

Sociodemographics

Knowledge

Stigma

Diagnostic and treatment delay in tuberculosis

An in-depth analysis of the health-seeking behaviour of patients and health system response in seven countries of the Eastern Mediterranean Region

Non-specialized care providers

National TB programme

Private sector

Health-seeking behaviour

Health system response



World Health Organization

Regional Office for the Eastern Mediterranean

Diagnostic and treatment delay in tuberculosis

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Preface

Tuberculosis control can be effectively achieved if individuals with the disease receive adequate and timely treatment. The main factors that determine 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. Therefore, the duration of infectiousness of an incident infectious case is of crucial importance with regard to the risk of the general population becoming exposed to such a case.

The proportion of contacts found to be infected at the time of diagnosis of a smear-positive index case is around 30%–40%. If the case were not detected and placed on adequate chemotherapy, a large proportion would remain who would still be susceptible to new infection. Therefore, early case detection and treatment with appropriate antituberculosis drugs reduce the time of infectiousness of this case in the community and hence the number of new individuals exposed and infected.

However, the actual situation is that the national tuberculosis control programmes in the Eastern Mediterranean Region are able to detect on average one third of smear-positive tuberculosis cases, while the rest continue to transmit infection in the community until treated, whether adequately, or inadequately by other health sectors. Analysis of health-seeking behaviour of patients managed by the national control programmes can shed light on those patients that are not detected by their programmes, and provide detailed information on other health care providers' practice and their contribution in increasing the duration of infectivity in the community.

This multicountry study was conducted in order to obtain reliable information about the extent of diagnostic and treatment delay and the factors implicated in the Eastern Mediterranean Region. It is a detailed analysis of the health-seeking behaviour of tuberculosis patients from onset of symptoms until reaching the health system, final diagnosis and treatment. It also provides a thorough analysis of the health system in relation to tuberculosis. The whole duration from onset of symptoms to treatment was categorized, and the factors causing delayed treatment were identified and analysed.

The study was designed and coordinated by the WHO Regional Office for the Eastern Mediterranean. It is envisaged that the information provided by this study could assist health policy-makers in devising suitable interventions in order to increase case detection and reduce transmission of infection in the community, and hence achieve proper tuberculosis control.

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Executive summary

A multi-country study was conducted during 2003–2004 in order to study the extent of delay in the diagnosis and treatment of tuberculosis patients, and its determinants. The study was conducted in seven countries of the WHO Eastern Mediterranean Region: Egypt, Islamic Republic of Iran, Iraq, Pakistan, Somalia, Syrian Arab Republic and Yemen.

In Pakistan, the study was conducted in the city of Karachi. Three chest centres where DOTS had been implemented were chosen as study sites. In Iraq, the study was conducted at the Respiratory and Chest Disease Institute in Baghdad and in three tuberculosis centres in other governorates (Missan, Babylon and Qadissiah). In Somalia, a convenience sample was selected from accessible centres implementing DOTS. In Egypt, Islamic Republic of Iran, Syrian Arab Republic and Yemen, nationwide cross-sectional studies were conducted.

Representative samples of newly diagnosed smear-positive pulmonary tuberculosis cases, 15 years of age and older, diagnosed in the study settings of the seven countries, were consecutively enrolled in the study. The total sample size was 5053 patients, distributed as follows: 802 in Egypt, 800 in Islamic Republic of Iran, 400 in Iraq, 844 in Pakistan, 809 in Somalia, 800 in Syrian Arab Republic, and 598 in Yemen.

Cases were interviewed according to a pre-tested and structured questionnaire including information about sociodemographic characteristics, risk factors of tuberculosis and health-seeking behaviour. The patients were also asked questions regarding the elements that might influence their health-seeking behaviour, such as fear of what would be found on diagnosis, fear of social isolation, stigma, knowledge regarding the disease, satisfaction with care and others.

The results showed that the mean duration of delay between onset of symptoms until treatment with anti-tuberculosis drugs ranged from one month and a half to 4 months in the different countries. The mean delay was 46 days in Iraq, 57 in Egypt, 59.2 in Yemen, 79.5 in Somalia, 80.4 in Syrian Arab Republic, 100 in Pakistan, and 127 in Islamic Republic of Iran.

Detailed analysis of the various factors interplaying to affect the health-seeking behaviour and timely treatment showed that they could be categorized into either patient or health system factors. Patient delay ranged from a mean of 9.9 days in Pakistan to 69 days in Somalia, while system delay ranged from 5 days in Iraq to 75 days in the Islamic Republic of Iran.

The private sector was the first choice for more than two-thirds of patients. The main determinants of delay were: sociodemographic (illiteracy, suburban residence); economic; stigma; time to reach the health facility; seeking care from non-specialized individuals; and visiting more than one health care provider before diagnosis.

In conclusion, an unacceptable delay in the treatment of tuberculosis patients was reported in all countries. This was mainly attributed to late diagnosis within the health system in Pakistan, Egypt, and Islamic Republic of Iran, but also to inadequate health-seeking behaviour of patients in the remaining countries.

1. Introduction

In 1993, the World Health Organization (WHO) declared a state of global emergency for tuberculosis (TB), due to the steady increase of the disease worldwide. In 1995 the DOTS (directly observed treatment, short course) strategy was established as the key intervention to achieve tuberculosis control worldwide. The global targets of this strategy are to achieve 70% case detection and 85% cure rates by 2005. [1] In 2003, DOTS programmes successfully treated 84% of all registered new smear-positive patients, but detected only 28% of the estimated tuberculosis cases in the world [2]. Therefore, the target of 70% case detection might not be reached until 2013, unless interventions are made that are able to increase the case-detection rate.

Early diagnosis and prompt effective therapy form the key elements of the tuberculosis control programme. Delay in diagnosis results in increased infectivity in the community and it is estimated that an untreated smear-positive patient can infect, on average, 10 contacts annually and over 20 during the natural history of the disease until death [3]. Delay in tuberculosis diagnosis may also lead to a more advanced disease state at presentation, which contributes to late sequelae and overall mortality. Smear-positive cases are more likely to infect other individuals.

Of the 22 countries of the Eastern Mediterranean Region of WHO, 9 contribute to 94% of the tuberculosis cases in the Region: Pakistan (43% of tuberculosis cases), Afghanistan (12%), Sudan (8%), Iraq (7%), Islamic Republic of Iran (6%), Somalia (6%), Morocco (5%), Egypt (4%) and Yemen (3%). The low case detection rate in the Eastern Mediterranean Region is chiefly due to the low detection rates in Pakistan and Afghanistan (3% and 9% in 2000, respectively) (Figure 1).

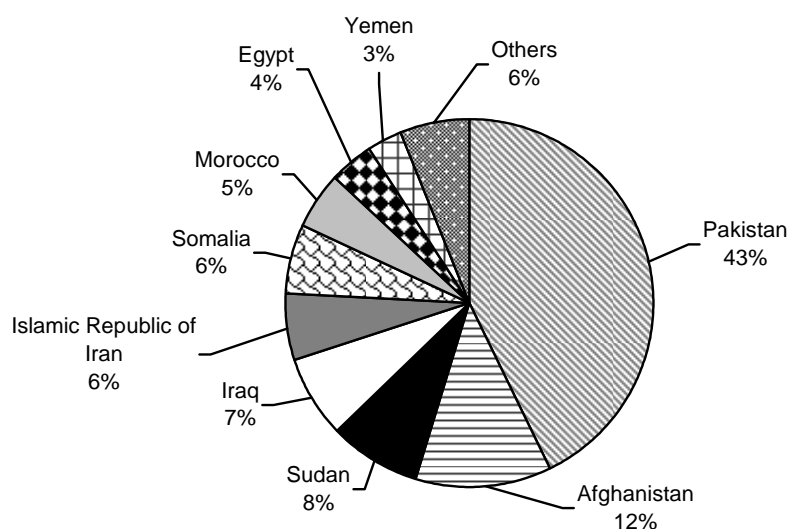


Figure 1. Contributions of the countries to the tuberculosis burden in the Eastern Mediterranean Region

Countries of the Eastern Mediterranean Region can be categorized into three distinct epidemiological categories: countries with estimated incidence of 50 or more tuberculosis patients (all forms) per 100 000 population, consisting of Afghanistan and Pakistan, which are among the 22 high burden countries in the world, and Djibouti, Iraq, Morocco, Somalia, Sudan and Yemen; countries with estimated incidence of 25–49 tuberculosis patients (all forms) per 100 000 population, consisting of Bahrain, Egypt, Islamic Republic of Iran, Kuwait, Saudi Arabia and Syrian Arab Republic; and countries with estimated incidence of 0–24 tuberculosis patients (all forms) per 100 000 population consisting of Jordan, Lebanon, Libyan Arab Jamahiriya, Oman, Tunisia, United Arab Emirates and Palestine [4]. This multicountry study on diagnosis and treatment delay in tuberculosis was conducted in seven high and middle burden countries of the Eastern Mediterranean Region.

Pakistan ranks first among the high burden countries in the Eastern Mediterranean Region, and sixth among high burden countries globally, with an estimated tuberculosis incidence of all forms of 171/100 000 population in 2001 [2]. Although DOTS was initiated in Pakistan in 1995, its expansion did not begin until 2000, when the National Tuberculosis Programme (NTP) was reactivated, which resulted in doubling of the DOTS coverage and DOTS detection rate [5]. Despite the increase in DOTS population coverage, from 24% in 2001 to nearly 63% in 2003, the smear positive case detection rate remained low (17% in 2003) [2]. However, the incremental increase has been high over recent years as it increased from a baseline of just 3% in 2000.

Somalia also has a high tuberculosis burden with an estimated incidence of tuberculosis (all forms) of 352/100 000, a smear positive case detection rate of 32% and a close to the target treatment success rate of 83% in 2001. With 100% DOTS coverage reached at the end of 2001, the smear positive case detection marked a slight increase to reach 37% in 2003 [2, 4].

Iraq is another high burden country with an estimated incidence of TB (all forms) of 129/100 000 and an estimated 30 512 new cases in 2001, of which 13 730 were smear-positive pulmonary tuberculosis [2,4,5]. Of these, only 3559 smear-positive cases were notified. This indicates that approximately 10 171 smear-positive cases were not detected and were free in the community. More importantly, the smear-positive case detection rate has not shown any significant increase over time (21% and 22% in 2000 and 2003, respectively). [2,4,6]

Yemen, with an estimated tuberculosis incidence (all forms) of 105/100 000 is another high burden country. It too achieved suboptimal smear-positive case detection rates of 55%–44% during the same period [2,4].

Egypt, Islamic Republic of Iran, Syrian Arab Republic are middle burden countries that achieved slight increase in the smear-positive case detection rates during the period 2000–2003 (45%–57%; 58%–60%; and 41%–45%, respectively) [2,4].

DOTS coverage has increased in all the health facilities of ministries of health in many countries of the Region since the late 1990s. However, such increased coverage was not coupled with a parallel rise in the case detection rate. Although coverage is crucial to ensure proper disease control, it is not the only factor that would influence timely access of patients to appropriate health services. There is growing evidence that access to treatment remains difficult for a high number of tuberculosis patients. Several factors have been identified as influencing delay in diagnosis and start of 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.

Such delay may occur at the level of the patient (patient delay) or at the level of the health system (system delay). Factors which contribute to patient or system delay are numerous, and it is important to identify and address these factors in order to devise strategies for the national tuberculosis control programme (NTP).

The challenge posed by the low case detection rate in the Region can be addressed by studying the delay in case finding. Understanding the causes behind delay in diagnosis and treatment is essential for all partners involved in tuberculosis control.

Delays in case-finding are common and have been studied in many countries whether developed or developing, low or high prevalence [7–10]. In low prevalence countries, delay is mainly attributed to the fact that tuberculosis is not suspected, or to disintegration of the previous infrastructure for tuberculosis control. In high prevalence countries, delays are often prolonged, and relate to both delays on the side of patients in seeking treatment, and on the side of physicians in diagnosis. Reported determinants of delay include being part of specific patient groups (i.e. women, rural versus urban residents, nationality, etc.) [7], or the availability of and accessibility to health services [8,9,10]. These studies also highlight the association between delay and an increased economic burden and mortality attributed to tuberculosis. Country-specific determinants of delay must be studied, clearly identified and addressed in order to improve the quality and effectiveness of the national tuberculosis control programmes.

The aim of the present study was to evaluate the extent of delay in diagnosis and treatment of tuberculosis patients, identify the major contributors to such delay (whether patient or system) and study its various determinants in seven countries, 4 high and 3 middle burden countries of the WHO Eastern Mediterranean Region. The ultimate goal of the study was to identify barriers interfering with case-finding activities under DOTS and to devise solutions to increase the case detection in the community and by the national tuberculosis control programmes. It is envisaged that the information obtained by this study will assist these programmes in achieving their targets.

