

Patient and health system delays: Health-care seeking behaviour among pulmonary tuberculosis patients in Pakistan

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Abstract

Objective: To determine the time taken for diagnosis and treatment of pulmonary TB and the factors responsible for delay, by studying the level of awareness regarding TB in the patients, and the extent of social stigmatization associated with TB in Punjab (Multan and Sialkot), Pakistan.

Methods: It was a hospital based cross-sectional study using a pre-structured questionnaire. The study was done in two areas Multan (Nishtar Hospital) and Sialkot (Bethania Hospital) in the province of Punjab, Pakistan from May - July 2006. The sample (n= 301) consisted of all the TB patients coming to the hospitals during the study period. The data was analyzed using SPSS version 14.0.

Results: The median patient delay was 33 days (range 2-90). The median health system delay was 60 days (range 4-365). The median total delay was 90 days (range 23-365). The percentage of patients aware about TB was 37%. The number of patients who perceived stigmatization was 27%.

Conclusion: The major portion of the delay is contributed by the health system, rather than the patient. The awareness about TB is low and emphasis should be given to increasing the awareness of TB among the community (JPMA 58:318;2008).

Introduction

Tuberculosis (TB) re-emerged as a public health problem globally, in the 1980's. World Health Organization (WHO) has estimated that about 5000 people die of the disease and 20000 are newly infected daily.¹ In developing countries young adolescents experience the highest rates of TB disease and death. The burden of TB and deaths due to TB in Pakistan are alarming. Every year 350,000 people in Pakistan develop TB², the majority of whom are economically productive adults. The condition is constantly escalating as mortality due to TB exceeds 50,000 annually. TB control programs currently emphasize the Direct Observed Treatment Short-Course (DOTS) strategy, promoted by the WHO and the International Union against Tuberculosis and Lung Disease (IUATLD). The current goals are to achieve 85% treatment success and 70% case detection. Since 2005, Pakistan with 139,605 identified TB cases, is offering DOTS Strategy in hundred percent of public sector health care facilities. Despite inception of DOTS strategy across the country, the TB case detection has not gone above 35 percent against the target of minimum 70 percent set by WHO.

Among others, TB global control currently faces two challenges to meet those goals: diagnosis delay and non-completion of treatment. According to a literature review for

most of the studies done on diagnostic delay between 1995-2004³, a delay of 2-3 weeks is acceptable as patient delay from TB control point of view. In our study we took 20 days as acceptable delay. Ideally the total delay from start of symptoms to the start of treatment should be 3-4 weeks.³

Many factors contribute to patient and health system delay, which are different in different settings. Studies should be carried out in each setting to determine the factors for delay which can guide proper intervention. Knowledge plays an important role in determining the behaviour and practices of the individuals. Therefore awareness regarding a certain type of disease is essential to mould the attitude or behaviour of the patients towards the disease. TB is a disease which is stigmatized by the community leading to social rejection. The study also identified the extent of stigmatization both from the individual as well as the community perspective.

We aimed at determining the time taken for diagnosis and treatment of pulmonary TB and the factors responsible for delay by studying the level of awareness regarding TB in the patients, and the extent of social stigmatization associated with TB.

Methods

The study was carried out in Punjab province

(Multan & Sialkot). It was a hospital based cross-sectional study. All TB patients coming to the hospital from May-July 2006 were included in the study sample. No missing cases were reported.

In Multan the study was carried out in the Tuberculosis Outdoor Unit of Chest Department, Nishtar Hospital. This is the biggest tertiary hospital of southern Punjab providing healthcare to patients under government supervision. Nishtar Hospital holds the capacity of 1000 beds with 30 wards and an outpatient department (OPD). The Nishtar Hospital adopted the DOTS strategy for the treatment of TB in 2004. In Sialkot the study was carried out in Bethania Hospital. Since its establishment in 1964, the hospital has worked extensively to detect and treat TB patients in the region. It is a 215 bed frontline and referral hospital, providing medical and surgical services. There is a specialized TB unit with 100 beds. Diagnosis of tuberculosis is done using direct microscopy examination.

Sampling was done according to the formula $N = \frac{Z^2 P (1-P)}{d^2}$, where N is the sample size, Z is the 95% confidence interval, P is the estimated prevalence of delay, d is the absolute precision required on either side of the proportion. Sample size calculation using this formula with $d = 5\%$, $P = 27\%$, $Z = 95\%$ confidence level, the sample size calculated was 302. The study sample was 308, but in total 301 subjects were available as 7 were excluded due to incomplete information.

