

National Tuberculosis Control Programme

*Formative Research for
Identifying Risky Behaviors
and Development of National BCC
Strategy*

Final Report

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LIST OF ABBREVIATIONS

DOTS	Directly Observed Treatment Short Course
HCP	Health Care Providers
IEC	Information Education and Communication
LHWs	Lady Health Workers
MNAs	Members National Assembly
MPAs	Members Provincial Assembly
NGOs	Non-government organizations
NTP	National Tuberculosis Programme
NWFP	North West Frontier Province
TB	Tuberculosis
WHO	World Health Organization

Chapter 1

Introduction

Tuberculosis remains a major cause of infectious disease mortality worldwide, responsible for an estimated 1.6 million deaths annually or 2.8% of global mortality.

Tuberculosis (TB)

Tuberculosis, a sometimes crippling and deadly disease, is on the rise and is revisiting both the developed and developing world. Globally, it is the leading cause of deaths resulting from a single infectious disease. Currently, it kills three million people a year and, if the present trend continues, it is likely to claim more than 30 million lives within the next decade. Recent increases in migration have rapidly mixed infected with uninfected communities and contributed to the spread of the disease.

WHAT IS TUBERCULOSIS?

Tuberculosis is an infectious disease caused by the microorganism *Mycobacterium tuberculosis*. It can affect several organs of the human body, including the brain, the kidneys and the bones; but most commonly it affects the lungs (Pulmonary Tuberculosis). The first stage of the infection usually lasts for several months. During this period, the body's natural defenses (immune system) resist the disease, and most or all of the bacteria are walled in by a fibrous capsule that develops around the area. Before the initial attack is over, a few bacteria may escape into the bloodstream and be carried elsewhere in the body, where they are again walled in. In many cases, the disease never develops beyond this stage - and is referred to as TB infection. If the immune system fails to stop the infection and it is left untreated, the disease progresses to the second stage, active disease. There, the germ multiplies rapidly and destroys the tissues of the lungs (or other affected organs). In some cases, the disease, although halted at first, flares up after a latent period. Sometimes, the latent period is many years, and the bacteria become active when the opportunity presents itself, especially when immunity is low.

The second stage of the disease is manifested by destruction or "consumption" of the tissues of the affected organ. When the lung is affected, it results in diminished respiratory capacity, associated with other symptoms; when other

organs are affected, even if treated adequately, it may leave permanent, disabling scar tissue.

WHAT ARE THE SYMPTOMS?

The primary stage of the disease may be symptom-free, or the individual may experience a flu-like illness. In the secondary stage, called active disease, there might be a slight fever, night sweats, weight loss, fatigue and various other symptoms, depending on the part of the body affected. Tuberculosis of the lung is usually associated with a dry cough that eventually leads to a productive cough with blood-stained sputum. There might also be chest pain and shortness of breath. This secondary stage, if affecting the lungs, is the contagious stage - when the bacteria can be spread to others.

HOW DOES TUBERCULOSIS SPREAD?

The TB germ is carried on droplets in the air, and can enter the body through the airway. A person with active pulmonary tuberculosis can spread the disease by coughing or sneezing. The process of catching tuberculosis involves two stages: first, a person has to become infected; second, the infection has to progress to disease. To become infected, a person has to come in close contact with another person having active tuberculosis. In other words, the person has to breathe the same air in which the person with active disease coughs or sneezes.

WHAT ARE THE CHANCES OF BECOMING INFECTED?

A person has to come in contact with someone who has active TB disease with TB germs present in the sputum. The likelihood of this happening also depends on the time spent in close contact with the person with active disease. The process of infection progresses to disease in about ten percent of those infected, and it can happen any time during the remainder of their lives. Although the chance of progression to disease diminishes with the passage of time, TB can develop more easily if the immune system weakens, as happens with malnutrition, AIDS, diabetes, cancer, or treatment with immunosuppressant drugs.¹(Tuberculosis-an infectious disease, McKinley Health center)

¹ Tuberculosis-an infectious disease, McKinley Health center, www.mckinley.uiuc.edu/health-info/dis-cond/tb/tb.html

Formative research

Formative research is the basis for developing effective strategies, communication channels, for influencing behavior change. It helps researchers to identify and understand the characteristics- interests, behaviors and needs- of target population

Required information about individuals, communities, and major stakeholders of tuberculosis is gathered through research. This enables development and implementation of effective *behavior change communication* (BCC) interventions. This also provides information about key stakeholders, who have a direct or indirect influence on behaviors at community or household level.

Rationale

Understanding behavior patterns and social cultural issues is best done through qualitative research. It also provides valuable background information about issues and problems

Objectives

To assess:

- Knowledge, attitudes and beliefs about Tuberculosis (TB) in Pakistan
- Health care seeking behavior of TB patients
- Attitude towards TB and TB Patients
- Social and cultural barriers in access and compliance to TB treatment
- Decision making authority at the household level regarding access of treatment
- Compliance and non-compliance issues
- Impact of social stigma on health care seeking behavior
- Suggestions from patients, families, communities and health care providers to increase compliance, decrease stigma and fight TB in Pakistan

Methodology

A sample of four districts in each province was selected in order to capture the provincial picture at the national level.

Province	Districts
NWFP	Haripur
Punjab	Rawalpindi
Sindh	Karachi
Balochistan	Quetta

Study Design

- Qualitative research to assess the knowledge, attitudes and behaviors and their determinants
- Sample

- Convenient and purposive

The study design consisted of Focus group discussions and in-depth interviews with the target audience.

FOCUS GROUP DISCUSSION (FGDs)

The FGD methodology was chosen because it has a free flow allowing participants to provide information beyond the questions that are asked. It also enables the researcher to gather a large amount of information in a short span of time.

