

The Role Of NGO's And CBO's In Neutralizing The Socio-Behavioral Hindrances Leading To Stigmatization Of TB

Dr. Mubina Agboatwalla ⁽¹⁾

Dr. G. N. Kazi ⁽²⁾

Dr. Karam Ali Shah ⁽³⁾

Dr. Asim Musarrat ⁽¹⁾

Mr. Asif Ahmed ⁽¹⁾

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1. Health Oriented Preventive Education (HOPE), Pakistan
2. World Health Organization, Pakistan
3. National Tuberculosis Programme (NTP)



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Executive Summary

In relation to the occurrence of tuberculosis, Pakistan is ranked as the 6th country in the descending order. WHO has estimated that the incidence of sputum positive cases in Pakistan is 81/100,000 population and the incidence of all TB cases is 181/100,000 population. Despite a high incidence of tuberculosis it is still regarded as the disease to be ashamed of, to be concealed and not to be even disclosed to spouses. The stigma associated with the disease results in less females reporting to TB centers because they and their families generally try to hide the disease. Stigma about the disease can only be dealt with at the community level by raising awareness at the household level and through interpersonal communication. The misconceptions about the disease can be removed by involving the NGO's and the CBO's who are working at the grass root level. This study was conducted with the overall aim of reducing the stigma associated with tuberculosis in patients suffering from tuberculosis, especially females by involving NGO's and CBO's. The main objectives of the study were

1. To reduce the stigma associated with tuberculosis with the help of NGO and CBO's
2. To clarify the misconceptions about the disease especially pertaining to females so as to alter health seeking behavior
3. Improve case detection and treatment success rate in both males and females by neutralizing the stigma associated with the disease.

The study was conducted in 2 rural settings of District Thatta. The Intervention area was within 5 km of the Diagnostic and Treatment Centre in Civil Hospital, Thatta. The control area included the villages located within 5 km of the Diagnostic and Treatment Centre located in Jhirk. Both sites were geographically distant. Villages have strong CBOs which had previously taken an active part in overall issues pertaining to health, education and social issues were involved in the study. At the baseline a pre intervention survey was conducted in both the control area

(Jhirk) and intervention area (Thatta). This was followed by intervention in the form of health awareness campaigns at the grass root level through NGO's and CBO's. The post intervention survey was conducted at the end of health awareness campaign. Interviews were conducted with TB patients, key informant interviews with community leaders and focus group discussions.

Interesting results were obtained in the study. In the pre intervention and control groups nearly 92% patients agreed that they felt ashamed on developing tuberculosis which was reduced to 59% post intervention. Around 89% patients said they tend to hide the disease from others but after intervention only 54.6% agreed to it. This took place secondary to the reaction of other family members including social boycott (esp. in females 58 to 60%) look down upon / hate (females 37 to 39%, males 56 to 60%), family members staying away (56 to 60%). Tuberculosis was considered a dangerous disease and pre intervention 44% female patients got scared on first hearing that they had developed tuberculosis which was reduced to 31% post intervention while 14.5% patients developed a fear of death reducing to 6.5% in post intervention. Initially only 8 to 9% patients considered starting treatment which was increased to 30% post intervention. In this they were supported by family members. In fact 35 to 40% family members had started to give support for treatment.

TB patients in the pre intervention and control groups had a number of misconceptions about tuberculosis regarding marital relations, female infertility and complications during pregnancy, whereby nearly 80 to 85% females and males patients agreed and strongly felt that tuberculosis strongly affects them. This also lead to the husbands divorcing their wives or families tending to break off engagement of unmarried female TB patients. Health awareness lead to a decrease in this perception about female reproductive issues being affected by tuberculosis, as post intervention only 40% of respondents still felt the same.

The impact of the health education campaign was manifest in the number of cases detected in the intervention and control groups. In the first quarter i.e in the baseline 27 TB cases were detected in the intervention area and 13 cases in the Jhirk area, giving an incidence of 21.6/100,000 in Thatta and 23.6/100,000 in Jhirk. Once the health awareness campaign started a substantial rise in the number of cases started taking place in Thatta whereby 35 cases were detected in the second quarter, 45 cases in the third quarter and 34 cases in the fourth quarter giving an incidence of 28/100,000 and 36/100,000 in the second and third quarter respectively. On the contrary in Jhirk (control area) the number of TB cases detected dwindled from 8 cases in the second quarter to only 4 cases in the fourth quarter, thus giving an incidence of 14.5/100,000 in the second quarter to 7.2/100,000 in the fourth quarter. The health awareness created at the community level through the network of CBO's and NGO's helped in removing the perceived misconception in minds of the masses at the community level. The stigmatization of TB as a disease was highly manifest at the baseline survey both in control and pre intervention areas.

Though this was a pilot project, it strongly demonstrated that in the masses TB is still considered a highly stigmatized disease and TB patients do not seek treatment, rather hide the disease due to fear of social boycott. This community intervention effectively demonstrated that involvement of NGO's and CBO's as well as key community leaders not only reduces perceived misconceptions about TB but also improves the case detection rate. It is strongly recommended that the project be replicated in other areas of the country at the national level. The National TB Control Programme (NTP) should involved community based organizations to improve case detection rates through the DOTs programme.

Introduction

In relation to the occurrence of tuberculosis, Pakistan is ranked as the 6th country in the descending order (1). WHO has estimated that the incidence of sputum positive cases in Pakistan is 81/100,000 population and the incidence of all TB cases is 181/100,000 population (2). Though Sindh has achieved 100% DOTs coverage in public health facilities, overall case detection rate is still low i.e. 37% with a high default rate ranging between 10-25% (2).