2. Materials and methods

A multi-country study was designed and coordinated by the EMRO/TDR Small Grants Scheme for Operational Research in Tropical and Other Communicable Diseases. The study was conducted during the period 2003–2004 in seven countries of the WHO Eastern Mediterranean Region: Egypt, Islamic Republic of Iran, Iraq, Pakistan, Somalia, Syrian Arab Republic and Yemen.

In Pakistan, the study was conducted in the city of Karachi. Three chest centres where DOTS had been implemented were chosen as study sites. The centres were Nazimabad Chest Clinic, Malir Chest Clinic and Ojha Institute of Chest Diseases. In Iraq, the study was conducted at the Respiratory and Chest Disease Institute in Baghdad and in three tuberculosis centres in other governorates (Missan, Babylon and Qadissiah). In Somalia, a convenience sample was selected from accessible centres implementing DOTS in Somalia. The selected centres in southern and central Somalia were: Mercy Mogadishu and Jawhar. In the north, the selected centres were: Hargeisa, Borama and Borao. In Islamic Republic of Iran, Egypt, Syrian Arab Republic, and Yemen, nationwide cross-sectional studies were conducted.

Representative samples of newly diagnosed smear-positive pulmonary tuberculosis cases, 15 years of age and older, diagnosed in the study settings of the seven countries, were consecutively included in the study. Based on the estimated incidence of tuberculosis for each of the countries studied, a maximum allowed error of 10%, and a 95% confidence interval, the least reliable sample size for the seven countries would have been 3097 patients. However, as it was planned to perform multivariate logistic regression analysis, the rule of thumb was used, hence the sample size per country was calculated at 800 study subjects owing to the large number of studied variables. The smaller sample size initially estimated would have affected the study power. Iraq and Yemen could not achieve this big sample size due to the war situation in the first, and difficulties in enrolment of patients in the second. Therefore, the total sample size was 5053 patients, distributed as follows: 802 in Egypt, 800 in Islamic Republic of Iran, 400 in Iraq, 844 in Pakistan, 809 in Somalia, 800 in Syrian Arab Republic, and 598 in Yemen.

In the countries where nationwide surveys were conducted, lists of all smear-positive cases in all the tuberculosis centres were obtained and the patients were randomly selected from the different centres in these countries using the probability proportional-to-size cluster sampling technique. In the other countries, all new pulmonary tuberculosis cases managed in the selected centres were consecutively enrolled until the required sample size was reached from each centre.

Data collection techniques and tools

Questionnaire. Cases were interviewed according to the questionnaire developed for this multi-country study. The questionnaire (Annex 1) was pre-tested and translated into the local language of each country. Health workers, who included doctors and paramedical staff, underwent intense training on interview and probing techniques. They then directly interviewed the patients during the first 2 weeks of their treatment, after obtaining their informed consent.

The questionnaire included information about sociodemographic characteristics, risk factors of tuberculosis and health seeking behaviour. The patients were also asked questions regarding the elements that might influence their health-seeking behaviour, such as fear of what would be found on diagnosis, fear of social isolation, stigma, knowledge regarding the disease, satisfaction with care and others.

Socioeconomic status. The socioeconomic status was measured using a summation score of the following variables: education, occupation and income (0 best and 7 worst).

Stigma. Variables measuring stigma were recorded on a 5-point Likert scale (0 the highest and 4 the lowest degree of stigma). These variables included: feeling ashamed of having tuberculosis; having to

hide tuberculosis diagnosis from others; cost incurred by the long disease duration; isolation due to tuberculosis; whether a girl is able to decide about getting tuberculosis treatment, and the extent to which tuberculosis affects the following: relation with others; work performance; marital relations; family responsibilities; chances of marriage; family relations; female infertility; complications during pregnancy; breastfeeding; and pregnancy outcome.

Satisfaction with care. Variables measuring satisfaction with care were recorded on a 4-point Likert scale (0 best and 3 worst). These included: availability of services in tuberculosis centres; prompt action from primary health care personnel; adequacy of equipment and free medications in these centres; proper coverage of tuberculosis centres in the area; health facility workload and waiting time.

Knowledge. Variables measuring knowledge were recorded on a 3-point Likert scale (0 best and 2 worst). These included: knowledge about the type of disease, its causes, curability, existence of vaccine, type of anti-tuberculosis drugs and duration of treatment.

Definitions (Figure 2)

The total delay is the time interval from the onset of illness until the initiation of anti-tuberculosis drugs. It is the sum of two time intervals: diagnostic delay and treatment delay. These are defined as follows:

- **Diagnostic delay:** time interval between the onset of symptoms and labelling of the patient as a tuberculosis patient (tuberculosis diagnosis).
- **Treatment delay:** time interval between tuberculosis diagnosis and initiation of anti-tuberculosis drugs.

The total delay is also the sum of patient and healthcare system delay since it can be attributed to these types of delay which are defined as follows:

- **Patient delay:** time interval between onset of symptom and presentation to a health care provider
- **Health care system delay:** time interval between the date of health-seeking behaviour at a health care provider and the initiation of anti-tuberculosis treatment.

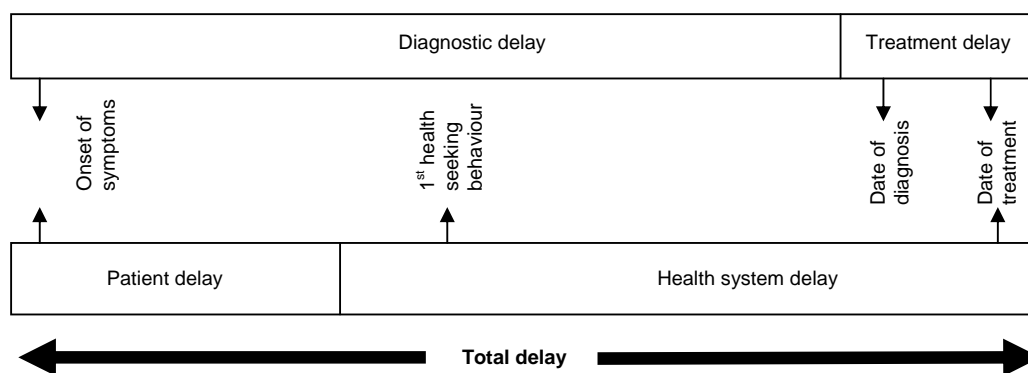


Figure 2. Flow-chart showing different delay durations contributing to the total delay

Pilot study and questionnaire testing

A pilot study was carried out to:

- Test the whole system of communication and supervision.
- Assess the suitability of the study tools (interviews and questionnaire).
- Estimate the required time for filling in the questionnaire and for data collection.
- Assess the performance of the data collectors and quality of training.

The instrument was first tested for content validity to determine if it still measured what it was intended to test. To carry out this procedure it was initially reviewed by experts in WHO's Regional Office for the Eastern Mediterranean and several researchers experienced in this field in order to clarify confusing items, and to comment on the apparent validity of each item. After examination by these individuals, several items were changed. The resulting form was then administered to interviewers who were asked to comment on and to clarify items which were not easily understood. To examine the internal consistency of the items of the questionnaire, Cronbach's alpha was calculated and was found acceptable.

A small number of individuals (30) were interviewed to evaluate the questionnaire's reliability. Test-retest reliability was assessed by giving the questionnaire to the same person twice at an interval of 2 weeks and measuring the intraclass correlation coefficient to evaluate the intrarater reliability. Re-interviewing the same person by two different interviewers and measuring the intraclass correlation coefficient was also performed to measure the interrater reliability. The questionnaire was modified according to the results of the pilot phase and the final form was translated into local languages.

Training of health workers and field supervisors included: discussion of the objectives and importance of the study and orientation about the formats used. Training on data collection, filling the forms, and revising the formats was performed through demonstration and role playing.

Data management and statistical analysis

With regard to scoring system, the score was first reversed before addition to its domain in order to reflect the increase in the studied variable. The mean percentage score for socioeconomic level, stigma, satisfaction with care and knowledge was calculated as follows:

$$(\text{Sum of scores obtained}/\text{maximum scores that could be obtained}) \times 100.$$

Then the mean percentage scores were computed, and the studied variables were expressed as falling between 0 and 100% with the highest percentage reflecting the increase in that characteristic/variable. For example, a 100% of socioeconomic level, knowledge, or satisfaction with care would indicate the best score for these variables and for stigma it would indicate the highest level of stigma experienced.

Cases with longer delays were categorized as "cases", while others with shorter delays were considered as "controls". The cut-off point(s) for "longer" delays were defined according to the median value obtained for each country. The latter was also used to categorize other variables such as stigma, knowledge and satisfaction with care, into adequate/acceptable and inadequate/unacceptable.

Data analysis was performed using the statistical packages *SPSS* for Windows version 11 and *EpiInfo* 2000. Descriptive statistics were used such as frequency, mean and standard deviation, median, minimum and maximum, etc. Comparisons between groups were made using the Chi-square test or Fischer's exact test as appropriate for qualitative/categorical variables, and using the t-test or Mann-Whitney test for quantitative variables. A multivariate regression analysis was performed to adjust for the confounding effect of several identified determinants of diagnostic and treatment delay of tuberculosis patients. Level of significance was determined at 95% (P value <0.05) and all tests were 2-sided.

All countries, except the Islamic Republic of Iran and Iraq, adopted the same variables while studying the determinants of delay. However, the Islamic Republic of Iran used another group of variables that were previously tested in a baseline study conducted in 1995, for comparability purposes. Therefore, analysis was performed separately and using multiple linear regression rather than multivariate logistic regression analysis. Similarly, the Iraqi study was greatly interrupted by the war in the country and was analysed independently using univariate analysis. For these reasons, data from these two countries might be missed in some sections of the results.

Ethical considerations

The proposals were approved by the institutional ethical review committees respective to each country and obtained national endorsement. Feedback about the major findings and recommendations was given to and requested from the managers and health staff.

With regard to informed consent and confidentiality, the following points were thoroughly clarified to all subjects:

- objectives, steps and expected outcome of the research;
- benefits of the research, both benefits to the subject and benefits to others;
- absolute confidentiality of information obtained;
- the right to withdraw from the study at any time without any way affecting his/her current care.

All participants gave their verbal consent voluntarily.

3. Results

3.1 Profile of tuberculosis patients

Sociodemographic characteristics of tuberculosis patients

With the exception of the Islamic Republic of Iran, the majority of patients were 35 years old and younger. Tuberculosis was common in males in Egypt, Iraq, Syrian Arab Republic, Somalia and Republic of Yemen, with a male/female ratio ranging from 1.4 in Yemen to 2.5 in Somalia. By contrast, it was slightly commoner in females in two countries (Islamic Republic of Iran and Pakistan) with a male/female ratio of 0.98 for each.

The proportion of patients who were illiterate/read and write ranged from 34.6% to 75.2% and the unemployment rate ranged from 43% to 74.3%. In Iraq, Islamic Republic of Iran, and Somalia, the majority of patients were living in urban areas, in Egypt and Syrian Arab Republic in rural areas, and in Pakistan in suburban areas. In Yemen, they were equally distributed in urban and rural areas. A limited proportion of patients were divorced, separated or widowed, and being in-debt was reported by a considerable proportion of patients (Table 1).

Frequency of risk factors for tuberculosis among the patients

Smoking, whether current or ex-smoking, was reported by more than half of the patients in Egypt and Syrian Arab Republic, around one-third of patients in the Islamic Republic of Iran, Pakistan and Yemen, and from almost three-quarters of patients in Iraq.

The median number of cigarettes smoked per day ranged from 7.5 in Somalia to 20 in Egypt, Islamic Republic of Iran, Syrian Arab Republic and Yemen, and the median duration of smoking varied from 6 years in Somalia up to 18 in Pakistan.

A positive history of previous exposure to a tuberculosis patient was recorded in 12%–20% of patients in Syrian Arab Republic, Egypt and Yemen, in more than one-third of patients in the Islamic Republic of Iran, almost half of the patients in Somalia, but in 93.4% of patients in Pakistan (Table 2).

Symptoms of patients with tuberculosis

The frequency of various symptoms experienced by tuberculosis patients are presented in Table 3 which shows that cough was the main symptom in almost all patients in the various countries. Cough with or without fever was the main symptom that prompted the patients to seek health care.

Gender differences

Table 4 displays a comparison between male and female patients regarding their socioeconomic status, knowledge and stigma. Females were at a significantly lower socioeconomic status compared to males in all countries, while knowledge was significantly higher in males in Egypt and Somalia but not in other countries. A higher degree of stigma was recorded in females compared to males in all countries but this was only significant in the Syrian Arab Republic. By comparing countries, knowledge was found to be significantly lower and feeling of stigma higher in Pakistan and Iraq.