FGDs provide valuable information to researchers while maintaining the group dynamics.

To attain the desired results

- Six focus group discussions in each province were carried out with
 - TB Patients (2 male X 2 female, married and unmarried)
 - Community members (2)

INDEPTH INTERVIEWS (IDIs)

In-depth interviews are considered as a great tool to discuss sensitive information i.e. socio cultural, gender and stigma related. They also help in validating the information collected during the FGDs.

In order to do so the In-depth interviews were carried out with :

- TB patients (male and female, married and unmarried, 2 x 2)
- Health care providers (6)
- Family members of the TB patients (4)

Qualitative Research Design

Activity	TB patients	Family members	Community members	Health care providers	Total
Focus Group Discussions	16 (with TB patients) -with married and unmarried male & female patients	Conditioned to the availability of family members	8 FGDs -male male and female community members (activists, religious leaders, councilors, notables)	Conditioned to the availability of HCPs	24
Semi-Structured/In-depth Interviews	16 (with male & female TB patients)	8 (with male and female family members of the patients)	If possible	24 (with each categories HCPs i.e. Doctor, Technician, LHV, Lab technician of both urban and rural settings)	48

Research Instrument:

Questionnaires were prepared for group and individual interviews. The instruments were shared with NTP. After consensus, the questionnaires were pre-tested and finalized.

Selection of Teams:

In each district a team consisted of two interviewers and a note-taker. One interviewer in each team was a female. This made it easy to get the female participation smoothly at each level.

These researchers were then trained in the use of the research instrument.

Feedback & supervision:

There was a constant liaison between the team leader (BCC consultant) and the teams during fieldwork.

Data cleaning and consolidation

The data received from the field was translated into English, consolidated and organized province wise and topic wise to facilitate analysis.

Analysis of data was done according to the analytical framework, the first section discussing the findings and the next presenting the findings in tabulated form.

Reporting

The Report has been organized in to the following three sections:

Section 1: Background of the study, methodology and process adopted for eliciting the behaviors. Some of the unusual and at times dangerous practices have also been highlighted.

Section 2: A narrative analysis is given on province level and information is grouped into subtopics as existing behaviors; determinants of the behaviors; levels of delay, how to eradicate TB, primary and secondary targets; strategies and suggestions

Section 3: The findings of the Study have been presented in accordance with an already agreed analytical framework. The section contains a separate table for each province.

Chapter 2

Findings and discussion

EXISTING BELIEFS ABOUT TB:

The respondents knew that TB is a curable disease however they were not fully aware about the signs of TB and the misconceptions varied among provinces.

In Balochistan the belief comes from age-old tradition that any one who has a regular cough and sputum has TB. However the belief about spread of TB varies from tension to not having breakfast to wearing a TB patient's slippers.

In Sindh the belief about spread of TB include sharing of food and utensils or sleeping on the bed of the patient. People do not recognize TB and in the beginning it is treated as a normal cough and fever. Once there is blood in the cough or sputum and lack of sleep, loss of weight then they seek professional help.

The respondents in Punjab of this area are well aware that TB is a curable disease. However the signs and symptoms are not recognized and for the first month or two the cough is taken as a seasonal flu. It is only when the patient starts spitting blood in the sputum that the family is concerned. Misconceptions regarding the spread of the disease include sharing of utensils and spitting freely.

On the other hand in NWFP people believe that sharing of utensils, food and sitting with a patient will cause TB. They know that it is a curable disease yet the social taboo of TB exists. People believe that unhygienic environment including garbage stacks and dust along with tensions in life cause a person to get TB.

DECISION TO SEEK HEALTH CARE:

The decision to seek health care rests primarily with the head of the family and in the case of married girls the mother in law plays an important role.

HEALTH CARE SEEKING BEHAVIOR:

Majority of people are unable to seek health care primarily due to poverty and distance from the facility. The poor tend to go to the government medical facility, while the relatively well off prefer *Hakim* and private practitioner before they resort to the government facility.

Patients tend to go to the nearest health care provider whether Hakim or Homeopath or a private practitioner. In most cases the diagnosis takes a long time and only when they are

diagnosed with TB or they exhaust this medical shopping do they resort to the government facility.

In Sindh most patients live in a one-room house and the monthly income is between Rs 1000-3500. Poverty and unemployment have been found as the major issues. TB is a major social taboo having consequences on the social aspects of a patient's life. This is the case particularly for women because if they are unmarried there is a problem of getting them married and if married they face constant pressure from their in-laws. Male patients are also marginalized and slowly the patient becomes a social outcast.

SUPPORT FROM COMMUNITY:

The family tries to support the patient but community support is non-existent because of the social stigma attached to the disease. The patient is marginalized and virtually ostracized from society.

Baluchistan being a tribal society, community support, networking and participation is strong and the norms allow the patient to be accommodated within mainstream society. However due to the taboo attached to TB patients themselves reduce interaction with the community.

In Punjab the family of the patient is supportive and provides care to the patient. Nevertheless the patient may not get adequate diet not only due to poverty but also because certain foods like milk, meat and seasonal fruits are presumed to be harmful and denied to the patient.

SOCIAL STIGMA:

TB is a major social taboo causing a lot of tension and mental torture for the patient. People ignore the patient and slowly the patient develops an inferiority complex and starts avoiding people. If the patient is unmarried there is a problem in finding a match, if engaged to be married the engagement is called off and if married the family relations are strained having consequences for the children as well. When the community gets to know that there is a TB patient in the family they start avoiding that family so the family tries not to disclose this.