Despite a high incidence of tuberculosis it is still regarded as the disease to be ashamed of, to be concealed and not to be even disclosed to spouses. Female health seeking behavior is determined by how tuberculosis is perceived by them. The stigma associated with the disease results in less females reporting to TB centers because they and their families generally try to hide the disease. One of the studies from Gambia-West Africa reported that females generally had negative perceptions about tuberculosis associated with stigma resulting in less females accessing health care for TB (3). In Vietnam it was seen that on being diagnosed as TB patients males were more concerned with economic related issues while females were more concerned with social consequences (4). Fear of social isolation lead to denial and concealment as seen in another study from Vietnam (5). A review of gender differences in tuberculosis by Hudelson showed that fear and stigma associated with TB had a greater impact on women leading to delay in accessing health care (6, 7). Similar results were obtained from Syria and Egypt (8, 9). In a recent study conducted in Pakistan showed that females feared social isolation if they were found to have tuberculosis. Rejection by friends and families is feared by both married and single women. Studies both in Pakistan and Egypt revealed that TB in females affected their marital aspects and relationships (9,10). Because of gender disparity low priority is given to females to travel and seek medical help. In addition, due to socioeconomic constraints females are unable to continue treatment for long time.. Because of traditional taboos females are not allowed to regularly visit the TB DOTs centers for treatment hence less female patients report to TB centers.

Stigma about the disease can only be dealt with at the community level by raising awareness at the household level and through inter personnel communication and the misconceptions about the disease can be removed by involving the NGO's and the CBO's who are working at the grass root levels.

Aims and Objectives

Goal

The overall aim of this study is to reduce the stigma associated with tuberculosis in patients suffering from tuberculosis especially females by involving NGO's and CBO's.

Objectives

1. To reduce the stigma associated with tuberculosis with the help of NGO and CBO's
2. To clarify the misconceptions about the disease especially pertaining to females so as to alter health seeking behavior
3. Improve case detection and treatment success rate in both males and females by neutralizing the stigma associated with the disease.

Methodology

The study was conducted in 2 rural settings of District Thatta. The intervention area was within 5 km of the Diagnostic and Treatment Centre in Civil Hospital, Thatta, having population of 125,000. The control area included the villages located within 5 km of the Diagnostic and Treatment Centre located in Jhirk with population of 55,000. Both sites were geographically distant. Rural areas of Thatta comprise of sparsely located villages with lack of basic amenities especially health and education facilities. Literacy rate is very low especially in females. Traditional practices and taboos control their health seeking behaviors.

Villages having strong CBOs which had previously taken an active part in overall issues pertaining to health, education and social issues were part of the study.

At the baseline a pre intervention survey was conducted in both the control area Jhirk and intervention area Thatta. . This baseline survey comprised of qualitative data collection from both the areas. In the intervention area Civil Hospital, Thatta data was obtained from the following villages

1. Shah Mohd Magsi Goth
2. Sharif Palari Goth
3. Allah Bachayo Goth
4. Shah Mohd Magsi Goth (2)
5. Allah Bachayo Goth (2)
6. Sommar Narijo Goth
7. Sommar Khaskhili Goth
8. Sommar Khaskhili Goth (2)

While in the control area Jhirk, baseline data collection took place in the following villages

1. Mir Bher (Jhirk)
2. Mir Bher (Solangi Para) Jhirk
3. Lassi Mohalla (Jhirk)

4. Rind Goth (Jhirk)
5. Memmon Goth (Jhirk)
6. Kumbar Para Goth (Jhirk)
7. Mir Bher Village (Jhirk)
8. Rind Mohalla (2) (Jhirk)

Community based organizations (CBO's) in the area were approached and information about project activities was given specially relating tuberculosis cases in the villages and the stigma associated with TB cases. A community based organization (CBOs) was defined as

CBOs having a minimum of 10 members team and being actively working for at least 3 years were included in the study. They should have had regular meetings in the past to confirm their activity.

With the help of the CBOs the following information was obtained at baseline.

Key informant interviews from the intervention and control area

Males

- School teachers
- Vaccinators
- School Principal
- Shopkeeper
- Nazim
- Naib Nazim

Females

- Lady Health worker
- Dais
- Female Councilors

- Staff Nurses
- Teachers
- Social Workers

Interviews from Patients suffering from Tuberculosis

Tuberculosis patients are being identified in various villages in the intervention and control area with the help of CBO's working in the area.. Treatment strategies and the problems encountered by TB patients were probed. Special emphasis was laid on the stigma factors associated with identification of tuberculosis. The major biases in community's perception regarding tuberculosis were identified. The interviews were conducted at baseline and after intervention.

Focus Group Discussions

Male and female Focus Group Discussions (FGDs) were held in various villages in the vicinity. These comprised of group of 10 to 15 men and women who were gathered with the help of active CBO members. The Focus Group Discussions revolved around the predisposing factors towards tuberculosis, the stigma associated with the disease and beliefs and perceptions concerning tuberculosis.

Health Education Messages to Neutralize Stigma against Tuberculosis

Health education messages to minimize the stigma associated with Tuberculosis were given to members of CBO's as well as male and female villagers. This was done in the form of group meetings for males and females. as well as individual counseling. This was conducted in the form of charts, pamphlets and interactive group discussions. The following messages were conveyed.

