

The factors contributing to non compliance of Anti-Tuberculosis Medication, and Social Stigma Associated with the Disease.

Zulfiqar Ali Shaikh¹, Masood Hameed Khan², Mukkaram Ali³

Abstract:

Background: Tuberculosis (TB) is a global threat infecting one third of the world's population. Around 9 million new cases occur, leading to about 2 million deaths annually. Because of non-compliance to the treatment drug resistant cases are increasing terrifically. Non adherence causes enormous economic and human costs. Treatment compliance is also associated with beliefs and attitude of people.

Pakistan is among one of the highest TB burden countries with estimated incidence of 250/100,000 population.

Objectives: To explore non-compliance with tuberculosis treatment amongst patients and determine the contributing factors and the phobia for drugs and disease; and also find out social stigma associated with the disease.

Methodology:

Study Design: Cross-sectional

Place: Ojha Institute of Chest Diseases (OICD), Karachi

Duration of study: June to December 2009

Sample size: 210

Sampling Technique: Non-randomized convenient technique

Results: The male to female ratio was 68:32, and 60% of total study participants were of 40-50 years' age group. All were from very low / low socio-economic class. Majority of the patients came for treatment at OICD after six months to two years of developing symptoms of T.B. All of them had gone to local GPs, who continued the treatment without a relief, but did not ask for diagnostic workup or referral. According to study participants, the mode of spread of T.B included coughing and sneezing, food, water, touching, close body contact, sharing cloths, sharing razor, blood transfusion, used syringes and hereditary; and 19% of them had no idea of the spread route. The patients were frightened to take treatment because it caused severe side-effects, other diseases, dependency, physical and sexual weakness. The various number of the patients thought that T.B was not a curable disease, treatment was not needed for long duration; the disease caused social isolation, marriage difficult / not possible for patients and off-springs, and also divorces. The factors contributing to non-compliance of T.B treatment included long duration, number of drugs, cost, waiting for hours to get medicine at government health facility, rude behaviour; and drugs not effective, better treatment / cure with homeopath / hakim / pir.

Conclusion: Non-compliance to the T.B treatment is the major cause of wide spread of the disease. There is a need of mass awareness and social support of T.B sufferers; and sympathetic attitude of Health Care Providers.

Key Words: Tuberculosis, Non-compliance, Phobia, Social Stigma.

Introduction:

Tuberculosis is a reemerging global threat. Presently, one third of the world's population is infected with TB and the estimated number of clinical cases is around 21 million¹; out of which 95% of cases are in developing countries.² This disease is a major cause of morbidity and mortality producing around 9 million new cases leading to about 2 million deaths annually.^{3,4} The total number of cases is rising every year because of various reasons including non-compliance to the

treatment which is also increasing multiple drug resistant (MDR) cases of tuberculosis.

The patients have to follow daily treatment for 6 to 8 months or more depending on the severity of disease.⁵ Compliance to the anti-tuberculosis treatment (ATT) is a complex and dynamic phenomenon, which relates to consumers, providers, health systems and broader social context. It is a challenge for the patient, society and health system to ensure treatment adherence. Non adherence causes human, economic and social costs. Treatment adherence is also affected by beliefs and attitude of people and resulting stigmatization of the affected.⁶ Most of the affected people are of young age group which makes a huge impact on the productivity of less developed countries. Such a huge impact of TB in the developing countries is of great public health concern. Pakistan along with India, Indonesia and Nigeria is among the highest TB burden countries. Presently, estimated incidence of TB in Pakistan is more than 250/100,000 population⁷; and is one of the hot spots for

1. MBBS, MSPH, DPM, MBE; Associate Professor, Community Medicine
2. MBBS, FCPS, FRCP, PhD; Professor, Medicine
3. MBBS, DMJ; Assistant Professor, Forensic Medicine

Institute: Dow University of Health Sciences, Karachi, Pakistan.

.=corresponding author :

Email: drzulfiqarshaikh@gmail.com

MDR-TB second only to Latvia.⁸ Pakistan, in its already dooming economy can not afford to handle a huge burden of such communicable diseases.

The aim of this study was to find out the factors contributing towards phobia and non-adherence to ATT and determine social stigma associated with the disease.

Patients and Methods:

This was a cross-sectional study in which patient's perspective about the factors contributing to non-adherence and phobias associated with ATT were explored. The study was conducted at Ojha Institute of Chest Diseases (OICD), Karachi. A convenient sampling technique was used, and the total number of study participants was 210. A verbal consent was taken from study subjects. Those who did not consent, and had come first time at OICD were excluded from the study. Initially, detailed discussions were held with six patients of different age groups (three males and three females), to find out their viewpoint regarding phobia and social stigma related with the disease. Accordingly a questionnaire was developed, pre-tested and finalized. The data were collected from June to December 2009; and analyzed by using SPSS software.