The social stigma attached to the disease is the major factor repeatedly mentioned by all respondents. Due to this stigma people hesitate in seeking health care lest the community finds out that they have TB, this has dire consequences for women particularly unmarried ones which is why the family avoids any mention of the disease.

Rishtadaron ki nazar badal jati hai, wo khandan ki taqreeb mai bhi nahi bulatai, apnai ghar mai bhi mareez kai samney aisi harkatain aur sargoshian kartey hain ke mareez mazeed ahsaase kamtari aur mehroomi ka shikar ho jata hai.

The relatives' attitude changes, they don't invite us to their family occasions and when they come to our house they whisper and make strange gestures in front of the patient due to which the patient gets more lonely and the inferiority complex intensifies.

The community in Baluchistan is found to be supportive of a TB patient. Once a person is diagnosed with TB the family and the community support the patient. In some instances the community admitted that there is a strained relationship between a husband and wife if the wife is the patient, which does not occur if the husband is diagnosed with TB. LHW has also been sited as a source of support in identifying the right place for treatment.

In NWFP it is perceived that the young boys and girls tend to get TB from the *Madrassas* in which they study. The primary reason given for this is that they share the utensils and live in close proximity. Students in these *madrassas*, particularly girls, tend not to follow treatment for long because having tablets will make their peers suspicious. If a person is found to have TB he is ostracized from the society. The family prefers to delay treatment as long as possible to avoid the community becoming aware of this.

NON-COMPLIANCE:

It was seen that a large number of people do not continue the treatment of TB and the respondents gave multiple reasons for this. Their responses did not vary among provinces and the reasons included the following:

- Lack of availability of medicines
- Once a patient feels better they stop treatment.
- Lengthy treatment
- Non availability of doctor and medicines
- Unfriendly attitude of health facility staff
- Long wait at the facility
- Feeling better after two or three months of treatment
- Distance of facility and the cost of traveling
- Employment – inability to skip the days work
- Fear of losing job if the disease is discovered
- Poverty
- *Purdah*
- Social stigma

Medicines are not available and if they are the paramedics sell them to the market.
Poor can not afford medicines
Without contacts and personal relationships poor people suffer a lot to get medicines and treatment.

DETERMINANTS OF BEHAVIOR

For recognition of danger signs of TB: word of mouth and community perception, blood in sputum, prolonged cough, loss of weight and lack of sleep.

Belief about spread of TB:

Belief about spread of TB:

Even though the belief about spread of TB varied among provinces the majority of respondents were of the following opinion.

- o Intake of cold food e.g.; buttermilk, yogurt etc.
- o Intake of unclean, dirty water
- o Intake of impure food
- o Eating pickles and oily food
- o Tension, frustration
- o Typhoid & Pneumonia
- o Overwork /hard work
- o Smoking cigarette, and other addictions
- o Polluted environment and Dirt
- o Poverty
- o Pre and post marital sexual relationships
- o Sharing *huqqa* in the villages
- o If anyone does not take breakfast
- o If a person goes for long walks before breakfast
- o Use of a patient's slippers and washroom
- o Sharing of utensils with a patient.
- o Close contact with a patient's sputum or with the patient

Decision-making within the family: availability of the head of the family sex of the patient and marital status of woman.

Health care seeking behavior: availability of resources and availability and distance of facility, *purdah*

Non compliance to treatment: various factors were identified for non compliance which included

- o Social Stigma
- o Lack of availability of medicines
- o Expense of tests and medicines
- o Poverty
- o Improvement in condition in the first two months: people tend to leave the treatment once they feel better.
- o Inability to take too much time off from work to go to the doctor or take the female patient to the doctor

CONSTRAINTS IN SEEKING HEALTH CARE :

First constraint: The first and foremost constraint occurs at the household level where the signs of TB are not recognized. If a person has continuous cough with sputum they decide to go to a doctor. In most cases TB is recognized when the patient starts spitting blood.

We find out after a long time that we have TB. In the beginning we take it as normal cough and fever. Sindh

*We are not doctors to recognize TB but we have heard from our elders that it can be recognized by regular cough and sputum.
TB is a ghost. Balochistan*

The decision to go to a health practitioner and to the type of practitioner depends on the head of the family. In the case of unmarried women it rests with their fathers or brothers and in the case of married women husbands are the primary decision makers. The mothers in law are also found to play a role in this. For men the decision depends solely on the availability of resources.

Mard ko ho jaiye to fauran elaj karaya jata hai khas taur par agar wo kamaney wala ho to
If a man gets it the treatment is immediate, particularly if he is an earning member of the family

Agar aurat roz shehr akaili jai to log kehte hein bimari to aik bahana hai ye sair karne jati hai
If a woman goes to the city alone every day people say that illness is an excuse she goes to the city for entertainment.

Sas samajhti hai ke us ke bete ko aur uski aulad ko lag jai gi iisleay larki ko talak dilwa deti hai
Mother in law thinks that her son and his children will get this too so she gets her daughter in law divorced
Kanwari larkiun ki shadian nahi hotin aur unke ma bap bechare bohat pareshan hote hain
Unmarried girls do not get married and their parents get really worried.

Second Constraint

The people tend to go to various medical practitioners before going to the government facility, which also causes a delay in the treatment. The Hakim and Homeopath treat this as normal cough and only when the patient is not cured does the family tend to go to a private doctor who in most instances also takes a long time to diagnose the disease. Once diagnosed there is an unwillingness to accept the diagnosis and the patient's family then takes them to various doctors, which also delays the treatment. Once they reach the government medical facility and they are treated for TB the long process of tests and medicines along with the waiting time in the hospitals makes the patients feel dejected.