Table 1. Sociodemographic characteristics of tuberculosis patients

Characteristics	Egypt		Iran, Islamic Republic of		Iraq		Pakistan		Somalia		Syrian Arab Republic		Yemen	
	N = 802 (%)		N = 800 (%)		N = 400 (%)		N = 844 (%)		N = 809 (%)		N = 800 (%)		N = 598 (%)	
Age (years)														
≤15–35	464	(57.9)	289	(36.1)	257	(64.2)	620	(73.5)	456	(67.8)	516	(64.5)	409	(68.5)
>35	338	(42.1)	511	(63.9)	143	(35.8)	224	(26.5)	217	(32.2)	284	(35.5)	189	(31.6)
Sex														
Male	545	(68)	395	(49.4)	26.0	(65.0)	417	(49.4)	577	(71.3)	510	(63.8)	345	(57.7)
Female	257	(32)	405	(50.6)	140	(35.0)	427	(50.6)	232	(28.7)	290	(36.3)	253	(42.3)
M/F ratio	2.1		0.98		1.9		0.98		2.5		1.8		1.4	
Education														
University/higher	32	(4)	94	(11.8)	18	(4.5)	8	(0.9)	39	(4.8)	20	(2.5)	31	(5.2)
Primary–secondary	230	(28.7)	288	(36.1)	198	(49.5)	358	(42.4)	162	(20.0)	503	(62.9)	234	(39.1)
Illiterate/R&W	540	(67.3)	418	(52.1)	184	(46.0)	478	(56.6)	608	(75.2)	277	(34.6)	330	(55.7)
Occupation														
Technical/professional	26	(3.2)	47	(5.9)	49	(12.3)	53	(6.3)	41	(5.1)	33	(4.1)	61	(10.2)
Clerical/workers	400	(49.9)	161	(20.1)	121	(30.3)	127	(15.1)	115	(14.2)	383	(47.9)	141	(23.6)
Students	31	(3.9)	34	(4.3)	25	(6.3)	77	(9.1)	52	(6.4)	31	(3.9)	85	(14.2)
Unemployed/housewife	345	(43)	558	(69.8)	205	(51.3)	586	(69.5)	601	(74.3)	353	(44.1)	311	(52.0)
Residence														
Urban	259	(32.3)	495	(61.9)	298	(74.5)	339	(40.2)	555	(68.6)	275	(34.4)	270	(45.2)
Suburban	94	(11.7)	–		25	(6.3)	464	(55)	151	(18.7)	162	(20.3)	40	(6.7)
Rural	449	(56)	305	(38.1)	71	(17.8)	34	(4)	73	(9.0)	343	(42.9)	275	(46.0)
Homeless					6	(1.5)	7	(0.8)	3	(0.4)	20	(2.5)	13	(2.2)
Marital status														
Married	482	(60.1)	513	(64.1)	226	(56.5)	498	(59)	424	(52.4)	432	(54)	340	(56.9)
Single	274	(34.2)	165	(20.6)	153	(38.3)	323	(38.3)	262	(32.4)	332	(41.5)	217	(36.3)
Divorced/separated	18	(2.2)	10	(1.3)	7	(1.8)	5	(0.6)	102	(12.6)	17	(2.1)	17	(2.8)
Widowed	28	(3.5)	112	(14.0)	14	(3.5)	18		21	(2.6)	19	(2.4)	24	(4.0)
Income														
Savings	37	(4.6)	NA		12	(3.0)	4	(0.5)	58	(7.2)	66	(8.3)	22	(3.7)
Income = expenses	501	(62.5)	–		360	(90.0)	314	(37.2)	559	(69.1)	538	(67.3)	305	(51.0)
In debt	264	(32.9)	–		28	(7.0)	526	(62.3)	192	(23.8)	196	(24.5)	271	(45.3)

HS = high school; R&W = read and write.

Table 2. Frequency of risk factors for tuberculosis among newly diagnosed patients

Characteristics	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Iraq N = 400 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
Smoking							
Never	376 (46.9)	540 (67.5)	102 (25.5)	594 (70.4)	436 (53.9)	396 (49.5)	377 (63.0)
Current	343 (42.8)	179 (22.4)	222 (55.5)	14 (1.7)	23 (2.8)	213 (26.6)	64 (10.7)
Ex-smoking	83 (10.3)	81 (10.1)	76 (19.0)	236 (28)	256 (31.6)	191 (23.9)	157 (26.3)
Daily consumption of cigarettes							
Median	20	20	NA	10	7.5	20	20
Min-max	3-100	(1-80)		(2-23)	(1-40)	(2-90)	(1-80)
Smoking duration (yrs)							
Median	15	13		18	6.0	13	10
Min-max	(1-66)	(1-70)	NA	(1-33)	(1-35)	(1-60)	(1-50)
Previous exposure to tuberculosis patient	135 (16.8)	272 (34.0)	NA	788 (93.4)	397 (49.1)	157 (19.6)	76 (12.2)

Table 3. Symptoms of patients with tuberculosis

Characteristics	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Iraq N = 400 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
Cough	769 (95.9)	642 (80.3)	377 (94.3)	844 (100)	796 (98.5)	786 (98.3)	589 (98.5)
Fever	559 (69.7)	241 (30.2)	348 (87.0)	844 (100)	672 (83.3)	613 (76.6)	476 (86.2)
Loss of weight	448 (55.9)	659 (82.4)	307 (76.3)	843 (99.9)	483 (60.0)	589 (73.6)	319 (68.8)
Haemoptysis	311 (38.8)	554 (69.3)	93 (23.3)	97 (11.5)	263 (32.5)	250 (31.4)	133 (36.6)
Chest pain	297 (37.0)	452 (56.5)	283 (70.8)	777 (92.3)	605 (74.8)	527 (65.9)	330 (82.9)
Other	101 (12.6)	214 (26.8)	25 (6.3)	109 (12.9)	82 (10.1)	38 (4.8)	32 (10.8)

Table 4. Comparison between male and female patients regarding socioeconomic status, knowledge, stigma and satisfaction with care

Variable	Egypt N = 802 mean % score (SD)	Iraq N = 400 mean % score (SD)	Pakistan N = 844 mean % score (SD)	Somalia N = 809 mean % score (SD)	Syrian Arab Republic N = 800 mean % score (SD)	Yemen N = 598 mean % score (SD)
Socioeconomics status						
M	38.95 (18.9)	59.8 (16.9)	24.7 (22.2)	25.8 (22.6)	45.6 (18.4)	38.1 (22.5)
F	16.2 (14.8)	55.3 (18.3)	15.7 (14.97)	16.9 (17.3)	23.7 (15.9)	15.1 (16.2)
P-value	P = 0.00	P = 0.01	P = 0.00	P = 0.00	P = 0.00	P = 0.00
Knowledge						
M	70.8 (21.2)	36.26 (17.42)	46.7 (22.2)	87.5 (12.4)	77.5 (18.8)	62.1 (28.4)
F	65.8 (24.9)	36.5 (18.4)	48.6 (22.5)	84.8 (19.9)	76.9 (18.7)	58.3 (29.6)
P-value	P = 0.003	P = 0.91	P = 0.21	P = 0.02	P = 0.67	P = 0.12
Stigma						
M	48.9 (13.7)	70.4 (17.1)	62.8 (11.4)	56.5 (15.9)	56.3 (15.9)	52.8 (10.9)
F	50.8 (14.4)	71.8 (16.9)	63.5 (11.4)	58.7 (16.7)	59.0 (17.0)	53.2 (9.9)
P-value	P = 0.06	P = 0.48	P = 0.47	P = 0.13	P = 0.02	P = 0.69

Perceived stigma and knowledge related to tuberculosis

Interestingly, both males and females had the same perceptions regarding the social factors which affect patients with tuberculosis in Pakistan. Some 85% to 95% of patients felt ashamed that they had developed tuberculosis and tried to hide the disease. Nearly 90% of patients, both male and females, said that family and marital relations were affected by tuberculosis. More females (96%) than males (90%) said that the chances of a girl getting married were less if she had tuberculosis. Similarly, more females (91%) than males (80.8%) were hesitant to start treatment for a young girl if she had tuberculosis, probably because of the stigma associated with visiting the chest clinic. The majority of males and females (73.8% and 67.8%, respectively) did not agree that tuberculosis would affect female fertility. Social isolation and stigmatization were overall manifest in each gender's perception about tuberculosis as an illness.

In Yemen, Somalia, Syrian Arab Republic and Egypt, around 30%–40% of patients reported feeling ashamed of the diagnosis, and one quarter had to hide the diagnosis. One quarter to 40% of patients agreed that tuberculosis affected social and marital relations, family responsibilities and work performance. A considerable proportion also agreed that tuberculosis was costly because of the long duration of the disease, and that girls were unable to decide on getting treatment on their own.

In Iraq, the degree of stigma was high (89.8%) for most tuberculosis patients. The majority of patients felt ashamed of being a tuberculosis patient, felt they had to hide their disease from society, that the disease affected their relations with others, and preferred to be isolated. They agreed that tuberculosis affected their work performance, their marital relationships and their family responsibilities, and thought that it affected their chances of marriage, their family relationships, might cause sterility and severe complications during pregnancy and affect breastfeeding and labour for mother and infant, and that girls could not take the decision to take tuberculosis medications on their own.

The percentage of patients whose knowledge about the disease in the different countries was correct is shown in Table 5. The source patients gave for their information was mainly friends and relatives and other tuberculosis patients in Iraq, Pakistan, Somalia, and Yemen. By contrast, the media played a significant role in Syrian Arab Republic (51.7%) followed by Egypt (20.3%), where the main source of information was from the health staff of chest facilities (44.8%) (Table 6).

Interestingly, before developing tuberculosis, 86% of the patients in Pakistan had not heard of the disease, irrespective of gender. The media did not play an important role in providing any kind of information about tuberculosis, being cited by only 5.8% of patients. The main source of information about tuberculosis was friends/relatives (44.6%) as well as other tuberculosis patients (51.9%).

Table 5. Correctness of patients' knowledge about tuberculosis

Knowledge items	Egypt	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
	N = 802 (%)	N = 400 (%)	N = 844 (%)	N = 809 (%)	N = 800 (%)	N = 598 (%)
Is tuberculosis hereditary?	32.8	24.8	37.3	96.5	80.2	44.7
Is tuberculosis contagious?	73.4	54.8	38.2	61.7	65.2	75.4
Is tuberculosis curable?	85.5	52.8	61.6	95.6	94.98	76.9
Is there a vaccine for tuberculosis?	39.2	19.5	4.0	95.9	13.4	29.0
Duration of antituberculosis treatment	72.6	30.5	43.7	75.0	69.0	54.4
Types of antituberculosis drugs	67.7	26.8	4.6	83.0	44.4	34.4

Table 6. Source of information about tuberculosis

Source of information	Egypt	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
	N = 802 (%)	N = 400 (%)	N = 844 (%)	N = 809 (%)	N = 800 (%)	N = 598 (%)
Health staff of chest facilities	359 (44.8)	–	–	–	–	–
Newspaper/television/ radio/Ministry of Health campaigns	163 (20.3)	–	49 (5.8)	68 (8.4)	412 (51.7)	131 (23.9)
Educational institutions	30 (3.7)	37 (12.5)	9 (1.1)	54 (6.7)	53 (6.7)	39 (7.1)
Friends/relatives	110 (13.7)	124 (42.1)	377 (44.6)	402 (49.7)	118 (14.8)	149 (27.1)
Tuberculosis patients	107 (13.3)	93 (31.5)	434 (51.9)	86 (10.6)	214 (26.95)	213 (38.8)

3.2 Delay in diagnosing and treating tuberculosis patients

Table 7 shows a comparison between the extent of delay recorded in the different countries and the different types of delay. The mean duration of delay between the onset of symptoms and treatment ranged from 46 days in Iraq to 127 in the Islamic Republic of Iran. The health system was the main contributing factor to delay in the Islamic Republic of Iran, Pakistan and Egypt. The delay was mainly attributed to the patient in the Syrian Arab Republic, Somalia, Yemen and Iraq (Figure 3).

