic.

Three in-patients had prolonged health services delay (7 - 36 months). They all had MDR-TB; it was not known to us whether resistance was primary or secondary. MDR-TB is on the increase, and expensive to manage. Routine culture and sensitivity of sputum is essential in people previously treated for TB. Health workers should be trained about the atypical presentation of TB in some HIV infected patients, particularly those with advanced HIV disease.

Sizwe Tropical Disease Hospital is a referral center for patients with complicated TB. In this study the in-patients had significantly longer mean patient, health services and total delays than out-patients, and probably had complicated or more advanced TB. So we may say that the longer TB is without treatment the worse it gets. So early presentation and rapid diagnosis are vital to reduce complications and hospitalization.

4.4 Limitations

Data for delay and symptoms were based on patient recall, and were not confirmed by other means such as interview with household members or review of health services records. Thus they may not be completely reliable and may suffer from recall bias, either underestimating or overestimating the delay. Non TB symptoms may have been classified as TB symptoms.

There is also no record of sputum samples having been sent and having been negative. No distinction was made between patients who were smear positive for tuberculosis and those who may have been smear negative but culture positive.

HIV serostatus, where known, was not included (see page - 15), so it's influence on delay in our settings could not be assessed.

No treatment delay was recorded in this study as it was not recorded in the files. But it was assumed to be zero delay. In other words doctor delay and health dervices delay will be used interchangeably.

Due to insufficient and inadequate information on the severity of disease (see questionnaire, question number d, Annexure B, page 42) specially in out-patients, we were unable to determine the association between the severity of the disease and the duration of illness. None of the out-patients had either X-rays or haemoglobin results.

CHAPTER 5

CONCLUSIONS

This study has demonstrated that the mean total delay in diagnosis was 69.2 days (median 60 days) comprising patient delay of 45.2 days (median 30 days) and health services delay of 24.0 days (median 22 days). In-patients had longer delays than out-patients. Half the patients utilised hospital services. Thirty nine (39%) patients visited private GP's first, and 22% visited traditional healers. The mean total number of visits per patient before diagnosis was 6.6 (median 5).

The reasons given for late presentation included ignorance of the symptoms of tuberculosis, negative perceptions of tuberculosis, economic burden, fears of being tested for HIV, non-cooperative employers and prolonged waiting time. The health services were accused of not caring and were blamed for not performing chest radiographs.

It is therefore recommended that the National Tuberculosis Control Programme (NTBCP) must emphasise the decentralization of the management of TB, extensive training of health personnel including GP's, and an appropriate network of TB smear laboratories throughout the country to which GP's have access. All patients with a productive cough of more than 3 weeks (or possibly 2 weeks despite antibiotics) should have a sputum specimen investigated. Extensive health education of the public is essential, and TB patients should be a special target or health education, as many of them in turn will have relatives with TB.

This study could be repeated after a few years in order to show whether the NTBCP has become more effective. At first, as doctors become more efficient in diagnosis, health services delay will be shortened. Later, as the community becomes aware that TB is curable, confidence should grow and patient delay should become shorter. Serial stu" of this nature at sentinel sites throughout the country will help t~ identify areas of weakness in the NTBCP, and will thus contribute to its strengthening.

CHAPTER 6

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ANNEXURE A

CONSENT FORM

Dear Patient,

As you know TB is very common in this country. The longer TB is without treatment the worse it gets. We are doing a study to try and find out why TB is not diagnosed earlier. To do that we would like to ask you a short series of questions. When we have done many of these questionnaires we will put the results through a computer and we will get some answers as to why TB is not diagnosed earlier.

These results may not help you because you already have TB but may help others who have not yet contracted the disease. This study will be done under the University of the Witwatersrand, department of family medicine. At the end of the study the results may be published in a journal for doctors and nurses.

This study will be anonymous, that means your name will not be used anywhere in this study.

We hope you will assist us in this study that might help others. If however you do not want to take part in this study you are free to do so. Your treatment, care and the attention from medical staff will be the same, whether you take part in the study or not. If you have any enquiry please feel free to ask me.