Third constraint: At the level of the facility the attitude of the health care provider is the major problem. The poor respondents primarily go to the government facilities where there is a lack of medicines and without contacts or bribery the patient is unable to get to a doctor. The attitude of the doctor and paramedics is also not friendly and enterprising with the poor people. This along with the long waiting time causes the patient to feel dejected and not comply with the treatment

Safarish walon ko saholiat milti hain ham gharibon ko muft mashwara

The ones who have contacts get the facilities, we poor only get free advice

Ham gharibon ke sath sarkari haspatal wale both badtamizi karte hain aur dawai bhi nahi dete

The people in the government hospitals are very rude with us poor people and they don't give us medicines either.

Sarkari haspatal mai rishwat chalti hai jis ke pas paisa hai uska kam ho jata hai sahoalat bhi milti hai

In the government hospital all that works is bribery, the ones who have money get their work done and have access to all the facilities.

Yeh to hai hi gharibon ki bimari aur ham gharibon ko kaun poochey ga doctor aur tamam log haspatal main hamai nafrat se dekhte hain jab tak ke aap ke pas paisa na ho tab tak eilaj mushkil hai

This is a disease of the poor and who will be concerned with the poor. The doctor and everyone else at the hospital look at us with contempt. Unless one has the money treatment is very difficult.

The delay occurring at this level is of particular importance and the most significant aspect that has been sited is the attitude of the health care provider. The provider may not diagnose the problem or may ask for tests, which are very expensive, and every health facility may not have the laboratories or the doctor may use delay tactics to get more money. Another issue that has been identified is that TB is seen as a disease of the poor and hence the attitude of the provider particularly in a government facility is derogatory.

The medical store keeper of government centers sells the medicines to the private stores and ask us poor people to buy them from there. We cannot afford to buy these drugs.

The doctor takes an unnecessarily long time in seeing the patients and when our turn comes it is either time for his tea or for him to go home. He asks the patients to come to the private clinic in the evenings where he will take a lot of money we can not afford to pay that every time.

Other aspects are

- Lack of availability of beds
- Lack of availability of laboratories for tests
- Lack of medicines
- Expense incurred during tests and for medicines.
- Delay in treatment seeking due to first interaction with private practitioner or late diagnosis.
- Paramedics have also been found to use delay tactics to make money.

HOW CAN TB BE ERADICATED:

The majority of respondents were of the opinion that the government can play a major role in eradicating TB. Many said that at the national level the federal minister can ensure provision of DOTS and TB treatment in all provinces particularly in the rural areas. Government should also ensure provision of medicines at every facility. Monthly camps in rural areas should also be set up to run tests for TB diagnosis and provide medicines to patients.

Awareness about the signs of TB, the facility where treatment is available and importance of compliance to the treatment can be raised through health education at the community level. The LHW can play a role in this. The tribal chiefs, Jirgas, community leaders and the Nazim along with community members can be involved to raise awareness among community members. Local representatives, religious leaders, community members and cured patients can be used to educate the community. Family members should be made responsible for DOTS and the campaign for DOTS should be widely advertised by the government.

The respondents suggested that the way to begin is from within the community. Awareness about TB symptoms, its treatment and cure should be raised within the community with the support of the community leaders, men and the cured patients

Social organizations at the community level can be used to assist the government in raising awareness as well as taking the patient to the right facility and preventing the delay in seeking health care.

The health care providers can be given trainings and capacity building sessions so that their attitude with the patients improves and they are able to provide counseling sessions to the patients and their families. The facilities should be equipped with medicines and laboratories so that the patient saves time and money. The LHW can also play a role in supporting compliance to DOTS

One important suggestion given by a majority of respondents from all provinces was that whereas the LHW and community should be involved in awareness raising, a family

member should be responsible for the compliance to TB treatment. This would ensure that the community will not be aware of a person contracting TB.

PRIMARY AND SECONDARY TARGETS:

The TB patients and their families should be primary targets. The community influentials and tribal chiefs should be the secondary targets for recognizing signs of TB and seeking treatment.

For providing treatment health care providers including the paramedics and LHWs should be the primary targets and the community social organizations and community leaders should be secondary targets.

STRATEGIES AND SUGGESTIONS:

- TB patients and their families should be given knowledge about a clean house and environment and healthy food.
- Awareness campaigns regarding signs and symptoms of TB and its treatment should be run regularly in communities with the help of social organizations and LHWs.
- Health care providers should be trained and their capacity built in order to provide better treatment and counseling to patients.
- Availability of medicines should be ensured at the facility.

- Mass awareness raising campaigns should be run to reduce the social stigma attached to TB and to bring to light the symptoms and treatment of TB.
- DOTS like polio should be a national campaign.
- Private public partnerships should be initiated to train the HCP in diagnosis of TB.
- Monthly camps should be set up in rural areas to facilitate treatment.
- Medicines and diagnostic test facilities should be ensured at all TB centers.
- Private doctors, *Hakims* and *Homeopaths* should be trained to recognize and diagnose TB for the timely referral of patients.

DISCUSSION

Most preventive health programme especially the TB control programme is implemented through the government facilities. The urban respondents had more contact with private doctors who are generally unaware of the TB control initiative and have no time to impart health education messages. It was only in the case of the rural men that the doctors were an important source of information on tuberculosis. The role of media both radio television and newspaper was limited.