- TB is not an illness to be ashamed of.
- TB is a curable disease. A patient with TB does not necessarily die because of the illness.
- TB can only be cured if anti tuberculosis drugs are taken in proper dosage and for the prescribed duration.
- There should be no gap during treatment.
- TB does not affect other family members staying in the same house if proper care of the TB patient is taken and treatment continued.
- There is no need to socially isolate a TB patient.
- A mother with tuberculosis should not be isolated from her children. Her children will not be infected with TB if treatment is started and proper care taken.
- A female with tuberculosis can have children.
- A married women / man will not necessarily infect his / her spouse if she has TB.
- A TB patient should be given good diet and nutrition.
- TB can affect any part of the body and not a necessarily only the lungs. TB can affect the bones, intestine, kidneys, skin, spinal cords etc.
- Germs of TB are not present in the air or environment around a TB patient but rather may be present in the droplets if it is an open case and treatment is not started. Hence the earlier the treatment started the better it is.
- TB patients can lead normal lives and continue to perform day to day activities.
- TB is not a curse from GOD.
- TB is not a manifestation of evil spirits or black magic.
- TB should be considered like any other chronic illness.

The health education campaign continued for 8 months followed by a post intervention survey.

Results

Interviews with TB Patients

Tuberculosis patients were identified in both intervention and control areas with the help of CBOs working in the area. Interesting results were obtained concerning the stigmas and social problems being faced by TB patients as well as the treatment issues. The post intervention survey was done to assess the change in the stigmatization pattern.

Table 1: Reaction of TB Patient on Hearing about TB (Male Respondents)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Felt sad	12.5	60.5	11.5	16.5
Got scared	12.5	8.2	13.6	4.5
Worried	87.5	60.5	88.5	36.5
Thought of expense on treatment	6.8	14.5	10.5	5.5
Thought about children	25	28.6	29	15.5
Thought of wife	22	14.3	28	9.5
Riverted to routine life after a while	12.5	9.5	11	20
Decided to start treatment	8.5	9.2	9.6	30
Decided to consult doctor	6.2	7.8	8.5	28

When asked their first reaction on hearing about tuberculosis, majority of the male patients (60.5%) said that they felt sad and worried. However, post intervention these negative feelings : feeling sad and worried decreased to 36%. Nearly a quarter of the patients (25 to 29%) heard about the future of their wives and children, this being reduced to 9 to 15% in the post intervention period. Around 41.5% patients in the pre intervention group were worried about the expense of treatment; however, this misconception was reduced to 5.5% in the post intervention period. Pre intervention only 6 to 9% patients considered starting treatment or going to the doctor, this increasing to 28 to 30% post intervention.

Table 2: Reaction of TB Patient on Hearing about TB (Female Respondents)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Felt sad	88.5	76.5	81.5	62.5
Thought it a dangerous disease	14.3	12.5	16.1	8.5
Got scared	42.8	37.5	44.1	31.1
Started crying	14.3	12.5	13.6	8.5
Worried	42.8	37.5	40.1	16
Fear of death	14.3	12.5	11.5	6.5
Decided to start treatment	6.1	5.6	7.2	25
Asked husband / father to start Rx	8.4	6.5	7.6	21
Consulted doctor	4.6	5.2	5.2	26

Incase of females, the greater percentage (80 to 88%) felt extremely sad. Post intervention this sad feeling was reduced to 62%. Around 13 to 14% patients started crying. It was seen that 40 to 44% patients pre intervention got scared, which was reduced to 31% post intervention. Around 12 to 14% patients considered it to be a dangerous disease, and a similar number developed fear of death. This was reduced to 6 to 8% in the post intervention period. Initially pre intervention only 4 to 7% patients considered starting treatment or consulting a doctor, however, post intervention nearly 25 to 26% patients contemplated initiating treatment of tuberculosis.

Table 3: Reaction of Wife on Finding Husband has Tuberculosis (Male TB Patient Response)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Sympathized	56	58	60	55
Gave moral support	58	60	64	76
Got worried for herself and her children	62	56	68	45
Persuaded to start treatment	6	8	6	15
Stayed away	3	2.5	1	2.2

Interestingly a sympathetic attitude was expressed by 55 to 60% wives when their husband developed tuberculosis and nearly 66 to 76% wives gave moral support to the husband. At the same time, 56 to 65% wives were worried about themselves and their children. Only 2 to 3% stayed away from their husbands. In the pre intervention and control groups 6 to 8% provided support to start treatment which increased to 15% post intervention.

**Table 4: Reaction of Husband on Discovering Wife Has Tuberculosis
(Female Patients Response)**

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Stayed away	35	28	41	23
Took children away	26	30	28	15
Sent back to mothers home	45	52	39	36
Gave divorce	14	12	11	6
Took to health centre to start treatment	8	6	8.6	30
Sympathized	15	18	13	25

Majority of the husbands were unsympathetic towards their wife when they found out that their wife was suffering from tuberculosis. Only 15 to 18% showed any sympathy. In the pre intervention 35 to 40% husbands stayed away from their wives in the pre intervention group which was reduced to 23% in the post intervention. A large majority, 40 to 50% sent their wives back to the mother's house while 30% took their children away. Post intervention this percentage was reduced to 15%. In the pre intervention and control groups only 6 to 8% husbands took their wives to the health centre to start treatment. But after giving health education in the post intervention group, 30% husbands took their wives to the health centre to start treatment.