Results:

The male to female ratio of study participants was 68:32, their age varied from 17 to 68 years with a majority (60%) of 40-50 years' age group. All of the 67 (32%) women patients were house-wives. Among 143 males, 26% (37) were either retired or unemployed; 54% (77) earned upto 10000 and the remaining 20% (29) from 11000 to 30000 rupees per month. As for the education, 34% (72) were uneducated, 13% (27) had primary education, 20% (42) secondary, 18% (38) intermediate, 11% (23) graduation, and 4% (8) were post-graduate.

Majority of the patients came for consultation and treatment at OICD after the lapse of a long time (six months to two years) even though they had developed typical symptoms of T.B, including persistent cough, temperature, sweating, loss of appetite and weight. All of them had gone to local General Practitioners (GPs), who continued the treatment at their clinics without a relief in the symptoms, but did not ask for diagnostic workup or referral. Surprisingly, 61% (128) of the interviewed patients came to OICD themselves or with the advice of their family / friends; 16% (34) were advised for x-ray chest and/or sputum test, and a total of 39% (82) patients were referred by treating GPs because of persistence of their symptoms. Only 6% (13) of these T.B patients were started with ATT by GPs.

Seventy eight percent (164) of the study subjects were permanent resident of Karachi, the remaining used to live in and out of Karachi with other family members. These 22% (46) also had an opportunity to seek treatment from their home place, but they preferred to come to OICD because of 'effective' drugs available there and comparatively better attitude of health care providers. The knowledge of the study participants regarding the

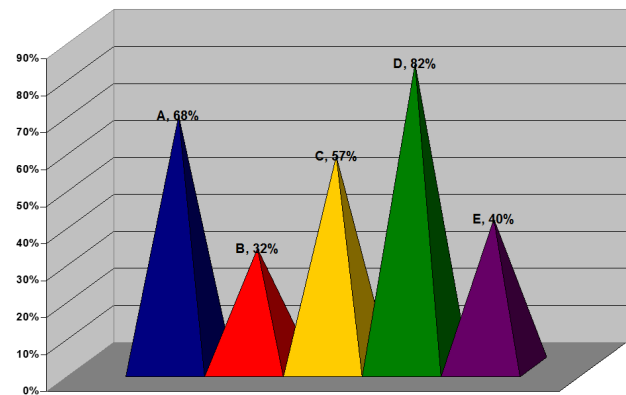
mode of spread of disease is shown in table 1.

TABLE 1. ROUTE OF SPREAD OF DISEASE AS MENTIONED BY STUDY PARTICIPANTS

Coughing & Sneezing	170 (81%)
Food	120 (57%)
Water	134 (64%)
Touching	88 (42%)
Close Body Contact	78 (37%)
Sharing Cloths	46 (22%)
Sharing Razor	54 (26%)
Blood Transfusion	143 (68%)
Used Syringes	98 (47%)
Hereditary	94 (45%)
Don't Know	40 (19%)

The patients had a fear and were reluctant of taking ATT. Their apprehensions are shown in graph 1.

GRAPH 1. PHOBIA REGARDING THE T.B TREATMENT



A= Severe Side-Effects B= Cause Other Diseases C= Create Dependency D= Make Weak Physically E= Make Weak Sexually

According to 18% (38) of the respondents, one or more of their family members had suffered from T.B, and 6% (13) stated that a family member had died of the disease. Various issues were identified by the patients and social stigmas associated with the disease were mentioned by them. These are shown in table 2.

Table 2. Social stigma associated with the disease

Not A Curable Disease	11 (5%)
Isolation from Family / Friends	174 (83%)
Marriage Difficult / Not Possible for Patients	58 (28%)
Marriage Difficult for Patients' Off-springs	40 (19%)
Married Females Forced to go to Parents' Home	46 (22%)
Patients should Not Marry to Stop Disease Spread	88 (42%)
Saya / Gin Cause of Disease	36 (17%)
Patients' Forbidden from Protein Rich Diet	34 (16%)
Treatment Not Needed for Long Duration	63 (30%)

Among these study participants, 34% (71) patients had discontinued the treatment for a period of six to twelve months and restarted with the advice / pressure of family and friends after redeveloping the typical symptoms of T.B. The reasons mentioned by the patients (all those who were regularly taking the treatment and those who after discontinuing had restarted the treatment) for non adherence to the ATT are shown in table 3.