These results highlight the dire need to intensify the health education component of the TB control programme. There should be more involvement of the private sector especially in urban areas. Many intensified efforts are needed by the media not only to promote health education, but also to help in the de-stigmatization of the disease in the rural areas. Lady health workers could be utilized to improve awareness on tuberculosis especially in rural females. TB patients especially females face social isolation by family and community. Females whether married or unmarried face a greater burden of rejection by friends and families. Misconceptions about the contagious nature and curability lead to the idea that TB is a disease to be feared and TB patients are to be social isolated. A concentrated effort by media, doctors and health workers is required to remove these misconceptions in order to remove the stigma associated with the disease. The policy makers should also keep in mind, the constraints expressed by females about regular visits to the health facilities and administration of TB medicines under supervision. To reduce defaulter rate alternative means like involving Lady Health workers have also been considered.²

Due to restricted mobility females are dependent on male family members to either accompany them or get the medicines on their behalf. It has been found that if accompanied women face other social barriers and problems.³

Majority of the patients and their family members had misconceptions about the actual cause of tuberculosis. Researches have found that people associate the disease with season, work, environmental hazards and other chronic physical problems like cold and constipation.²

Transport was the major problem encountered by majority of the interviewed patients. A large number of researches have also sited availability and cost of transport as major constraints expressed by the patients.²

Economic difficulties were faced by majority of the families during the illness. Employment productivity of the males was affected in almost all cases, and many men

2 Agboatwalla, Mobina, 2001-2002, Studying gender perspective in knowledge, attitude and practices concerning tuberculosis in Pakistan's Sindh province

3 Javed Sarah, Qualitative research on TB trial patients of DOTS.

had to abandon their jobs temporarily or permanently in a few cases. Economic support had to be given by other family members, like wife, daughter, son and brother.²

This adds to the economic burden along with the emotional and mental trauma of the patient. From the patient's point of view since the course of treatment is long and since most patients' symptoms are cured in 3-4 weeks of treatment, patients are often unwilling to continue their treatment.⁴

Medical shopping is common practice in Pakistan. Patients tend to decide very quickly if a treatment is successful or not, they want rapid relief from their major symptoms, any side-effects make them question the effectiveness of the treatment. When they do not see improvement within a few days they go somewhere else. As a result, a succession of different health care providers is consulted in a relatively short span of time.⁵ There is an urgent need to educate people and raise their awareness regarding TB treatment, its time span and the need to continue treatment for the required time.

In Pakistan TB is perceived as a serious contagious disease. People fear TB and consider it a dangerous and major disease. It is seen as a family disease that may destroy whole families. Although it is a well-known disease, it was found that the cause of disease, its early signs and symptoms, the length of the treatment and the danger of defaulting are not well understood. (Dataline Services, 1998) Treatment defaulting not only increases the risk of spreading the disease but also of drug resistance, hence the importance of case holding. In Pakistan treatment adherence is overall very low (Arif et al., 1998). In dataline study (Dataline Services, 1998) non-satisfaction with the disease was the main reason for defaulting.

In Pakistani communities, social costs are especially high for individuals identified with TB; women in particular are fearful of contracting TB because it decreases a single woman's marriage prospects and increases married women's vulnerability to divorce. Such stressors discourage women from acknowledging symptoms and seeking appropriate care.⁶

Stigmatization of TB patients is almost universal (Carey et al., 1997; Sumartajo, 1993). TB is a problem not only in the affected person. Once a family member is known to have TB, the entire family might be shunned. It is easily understood then, why family members are shocked when informed about the diagnosis of TB and why they often try to hide the truth from others.

Young TB patients in Pakistan related how they might experience difficulty in finding a partner and how engagements might be broken off. Difficulties might even be

⁴ Khan A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment. *Social science and medicine* 50 (2000) 247-254

⁵ Leifoghee. R. Tuberculosis in Pakistan: The forgotten plague 2000, 41

⁶ Tuberculosis, gender and health seeking behaviors, WHO, 2004

experienced in consolidating a marriage arrangement for family members of the TB patients. Patients may be reluctant to send their children, especially children of marriageable age for treatment. Divorce is another indirect consequence of tuberculosis. Divorce and broken engagement appear to occur more in female TB patients.⁴

Health care providers are also seen to contribute to non-adherence by their behavior and attitude. Researches on HCP behavior included observation in consultation room in BH which pointed out the physicians' reluctance to examine TB patients; they tried to keep a considerable distance between the patients and themselves/ some attitudes of the medical staff reinforced the erroneous ideas that even after several weeks of treatment, patients remained very infectious (Grange & Festenstein, 1993). Health education messages isolation and the use of separate utensils rather than the curability of the disease further strengthen the existing stigmatization among the population (Dataline Services, 1998).⁴

Private Doctors are often considered an obstacle and are said to have a negative impact on the implementation of the national disease control program.

CONCLUSION AND RECOMMENDATIONS:

People have become aware that TB is a treatable and curable disease yet the social stigma is prevalent in all segments of the society. This has consequences for all patients, causing delay in seeking treatment. Nonetheless the consequences are much stronger for women. This social stigma can be eradicated with effective awareness raising campaigns and health education at all levels.

People take the cough as normal and treat it with home remedies. It is only when the severe symptoms start appearing that they consult a doctor. If the typical symptoms do not occur the disease is not diagnosed which further delays the treatment. Once diagnosed with TB people prefer to consult various health care providers, which cause a further delay in treatment.

Patients also get tired of the long treatment, the cost in terms of money and time are a major reason for non-compliance to treatment. Distance of the facility, non-availability of tests and medicines coupled with the non-friendly attitude of the health care provider further deters the patient from treatment.

In 1998 the government of Pakistan recognized TB as a social problem, consequently due to political commitment the policy also changed and the government showed an enhanced commitment to eradicate TB from the society. DOTS is a new strategy which involves the family, community and Health Care Provider. It takes TB as a collective social problem instead of an individual one. DOTS was piloted in 3 districts in Pakistan and at this point it is running in 94 districts. None of the patients were aware of DOTS and there is an urgent need to make people aware of DOTS for which the government can play a major role.