Patient's Signature: _____

Code No: _____

ANNEXURE B

QUESTIONNAIRE

a) **DEMOGRAPHIC DATA:**

Age	Sex	Occupation	Education	Monthly Income	No. of persons in Household

Walking distance (time) to the nearest clinic / doctor or driving distance and cost	Family history of TB	Past history of TB	If yes. Treatment completed / not completed

TB treatment is free	Known	Not Known

b) **PATIENT'S COMPLAINTS:** It will consist of both open and closed ended questions

Symptoms	Duration			
	1 - 6 days	7 - 29 days	30 - 89 days	> 90 days
Cough				
Coughing blood				
Loss of Weight				
Night Sweats				
Fever				
Tiredness				
Chest Pain				
Lumps on Body				
Anything else State:				

c) PREVIOUS MEDICAL ATTENTION FOR SAME PROBLEM:

Attended Where/ Who	When	What told	What treatment given	Why did you leave
Hospital				
General Practitioner				
Nurse (PHC)				
Traditional Healer				

d) **TO DETERMINE THE ASSOCIATION BETWEEN THE SEVERITY OF THE DISEASE AND THE DURATION OF ILLNESS:** Duration of illness will be determined from questionnaire No. b) and severity from investigations (Hb and CXR) and patients body weight.

Duration of illness	Hb		Body Weight		CXR Involvement	
	<11.5gm %	>11.5gm %	<50kg		<40%	>40%

e) **REASON/S FOR PRESENTING NOW:** These will be open ended and non-judgmental questions. Why the patient is presenting now.

Factor/s stated by patient	Duration of illness

ANNEXURE C

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/49 Alam

CLEARANCE CERTIFICATE PROTOCOL NUMBER M980501

PROJECT Patients With Pulmonary Tuberculosis:
Factors Associated With Time Of Presentation
To The Health System

INVESTIGATORS Dr MS Alam

DEPARTMENT Dept of Family Medicine, Hillbrow Hospital

DATE CONSIDERED 980529

DECISION OF THE COMMITTEE *

DATE 980624 CHAIRMAN ..... 20/11/97 (Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

c c Supervisor: Prof BHW Sparks
Dept of Dept of Family Medicine, Hillbrow Hospital

Works2\lain0015\HumEth97.wdb\M 980501

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 10th Floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

DATE 29.6.97 SIGNATURE .....

PROTOCOL NO.: M 980501

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

ANNEXURE D

SUMMARY

TITLE: PATIENTS WITH PULMONARY TUBERCULOSIS : FACTORS ASSOCIATED WITH TIME OF PRESENTATION TO THE HEALTH SYSTEM.

NAME OF AUTHOR: Mohammed Shamsul Alam

DEGREE: M Fam Med

RESEARCH QUESTION: (Problem & Purpose Delay in presentation in tuberculosis is associated with increased morbidity, mortality and rapid spread. The purpose of this study is to find out factors associated with time of presentation to the health system.

AIM: To find out the factors stated by patients associated with time of presentation to the health system.

OBJECTIVES: To collect demographic data. To find out duration of illness and symptoms. To determine previous medical attention for same problem. To determine the association, if any, between the severity of the disease and the duration of illness. To determine factors stated by patients which influence the time of presentation to the health system.

METHODOLOGY:

a) **Study design:** cross-sectional descriptive type of study.

b) **Setting:** Sizwe Tropical Disease Hospital (previously Rietfontein Hospital) and Hoek Street TB Clinic.

c) **Study population:** The patients with confirmed pulmonary tuberculosis attending the above two sites.

d) **Sampling:** Systematic random sampling.

e) **Sample size:** 100 patients, 50 admitted patients from Sizwe Tropical Disease Hospital and 50 ambulatory patients from Hoek Street TB Clinic.

f) **Measurements:** By structured interview.

g) **Data gathering:** By questionnaire.

ETHICAL CONSIDERATION:

Informed consent.