Table 3. Factors contributing to non-compliance of T.B Treatment

Long Duration	183 (87%)
Number of Drugs	174 (83%)
Difficult to take before Breakfast	170 (81%)
Non Availability	58 (28%)
Non Affordability / Cost	63 (30%)
Waiting for Hours to get Medicine at Government Health Facility (GHF)	143 (68%)
Rude Behaviour at GHF	153 (73%)
Difficult Accessibility (Geographical / Financial) to GHF	94 (45%)
Drugs of GHF Not Effective	36 (17%)
Better Treatment / Cure with Homeopath / Hakim	17 (8%)
Better Treatment / Cure with Pir / Murshid	19 (9%)

Discussion:

Tuberculosis is a major contributor of the burden of disease in developing countries including Pakistan. In this study, a significant number (60%) of the patients were of earning age i.e. 40-50 years. They might be an economic burden on family and society as a whole. The employees might not disclose their disease because of the fear of losing their jobs as also was found in another study.⁹

As most of the time, the females remain inside the home, they could become an easy victim of overcrowding and hence contract the disease easily; but among total patients, 68% were males. This suggests the health seeking behaviour and the gender discrimination prevalent in society. Females in Pakistan, depend on their husbands and other males in the family for social and financial support, and they have limited freedom to move.¹⁰

All of the study participants were from low socio-economic strata. This supports already known fact that T.B is the 'disease of the poor and socially disadvantaged', where there are the problems of over crowding, poor hygiene and malnutrition.^{11,12}

It has also been found that majority of the patients in Pakistan visit private practitioners. Many of the doctors often lack knowledge and training in TB, resulting in under or over-diagnosis and wrong or inadequate treatment of T.B.¹³ In this study, only 6% patients were given ATT, and 39% referred by local treating GPs after 6-24 months.

Despite the prevalence of T.B in the family members of 18% and mortality due to the disease reported by 6% of the study respondents, they delayed to seek proper treatment, apparently due to lack of awareness. This also could be found in the response of patients regarding the knowledge of spread of T.B.

A friendly attitude of health care providers has a positive impact on patients¹⁴ as many patients came at OICD for this reason.

The phobia for T.B and ATT is a common problem. The fear of being rejected by the family and the community caused denial and concealment of symptoms and non compliance of the treatment.¹⁵ People consider TB as a precarious and incurable disease associated with 'sins'. This causes social isolation of the patients and sometimes their families; diminished marriage chances for young TB patients, and even for their family members. Engagements are often broken and divorces are reported. The female patients are more affected. These misperceptions and social stigma have led to denial of diagnosis and rejection of treatment.¹⁶ Social and cultural factors must be considered in the compliance of T.B treatment.

Many factors are associated with the non-compliance of T.B treatment. These include expense, knowledge about the disease, disbelief about the Western-oriented treatment and inclination for traditional alternatives, attitude of care providers and social stigma of T.B sufferers. Access to a treatment centre depends on the cost, distance and trouble of travel to and from treatment centers, so the

adherence to treatment becomes compromised.^{17,18,19} Poor compliance was also found because of complexity, duration and adverse side effects of ATT, and difficult access to health care services.²⁰

Non-compliance is leading to the emergence of MDRTB that is more expensive and difficult to treat. Before completion of the treatment, around 40% of the T.B patients discontinue their treatment.²¹ A high proportion of MDR-TB has been found in patients with poor compliance and inadequate anti-TB treatment.²² The emergence of MDR-TB is now a problem of global concern.⁸

The number of new T.B cases is rapidly increasing, particularly in the WHO regions of Africa, the Eastern Mediterranean and South-East Asia.²³

TB incidence and deaths will be decreased in many countries by 2015, but the challenge would be greatest in developing countries.²⁴ Over the years there is an upward trend in the resistance rate in different areas of Pakistan.²⁵ The prevalence of MDR-TB in Rawalpindi and Lahore was found 13.66% and 16% respectively.^{26,27} It was very high (24.44%) in Sindh.²⁸ This is most probably due to poverty, ignorance, poor management, lack of health services and poor follow up of patients.²⁹

Present study also revealed the similar results.

Tuberculosis treatment costs about 10 US\$, but treating MDR TB costs 500 to 6000 US\$.³⁰ To afford such a high cost is not possible for the government or people of Pakistan.

The failure to complete ATT rather than failure of the treatment itself is the cause of MDR-TB.^{31,32} Poor compliance is the most challenging obstacle in the success of T.B control programs.^{33,34} The WHO has declared TB as a global emergency, because TB has become out of control in many parts of world.^{35,36}

Conclusion:

Non-compliance to the T.B treatment is the major cause of wide spread of the disease.

There should be Continuous Medical Education of both public and private practitioners for diagnosis and treatment of T.B; with regular and easy availability of the drugs.

There is a need of mass awareness and social support of T.B sufferers; and sympathetic attitude of Health Care Providers.

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