A pre-structured questionnaire was used for data collection. Some areas were predominantly emphasized during the interviews like sociodemographic factors, patients delay, and health system delay. All newly diagnosed pulmonary tuberculosis patients (both the smear positive as well as smear negative) diagnosed in the last 2 weeks were included, whereas relapses, re-treatment as well as other forms of TB were excluded from the study. All patients below 15 years were also excluded. All patients studied were out-patients.

Three types of delay were defined. Total delay: period from the onset of the symptoms to the time of presentation at the DOTS center. Patients' delay is the period from the onset of the symptoms to the time of contact of any health facility. Doctors' /health system delay is the time of first contact of a health facility by the patient to the presentation at DOTS facility in our study.

Ethical clearance to conduct the study was obtained from the authorities of the Nishtar Hospital, Multan as well as from Bethania Hospital, Sialkot. A written or verbal consent, depending on the literacy level, was also obtained from the patients.

Data analysis was done using SPSS for windows version 14.0. Descriptive statistics were used such as

frequency, median, minimum and maximum (range). Chi-square test or Fischer's exact test were used for analyzing categorical data, and the Mann-Whitney test was used for two group comparisons. The level of significance was set at 5%.

Results

Table 1 presents the general characteristics of patients studied. A total of 301 patients were studied (160 men, 141 women). The male to female ratio was 1:1. The median age of the female TB patients was lower as compared to the males, 32 years and 35 years respectively. There was a dominance of the age group 15-44 years. There were more females than males in the 15-24 years age group. Illiteracy rate was higher among females as compared to the males. Uneducated group included those patients who could neither read nor write. Educated patients were those who had primary and above education.

Table 2 presents the median time taken by the patient to consult any health facility for a number of socio-demographic factors. Sixty four percent of the patients contacted any health facility after the acceptable 20 days, whereas only 36% did not delay their first contact with any health facility. The median delay for all patients was 33 days (range 21-90 days). Females delayed more as compared to males ($p < 0.001$), while no statistical significance was found

Table 1. General characteristics of patients studied n=301.

Characteristics		Patients
		n=301
Sex	male	160 (53%)
	female	141 (47%)
Age	<55 yrs	271(90%)*
	≥ 55 yrs	30 (10%)*
Occupation	laborers	69 (23%)
	students	32 (11%)
	housewives	105 (35%)
	Others	95 (31%)
Education	uneducated	213 (71%)
	educated	88 (29%)
Smoking	male	160 (57%)
	smokers	52 (32.5%)
	non-smokers	108 (67.5%)
	female	141 (43%)
	smokers	-
	non-smokers	141 (100%)

n= number of patients

Table 2. Time taken by PTB patients from the onset of symptoms to the first contact with any health facility and their correlation with sociodemographic factors n=301.

Characteristics		Median(range)in days for patients contacting = 21 days	Patients contacting within 20 days%
	All patients	33(21-90)	36
Sex	male	29 (21-90)*	34
	female	35 (21-90)*	35
Age in years	< 55 yrs	34 (21-90)	36
	= 55 yrs	30 (21-60)	37
Education	uneducated	30 (21-90)	36
	educated	28 (21-64)	36
Awareness	unaware	30 (21-90)	34
	aware	35 (21-90)	39
Occupation	labourers	30 (21-60)	48
	students	35 (21-60)	33
	housewives	30 (21-90)	38
	others	28 (21-64)	46
Smoking(males only)	smokers	24 (21-60)	56
	nonsmokers	35 (21-75)	38

Table 3. Level of awareness between patients who delayed and those who did not delay seeking care.

	Patients contacting within 20 days		Patients contacting = 21 days	
	Aware n (%)	Unaware n (%)	Aware n (%)	Unaware n (%)
Knowledge of TB				
Heard TB	114 (88)	15 (12)	15(12)	29 (17)
Cause(germs)	24 (19)	105 (81)	105 (81)	155 (90)
Duration of treatment	108 (84)	21 (16)	21 (16)	33 (19)
Side-effects	29 (22.5)	100 (77.5)	100 (77.5)	144 (84)
Signs/symptoms	81 (63)	48 (37)	48 (37)	91 (53)
Contagious	75 (58)	54 (42)	54 (42)	79 (46)
Routes of Transmission	68 (53)	61 (47)	61 (47)	96 (56)
Prevention	39 (30)	90 (70)	90 (70)	132 (77)

by age, education, level of awareness, occupation and smoking.

The health system delay was 60 days (range 4-365), which was also more than the cut off time 28 days.³ Seventy six percent of the patients contacted the GPs and 18% contacted the hakeems. The contact of the patients with these two major private sectors was associated with delay. About 46% also had to undergo a number of investigations as advised by the doctor consulted, adding the financial burden and hence the patients delayed seeking care and

ultimately contacted the DOTS Center. The median total delay from the onset of the symptoms up to the presentation at the DOTS center was 90 days (range 23-390).