Table 7. Different types of delay for tuberculosis patients in the community and health care facilities

Type of delay	Egypt	Iran, Islamic Republic of	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
	N = 802 (%)	N = 800 (%)	N = 400 (%)	N = 844 (%)	N = 809 (%)	N = 800 (%)	N = 598 (%)
Patient delay (days)							
Mean (SD)	24.3 (37.2)	51 (74.4)	39.96 (20.6)	9.9 (9.4)	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 (days)							
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 (days)							
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	91	58	55	35
Range	0–364	3–728	3–114	21–256	0–786	2–698	0–720
Treatment delay (days)							
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 (days)							
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

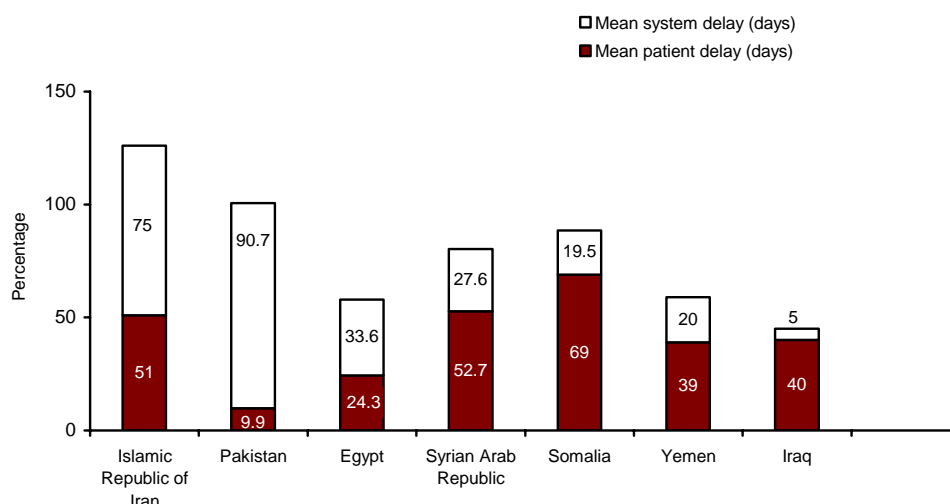


Figure 3. Contribution of patient or health system to the total delay in treatment of tuberculosis patients

3.3 Patient delay

Health-seeking behaviour of tuberculosis patients with onset of symptoms

In Pakistan, nearly 50% of patients practised self-medication immediately after the onset of symptoms or, in 42.2% of cases, consulted the drug store for medication. Only 25 patients went to a health care provider (Table 8, Figure 4). However, the number of patients consulting a health care provider increased to 239 (28.3%) when the symptoms did not subside. As the second action, 33.5% went to a traditional healer, or consulted a drug store (26.2%). Traditional healers continued to play a very important role as 210 patients consulted them, the third time when the symptoms did not subside, but a higher percentage (66.1%) also consulted a health care provider. When symptoms continued to occur, 197 patients continued to seek health care for the fourth time and of them 93 patients consulted a traditional healer.

Table 8. Health-seeking behaviour with the onset of illness

Health-seeking behaviour	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Iraq N = 400 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
First action	N = 802	N = 772	N = 333	N = 844	N = 629	N = 800	N = 591
Health care provider	802 (100)	660 (85.5)	279 (83.8)	25 (3)	419 (66.6)	735 (91.9)	531 (89.9)
Self-medication	62 (7.7)	41 (5.3)	43 (12.98)	422 (50)	53 (8.4)	21 (2.6)	8 (1.4)
Traditional healer	32 (4.0)	8 (1)	5 (1.5)	32 (3.8)	43 (6.8)	7 (0.9)	5 (0.9)
Health worker	–	–	–	9 (1.1)	–	2 (0.3)	34 (5.8)
Drug stores	83 (10.3)	25 (3.2)	6 (1.8)	356 (42.2)	114 (18.1)	35 (4.4)	13 (2.2)
Health house	–	38 (4.9)	–	–	–	–	–

Note. The total does not add up in some situations due to combined actions.

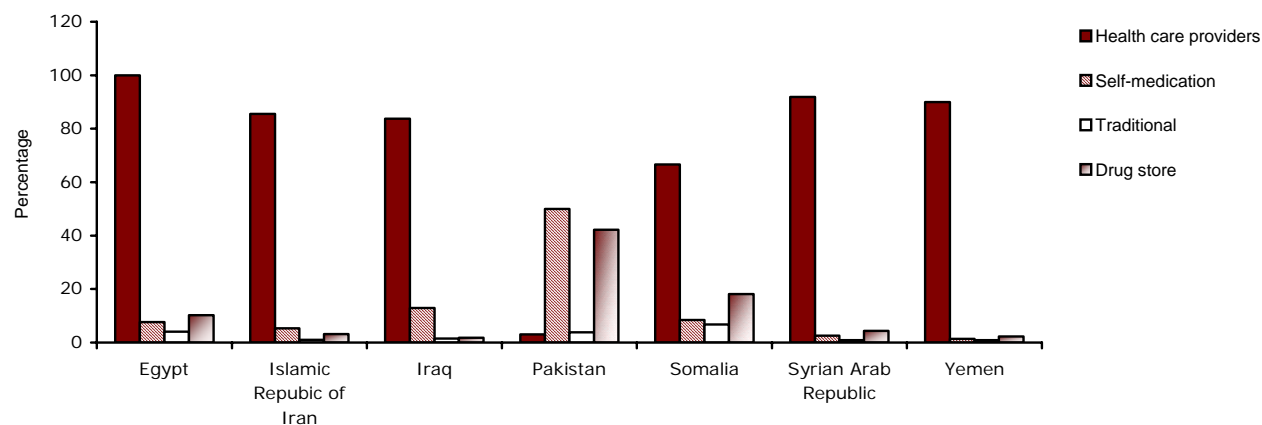


Figure 4. Health-seeking behaviour with the onset of illness

Most patients incurred heavy expenditures before the diagnosis of tuberculosis was made. The median expenditure incurred was US\$ 17.1 with a mean of US\$ 18.6 (± 14.62), some even incurring an expenditure of US\$ 296.

In Egypt, Islamic Republic of Iran, Syrian Arab Republic and Yemen, more than 85% of patients consulted a health care provider with the onset of symptoms. The different types of health-seeking behaviour with the onset of illness are shown in Table 8. The first health care provider consulted belonged to the private sector in almost all patients in Pakistan (96.3% of cases) compared to around two-thirds of patients in Egypt, and three-quarters of patients in Islamic Republic of Iran and Syrian Arab Republic. More than three-quarters of patients initially visited the tuberculosis centre with the onset of symptoms in Somalia and almost one-third in Yemen (Table 9).

Table 9. Health facility of the health care provider from whom patients first sought consultation

Health facility	Egypt <i>N</i> = 802 (%)	Iran, Islamic Republic of <i>N</i> = 800 (%)	Pakistan <i>N</i> = 844 (%)	Somalia <i>N</i> = 809 (%)	Syrian Arab Republic <i>N</i> = 800 (%)	Yemen <i>N</i> = 598 (%)
First action	<i>N</i> = 802	<i>N</i> = 660	<i>N</i> = 844	<i>N</i> = 769	<i>N</i> = 800	<i>N</i> = 580
Tuberculosis centre	89 (11.1)	84 (12.7)	–	586 (76.2)	9 (1.1)	159 (27.4)
Primary health care centre	55 (6.9)	–	14 (1.7)	8 (1.0)	14 (1.8)	10 (1.7)
Chest hospital	61 (7.6)	–	5 (0.6)	4 (0.5)	–	–
Public hospital/ outpatient clinic	43 (5.4)	63 (9.6)	12 (1.4)	25 (3.3)	143 (17.9)	183 (31.6)
Private practice	518 (64.6)	468 (70.9)	813 (96.3)	131 (17.0)	633 (79.1)	186 (32.1)
Health house	–	38 (5.8)	–	–	–	–
Other	36 (4.5)	–	–	15 (2.0)	1 (0.01)	42 (7.3)

Risk factors of patient delay

Delay was mainly attributed to the patient in Iraq, Somalia, Syrian Arab Republic and Yemen. Patient delay in the Syrian Arab Republic was significantly associated with inadequate knowledge regarding tuberculosis (adjusted odds ratio (AOR) = 1.07 (1.01–1.14)), seeking health care from a non-specialized individual at onset of symptoms, such as a traditional healer, (AOR 5.66 (3.02–10.62)), and seeking care from more than one health care provider (AOR 1.20 (1.02–1.40)).

The significant risk factors for patient delay in Somalia were: living in the suburbs and rural areas (AOR = 2.0 (1.2–3.6) and 4.8 (1.5–15.3), respectively, compared to urban areas), and inadequate satisfaction with care (AOR = 1.2 (1.02–1.3)). High degree of stigma was protective (AOR = 0.64 (0.51–0.82)), in that the high degree of stigma attached to tuberculosis by some patients is presumed to have motivated them to seek health care earlier than others.

Results from Yemen showed that the significant risk factors for patient delay were: female sex (AOR 2.03 (1.1–3.6)), and inadequate knowledge regarding the disease (AOR 1.1 (1.04–1.2) for each unit of poor knowledge).

3.4 Health system delay

Physicians consulted by tuberculosis patients

In Pakistan, the first consultation of nearly 90% of tuberculosis patients was with the general practitioner most likely to be practising within the neighbourhood, while 7.7% of patients consulted chest specialists (Table 10). For the majority of patients in Egypt, Somalia, Syrian Arab Republic and Yemen, the health care providers most frequently consulted with the onset of symptoms were chest specialists or internists.

Patients in all seven countries consulted several private health care providers before finally reaching the chest clinic. The number varied from 1 to 17 health care providers. The highest mean number of health care providers visited before diagnosis was recorded in Pakistan (mean = 5 (3.6)), and the lowest in Somalia (mean = 1.2 (0.9)). In the remaining countries, the mean number varied between 1.6 and 1.8 health care providers (Table 11).

Table 10. Health care providers consulted by tuberculosis patients

Health care provider	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Iraq N = 400 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
Chest specialist	210 (35.4)	15 (1.9)	186 (46.5)	65 (7.7)	198 (64.7)	319 (50.0)	95 (34.7)
Internist	174 (29.3)	113 (14.2)	142 (35.5)	12 (1.4)	14 (4.6)	163 (25.7)	104 (38.0)
General practitioner	154 (25.9)	558 (70.2)	72 (18.0)	766 (90.9)	89 (29.1)	122 (29.2)	69 (25.2)
Infectious disease specialist	0 (0)	46 (5.8)	–	0 (0)	0 (0)	0 (0)	0 (0)
Other	56 (9.4)	63 (8.9)	–		5 (1.6)	29 (0.4)	3 (2.2)

Note. Missing cases were excluded.

Table 11. Number of visits to health care provider before the patient reached the tuberculosis clinic/centre

No. of encounters before diagnosis	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
Mean (SD)	1.8 (1.6)	.8 (0.4)	5.2 (3.6)	1.2 (0.9)	1.7 (0.98)	1.6 (0.9)
Median	1.00	2.00	5	1.00	1.00	1.00
Min-max	0–17	1–2	1–12	0–5	0–5	0–6

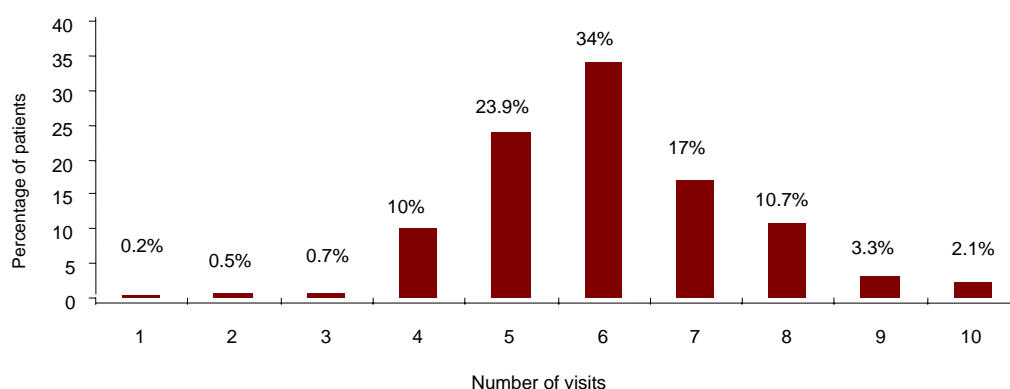


Figure 5. Number of visits of patients to health care providers before being finally diagnosed in Pakistan

In Pakistan, nearly 56% of patients visited four to five health care providers before they reached the chest clinics and only 1.5% of patients consulted two health care providers before they were referred to a tuberculosis clinic.

The number of patient visits to health care providers in Pakistan before final diagnosis is shown in Figure 5, which indicates that about 85% of patients paid 4–7 visits to health care providers before being finally diagnosed.

Tuberculosis diagnosis in the health system

Table 12 shows that the diagnosis was mainly made by chest specialists at the tuberculosis clinics in Pakistan (81.3%) though they were the last ones to be consulted. Internists made the diagnosis in 13% cases while general practitioners could diagnose only 5.7% cases although most of the patients initially consulted a general practitioner.

The majority of patients were diagnosed by chest specialists in Iraq, Syrian Arab Republic and Yemen, in addition to internists in Iraq (35.5%).

On the other hand, the first diagnosis was made by general practitioners in 37% and 42.3% of cases in Islamic Republic of Iran and Somalia, respectively.

Figure 6 displays a comparison between the proportion of patients diagnosed by the NTPs compared to other health care sectors in the studied countries.