Table 5: Reaction of In laws on hearing their daughter-in-law has TB(Female TB Patient)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Stopped talking	23	26	24	15
Stayed away	45	48	41.5	23
Took children away	23	21	19	14
Sent back to mothers home	15	12	14	8
Kept in separate room	12	10	11	6

When the female patients were asked about the reaction of the in laws when she developed tuberculosis, nearly 40% said that they stayed away while 24% stopped talking to her. In the intervention group that was imparted health education, these negative approaches were reduced to 15 to 20%. An important aspect was that in nearly 20% cases the children were taken away from the female patient. About 14 to 15% women were sent back to their mother's house. About 25 to 26% in laws stopped talking to the married women though this was reduced to 15% after counseling.

Table 6: Was the Male Patient Ashamed of TB?

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Yes	86.6	83.5	78	40
No	13.4	16.5	22	60

If yes, reasons for feeling ashamed

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Only when people mention it I am ashamed	25	13	26	11
No but peoples hatred worries me	18	26	15	10
Ashamed to some extent	28	31	15	8

When the male patients were asked if he was ashamed of having tuberculosis, 78 to 86% said that they were ashamed of the disease. Of them 25 to 26% said that they felt ashamed only when people mentioned it. While 26% felt that feeling of hate in other people worried them and produced a feeling of shame.

Table 7: Was the Female Patient Ashamed of TB?

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Yes	89	88	87.6	66
No	11	12	12.4	44

If Yes, reasons for feeling ashamed

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Only when people mention it	34	21	38	10
People stay away from me making me feel ashamed	65	52	60	30
I have a feeling of guilt	24	26	29	14

Nearly 86-89% female patients said that they were ashamed of developing tuberculosis. After intervention this feeling of shame was reduced to 44%. Around 60 to 65% female patients said that they felt ashamed when people stay away from them because of the disease. About 38% also said that feeling of shame came when people mentioned the disease.

Table 8: When Person Develops Tuberculosis should other people be told About it (Male TB Patient Respondent)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
No one should be told	57	25	56	18
Outsider should not be told	42.9	62.5	40	36
Relative should not be told	28	10	29	8

When asked whether other people should be told when a person develops tuberculosis in the pre intervention group, nearly 56 to 57% male TB patients felt that no one should be told about the disease. However, after health education this percentage was reduced to 18% in the post intervention group. People were very specific about not telling outsiders and 40 to 60% male patients felt that outsiders should not be told about the disease. Awareness about the stigma factors reduced this percentage to 36%. Around 20 to 29% male patients did not want to reveal about the disease to relatives.

Table 9: When a Person Develops Tuberculosis should other people be told about it (Female TB Patient Respondent)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
No one should be told	86	100	85	60
Only household members should be told not outsider	57	46	60	20
Relative should not be told	42.9	46	48	30

Female patients were more prone to hide the disease and 85% of them said that no one should be told about the disease. Post intervention awareness reduced this to 60%. About 40 to 60% females strongly felt that outsiders should not be told about the disease while 46 to 48% said that relatives should not be told. Health awareness reduced this to 20 to 30%.

Table 10: Did the Male TB Patient exchange information about the disease with any one

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Uncle (Chacha)	0	0	2	15
Parents	15	18	16	76
Father	16	17	18	77
Friends	20	25	21	46
Household members	20	21	24	68
Sons	12.5	14	10	30
Wife	5	0	6	40
No one at all	46	42.9	49	20
Doctors	12.5	0	12.5	28

Incase of male patients it was seen that 15 to 25% male patients discussed their illness with their parents, father or friends and sons. However, after several health education sessions around 76% male patients discussed their illness with their parent, while 46% discussed it with the friends. Only 5 to 6% patients discussed their illness with their wives, but with increased awareness this percentage improved to 40%. Initially 12% patients had discussed their diagnosis of tuberculosis with the doctor but with health education this increased to 28%.

Table 11: Did the Female TB Patient exchange information about the disease with anyone

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Uncle (Chacha)	12.5	0	10	6
Parents	25	12	26	70
Sister	12.5	0	14	50
Friends	12.5	0	10	30
Household members	37.5	42.9	39	66
Sons	8	14.3	10	20
Daughter in law	16	14.3	18	20
Husband	14.3	9	10	70

When asked whether the female patient exchanged information about the disease with any one it was found that only 25% discussed this with the parents while only 12 to 14% females discussed their illness with their sisters, husbands, sons and friends. After providing health awareness this percentage was raised to 30 to 50% in the post intervention group. No female discussed about the illness with a near by doctor.

Table 12: Did you complete the TB Treatment course as Prescribed by the Doctor (Male TB Patient Response)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=15	n=18	n=20	n=25
Full course	30	28	26	35
Stopped when symptoms subsided	23	20	28	7
Stopped because health centre too far	22	18	21	18
Stopped because treatment expensive	5	8	6	2
Treatment continuing	20	18	19	38

When the male patient were asked if they had fully completed the treatment of tuberculosis as prescribed by the doctor, only 25 to 26% in the pre intervention and control groups answered in affirmative. After health education 35% said that they had completed the treatment while 38% said that the treatment was still going on. Although initially in the pre intervention and control group 23 to 28% patients said that they stopped the treatment when the symptoms subsided, after intervention this figure was reduced to 7%. About 15 to 20% patients said that they had stopped treatment because the health centre was to far away.

Table 13: Did you complete the TB Treatment course as Prescribed by the Doctor (Female TB Patient Response)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=14	n=16	n=21	n=26
Full course	26	23	28	31
Stopped when symptoms subsided	30	35	38	23
Stopped because health centre too far	20	18	7	15
Stopped because treatment expensive	4	3	6	2
Treatment continuing	18	21	21	29

Incase of females, around 23 to 26% patients had completed the full course of treatment while 20% were under going treatment in the pre intervention and control group. After health education, 30 to 31% had completed the full course of treatment or were undergoing treatment. About 35 to 38% patients in the pre intervention and control group stopped the treatment when the symptoms had subsided. This figure reduced to 23% post intervention. Around 18 to 20% females had stopped treatment because the health centre was too far.