After presentation to a DOTS facility, time taken to diagnosis was 3 days for 243 (81%) patients. The rest 52(17%) had their diagnosis within 14 days. After diagnosis 253 (84%) got their treatment on the first day, while only 2 (0.7%) patients delayed treatment up to 21 days.

Table 3 gives the level of awareness among the two groups of patients those who delayed seeking care and those who did not. The level of awareness was not significantly related to delay. There was no significant difference in the level of awareness between males and females. Fifteen percent patients said that they had never heard the word TB. Of those who had heard about TB, 30% could not identify a source. Only 14% were aware that TB is caused by germs. Thirty six percent mentioned that the doctors were the source of information, while media (radio/TV) as a source of information was reported by only 8 (4%) patients.

Twenty seven percent reported the presence of stigma attached to TB. Among these only 40% were educated. Stigma related to TB was found to exist in the society. People do not disclose their disease and delay seeking health care for the fear of being stigmatized. Both men and women were affected by the stigma. Many were misconceptions due to lack of awareness.

Discussion

This study has identified the duration of delay in health seeking by the patients as well as the delay caused by the health system. In our study the delay from the onset of symptoms to the patients self seeking a health facility was 33 days which is above the acceptable 20 days. Patient delay has been the major component of delay in countries such as the United States of America (25 days patient delay vs. 6 days health care system delay) and Tanzania (120 days vs. 15 days).^{5,6} Females had a longer median delay than males, which is in contrast to a study done in India where males delayed longer.⁷ Females can delay longer for a number of reasons, for example not having the authoritative powers in the household as most of the females in our study population were housewives being dependant on their husbands both economically and on social issues. Lack of education can also play a role in delaying health seeking, although in our study there was no significant difference between the educated and the uneducated. We found that patients delayed seeking health care until the symptoms became severe, and majority of the patients first contact with health facility was the private doctor especially GPs and very few came directly to DOTS. This was similar to the findings of another study done in Pakistan.⁸ The other

factors responsible for delay were the fear of the financial burden being brought by the disease, the hours lost from work, the price of the frequent visits, all contributing to the overall patient delay.

We divided the health system into the GPs, hakeems/homeopaths and DOTS centers. In our study we found a longer health system delay (33 days patients' delay vs. 60 days health system delay), whereas ideally the total delay from start of symptoms to the start of treatment should have been 3-4 weeks.³ Long health care system delays have also been reported from other countries such as Vietnam⁹ (49.7 days health care system delay vs. 21.7 days patient delay), Ghana¹⁰ (56 days vs. 28 days) and Botswana¹¹ (35 days vs. 21 days). In our study the total delay from onset of symptoms to the time of presentation at a DOTS facility was 90 days, which is similar to another study done in Karachi, Pakistan where a total delay of 97 days was reported.⁸ This study indicated that many patients made several visits to the care-providers before reaching the TB center. In our study some of the patients (30%) were diagnosed to have TB by the private doctors and 28% were put on anti-tuberculous treatment (ATT) while only 2% were referred to the DOTS center. But most of the patient did not complete treatment because of the financial burden and ultimately contacted the DOTS center. For most of the patients private doctors were their first contact with health system. Efforts must be made to encourage private doctors to work closely with the public sector and adopt the DOTS strategy for the treatment of TB. This will not only improve their ability to diagnose and treat TB, it will also enable them to disseminate their knowledge in a more effective way. This highlights the establishment of a strong link between the private sector and the NTCP.

In our study we found that the level of awareness regarding TB in the patients was very poor. As is evident from the comparison of level of awareness between those who did not delay seeking care and those who did, the awareness was better among the former group than the latter. This is a very important aspect from the Control Programme point of view, as this can affect the health seeking behaviour of the patients and the patients can continue to transmit the infection to the rest of the healthy contacts. Emphasis should be given to increasing the awareness of TB among the community to decrease the

delay by patients.

Despite a continuous expansion of the DOTS programme to all the districts of Pakistan, there are still many short-comings especially lack of an effective educational programme regarding TB. To our knowledge, this is the first study done on delay in Multan and Sialkot.

In conclusion, there is a delay both from the patient as well as the health system in treating TB. Females delayed longer as compared to males. Awareness about TB was very poor. The results from the study can be used for future policy formulation by the control programme.

Acknowledgements

We acknowledge the cooperation of the staff of Nishtar Hospital as well as Bethania hospital, who assisted in data collection. We are highly grateful to all the patients who agreed to participate in the study.

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