The government needs to have a more proactive approach to eradicate TB from Pakistan and launch a strong DOTS campaign with the help of media and the community leaders. Simultaneously the public health services need to be improved to ensure that the poor are able to access the facilities, medicines and diagnostic treatment. This multipronged approach will be the most effective way to ensure better compliance to TB treatment and get rid of the stigma attached to it.

STRATEGIES AND RECOMMENDATIONS:

- ✓ Awareness regarding TB should be raised at school level.
- ✓ A political commitment to DOTS needs to be enhanced at the government level.
- ✓ Private public partnership should be strengthened in order to effectively diagnose and treat TB.
- ✓ Community leaders, religious leaders and social organizations at the community level should be included to run the DOTS awareness campaign and eradicate the social stigma.
- ✓ At Federal and provincial level medicines supply should be ensured at all facilities.

- ✓ The tests and other diagnostic treatment should be made accessible to the communities.
- ✓ MNAs MPAs and local Nazims and councilors should be involved in the TB campaign.
- ✓ TB day should be celebrated at the national level.
- ✓ Like Polio TB campaign should be launched in Pakistan through mass media.

**List of Existing Behaviors Vs. Risky Behaviors regarding Tuberculoses
BALUCHISTAN**

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
Knowledge of Signs and Symptoms	Lack of knowledge of tuberculosis Health Seeking behaviors	Word of mouth and community perception of signs of TB The belief comes from age old tradition that any one who has a regular cough and sputum has TB.	-Mostly patients are unaware of the signs and symptoms of the disease at the initial stages. Till the person's cough persists for more than a month it is not considered significant	-Although they are unaware of the signs and symptoms but they know that it is curable -People also recognize some signs and symptoms of the disease cough, blood in sputum.
Barriers in Access and Treatment	-Lack of awareness Poverty /Socio economic factors	-Due to ignorance, unawareness and lack of knowledge patients initiate the treatment very late -Lack of resources is one of the major barrier in timely health care seeking -Inability of the patients to purchase all the medicines. Treatment is available in Quetta only and most patients can not afford it.	The attitude of HCP and lack of medicines and diagnostic facilities causes the patients to be dejected. -A lot of precious time is wasted before the right treatment and care is provided	Parents and some husbands are very cooperative to facilitate the patient for TB treatment. They help the patient in getting the treatment and provide moral support. Community is very supportive of the patient.
Misconceptions	Misconception regarding the spread of disease	The belief about spread of TB includes Dust in water	-Timely treatment is not received -Sharing of utensils with the patients can be a potential risk as this, can be a	

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	-At health facility level	in diagnosing the disease in order to make money -Time wasted during tests -Non availability of HCP -Non availability of medicine		

**List of Existing Behaviors Vs. Risky Behaviors regarding Tuberculoses
SINDH**

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
Knowledge of Signs and Symptoms	Lack of knowledge of tuberculosis Health Seeking behaviors	Until the patient starts spitting blood in the sputum the cough is considered normal and is treated with home remedies.	-Mostly patients are unaware of the signs and symptoms of the disease at the initial stages. -Cough and fever is considered normal.	-Although they are unaware of the signs and symptoms but they know that it is curable -People also recognize some signs and symptoms of the disease cough, weight loss, blood in sputum and fever.
Barriers in Access and Treatment	-Lack of awareness Poverty /Socio economic factors	-Due to lack of awareness about symptoms of TB the treatment is delayed. The decision to seek health care rests with the male head of the family lack of resources is one of the major barrier in timely health care seeking -distance of the facility also serves as a deterrent -non availability of health care providers and medicines at the treatment centers -Inability of the patients to purchase the medicine	-the attitude of the HCP is not friendly and hence people do not get relevant knowledge about TB or its treatment -A lot of precious time is wasted before the right treatment and care is provided	

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
Misconceptions	Misconception regarding the spread of disease	people believe that any form of close proximity can be contagious.	The patient is ostracized and hence faces low self esteem which causes the patient either not to seek medical treatment or not comply with it.	
Health care seeking behaviors	Lack of information Poverty and unemployment Length of treatment makes it difficult to comply	-People initially seek traditional home remedies for cough the men if employed/earning members of the family easily seek treatment. Females are unable to do so. The cost of medication and tests is unaffordable for most people. The non availability of doctor at the government facility also causes patients to feel dejected. The distance to travel to the health facility and the cost of traveling is another deterrent. Length of treatment also increases non compliance. Complete treatment is not practiced	This takes 2-8 months of their precious time and the disease becomes bad to worse during this period Drug resistance occurs when the medicines are not taken in the prescribed way	
Stigma	Attitudes of the community members towards the patients	-Patients are marginalized and ostracized from society. -Community members and relatives avoid the patient and his family. They act strangely and do not invite the patient and his family to social gatherings which further pushes the patient towards an inferiority complex.	-Treatment is delayed for many months which results in to dangerous consequences -To keep hiding their health problem delays in treatment occur patients may stop treatment	-Immediate family members are supportive and understanding (Parents, siblings and spouses)