Table 12. Specialty of the health care provider who made initial diagnosis of tuberculosis

Health care provider*	Egypt <i>N</i> = 802 (%)	Iran, Islamic Republic of <i>N</i> = 800 (%)	Iraq <i>N</i> = 400 (%)	Pakistan <i>N</i> = 844 (%)	Somalia <i>N</i> = 809 (%)	Syrian Arab Republic <i>N</i> = 800 (%)	Yemen <i>N</i> = 598 (%)
Chest specialist	796 (99.3)	43 (5.4)	186 (46.5)	686 (81.3)	441 (55.5)	45 (68.1)	396 (66.6)
Internist	3 (0.4)	208 (26.0)	142 (35.5)	110 (13.0)	12 (1.5)	164 (20.5)	87 (14.6)
General practitioner	2 (0.2)	295 (36.9)	72 (18.0)	48 (5.7)	336 (42.3)	74 (9.3)	89 (15.0)
Infectious disease specialist	0 (0)	119 (14.9)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Other	1 (0.1)	135 (16.9)	0 (0)	0 (0)	5 (0.6)	17 (2.1)	23 (3.9)

* Affiliated to the NTP or other sectors

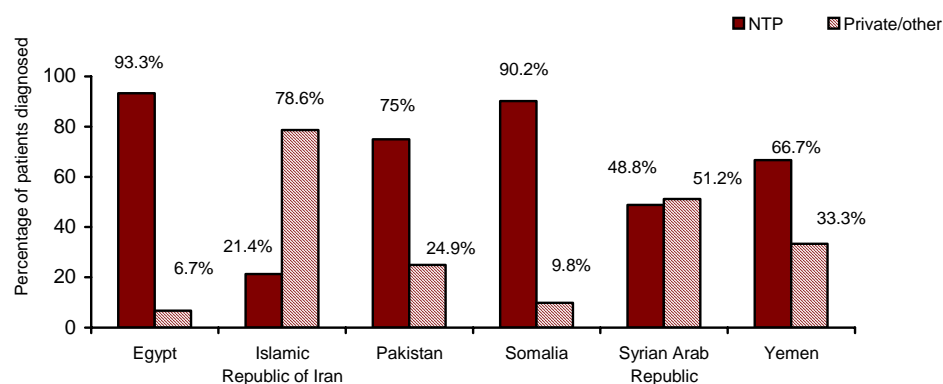


Figure 6. Proportion of patients diagnosed by NTP compared to the private sector

Table 13. Investigations performed for tuberculosis patients

Investigation	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Iraq N = 400 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
Sputum smear examination (only)	29 (3.6)	84 (10.5)	7 (1.8)	14 (1.6)	719 (96.0)	5 (0.6)	134 (23.3)
X-ray (only)	318 (39.7)	45 (5.6)	5 (1.3)	201 (23.8)	9 (1.2)	14 (1.8)	9 (1.6)
Both sputum smear and X-ray	455 (56.7)	450 (56.3)	371 (92.8)	634 (75.1)	18 (2.4)	762 (95.3)	417 (72.6)
Referred to other doctor/hospital	0 (0)	152 (19.0)	17 (4.3)	2 (0.2)	3 (0.4)	19 (2.3)	4 (2.4)
Blood (CBC)	0 (0)	152 (19.0)	0 (0)	149 (17.6)	0 (0)	0 (0)	0 (0)
Other	0 (0)	0 (0)	0 (0)	89 (10.1)	0 (0)	0 (0)	0 (0)

The majority of patients were diagnosed by both sputum smear examination and X-ray (56.7% of patients in Egypt and Islamic Republic of Iran, around three-quarters of patients in Pakistan and Yemen, but up to 92.8% and 95.3% in Iraq and Syrian Arab Republic, respectively). A small proportion of patients were diagnosed by sputum smear examination only except in Somalia where almost all patients are diagnosed by sputum smear examination (Table 13).

Health system factors associated with delay

Satisfaction with care

Reasons for first consultation with health services

Health services were consulted chiefly because the clinics were located close to the patients' residence (61% of patients in Pakistan, 53% in Iraq, 30%–32% in Egypt, Somalia, and Yemen, respectively, and 22% in Syrian Arab Republic). The second reason mentioned was confidence in getting cured (28%–32% in the various countries). The third reason given was advice by friends or relatives in 13%–30% of cases in the various countries. Other reasons were referral by other health services, availability of services and free services in these facilities.

Table 14. Comparison between male and female patients regarding their satisfaction with care

Satisfaction with care	Egypt	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
	<i>N</i> = 802 mean % score (SD)	<i>N</i> = 400 mean % score (SD)	<i>N</i> = 844 mean % score (SD)	<i>N</i> = 809 mean % score (SD)	<i>N</i> = 800 mean % score (SD)	<i>N</i> = 598 mean % score (SD)
M	88.9 (14.1)	76.5 (12.5)	45.7 (8.96)	68.8 (20.6)	94.8 (12.4)	54.1 (27.8)
F	87.9 (14.3)	74.97 (15.4)	46.4 (9.2)	69.5 (20.5)	96.03 (9.1)	51.2 (26.6)
<i>P</i> -value	<i>P</i> = 0.36	<i>P</i> = 0.28	<i>P</i> = 0.28	<i>P</i> = 0.63	<i>P</i> = 0.13	<i>P</i> = 0.21

Reasons for not consulting tuberculosis clinic/centre as an initial consultation

The reason why patients did not initially consult a tuberculosis clinic as the first health-seeking behaviour was either because it was too far from their houses (54.7% in Pakistan, compared to a range of 16.2%–30% in the other countries) or because they felt the tuberculosis clinic was too crowded or they would have to wait for a long time in the queue (37.8% in Pakistan, compared to 9.4%–30% in the other countries). A previous bad experience was mentioned by a limited proportion of patients.

Satisfaction with care delivered at the health facility providing treatment

Table 14 shows that there were no significant differences between both sexes regarding satisfaction with care delivered in the health facility providing treatment. By comparing countries, satisfaction with care was significantly lower in Pakistan and Yemen compared to the other countries.

Accessibility of patients to the tuberculosis clinics/centres

The accessibility of patients to tuberculosis health services also varied greatly across the different countries. In Islamic Republic of Iran and Syrian Arab Republic, around 90% of patients were living within half an hour of a health facility compared to around half of patients in Egypt, Somalia and Yemen. In contrast, almost two-thirds of patients were living more than one hour from a health facility in Iraq, and three-quarters of patients were within reach of a health facility within one-half to one hour in Pakistan (Table 15). A tuberculosis clinic was located within 6–10 km for 44% of patients in Pakistan, while 27.7% patients had to travel a distance of 11–20 km before reaching a tuberculosis clinic. In some cases, the nearest tuberculosis clinic was as far as 30 km away, or more (5%) (Table 16).

Table 15. Time taken to reach a tuberculosis clinic/centre

Time to reach	Egypt	Iran, Islamic Republic of	Iraq	Pakistan	Somalia	Syrian Arab Republic	Yemen
	<i>N</i> = 802 (%)	<i>N</i> = 800 (%)	<i>N</i> = 400 (%)	<i>N</i> = 844 (%)	<i>N</i> = 809 (%)	<i>N</i> = 800 (%)	<i>N</i> = 598 (%)
<1/2 hour	448 (55.9)	722 (90.2)	121 (30.3)	211 (25)	463 (58.0)	722 (90.3)	304 (50.8)
½–1 hour	260 (32.4)	52 (6.5)	33 (8.3)	604 (71.6)	163 (20.4)	50 (6.3)	179 (29.9)
>1 hour	94 (11.7)	26 (3.3)	246 (61.5)	29 (3.4)	172 (21.6)	28 (3.5)	115 (19.2)

Table 16. Distance to a tuberculosis clinic/centre for patients in Pakistan

Distance	No. of patients	(%)
1 to 5 km	132	(15.7)
6 to 10 km	373	(44.4)
11 to 20 km	233	(27.70)
21 to 30 km	14	(1.70)
>30 km	46	(5.50)
Don't know	46	(5.50)

Role of health system in raising community awareness about the disease

Patients were asked why they reached a tuberculosis clinic late or why the treatment of tuberculosis was initiated after the delay. In Pakistan, fear of being diagnosed with tuberculosis was evident in causing a delay in reaching chest clinics for 37.9% of patients in Pakistan. Fear of social isolation if diagnosed with tuberculosis was expressed by 18.1% of patients, indicating the stigma attached to the disease. The fatalistic attitude of patients was expressed by the fact that 60.5% patients felt that the illness would cure itself. This is also an indirect indicator of fear of being diagnosed with tuberculosis and the cultural isolation associated with it. Financial issues creating a delay in accessing health facility were the reason given by 16% patients.

The main reason for delay differed in other countries, for example, in Egypt, Syrian Arab Republic, Yemen and Somalia, it was the hope that symptoms would disappear without treatment. Other reasons were economic constraint, fear of diagnosis and social isolation (stigma) and perceived poor quality of health services or inadequate staff attitude.

Risk factors of health system delay

Delay was mainly attributed to the health system in Egypt, Islamic Republic of Iran, and Pakistan. In the Islamic Republic of Iran, the significant risk factors for health care system delay were: older age (AOR 1.001 (1.003–1.007) per year), obtaining a negative smear result for acid-fast bacilli (AOR 3.3 (2.94–3.66)), positive history of chronic pulmonary disease (AOR = 1.3 (1.2–1.5)), and seeking initial care from the private sector (AOR = 1.2 (1.1–1.3)). Being subjected to a sputum smear examination or chest X-ray and presentation with cough on first attendance at a health facility were all protective factors.

In Pakistan, patients who were referred earlier to a tuberculosis centre had a shorter time period between first consultation with a health care provider and diagnosis (mean health care system delay = 95.6 days) with a minimum of 21 days. The diagnosis in these cases was made by the tuberculosis centre. In cases where private practitioners made the initial diagnosis a longer time period of diagnostic delay elapsed (mean 101 days) with a minimum of 32 days.

A significant difference was seen in initiation of treatment after diagnosis between private health care providers and tuberculosis centres. When a patient was diagnosed by a tuberculosis centre a median of 2 days and mean of 33 days was seen between diagnosis and initiation of treatment. However when private practitioners diagnosed a case of tuberculosis they took a very long time to initiate treatment (median 10 days; mean 98 days).

The significant risk factors for health care system delay in Egypt were: time to reach health facility of more than half an hour (AOR 1.45 (1.00–2.11)), high cost of medical services (AOR 1.0 (1.00–1.01) per pound), seeking care at non-specialized health facility (non-NTP) (AOR 1.89 (1.2–2.9)), and more than one health care encounter before diagnosis (AOR 6.87 (4.8–9.9) per encounter).

3.5 Risk factors of total delay

The duration of delay was significantly longer in patients treated in the private sector compared to those treated by the NTP health services in all countries except Somalia and Syrian Arab Republic, where the duration of delay in the private sector was longer but was not significant. (Table 17).

Table 18 shows the predictors/risk factors for total delay in Egypt, Pakistan, Somalia, Syrian Arab Republic and Yemen. The significant predictors/risk factors for total delay in Egypt were: being illiterate (2.76 fold increased risk); time to reach health facility >1/2 hour and > 1 hour (1.73 and 1.75 fold increased risk compared to those ≤1/2 hour); high crowding index (1.2 fold); and more than one health care provider before diagnosis (2.55 fold increased risk). Being female or a student was protective in motivating patients to seek health care earlier than others.

Table 17. Difference observed in total delay between private health care providers and NTP in the studied countries

Health facility	Egypt N = 802 (%)	Iran, Islamic Republic of N = 800 (%)	Pakistan N = 844 (%)	Somalia N = 809 (%)	Syrian Arab Republic N = 800 (%)	Yemen N = 598 (%)
NTP	47.6 (47.1)	113.8 (111.5)	99.02 (34.7)	79.7 (67.5)	67.0 (53.1)	50.5 (55.1)
Private HCP	60.3 (53.3)	134.7 (115.0)	110.8 (34.2)	84.1 (100.6)	86.0 (97.3)	63.1 (67.9)
P-value*	P = 0.00	P = 0.00	P = 00	P = 0.91	P = 0.32	P = 0.01