**Table 14: Perceived Stigma's Concerning Tuberculosis In Males Patients
(Pre Intervention)**

Male	Strongly Agreed	Agree	Average	Don't Agree	Don't Agree at all
Feeling of shame on having TB	6.8	86.6	2.1	3.9	0.6
Tend to hide diagnosis of TB	6.1	84.4	1.4	7.9	0.2
Affect relations with others	6.8	83.6	3.2	6.4	-
Costly treatment because of long duration	5.2	85.5	1.5	7.8	-
Prefer to live isolated because of TB	4.2	89.9	1.7	4.2	-
Affects performance of work	3.1	95.6	-	1.3	-
Affects marital relations	6.1	82.6	6	4.5	0.6
Affects family responsibilities	3.2	93.1	0.9	2.8	-
Chances of marriage reduced	5.1	91.1	0.7	3.1	-
Affects family relations	5.8	89.4	2	2.8	-
Affects Female infertility	8.8	64.5	23.6	3.1	-
Leads to serious complication during pregnancy	5.9	82.4	1.8	9	0.9
Affects breast feeding	5.8	86.4	1.0	6.2	0.6
Affects outcome of pregnancy	6.2	85.6	1.7	5.8	0.7
Unable to decide for girl treatment	4.6	88.8	2.4	4.2	-

Table 15: Perceived Stigma's Concerning Tuberculosis In Male Patients (Pre Intervention)

Male	Strongly Agreed	Agree	Average	Don't Agree	Don't Agree at all
Feeling of shame on having TB	3.2	56.8	1.2	38.6	0.2
Tend to hide diagnosis of TB	0.9	54.6	1.4	40.8	2.3
Affect relations with others	0.8	60.6	0.9	34.6	3.1
Costly treatment because of long duration	0.3	36.6	0.1	48.2	3.8
Prefer to live isolated because of TB	0.6	43.8	0.8	52.6	3.2
Affects performance of work	0.2	41.2	0.1	57.2	0.4
Affects marital relations	0.4	52.6	3.8	39.8	3.4
Affects family responsibilities	3.1	56.9	1.3	38.4	0.3
Chances of marriage reduced	3.8	56.4	3.8	34.6	1.4
Affects family relations	2.4	52.6	2.3	46.1	2.6
Affects female infertility	2.3	40.6	3.8	51.8	1.5
Leads to serious complication during pregnancy	3.2	41.6	2.4	52.6	0.2
Affects breast feeding	2.8	44.6	0.6	51.8	0.2
Affects outcome of pregnancy	1.9	43.11	1.00	53.1	0.9
Unable to decide for girl treatment	2.1	51	0.4	46.2	0.3

Very interesting results were obtained regarding perceived stigma's concerning tuberculosis in male TB patients. When asked about the feeling of shame on having tuberculosis pre intervention 86.6% agreed while 6.8% strongly disagreed. Post intervention 38.6% patients did not agree on having shame about the disease. Pre intervention 84.4% patients agreed that they tried to hide the disease while 7.9% did not agree. Post intervention 40.8% patients did not agree that they tried to hide the disease

while 54.6% did hide the disease. 83.8% patients felt the disease affected relations with others. However, 37.7% patients post intervention felt it did not affect relations with others. About 90% patients pre intervention felt that treatment was expensive because of a long duration. However, post intervention this figure was reduced to 46%. Nearly 96% patients stayed isolated after onsets of disease. But post intervention only 44% patients stayed isolated. Work performance was very important in males and was affected in 98% patients. Post intervention 57% patient felt that the work performance was not affected by the disease. Only 5.3% male patients thought that marital relations were not affected by TB. But post intervention 40% patients felt TB did not affect marital status. Again a vast majority (96%) said family responsibilities were affected by the disease and post intervention this figure was reduced to 60%. About 95% patients were of the view that the chances of marriage are reduced after an un married girl is afflicted with TB. Though this reduced to 59% post intervention. About 64.5% patients agreed and 8.8% strongly agreed that TB affects female's infertility though this was reduced to 40.6% after health education. Nearly 88% agreed that serious complications occur during pregnancy because of the disease but post intervention 52.6% did not agree. Also 90% said that outcome of the pregnancy is affected by the disease but after health awareness 54% did not agree to this.

**Table 16: Perceived Stigma's Concerning Tuberculosis In Female Patients
(Pre Intervention)**

Female	Strongly Agreed	Agree	Average	Don't Agree	Don't Agree at all
Feeling of shame on having TB	5.1	87.6	0.4	6.6	0.3
Tend to hide diagnosis of TB	3.2	88.6	2.2	5.6	0.4
Affects relations with others	2.8	92.6	0.7	3.6	0.3
Costly treatment because of long duration	5.1	81.1	6.7	6.1	1.00
Prefer to live isolated because of TB	3.6	93.1	2.2	0.9	0.2
Affects performance of work	0.3	-	-	0.2	-
Affects marital relations	12.2	81.1	0.9	5.6	0.2
Affects family responsibilities	6.2	92.6	0.7	0.4	0.1
Chances of marriage reduced	9.6	82.1	4.2	3.6	0.5
Affects family relations	6.2	90.1	3.2	0.5	-
Affects female infertility	6.4	83.7	5.1	4.1	0.7
Leads to serious complication during pregnancy	6.5	88.3	0.8	4.2	0.2
Affects breast feeding	0.8	83.4	0.9	14.9	0
Affects outcome of pregnancy	4.6	88.6	0.7	6.1	0
Unable to decide for girl treatment	3.8	92	0.8	3.4	0