PROTOCOL

Title : **PATIENTS WITH PULMONARY TUBERCULOSIS : FACTORS ASSOCIATED WITH TIME OF PRESENTATION TO THE HEALTH SYSTEM.**

Name of author : **Mohammed Shamsul Alam**

Supervisor :

A) Literature review:

In 1995, tuberculosis accounted for more than 80% of communicable Disease notifications in South Africa. At least 140 000 new cases were estimated to have occurred in the country in that year. In 1996 there were 160 000 reported cases. Of these, at least 25% were attributable to infection with the human immunodeficiency virus. If these trends continue, 3,5 million new cases of TB will occur in South Africa over the next decade. The overall incidence in 1996, estimated by the Medical Research Council (MRC), was 311 per 100 000, with 80% of these occurring in the 15 - 49 years age group. This confirms tuberculosis as South Africa's number one health problem and South Africa as a country with one of the highest incidence rates in the world. The current cure rate is 50 - 60%. Though we are living in the era of effective chemotherapy.[1]

It is not possible to present exact global data for tuberculosis incidence and mortality. Approximately 1.7 billion people in 1990 (about one third of the world's population) were infected with tuberculosis.[2]

At Sizwe Tropical Disease Hospital (previously Rietfontein Hospital, Johannesburg), deaths from diagnosed tuberculosis between 1996 and 1997 were 30%. 50% of deaths occurred within 19 days and 32% within the first week of admission. Death rates were 16 times higher among patients who

had Hb less than 11.5gm%, body weight less than 50kg and radiologically determined lung involvement more than 40% at presentation.[3]

The mortality and morbidity from childhood tuberculosis is influenced by the delay from the time of first symptoms until the start of and compliance with treatment. The delay in presentation (patient's delay) is shorter than the delay in diagnosis (doctor's delay) in children.[4] This study was done at Tygerberg Hospital, Western Cape Province. Another study was done in adult TB patients in Korea. Patient's delay was 1.8 months. This delay is longer in the rural areas. Doctor's delay was within 2 weeks. Mean total delay (patient's delay plus doctor's delay) was 2 months, with 80% of this being patient's delay.[5]

Mortality from TB is high, even among patients without multidrug resistance who are not infected with HIV. Most HIV seropositive patients with delayed therapy die. Multidrug resistance predicts higher mortality. Treatment completion is associated with improved patient survival.[6] The most common problem is failure to obtain sputum samples for acid-fast smear and mycobacterial culture in patients with HIV infection with clinical and chest radiographic findings compatible with tuberculosis.[7]

Delays in presentation, diagnosis and treatment are the most important causes of rapid spread of tuberculosis. 14% of nurses working in the medical ward at Blantyre Hospital, Malawi developed TB between 1993 and 1994.[8] Delay in diagnosis is the major factor responsible for the spread of TB among co-workers.[9] Inadequate clinical acumen and slow diagnostic tests are the most important factors for delays in the diagnosis of TB.[10] Delayed diagnosis of TB commonly causes serious consequences.[11]

Patients' attitude to tuberculosis is interesting. In Vietnam, TB is considered a 'dirty' disease, which mainly affects poor people. Patients with symptoms of suspected TB avoid to visit doctors unless at advanced stage. There is a tendency to avoid telling others about it. It is considered as a social stigmata.[12] A knowledge of the health culture of patients is a critical tool if tuberculosis control programmes are to be successful.[13] Kleinman coined the term "explanatory model" to describe the way patients give meaning to their illness. Explanatory models provide answers to the following questions for the patients: What has happened? Why has it happened to me? Why now? What should be done about it? What would happen if nothing is done about it? Often by extracting these concerns from the patient, a better idea of etiology and perceived seriousness is obtained.[14]

General physicians play an important role in improving the case-finding process in Mongolia. A study shows, patients who initially consulted general physicians had shorter patient's delays and long doctor's delays than those who visited TB specialized facilities. The reduction of patient's delay outweighs the extension of doctor's delay among patients who initially consult general physicians, their total delay is shorter than that of patients who visit TB specialized centres.[15]

B) Research question (problem and purpose):

As demonstrated in the literature review, delay in presentation in tuberculosis is associated with increased morbidity and high mortality and rapid spread. The purpose of this study is to find out factors associated with time of presentation to the health system, to identify the causes of their inappropriate health seeking behaviour. From an epidemiological point of view it is very important to find out the reasons. The results may contribute to the development of new strategies for tuboculosis presentation. Information from the study may be used by planners to allocate resources efficiently, and may generate hypotheses for further studies.