*Z test

Table 18. Risk factors for total delay among tuberculosis patients

Risk factor	Egypt	Pakistan	Somalia	Syrian Arab Republic	Yemen
Adjusted OR and 95%CI					
Age					
≤35 years ^a	1		1	1	1
>35 years	1.01 (0.99–1.02)	0.997 (0.98–1.01) ^b	1.002 (0.98–1.02)	1.02 (1.00–1.04) ^c	1.003 (0.98–1.02)
Sex					
Male ^a		1			
Female	0.62 (0.39–0.99) ^c	1.03 (0.71–1.51)	0.95 (0.57–1.60)	1.01 (0.65–1.57)	2.29 (1.26–4.14) ^c
Education					
University ^a		1	1	1	1
Primary–secondary	2.45 (0.94–6.34)	2.38 (0.45–12.42)	0.23 (0.02–2.50)	1.06 (0.37–3.03)	0.77 (0.28–2.14)
Illiterate	2.76 (1.03–7.40) ^c	2.61 (0.49–13.91)	0.38 (0.04–4.16)	0.96 (0.32–2.91)	0.91 (0.32–2.60)
Occupation					
Technical ^a			1	1	1
Clerical/worker	0.41 (0.16–1.09)	0.41 (0.19–0.89)	0.44 (0.07–2.59)	1.29 (0.56–2.99)	0.77 (0.34–1.74)
Student	0.27 (0.08–0.94) ^c	0.71 (0.29–1.73)	0.73 (0.096–5.59)	1.47 (0.47–4.61)	0.87 (0.37–2.07)
Unemployed/housewife	0.60 (0.22–1.60)	0.52 (0.25–1.06)	1.96 (0.45–8.58)	1.42 (0.59–3.42)	1.44 (0.62–3.35)
Residence					
Urban ^a		1	1	1	1
Suburb	1.13 (0.67–1.90)	2.47 (1.68–3.61) ^c	2.16 (1.21–3.86) ^c	0.84 (0.53–1.35)	0.58 (0.21–1.60)
Rural	0.73 (0.51–1.05)	0.84 (0.31–2.30)	2.73 (0.91–8.19)	0.92 (0.63–1.35)	1.03 (0.62–1.72)
Homeless				1.36 (0.45–4.13)	4.98 (0.86–28.77)
Income					
Savings ^a		1	1	1	1
Income = expenses	1.08 (0.51–2.30)	0.32 (0.02–4.81)	1.49 (0.38–5.84)	0.45 (0.25–0.80) ^c	0.97 (0.30–3.11)
In debt	1.16 (0.53–2.56)	0.57 (0.04–8.41)	3.59 (0.79–16.29)	0.39 (0.20–0.74) ^c	1.18 (0.36–3.85)
			0.84 (0.02–31.69)		
Marital status					
Married ^a		1	1	1	1
Single	0.93 (0.61–1.42)	1.28 (0.63–2.60)	0.94 (0.52–1.69)	1.04 (0.69–1.58)	1.03 (0.62–1.74)
Separated/divorced	1.80 (0.62–5.18)	7.74 (0.53–113.86)	0.89 (0.46–1.71)	1.39 (0.60–3.19)	0.31 (0.11–0.90)
Widowed	1.07 (0.45–2.57)	2.47 (0.75–8.13)	0.20 (0.01–3.58)		
Crowding index*					
≤52 ^a	1		1		1
>52	1.19 (1.03–1.37) ^c	0.99 (0.92–1.09) ^b	1.09 (0.95–1.24)	1.10 (0.99–1.22) ^b	1.25 (0.82–1.91)
Time to reach health facility					
≤½ hour ^a	1	1	1	1	1
½–1 hour	1.73 (1.23–2.41) ^c	0.58 (0.39–0.87)	0.71 (0.37–1.38)	2.51 (1.27–4.98) ^c	1.79 (1.09–2.94) ^c
>1 hour	1.75 (1.06–2.88) ^c	0.90 (0.31–2.67)	0.57 (0.25–1.26)	1.34 (0.54–3.27)	1.44 (0.76–2.73)
Expenses					
Low cost ^a					
High cost	1.00 (1.001–1.00)	0.44 (0.22–0.88) ^c	1.004 (0.995–1.01)	–	1.00 (1.00–1.00)

Risk factor	Egypt	Pakistan	Somalia Adjusted OR and 95%CI	Syrian Arab Republic	Yemen
First health-seeking behaviour before diagnosis					
Health care provider ^a	1		1	1	1
Other	1.37 (0.78–2.40)	1.35 (0.53–3.46)	2.17 (1.21–3.90) ^c	3.56 (1.91–6.64) ^c	1.52 (0.73–3.17)
Health facility first consulted					
NTP ^a	1	–	1	1	1
Other	1.09 (0.75–1.58)		1.17 (0.53–2.61)	1.21 (0.44–3.38) 1.25 (0.49–3.21)	1.31 (0.78–2.21)
Health facility that made initial diagnosis					
NTP ^a	1			1	1
Other	0.80 (0.43–1.46)	4.01 (2.64–6.095) ^c	0.34 (0.12–0.94)	1.01(0.62–1.65) 1.01(0.70–1.45)	0.78 (0.48–1.26)
No. of health care encounters					
0–1 ^a			1	1	1
>1	2.55 (1.83–3.57) ^c	2.03 (1.77–2.33) ^{b,c}	1.50 (1.04–2.17) ^c	2.04 (1.68–2.47) ^c	1.39 (0.85–2.25)
Satisfaction with care^d					
Adequate (≤0.68) ^a	1	1	1	1	1
Inadequate	1.02 (0.94–1.10)	1.15 (1.02–1.30) ^c	1.14 (0.999–1.29)	0.96 (0.86–1.06)	1.04 (0.98–1.10)
Stigma^d					
Low degree (≤3.44) ^b	1	1	1	1	1
High degree	1.09 (0.93–1.29)	1.11 (0.75–1.65)	0.62 (0.48–0.79) ^c	1.17 (1.01–1.37) ^c	1.72 (1.24–2.37) ^c
Knowledge^d					
Good (≤4.08) ^a	1	1	1	1	1
Poor	0.998 (0.95–1.05)	1.13 (1.07–1.19) ^c	0.92 (0.82–1.04)	1.06 (0.998–1.13)	1.09 (1.04–1.16)

^a Reference category, ^b Introduced in the model as quantitative variable, ^c $P < 0.05$, ^d Median cut-off

In Pakistan, the significant risk factors for total delay were: living in suburbs (2.5 fold increased risk, as compared with living in urban area); belief that low cost services were inadequate, hence reluctance to seek care from public services; being diagnosed in health facilities not belonging to the NTP (4 fold increased risk); visiting several health care providers before diagnosis (2 fold increased risk for each encounter); inadequate knowledge regarding the disease (1.13 fold increased risk); and poor satisfaction with care (1.15 fold).

In Somalia, the significant risk factors for total delay were: living in suburbs (2.2 fold increased risk compared to urban areas); seeking care from non-specialized individuals (2.2 fold increased risk compared to health care provider); and more than one health care encounter before diagnosis (1.5 fold increased risk). High degree of stigma was protective.

The significant risk factors for total delay in the Syrian Arab Republic were: age older than 35 years (1.02 fold); living far from the health facility (2.5 fold increased risk); high degree of stigma (1.2 fold increased risk), seeking care from non-specialized individuals (not a health care provider) (3.6 fold increased risk compared to health care provider); and more than one health care encounter before diagnosis (2.0 fold increased risk).

The significant risk factors for total delay in Yemen were: being female (2.3 fold increased risk); time to reach the health facility >1/2 hour (1.8 increased fold); and high degree of stigma (1.7 fold increased risk).

The significant risk factors for total delay in Islamic Republic of Iran were: age older than 35 years (1.01 fold increased risk), economic constraint (1.3 fold), non-Iranian nationality (1.3 increased risk); number of symptoms at first attendance (1.12 fold); positive history of chronic pulmonary disease (1.3 fold increased risk); and having negative sputum smear results for acid fast bacilli on entering the health system (1.6 fold increased risk). Fever as the first symptom, presenting with cough at the first attendance to the health facility, performance of sputum smear or chest X-ray examination on first attendance at the health facility, and high tuberculosis notification rate in the governorate, were associated with reduced risk for total delay (Table 19).

Table 19. Risk factors for total delay among new sputum smear-positive pulmonary tuberculosis patients in Islamic Republic of Iran (multiple linear regression analysis)

Risk factor	β coefficient	(95% confidence interval)	P value
Constant	59.086	(50.149–69.616)	<0.001
Female	1.005	(0.950–1.064)	0.998
Age	1.006	(1.005–1.007)	<0.001
Chest X-ray at 1st attendance	-1.337	(-1.459–(-1.226))	0.001
Number of symptoms at 1st attendance at a health facility	1.115	(1.093–1.137)	<0.001
Having at least a negative smear for acid-fast bacilli	1.627	(1.479–1.789)	<0.001
Taking sputum smear at 1st attendance at a health facility	-1.386	(-1.503–(-1.278))	<0.001
Cough at 1st attendance at a health facility	-1.378	(-1.531–(-1.241))	0.002
High tuberculosis notification rate in region	-1.178	(-1.248–(-1.111))	0.005
Economic constraints	1.349	(1.214–1.500)	0.005
Non-Iranian nationality	1.254	(1.162–1.353)	0.003
Fever at 1st attendance at a health facility	-1.202	(-1.282–(-1.126))	0.005
History of chronic pulmonary disease	1.287	(1.159–1.430)	0.016

In Iraq, the significant risk factors for total delay (according to univariate analysis) were: age older than >35 years (1.66 fold increased risk); suburban and rural residence (3.0 and 1.8 fold increased risks, respectively); overcrowded houses (1.6 fold increased risk); smoking (2.3 and 2.2 fold for current and ex-smokers, respectively); self-medication with onset of illness (2.5 fold increased risk); initially diagnosed by general practitioner rather than chest specialists (2.1 fold); inadequate satisfaction with care (10.5 fold increased risk); high degree of stigma (2.1 fold increased risk); and poor knowledge regarding the disease (1.7 fold). Living far from the health facility, lower educational levels, and co-existent diabetes mellitus were protective factors (Table 20).

Table 20. Risk factors for total delay of patients with tuberculosis in Iraq (univariate analysis)

	≤ Median		> Median		OR and 95% confidence interval
	No.	%	No.	%	
Age					
≤35 years ^a	140	54.5	117	45.5	1
>35 years	60	41.9	83	58.1	1.66 (1.07–2.56) ^b
Sex					
Male ^a	131	50.4	129	49.6	1
Female	69	49.3	71	50.7	1.04 (0.68–1.61)
Residency					
Urban ^a	161	54.0	137	46.0	1
Suburban	7	28.0	18	72.0	3.02 (1.16–8.79) ^c
Rural	28	39.4	43	60.6	1.80 (1.03–3.18) ^c
Homeless	4	66.7	2	33.3	0.59 (0.05–4.18)
Education					
University ^a	4	22.2	14	77.8	1
Primary-secondary	103	52.0	95	48.0	0.26 (0.06–0.88) ^b
Illiterate	93	50.5	91	49.5	0.28 (0.07–0.94) ^b
Occupation					
Technical ^a	23	46.9	26	53.1	1
Clerical/worker	64	52.9	57	47.1	0.79 (0.38–1.62)
Students	13	52.0	12	48.0	0.82 (0.28–2.39)
Unemployed/housewife	100	48.8	105	51.2	0.93 (0.47–1.82)
Crowding index					
≤3 ^a	119	55.3	96	44.7	1
>3	81	43.8	104	56.2	1.59 (1.05–2.41) ^b
Income					
Saving ^a	6	50.0	6	50.0	1
Income = expenses	185	51.4	175	48.6	0.95 (0.25–3.61)
In debt	9	32.1	19	67.9	2.11 (0.42–10.40)
Marital status					
Married ^a	117	51.8	109	48.2	1
Single	75	49.0	78	51.0	1.12 (0.72–1.72)
Separated/divorced	3	42.9	4	57.1	1.43 (0.24–9.98)
Widowed	5	35.7	9	64.3	1.93 (0.56–7.56)
Smoking					
Non-smoker ^a	66	64.7	36	35.3	1
Smoker	99	44.6	123	55.4	2.28 (1.37–3.82) ^b
Former smoker	35	46.1	41	53.9	2.15 (1.12–4.12) ^b
Medical diseases					
No medical diseases ^a	156	47.4	173	52.6	1
Asthma	12	70.6	5	29.4	0.38 (0.10–1.18)
Diabetes mellitus	28	66.7	14	33.3	0.45 (0.21–0.93) ^c
Ischaemic heart disease	4	33.3	8	66.7	1.80 (0.47–8.33)
Time to reach health facility					
<1/2 hour ^a	41	33.9	80	66.1	1
1/2–1 hour	15	45.5	18	54.5	0.61 (0.26–1.46)
>1 hour	144	58.5	102	41.5	0.36 (0.22–0.58) ^b
First health-seeking behaviour before diagnosis					
Health care provider ^a	138	49.5	141	50.5	1
Self	12	27.9	31	72.1	2.53 (1.20–5.62) ^b
Traditional healer	2	40.0	3	60.0	1.47 (0.17–17.80)
Health care worker	2	40.0	3	60.0	1.47 (0.17–17.80)
Pharmacist	2	33.3	4	66.7	1.96 (0.27–21.92)
Specialty of health care provider that made initial diagnosis					
Chest physician ^a	100	53.8	86	46.2	1
Internist	70	49.3	72	50.7	1.20 (0.75–1.90) ^b
General practitioner	26	36.1	46	63.9	2.06 (1.14–3.77) ^b
Expenses					
Free ^a	37	51.4	35	48.6	1
High cost	163	49.7	165	50.3	1.07 (0.62–1.84)
Satisfaction with care					
Adequate (≤ median) ^a	199	51.2	190	48.8	1
Inadequate (> median)	1	9.1	10	90.9	10.47 (1.46–456.76) ^b
Stigma					
Low degree (≤ median) ^a	27	65.8	14	34.2	1
High degree (> median)	173	84.2	186	51.8	2.07 (1.01–4.42) ^b
Knowledge					
Good (> median) ^a	69	58.9	48	41.1	1
Poor (≤ median)	131	46.3	152	53.7	1.67 (1.05–2.65) ^b

^a Reference category, ^b $P < 0.05$, ^c Median cut-off

4. Discussion

This study reported the unacceptably long delay duration between onsets of symptoms till treatment with anti-tuberculosis drugs. This duration ranged, on average, from one month and a half to 4 month in the different countries during which the diseased person is transmitting infection in the community.