**Table 17: Perceived Stigma's Concerning Tuberculosis In Female Patients
(Post Intervention)**

Female	Strongly Agreed	Agree	Average	Don't Agree	Don't Agree at all
Feeling of shame on having TB	0.8	44.1	0.9	46.1	8.1
Tend to hide diagnosis of TB	1.1	42.8	2.1	47.8	6.2
Affects relations with others	1.2	38.9	3.2	48.1	8.6
Costly treatment because of long duration	1.3	41.9	2.4	46.8	7.6
Prefer to live isolated because of TB	1.2	41.1	0.8	51.1	5.8
Affects performance of work	-	0	0	3.2	6.5
Affects marital relations	1.1	41.2	0.6	48.2	8.9
Affects family responsibilities	1.6	44	2.1	44.2	8.1
Chances of marriage reduced	0.6	40.7	2.4	48.1	8.2
Affects family relations	1.1	41.1	3.6	44.6	9.6
Affects female infertility	1.2	37.3	4.2	48.1	9.2
Leads to serious complication during pregnancy	1.8	39.4	5.1	46.1	7.6
Affects breast feeding	1.3	41.2	4.5	44.8	8.2
Affects outcome of pregnancy	1.4	40.4	4.2	46.6	7.4
Unable to decide for girl treatment	1.6	40.2	4.3	47.1	6.8

Perceived stigmas were much more in female patients than in male TB patients. Pre intervention 87.6% patients agreed while 5.1% strongly agreed on feeling ashamed of having tuberculosis. After health education this figure was reduced to 44%. Similarly, 88.6% patients agreed that they tend to hide the disease as opposed 42.8% post intervention. Relations with others were affected as stated by 97% patients pre intervention which reduced to 39% after health education messages. About 81% female patients agreed that the treatment of tuberculosis was costly because of long duration.

However, post intervention 54% patients did not agree. About 97% female patients agreed that they were living isolated because of tuberculosis but later after health education this attitude changed and 51% of them did not agree to live isolated from the family because of tuberculosis. Around 81.1% patients agreed and 12.2% strongly agreed that the marital relations were affected by the disease but post intervention only 41.2% thought this was correct. Family responsibilities of 98% patients were affected by TB but post intervention 52% did not think so. Nearly 93% said that chances of marriage get reduced after TB but later after health education 56% didn't agree. Around 90% females said that female fertility is affected by TB but after intervention 57% did not think so. About 92 to 95% female patients agreed that tuberculosis results in complications of pregnancy and affects outcome of pregnancy. This figure was reduced to 40% after health education messages. Again 83% felt that breast feeding gets affected by TB but later only 41.2% agreed. Getting treatment for a girl patient was difficult in the opinion of 96% female patients but this figure was later reduced to 4.2% post intervention.

Key Informant Interviews

The key informant interviews from community leaders also concentrated on the stigmatization issues of tuberculosis and the perceptions of the common man regarding tuberculosis and its treatment.

Table 18: Perception of Male Community Leaders When a Married Woman Develops Tuberculosis.

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=21	n=22	n=21	n=22
Women sent back to mother house	38	31	41	22
Children taken away	76	64	72	32
In laws stay away	37.5	41.5	32	18
In laws start hating her	18	16	21	12
Husband stays away	17	21	13	9
Husband start treatment	21	26	19	41

Around 38 to 40% male community leaders said that the woman was sent back to the mother's house when she develops tuberculosis while, 72 to 76% in the pre intervention and control group said that the children of such women are taken away. Post intervention this figure was reduced to 30%. In the control and pre intervention areas, the male community leaders said that in 37 to 40% cases the in laws and husbands stay away. Health education reduced this response to 9 to 18%. About 21 to 25% males felt that the husband start the treatment in the control and pre intervention group. Post intervention this figure increased to 41%.

Table 19: Perception of Female Community Leaders When a Married Woman Develops Tuberculosis.

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=20	n=22	n=20	n=22
Separation from husband	55	35	40	21
Divorce	12	18	22	9
Second marriage by husband	8	9	10	6
Children taken away from mother	44	58	51	29
In laws stay away	51	68	56	31
Sent back to mothers house	28	36	34	15
Husband start treatment	11	13	16	41

When asked what happens to a married female when she develops tuberculosis, 40 to 55% females said that she is separated from the husband, this being reduced to 21% post intervention. Nearly 18 to 20% female community leaders said that the husbands divorce their wives, this being reduced to 9%. In pre intervention and control group 56 to 60% said that the in laws stay away and the children are taken away from the mother which was reduced to 30% post intervention. Nearly 28 to 34% female community leaders in the pre intervention group said that 34 to 36% are sent back to the mother's house. Though this was reduced to 15% post intervention. Only 13 to 16% in the pre intervention and control groups said that the husband would start the treatment. However, post intervention nearly 41% said that husband would start treatment.

Table 20: Family Reaction if any Family Members Develops TB (Response of Male Community Leaders)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=21	n=22	n=21	n=22
Family members stay away	75	76	76	30
Look down upon / hate	56	60	59	29
Social boycott	10	12	10	6
Consider TB to be dangerous	12	35	18	12
Sympathetic attitude	25	28	26	51
Help in starting treatment	19	18	25	45

When the male community members were asked the reaction of the family, if any family members develops tuberculosis, nearly 60 to 75% in the pre intervention and control groups said that the family members stay away or look down upon the patient. This attitude underwent a change reducing the figure to 30%. Initially 30% family members considered tuberculosis to be a dangerous disease which reduced to 12% post intervention. In the control and pre intervention group, only 18% said that family members help in starting treatment. But after health education nearly 45% said that family members help in starting the treatment.