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	Gendered face of TB	<ul style="list-style-type: none"> -Female faces more problems regarding marriages, engagements are called off if a girl gets TB and parents of girls face problems in finding suitors for them. -Married women are divorced with the fear that disease will affect the husband and children -Mother in Laws make the life of her daughter in law miserable -Parents hide the disease of their daughter as other wise she will remained unmarried 	<ul style="list-style-type: none"> -Parents hesitate to take their daughter for checkup as it may reveal the secret. This causes a delay in seeking care as well as increasing non compliance 	
Non Compliance		<ul style="list-style-type: none"> Lengthy treatment Non availability of doctor and medicines Unfriendly attitude of health facility staff Long wait at the facility Feeling better after two or three months of treatment Distance of facility and the cost of traveling Cost of treatment 		
Delays in treatment	-At household level	<ul style="list-style-type: none"> -Lack of knowledge about signs and symptoms -Lack of support from the family -social stigma attached to TB 	Treatment is delayed	<ul style="list-style-type: none"> -Family is very supportive -Some health care providers are very cooperative

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	-Community level -At health facility level	particularly for women -Fear of community -Non availability of HCP -Non availability of medicine unfriendly attitude of the HCP		

**List of Existing Behaviors Vs. Risky Behaviors regarding Tuberculoses
PUNJAB**

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
Knowledge of Signs and Symptoms	Lack of knowledge of tuberculosis Health Seeking behaviors	2 - 8 months are wasted before tuberculosis disease is diagnosed (Medical shopping)	-Mostly patients are unaware of the signs and symptoms of the disease at the initial stages. -Cough and fever is considered normal due to weather change and no attention is given at least at the first month of disease	-Although they are unaware of the signs and symptoms but they know that it is curable -People also recognize some signs and symptoms of the disease cough, weight loss, blood in sputum and fever.
Barriers in Access and Treatment	-Lack of awareness Poverty /Socio economic factors	-Due to ignorance, unawareness and lack of knowledge about the TB treatment centers, patients initiate the treatment very late -Money and lack of resources is one of the major barrier in timely health care seeking -Inability of the patients to purchase the medicine -Inability of the patients to eat a balanced diet -Precaution is difficult, as patient is restricted to eat some foods because other foods like buttermilk, pickles etc are told to be harmful -Fear of the large amounts of	A lot of precious time is wasted before the right treatment and care is provided They ask us to buy the medicines from private stores. , x-rays and tests etc.	Parents, and some husbands are very cooperative to facilitate the patient for TB treatment. They help the patient in getting the treatment and provide moral support.

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	Cultural restrictions	<p>medicines given, patient get fed up with eating medicines for such a long time</p> <ul style="list-style-type: none"> -Daily laborer/bread earner cannot afford to waste time in hospital as he has to support the family members as they have to keep working everyday in order to earn their day's living -Inability of old and weak patients to go regularly to the hospital to get treatment and medicine because of limited resources <p>The availability of the male family members to assist in taking the females to the health care centers is difficult due to their professional commitments and their financial status.</p>		
Misconceptions	Misconception regarding the spread of disease	<ul style="list-style-type: none"> -Intake of cold food e.g; buttermilk, yogurt etc. -Intake of unclean, dirty water -Intake of impure food -Tension, frustration, -Typhoid & Pneumonia -Overwork /hard work -Eating pickles and oily food -Smoking cigarette, and other addictions -Polluted environment and Dirt -Poverty, -Pre and post marital sexual relationships 	<ul style="list-style-type: none"> -A number of foods like milk, meat and seasonal fruits are denied to the patients which can provide the required calories in limited budget -Timely treatment is not received -Sharing of utensils with the patients can be a potential risk as this, can be a source of spreading the bacilli -Spitting openly / sputum is not disposed of with care 	Some patients take care of the family members and avoid sharing of utensils and spitting in the house to keep them safe from the disease.

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
		-Eating at hotels -Sharing huqqa in the villages		
Health care seeking behaviors	Lack of information Poverty Stigma Attitudes of the community members towards the patients	-Consult the private doctors - When TB is diagnosed patients prefer TB center -Inability to buy the treatments because of the unavailability of the medicines at the government treatment center -Employment – inability to skip the days work Patients are left out of the social systems -They look down upon the TB patients. -Employers make the TB patients	This takes 2-8 months of their precious time and the disease becomes bad to worse during this period Treatment is stopped -Treatment is delayed for many months which results in to dangerous consequences -To keep hiding their health problem	-Few people after diagnosis of the TB, seek regular treatment from TB centers -Parents of the patients and some husbands of the female patients are very supportive for female treatment Treatment is available at the treatment centers -Immediate family

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	Length of treatment makes it difficult to comply	<p>leave their jobs (small scale businesses, household servants)</p> <p>-Friends and relatives change their dealings</p> <p>-Married women are divorced with the fear that disease will affect the husband and children</p> <p>-Parents hide the disease of their daughter as other wise she will remained unmarried</p> <p>-People don't share the disease as it labeled them from Low socio economic status</p> <p>-Fear of the relatives and community members</p> <p>-Remaining unmarried</p> <p>-Social exclusion</p> <p>Complete treatment is not practiced</p>	<p>delays in treatment occur</p> <p>Drug resistance occurs when the medicines are not taken in the prescribed way</p> <p>Length of treatment</p>	members are supportive and understanding (Parents, siblings and spouses)
Non Compliance		<p>-Fed up with long treatment</p> <p>-After the symptoms disappear the patients skip or sometimes stop the treatment</p> <p>- The HCP ask them not to eat rice, pickles and oily food.</p>		
Delays in treatment	-At household level	<p>-Lack of knowledge about signs and symptoms</p> <p>-Lack of support from the family</p>	Treatment is delayed	<p>-Family is very supportive</p> <p>-Some health care providers are very</p>

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	<p data-bbox="443 651 638 678">-Community level</p> <p data-bbox="443 776 695 803">-At health facility level</p>	<p data-bbox="730 321 940 378">-Fear of community -Medical shopping</p> <p data-bbox="730 410 1045 500">-Time wasted during tests -Non availability of HCP -Non availability of medicine</p> <p data-bbox="730 621 1098 678">stigma attached to the disease so people do not follow the treatment</p> <p data-bbox="730 719 1066 833">poor attitude of the provider lack of medicines and non availability of facilities for tests cost of treatment</p>		<p data-bbox="1589 321 1715 349">cooperative</p>