Detailed analysis of the various factors interplaying to affect the health seeking behaviour and timely treatment showed that they could be categorized into either patient or health system factors. The former being the major contributor to delay in Somalia, Syria, Iraq and Yemen, and the later in the remaining countries.

As the socioeconomic indicators are strong determinants of the health seeking behaviour of the patients which is, in turn, the main determinant of patient delay, their in-depth analysis was crucial to provide detailed information about the situation. Such analysis showed that tuberculosis patients are a disadvantaged group in their communities. The illiteracy rates reported were significantly higher than those of the general population in most of these countries, as follows: Egypt (67.3% versus 30% in the general population); Islamic Republic of Iran (52.1% versus 6%); Iraq (46% versus 44%); Pakistan (56.6% versus 47%); Somalia (75.2% versus 65%); Syrian Arab Republic (34.6% versus 14%); Yemen (55.7% versus 53%) [11].

Similarly, the unemployment rate ranged from 43% in Egypt up to 74.3% in Somalia compared to a range of 3%–12% recorded for the general population in the studied countries, except Iraq which recorded a high unemployment rate of 50%, mainly attributed to the war situation [11].

More than one quarter of patients reported being in debt. This known association between poverty and tuberculosis has been well documented and tuberculosis has been labelled as a “disease of poverty.” Hence poverty reduction, one of the United Nation’s millennium development goals, would contribute to reduction of the tuberculosis burden in endemic countries. [12,13]

In all the countries studied, females were of significantly lower socioeconomic status compared to males. However, their knowledge regarding the disease was not significantly different from males, except in Egypt and Yemen. Gender did not seem to affect knowledge and attitudes of tuberculosis patients, in line with what has been previously reported from the Region [14]. Females experienced a significantly higher level of stigma regarding tuberculosis in Syrian Arab Republic and Yemen, but their level of satisfaction with care was not significantly different from males in all the seven countries. Such gender differences in regard to stigma and satisfaction with care are consistent with reports from other developing countries [15].

Across the countries, there were significant differences in socioeconomic status, feeling of stigma, knowledge and satisfaction with care, but detailed comparison was considered outside the scope of this study.

Health-seeking behaviour of tuberculosis patients

Cough followed by fever were the main symptoms reported by tuberculosis patients and which prompted them to seek health care. Other symptoms were reported less frequently, such as weight loss, haemoptysis and chest pain. These findings are consistent with reports from India where 98% of tuberculosis patients presented with cough while 61% of patients in Malawi presented with cough and 16% with fever [16,17]. By contrast weight loss was the most frequent symptom reported from Islamic Republic of Iran followed by cough. It is worth mentioning that tuberculosis is initially suspected by the cough symptom. It might be that more ‘missed’ cases occur among those who present with other symptoms.

With the onset of symptoms, patients initially practised self medication, visited traditional healers, or resorted to non-prescribed medications from pharmacies. Meanwhile, they would also seek care at a

health care provider. These different actions varied across countries where the proportion of patients seeking care from a health care provider ranged between 66.6% and 100% in all countries except Pakistan where the situation was completely reversed and only 3% of patients first consulted a health care provider. However, the health care provider consulted were mainly private practitioners in all countries except Somalia, where patients mainly sought care at the tuberculosis centres due to the limited number of private practitioners and high cost of consultations. Within the private sector, general practitioners were consulted by the majority of patients in Pakistan and Islamic Republic of Iran (90% and 70.2%, respectively). Two-thirds of patients in Somalia visited chest specialists, mainly at the tuberculosis centres, while in the remaining countries, the majority of patients visited private chest specialists or internists.

Patients visited on average 1.2–1.8 health care providers before being finally diagnosed, mainly by chest specialists within the National Tuberculosis Control Programme. In Pakistan, the mean number of health care providers visited before diagnosis, was significantly higher than other countries. Education and collaboration with private health care providers in all countries is therefore essential to reduce enrolment delays in DOTS programmes. The free services of the DOTS programmes should be made more widely known to the community.

Most patients acknowledged accessibility of private practitioners and greater confidence in being cured as the main reasons for seeking initial care from the private sector compared to their lack of confidence in the quality of services in the public sector. More than 90% of patients in Islamic Republic of Iran and Syrian Arab Republic lived less than half an hour away from a tuberculosis centre, while the majority of patients in Iraq and Pakistan lived more than half an hour away from a tuberculosis centre.

Stigma proved to be a major determinant of health-seeking behaviour, where fear of being diagnosed with tuberculosis and fear of social isolation, were the main obstacles to timely health-seeking behaviour in almost all the studied countries. Conversely, it prompted patients to seek timely care in Somalia.

A considerable proportion of patients felt ashamed that they had developed tuberculosis, had tried to hide the disease, felt that tuberculosis affected family and marital relations, and work performance. More females than males said that the chances of a girl getting married were less if she had tuberculosis. Similarly, more females were hesitant to start treatment for a young girl if she had tuberculosis, probably because of the stigma associated with visiting the chest clinic. The association between the accessibility of health facilities and stigma associated with tuberculosis and the health-seeking behaviour of the population is in agreement with other reports [17].

Only 38.2% of patients in Pakistan correctly knew that tuberculosis is contagious, compared to 54.8%–75.4% in the other countries. This is key information that should be well communicated to the community to reduce transmission of the disease. An overall better knowledge score was recorded for curability of the disease but inadequate knowledge was reported concerning the types of anti-tuberculosis drugs and treatment duration. A significantly lower knowledge score was reported from Pakistan compared to other countries which uncovers marked deficiency in health education for newly diagnosed patients.

A strong emphasis on health education is therefore recommended in all countries, to provide basic knowledge about the disease and to reduce stigma, and further decentralization of tuberculosis services is needed to improve access.

Patient delay

Patient delay was the main contributor to the total delay in Somalia, Syria, Iraq and Yemen. 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 [18, 19]. The mean duration between onset of symptoms and health-seeking behaviour significantly varied across countries, being lowest in Pakistan (9.9 days) and highest in Somalia (69 days). By comparison, a mean patient delay of 3 weeks was seen in Botswana [20], while a mean patient delay

of 161.7 days was reported from Tanzania, and contributed to more than 90% of the total delay [21]. A longer distance from the health facility, education level of patients and knowledge about tuberculosis all contributed to this long delay.

Stigma plays an important role in determining the health-seeking behaviour of patients suspected of tuberculosis as has been documented by one of the co-authors in a previous study from Pakistan where it played an important part in hindering patients from seeking early health care [22,23]. Moreover, as patients were not satisfied with health care services, they did not seek care from health care providers, rather they consulted alternate providers of treatment, including homeopaths. Lower incomes, or the long distance to reach the health care providers prompted the patients to either try self-medication (50%) or consult a pharmacy (42.2%) as the first action after symptoms in Pakistan.

The significant risk factors for patient delay that were frequently reported from the studied countries were living in suburbs and rural areas, inadequate knowledge regarding tuberculosis, a high degree of stigma, inadequate satisfaction with care, seeking health care from a non-specialized individual at onset of symptoms, and seeking care from more than one health care provider.

In conclusion, patient delay is mainly dependent upon the health-seeking behaviour of tuberculosis patients which is mainly determined by their socio-demographic characteristics, degree of stigma felt and knowledge regarding the disease.

Health system delay

Health system delay was mainly attributed to delayed diagnosis rather than delayed treatment as the later did not exceed 4 days in the studied countries (mean ranging between 1.2-4.5 days). The mean duration between the first health-seeking behaviour and receiving treatment was lowest in Iraq, Somalia and Yemen (5–27.6 days), but reached 90.7 (33.5) days in Pakistan. Health system delay was the main contributor to the total delay in Pakistan, Islamic Republic of Iran and Egypt.

A long health care system delay has been also reported from other countries such as Viet Nam (49.7 days median health care system delay vs. 21.7 days median patient delay), Ghana (56 days vs. 28 days) and Botswana (35 days vs. 21 days) [7,20,21]. By contrast, a patient delay has been the major component of delay in countries such as the United States of America (25 days median patient delay vs. 6 days median health care system delay) and Tanzania (120 days vs 15 days) [22, 24].

In Pakistan, except for one patient whose family member was already registered at the national tuberculosis control programmes, all patients consulted private health care providers and in 90.9% of cases this was a general practitioner practising within the neighbourhood. A limited proportion of patients (7.7%) consulted a private chest specialist.

This study showed that visiting several health care providers was significantly associated with longer delay. The majority of the patients in Pakistan were not satisfied with consultation from one health care provider. Only 1.5% of patients consulted two health care providers before being referred to a tuberculosis centre and a mean of 5 health care providers were consulted by each patient, some patients even consulting 12 health care providers. Not only did patients consult several health care providers, but they also contacted homeopaths or took advice from drug stores. In spite of frequent consultation with local health care providers, the final diagnosis of tuberculosis was made by the NTP in 81.3% of cases and the local health care providers made the diagnosis in only 5.7% cases. The factors contributing to this included consultations with individuals other than health care providers (e.g. traditional healers or pharmacists). These results are in agreement with reports from other countries. In Tanzania, a longer health care system delay was seen when patients, especially in rural areas, consulted traditional healers [22]. In Gambia, patients who initially consulted health care providers had a shorter delay compared to patients who initially consulted alternate healers [29]. In Nepal longer patient delay in women was contributed to by consultation with traditional healers and more frequent visits to health care providers before final consultation with the NTP [26]. A study from India showed that tuberculosis patients on an average visited 2.5 doctors before reaching the NTP [16].

Socioeconomic status is an important contributor towards delay, as patients consulted private health care providers who advised investigations which many patients were unable to pay for and therefore consulted other health care providers before finally reaching the NTP. The long delay in reaching a tuberculosis centre may also be due to the distance to the tuberculosis centres, as well as to the stigma associated with tuberculosis.

Private health care providers tend to avoid referring patients to the NTP facilities and a proper link between the private and public health facilities does not exist. Long health care provider delays have been seen in Gambia, Botswana and Ghana, and have been attributed to poor access to health services, and prior visits to private health care providers [18,20,21].

Lack of resources in the private sector are further manifest by the long time interval between diagnosis and initiation of treatment (treatment delay). In cases where NTP facilities made the diagnosis a mean of 3.3 days with a median of 2 days, compared to a mean of 9.8 days and a median of 10 days, when a private health care provider made the diagnosis. Treatment delay was significantly longer if the patient first consulted a private health care provider, and if diagnosis was made by the private sector. Income also played an important part, as patients whose diagnosis was made in the private sector could not afford to purchase the antituberculosis medicines, which are otherwise provided free of charge by the NTP. These patients, already in debt because of their illness, were finally referred to the NTP.

In the Islamic Republic of Iran, the reported diagnostic delay in this nationwide study was significantly higher than that of a hospital-based study conducted in 1995 [27]. The baseline study reported a mean diagnostic delay of 93 (80) days compared to 124 (114) in the present study, implemented 8 years later (2003–2004). But in both of these studies, health care system delay was significantly longer than patient delay and was the main contributor to the total delay.

The significant risk factors for health care system delay that were frequently reported from the studied countries were: time to reach health facility of more than half an hour, economic burden of the disease and high cost of medical services, seeking care at a non-specialized health facility including the private sector, and more than one health care encounter before diagnosis.

In conclusion, health system delay is mainly attributed to the fact that private health care providers have a low index of suspicion for tuberculosis, and do not adhere to the NTP guidelines in diagnosis and in referral of suspects/patients to the NTP owing to the weak referral link between the private health care providers and the public health system.

Total delay

The mean duration between the onset of symptoms and treatment was 46 days in Iraq, 57 in Egypt, 59.2 in Yemen, 79.5 in Somalia, 80.4 in Syrian Arab Republic, 100 in Pakistan, and 127 in Islamic Republic of Iran.

Various mean delay durations were reported from different endemic countries: 60 days from India, 87.5 days from Malaysia, and a median delay of 99 days from Nepal [16,24,26]. The delay reported from Pakistan was comparable to the rates reported from Viet Nam, i.e. a mean of 69.3 days and median of 44.1 [28].

Sociodemographic characteristics proved to be significant predictors of delay in almost all countries. Age above 35 years was associated with a 1.01–1.7 fold increased risk per year in Syrian Arab Republic, Islamic Republic of Iran and Iraq. Female gender was associated with an increased risk for delay in Yemen but was protective in Egypt, prompting patients to seek timely health care. Illiteracy and overcrowding were also significant risk factors in Egypt and Iraq, respectively. Residence proved to be a significant risk factor for delay in Iraq, Somalia, and Pakistan where living in suburban areas was associated with a 3, 2.2 and 2.5-fold increased risk for delay in treatment, respectively, compared to urban areas.