Table 21: Family Reaction if any Family Members Develops TB (Response of Female Community Leaders)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=20	n=22	n=20	n=22
Family members stay away	44	37	48	25
Social boycott	55	62	49	23
Look down upon / hate	33	37	39	15
Use of separate utensils	5	10	3	8
Help in starting treatment	12	16	14	35

When the female community leaders were asked the reaction when a family member develops tuberculosis. Nearly 44 to 48% females in the control and pre intervention group said that the family members stay away while 60 to 66% said that there is social boycott of the female patient. These figures reduced to 23% after health education in the post intervention group. Other feelings expressed by family members included feelings of hate and look down, expressed by 39% female community leaders, this was reduced to 15% post intervention. Only 12 to 14% family members were supportive to start treatment in the control and pre intervention group. After health education this figure increased to 35%.

**Table 22: Have the Community Leaders Heard of the DOTS Programme
(Male Response)**

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=21	n=22	n=21	n=22
Yes	9	10.5	12.5	71.5
No	91	89.5	87.5	28.5

If Yes where did you heard about It.

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=21	n=22	n=21	n=22
Friends	15	18.5	21	31
Relative	18	16.5	22	28
TV	11	12.5	16	14
Radio	16.1	17	18	26
Doctors	25	31	26	38
Health workers	-	-	-	81
Newspapers	21	28	29	36

On being asked whether the male community leaders had heard about the DOTs programme, in the control and pre intervention group only 10 to 15% answered in affirmative. After the health education post intervention 71% male community leaders

said they had heard about the DOTs programme. Nearly 15 to 20% had heard about the DOTs programme from friends and relatives, while 16 to 20% had heard about the programme on TV and Radio. Around 30% had read about it in the newspapers. After intervention 81% said that they had heard about it from the health workers.

Table 23: Have the Community Leaders Heard of the DOTs Programme (Female Response)

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=20	n=22	n=20	n=22
Yes	6	7.5	8.2	56
No	94	92.5	91.8	44

If Yes where did you heard about It

	Pre Intervention		Post Intervention	
	Control Group	Intervention Group	Control Group	Intervention Group
	%	%	%	%
	n=20	n=22	n=20	n=22
Friends	10	8	11	21
Relative	12	12.5	13.5	29
TV	12	13.5	5	-
Radio	4	3	5	55
Doctors	6	7.2	10.2	26
Health workers	-	-	-	76
Newspapers	-	-	-	-

Only 7 to 8% female's community leaders had heard about the DOTs programme in the pre intervention and control group. After health awareness this was increased to 56%. Most females in the pre intervention and control groups had heard about DOTs from friends and relatives (8 to 10%) increasing to 21% in the post intervention group. After the health awareness campaign 76% females had heard about DOTs from health workers.

Focus Group Discussions

1. *Are there any socio cultural issues related to stigmatization of tuberculosis*

Pre Intervention Response:

Males

- Tuberculosis is black fever.
- It happens when you hurt other people and they pray to God to inflict you with a calamity.
- TB is an illness of death.
- It inflicts people who do evil thing.
- It is a curse from God.
- It is a familial illness.
- May be a curse from a saint if any person does not show respect to the saint.

Females

- Tuberculosis occurs due to a curse especially by a religious person or saint.
- It also occurs in people who sacrilege a shrine or show disrespect to saints or religious people.
- It also occurs due to magic done by evil people.
- It is a familial illness.
- It occurs in children who rebel against their parents and are disobedient to them.

Post Intervention Response:

Males and Females

- People have misconceptions about tuberculosis.
- Due to social stigma people tend to hide the disease from others.
- When someone is diagnosed as having TB, he/she thinks that is the end of life for him and does not even consider starting treatment.
- Many people relate Tuberculosis to Black Magic and instead of starting treatment tend to consult faith healers.
- We now realize that TB is curable and instead of going to faith healers, we should go to a doctor and start treatment.
- There should be efforts at the government level to increase awareness about tuberculosis and remove misconceptions of the people about the disease.

2. *What is the attitude of the co workers if their colleague develops tuberculosis?*

Pre Intervention Response:

Males

- Coworkers stay away from TB patients.
- Some coworkers sympathized with TB patients.
- TB patients himself interacts less with other patients.

Females

- The coworkers develop a feeling of hate towards their colleague.
- They stay away from the TB patients and their behavior changes.
- They will not eat or drink with the TB patient.
- They will socially interact less with the TB patient.

Post Intervention Response:

Male and Females

- Some colleagues stay away from TB patients.
- Some colleagues advise the TB patient to start treatment
- Some colleagues take the TB patient to the near by government facilities.

3. *What is the reaction of the family when an unmarried engaged girl develops Tuberculosis?*

Pre Intervention Response:

Males

- The parents will get very worried
- The parents will hide the illness from the in laws.
- The parents will not reveal this to any one even the friends.
- Some parents will start the treatment but will hide this fact from the in laws.
- Many in laws will break the engagement.
- Some in laws wait till treatment is completed.
- Many in laws are afraid that their son will get afflicted with TB.
- Some in laws feel that other villagers will make an issue that their prospective daughter in law is an ill person.