**List of Existing Behaviors Vs. Risky Behaviors regarding Tuberculoses
NWFP**

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
Knowledge of Signs and Symptoms	Lack of knowledge of tuberculosis Health Seeking behaviors	2 - 8 months are wasted before tuberculosis disease is diagnosed (Medical shopping)	-Mostly patients are unaware of the signs and symptoms of the disease at the initial stages. -Cough and fever is considered normal and no attention is given at least at the first month of disease women prefer not to say that they are unwell.	-Although they are unaware of the signs and symptoms but they know that it is curable -People also recognize some signs and symptoms of the disease cough, weight loss, blood in sputum and fever.
Barriers in Access and Treatment	-Lack of awareness Poverty /Socio economic factors	-Due to ignorance, unawareness and lack of knowledge about the TB treatment centers, patients initiate the treatment very late -Money and lack of resources is one of the major barrier in timely health care seeking -Unavailability of reliable transport in the rural areas particularly for women -Unavailability of health care providers and medicines at the treatment centers -Inability of the patients to purchase the medicine -Inability of the patients to eat a balanced diet	-Attitudes of HCP is not very encouraging and cooperative. They don't give attention to the patients. -A lot of precious time is wasted before the right treatment and care is provided	

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	Cultural restrictions Gendered face of TB	-Store keepers of the government treatment centers sell the medicines to the private stores and the poor patients have to buy it from there, which in most cases is not possible for them due to limited resources -Male members do not allow their female family members to go to hospital for treatment alone. The availability of the male family members to assist in taking the females to the health care centers is difficult due to their professional commitments and their financial status. -Mother in laws do not allow their daughter in laws, as they think that they are wasting their husbands money and time.	-Mothers in law suspect their daughters in law that they are just going to have fun outside; They want to avoid domestic chores. Hence women evade treatment	
Misconceptions	Misconception regarding the spread of disease	coming in close contact with the patient, sharing of utensils	-Spitting openly / sputum is not disposed of with care	Some patients take care of the family members and avoid sharing of utensils and spitting in the house to keep them safe from the disease.
Health care seeking behaviors	Lack of information	-People initially seek traditional home remedies for cough -Resort to easily accessible dispenser, hakeems and homeopaths -Consult the private doctors - When TB is diagnosed patients prefer TB center	This takes 2-8 months of their precious time and the disease becomes bad to worse during this period	-Few people after diagnosis of the TB, seek regular treatment from TB centers -Parents of the patients and some

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	<p>Poverty</p> <p>Cultural factors</p> <p>Length of treatment Makes it difficult to comply</p>	<p>-Inability to buy the treatments because of the unavailability of the medicines at the government treatment center</p> <p>-Inability to bear the transportation costs</p> <p>Observance of Purdah</p> <p>Male health care providers</p> <p>Complete treatment is not practiced</p> <p>girls in particular fear that having tablets will disclose to others that they have TB</p>	<p>Treatment is stopped</p> <p>Females are unable to access the health facility on their own which denies timely treatment</p>	<p>husbands of the female patients are very supportive for female treatment</p>
Stigma	Attitudes of the community members towards the patients	<p><i>-Patients are marginalized and community avoids them</i></p> <p>-Community members, relatives and other outsiders are non-cooperative as they think that this disease can be transferred with the slightest of interaction</p> <p>-Friends and relatives change their attitudes</p> <p>-Female faces more problems regarding their marriages</p> <p>-Married women are divorced with the fear that disease will affect the</p>	<p>-Treatment is delayed for many months which results in to dangerous consequences</p> <p>-To keep hiding their health problem delays in treatment occur</p> <p>Drug resistance occurs when the medicines are not taken in the prescribed way</p>	<p>-Immediate family members are supportive and understanding (Parents, siblings and spouses)</p>

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
		husband and children -Mother in Laws make the life of her daughter in law miserable and suspect that she is only showing tantrums -Parents hide the disease of their daughter as other wise she will remained unmarried -People don't share the disease as it labeled them from Low socio economic status - -Parents hesitate to take their daughter for checkup as it may reveal the secret		
Non Compliance		- Non availability of medicines Expense of tests and medicines Purdah Lack of transportation Poverty		
Delays in treatment	-At household level	-Lack of knowledge about signs and symptoms In case of female patients the care provision is even delayed as she is not considered a productive/earning hand of the family The stigma is also stronger in females -Lack of support from the family -Timely transportation is difficult to	Treatment is delayed	

Specific area	Behavior determinant	Current practices	Risky Behaviors	Positive Behaviors
	<p data-bbox="443 407 638 435">-Community level</p> <p data-bbox="443 529 699 557">- At health facility level</p>	<p data-bbox="730 318 1115 375">find at the community especially for females</p> <p data-bbox="730 380 942 407">-Fear of community</p> <p data-bbox="730 412 930 440">-Medical shopping</p> <p data-bbox="730 469 968 496">Lack of transportation</p> <p data-bbox="730 501 814 529">Poverty</p> <p data-bbox="730 534 806 561">Purdah</p> <p data-bbox="730 566 873 594">Social stigma</p> <p data-bbox="730 599 1089 656">Non availability of medicines and tests</p> <p data-bbox="730 660 894 688">Long treatment</p> <p data-bbox="730 693 1003 721">Non availability of doctor</p> <p data-bbox="730 725 1104 782">Poor attitude of doctor and hospital staff.</p>		