Accessibility of the health facility was a significant predictor of delay in Egypt, Syrian Arab Republic, Yemen, where patients spending more than half an hour to reach the health facility were at a significantly higher risk for delay compared to those living closer to the health facility.

Stigma was associated with significantly higher risk for delay in Syrian Arab Republic, Yemen, and Iraq (1.2, 1.7 and 2.1-fold, respectively). Inadequate knowledge regarding the disease and poor satisfaction with care were significant predictors of delay in Pakistan and Iraq.

Interestingly, having a negative sputum smear examination on entering the health system in the Islamic Republic of Iran was associated with a 3-fold increased risk of delay. This could be explained by the fact that the patients feel reassured about their health condition and do not proceed with the necessary investigations to diagnose the condition. Fever and performance of chest X-ray were protective factors, prompting patients to seek early health care.

Smoking, whether current or ex-smoking, was also reported as a significant risk factor for delay. Smokers often do not present themselves to the health facilities in the belief that their cough is due to smoking.

An overall assessment of the delay in initiating treatment after onset of symptoms, brings forth the important point that in Egypt, Islamic Republic of Iran and Pakistan, patients sufficiently knowledgeable to consult health care providers, within a short time after onset of their symptoms. However, the private health system is accessed rather than the public health system. In fact, in almost all the countries, seeking initial care from a non-specialized individual or the private sector and seeking care from more than one health care provider before diagnosis were invariably significant risk factors for delay.

Private health care providers do not have strong linkages with the mainstream public health system. In addition, lack of continuing medical education contributes to poor knowledge and therefore poor ability to immediately diagnose a case of tuberculosis. Patient dissatisfaction results in repeated consultations with private health care providers, including homeopaths or traditional healers. Repeated and unfruitful consultations drain the patients' financial resources, which would otherwise be used for antituberculosis treatment. There is dire need to integrate the private health sector with the mainstream public health intervention: DOTS. An important step in this context could be to allow the private sector access to the central laboratory for sputum microscopy through the Tuberculosis Control Programme as well as to enable the NTP to register these patients. Patients could then easily pass between the public and private health systems without redundant investigations, unnecessary paper work and associated delay. One of the reason cited for all the delays was the long travel time to tuberculosis centres. One of the reasons for initial consultation with a private health care provider was the proximity of the general practitioner's clinic to the patient's residence. The private health care provider could be used to dispense antituberculosis treatment through their own clinics which could be part of the DOTS strategy. There is also need to decentralize the tuberculosis centres so as to have more treatment and diagnostic facilities in the peripheral centres to allow easy access for the patients. This needs to be accompanied by awareness-raising in the population regarding tuberculosis.

Tuberculosis patients in Egypt spent on average US\$ 21 before diagnosis, and a total of US\$ 16 870 was spent by all patients before diagnosis. Similarly, in Pakistan, an average of US\$ 18.6 was spent per patient before diagnosis. These results indicate the extent of economic burden such delay exerts on families without a corresponding gain in health care.

Other factors affecting tuberculosis control

Age and gender distribution of the studied patients are considered indicators of the progress in the control of the tuberculosis epidemic. Patients are, on average, around 30–35 years of age or younger, except in Islamic Republic of Iran where the mean age was 45.9 years (20.1). A shift in the mean age towards older age groups points at a lessening of the problem in the society. It indicates that transmission of tubercle bacilli is decreasing and that an increasing proportion of cases emanates from the pool of infected many years in the past. The shift implies that cohorts with less and less infection are successively replacing cohorts born at the time when risk of infection was much higher [29].

A male predominance existed in Egypt, Iraq, Somalia, Syrian Arab Republic and Yemen, ranging from 2.5:1 in Somalia to 1.4:1 in Yemen, while a slight female predominance was reported from Pakistan and Islamic Republic of Iran. This observed difference in gender distribution in tuberculosis could be attributed to racial, genetic or sociocultural factors. It could be also attributed to a combination of the fairly similar (but slightly lower) prevalence of tuberculosis infection among females compared to males, but a higher risk of progression to disease among young females. Experience from developed countries have shown that with an improving epidemiological situation, the age of tuberculosis patients increased to the point in age where the risk of progression from infection to disease inverted among sexes and became larger for men than for women [29].

The distribution of the various risk factors of tuberculosis were also investigated in the studied patients. History of smoking, whether of cigarettes and/or water pipe, was reported from a considerable proportion of patients in all countries: around one quarter in Iran, three-quarters in Iraq, and more than half of the patients in the remaining countries.

The association between smoking and tuberculosis has been well documented [30, 31]. Reports showed that the rates reported in this study are significantly higher than those from the general population, as follows: Egypt (42.8% were current or ex-smokers who quit smoking recently mainly due to the disease, versus 20% current smokers in the adult general population); Islamic Republic of Iran (32.5% versus 12%); Pakistan (29.7% versus 23%); and Syrian Arab Republic (50.5% versus 26%) [11]. However, this comparison did not take into consideration the potential confounders for the association between smoking and tuberculosis such as age, socioeconomic status, etc.

History of previous exposure to a tuberculosis patient was reported from 12%–49% of patients in Yemen, Egypt, Syrian Arab Republic, Islamic Republic of Iran and Somalia, in increasing order of frequency. Interestingly, Pakistan recorded 93.4% positive history of previous exposure to a tuberculosis patient. These high rates uncover marked deficiency in contact investigations in these countries. Strengthening contact investigations is, therefore, likely to increase the case detection rate in countries that did not achieve the 2005 target of detecting 70% of tuberculosis cases in their populations.

Conclusions and recommendations

The risk factors for delay identified in this study should be the subject of future interventions in order to reduce delay in delivery of treatment to tuberculosis patients, and hence transmission of the disease in the community. As delay in the treatment of tuberculosis patients is attributed to both the patient and the health system, countries where the patient component is large should put more emphasis on increasing awareness of the community about tuberculosis symptoms. Countries where the delay is mainly attributed to their health systems should put more efforts into building effective collaboration between the national tuberculosis control programme and the private sector, often the recipient of the first health-seeking action of the community.

The study gave tuberculosis coordinators the opportunity to observe the need for better linkage with the private sector. Since they were the data collectors in the different provinces/governorates of the seven countries, the study brought them into contact with health care providers in both the public and private sectors, to inform them about the NTP and the DOTS strategy and to develop a system for referral. For the NTP doctors, the study enhanced their knowledge and skills with regard to ensuring adequate and successive sputum examination and early suspicion of tuberculosis cases. As for the community, the health education sessions emphasized the availability of treatment and curability of tuberculosis to reduce the stigma.

In view of these conclusions, the following are the study recommendations to NTPs.

1. Detection, follow-up and treatment of tuberculosis among people living in suburbs and rural areas, especially among females in all areas and among the poor, should be improved by: integrating the tuberculosis programme into other existing health services at all levels; involving

outreach community workers and other agencies working in the health sector; and increasing community awareness through health education, using appropriate channels.

2. Efforts should be made to increase public awareness about the symptoms of tuberculosis and to educate them about the importance of seeking early care and the availability and location of free diagnostic services. Tuberculosis patients should be a special target for health education as many of them could infect their contacts.
3. Efforts should be made to educate both public and private physicians about the need to maintain a high index of suspicion of tuberculosis and rapidly performing appropriate tests. Sputum must be examined in all patients with prolonged productive cough, negative investigations should be repeated, and patients should be informed to return if symptoms persist.
4. Effective collaboration should be developed between private and public providers to ensure an effective public–private mix of services.
5. Training and retraining of health care providers about tuberculosis at regular intervals should be instituted. Integration of tuberculosis re-training courses into national systems of continuing medical education for private physicians is also recommended to ensure early case detection.
6. The various delay durations and the significant determinants of delay identified in the present study should be incorporated into routine surveillance reports. This would allow monitoring of the effectiveness of the interventions and control measures in reducing the duration of delay, hence reducing the transmission and burden of tuberculosis in the community.

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Annex 1. Patient questionnaire

Case-finding in tuberculosis patients: Diagnostic and treatment delays and their determinants

1. TB register no:
2. Code of the health facility:
3. Name of interviewer -----
4. Date of the interview (dd/mm/yy):

Socio-demographic characteristics and risk factors:

5. Name (last, first, middle):------
6. Age (years):
7. Sex:
8. Number of household members:
9. Number of rooms in the house:
10. District: -----Full address:-----
11. Educational level:
 - o University or higher
 - o Primary/Middle/Senior
 - o Illiterate/read & write
12. Occupation:
 - o Technical/professional
 - o Clerical/workers
 - o Student
 - o Unemployed (or HW)
13. Income:
 - o Savings
 - o Income=expenses
 - o In debt
14. Residence:
 - o Urban
 - o Suburban
 - o Rural
 - o Homeless/displaced
15. Marital Status:
 - o Married
 - o Single
 - o Divorced/separated
 - o Widowed
16. History of smoking:
 - o Never
 - o Current smoker
 - o 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:
 20. Nationality: -----
 if national, specify ethnic group, tribe, etc:-----
 21. Other chronic diseases (eg. HIV/AIDS, Diabetes, COPD, Disability, etc): -----
 History of current illness
 Chief symptoms and date of onset of the current illness:
 22. Cough
 23. Date1 (dd/mm/yy): [] [] []
 24. Fever
 25. Date2 (dd/mm/yy): [] [] []
 26. Loss of Weight:
 27. Date3 (dd/mm/yy): [] [] []
 28. Haemoptysis
 29. Date4 (dd/mm/yy): [] [] []
 30. Chest pain:
 31. Date5 (dd/mm/yy): [] [] []
 32. Others (specify)
 33. Date6 (dd/mm/yy): [] [] []
 34. Which symptom(s) made you seek healthcare:
 35. Health seeking behavior with onset of symptoms (before initial diagnosis) and cost of one consultation:

First action	code	Date(dd/mm/yy)	Total expenses
HCP	0		
Self medication	1		
Traditional medicine	2		
PHC worker at home	3		
Drug stores (pharmacies)	4		
Others (specify)	5		

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

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

Order	Code of health facility	Date (dd/mm/yy)
1 st		
2 nd		
3 rd		
4 th		
5 th		

Code of Health Facility	
TB Centre	[0]
PHC	[1]
Chest Hospital	[2]
Public Hospital/outpatient clinic	[3]
Private Practice (Hospital or Clinic)	[4]
Others (specify)	[5]

38. If private practice, specify the specialty of the HCP whom you first sought his consultation:

1. Chest specialist
2. Internist
3. GP
4. Others (specify)

39. Reasons of first consultation of the health facility (mentioned in q.37) with the onset of symptoms (i.e first in order in q.37) (check):

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)

40. Reasons of non-consultation of health facility (coded 0,1,2 in q.37) 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)

Satisfaction with Care (score: 0 best, 3 worst)

Score

41.		Availability of services in PHC/TB centres
42.		Prompt action from HCP in PHC
43.		PHC well equipped
44.		PHC giving free medicine
45.		There is enough PHC in the area
46.		Health facility workload
47.		Waiting time (0: <= 15mn, 1: 15-30 mn: 2: >30 mn-1 hr 3: >1 hr)

48. 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 (mention)

49. TB stigma

<i>Strongly agree=0</i>	<i>Agree=1</i>	<i>Average=2</i>	<i>Do not agree=3</i>	<i>Do not agree at all=4</i>
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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 the 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?

11. Does TB cause female infertility?
12. Does TB lead to serious complications during pregnancy?
13. Does TB affect breast feeding?
14. Does TB affect pregnancy outcome?
15. Is a girl unable to decide for getting TB treatment?

50. Date of first TB diagnosis (dd/mm/yy):

51. No of health seeking encounters (HCP) before initial TB diagnosis:

52. Health facility of the HCP who made the initial TB diagnosis (by code mentioned in q.37)

53. Speciality of the HCP who made the initial TB diagnosis:

1. Chest specialist
2. Internist
3. GP
4. Others (specify)

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

- | | |
|-----------------------|--------|
| 1. Sputum examination | date0: |
| 2. X-ray | date1: |
| 3. Both | date2: |
| 4. Referral | date3: |
| 5. Others (specify) | date4: |

55. X-ray: 1.negative 2.positive 3.not performed

56. Date of initiation of treatment (dd/mm/yy):

Accessibility to the public health facility providing treatment

57. Time to reach from home to the nearest public health facility:

1. <1/2 hr ; 2. ½-1 hr; 3. > 1hr

58. Distance (in Km) from home to the nearest health facility providing treatment:

Patient's knowledge on TB

59. Have you previously heard of TB?

60. 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]

61.				What kind of disease do you have?
62.				Is TB hereditary?
63.				Is TB contagious?
64.				Is TB curable?
65.				Do you know if there is a vaccine for TB?
66.				Do you know the approximated duration of treatment?
67.				Do you know the kind of TB drugs?



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