C) **Aim:** To find out the factors stated by patients associated with time of presentation to the health system.

D) **Research objectives:**

a) To collect demographic data from patients and their files (age, sex, employment, monthly income, family size, accessibility to clinic or doctor, past history of TB, family history of TB).

b) To find out when and how did they know they were sick (duration of illness and symptoms before presentation as well as before diagnosis).

c) To determine previous medical attention for the same problem (whether or not they have attended the nearest clinic, any doctor or traditional healer; treatment received/not received; defaulted/completed treatment; X-rayed/not x-rayed).

d) To determine the association, if any, between clinically determined severity of tuberculosis and the time of presentation to the health system.

e) To determine factors stated by patients which influence the time of presentation to the health system.

E) **Methodology:**

a) Study design : It will be a cross-sectional descriptive type of study. It will describe the information given by the patients with pulmonary tuberculosis. This study will consist of both qualitative and quantitative components.

b) Setting :

1) Sizwe Tropical Disease Hospital (previously Rietfontein Hospital). It is a 500-bed, referral hospital, situated in Johannesburg. Patients are mainly black. The study sample of admitted patients will be selected here.

2) TB Clinic. It is situated at 18 Hoek Street, in the Johannesburg inner-city. It is a day clinic which provides diagnostic and continuing type of health care. Patients are mainly black. This clinic will be used to select the sample of ambulatory patients.

c) Study population: The study population will be the patients with confirmed pulmonary tuberculosis (TB) attending the above two sites. TB Cases are confirmed by tracing acid-fast bacilli in sputum and/or culture. Both admitted and ambulatory patients will be selected for comparison.

d) Sampling : Systematic random sampling will be used for admitted patients. The starting point will be selected at random. Sampling interval will be calculated depending on the number in the population in the hospital beds at the time of the study and the size of the sample,. For example, for a sample size of 50 in a population size of 400 the sampling interval will be 400/50 = 8. This is the best way of sampling for admitted patients as the patient beds are not ordered according to any order or cyclical pattern. (This has been calculated with the assistance of Mrs E Viljoen, MRC Statistician).

The sample of ambulatory patients will be selected in a different way. Most of them may wish to return to work and the processing rate of these patients will vary according to the professional staff employed by the clinic from time to time and patient load, a systematic random sampling of every 10th patient presenting to the clinic will be attempted. The sampling interval may have to be adjusted after the pilot study to ensure the least disruption

to both the patients and the clinical services. Should a patient refuse to participate the next patient in sequence will be chosen.

e) Sample size : If the proportion of patients with severe TB in the hospital is approximately 0.80 and the proportion of severely infected patients attending the TB clinic is approximately 0.25, a sample size of 50 in each group will be sufficient to show statistical significant difference between the two groups. This is based on a 5% level of significance and 90% power.

f) Measurements (instrument) : Measurements will be done by structured interview. The questionnaires will consist of both open and closed ended questions. The patients will be interviewed by the researchers assisted by a trained objective, medically orientated interpreter.

F) **Data analysis :** Data will be analysed using frequency, rates and proportion for categorical variables and means and standard deviation for continuous variables. Groups will be compared using the Fisher's Exact test and Chi square test where appropriate. Qualitative data will be described in the report.

G) **Ethical Considerations :**

The patients will be handed an information letter regarding this study. The letter will be verbally explained who cannot read. Informed consent will be sought and the patient will be assured about anonymity. This study will be submitted to ethics committee of the health science faculty of the University of Witwatersrand.

H) Anticipated problems:

There may be a communication problem. An independent, medically orientated interpreter will be employed.

I) Exclusion criteria : Patients who decline to consent or unable to consent (confused and fatal cases).

J) Data gathering: By questionnaire

CONSENT FORM

(See Annexure A, page 41)

QUESTIONNAIRE

(See Annexure B, page 42)

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