Females

- The parents will get very worried.
- The parents will get very sad.
- The parents will get worried that their daughter will now not be able to get married.
- The parents will hide the illness from the in laws.
- The parents will try to get their daughter treated but will not inform the in laws.

- The in laws will break the engagement
- Some in laws will say that treatment of the female patients should be completed before they will accept her as their daughter in law.

Post Intervention Response:

Males and Females

- The parents will get very worried.
- The parents will hide the illness with the in laws.
- The parents will start the treatment of the TB patient.
- The parents will discuss the illness of the patient with the in laws so as to start treatment
- Some in laws will break the engagement.
- Some in laws will help in treatment of their prospective daughter in laws.

4. *Who are the people are most likely to be affected by TB?*

Pre Intervention Response:

Males

- TB affects weak people
- It affects poor people
- It affects drug addicts
- It affect anemic people
- It affects people who stay in unhygienic conditions.
- If a TB patients is in the household family members may be affected
- Close contact with TB patients.
- It affects malnourished people
- Occurs secondary to infected blood transfusion.

Females

- People who smoke
- Drug addicts.
- Patients who use expired medicines from government hospitals.
- When the same needle and syringe are reused from one patient to another
- When a close relative or a family members develops TB
- People who are weak
- People who are anemic
- TB occurs due to unsanitary conditions and people who do not look after their personal hygiene..
- TB affects poor people.
- Sharing meals with TB patients can affect other people
- Eating unhygienic food.

Post Intervention Response:

Males and Females

- TB can affect any person of any age or sex but chiefly affects the weak and debilitated.
- An untreated TB patient in the house can cause infection to others.
- Vaccinated children do not get tuberculosis.
- Anemic women can get tuberculosis.

5. *Who all are consulted when a patients develop Tuberculosis.*

Pre Intervention Response:

Males

- People generally go to big cities like Karachi and Thatta
- People consult private practitioners.

- Many people consult traditional healers (*Hakeems*)
- Many TB patients consult Public Hospitals.
- Many TB patients consult chest clinics through TB Control Programme.
- People consult traditional faith healers.
- Private health system is very expensive

Females

- Most people consult traditional healer (*Hakeems*)
- People who have money consult private hospitals in Karachi and Hyderabad
- Poor people go to public hospitals like Civil Hospital
- Few patients go to Chest Clinics through TB Control Program
- Many poor people prefer going to Traditional and religious healers.
- Some women said they believe in using traditional remedies

Post intervention Response:

Males and Females

- Initially patients consult local tradition healers.
- A few patients especially females go to religious healers.
- We have heard of the DOT's programme and people have now starting started visiting TB clinics through the TB Control Programme.
- People prefer to go to closeby TB clinics.
- Some patients still prefer to go to big cities like Karachi and Hyderabad.
- More people are now visiting medical doctors whether private or public.

6. *Are female TB patients allowed to visit the doctor with the female friends?*

Pre Intervention Response:

Females

- No they are not allowed to visit the doctor with female friends.
- They can only visit the doctor with their husband, brother or father.
- They can only visit the doctor with an elderly female.
- It is the fashion of the cities for female patients to visit doctors with their friends it is not done in our villages.
- Only married women are allowed to visit the doctor, unmarried girl are not allowed to visit the doctor.

Post Intervention Response:

Males and Females

- Female patients are allowed to visit the doctor with another elderly female.
- They are allowed to visit the doctor with their female friend if the TB treatment centre is close to the house.
- It is easier for married women to visit the health centre.
- Although initially the village elders objected to this we are now trying to change the system.

TB Cases Detected In Intervention And Control Areas

At the end of the intervention the number of TB cases which were diagnosed and treatment started was obtained from the diagnostic and treatment centers in Thatta (intervention area) and Jhirk (control area)

Table 24: Number of TB cases detected in Intervention and Control Areas

Number of TB cases					
<i>Areas</i>	First Quarter n	Second Quarter n	Third Quarter n	Fourth Quarter n	Total no of Cases
Thatta (Intervention Area)	27	35	45	34	141
Jhirk (Control Area)	13	8	6	4	31

Chi sq = 8.48 p value < 0.05

Table 25: Incidence of TB cases in Intervention and Control Areas

	Jhirk Incidence Per 100000	Thatta Incidence Per 100000
1 st Quarter	23.6	21.6
2 nd Quarter	14.5	28
3 rd Quarter	10.9	36
4 th Quarter	7.2	27.2

The intervention had a significant effect on the case detection rate as seen in the above table, the total number of cases in the intervention area (Thatta) over a

period of one year was 141 while the number of cases in the control area (Jhirk) was 31. In the first quarter which was the base line data, the number of cases in the intervention area (Thatta) was 27 giving an incidence of 21.6/100,000 cases. While the number of cases detected in the control area (Jhirk) was 13 giving an incidence of 23.6 per 100,000. The number of cases detected in Thatta gradually increased being 35 in the second quarter, 45 in the third quarter and 34 in the fourth quarter leading to an increased incidence of 28 per 100,000 in the second quarter and 36 per 100,000 in the third quarter. On the contrary in the control area (Jhirk) the number of cases decreased from 8 in the second quarter, 6 in the third quarter and 4 in the fourth quarter. The incidence of TB cases progressively decreasing to 14.5 per 100,000 in the second quarter, 10.9 per 100,000 in the third quarter and 7.2 per 100,000 in the fourth quarter.

Table 26: Sputum +ve and Sputum –ve TB Cases in the Intervention and Control Areas

Thatta (Intervention Area)	Total No of Patient	Sputum +ve Cases	Sputum -ve Case	Extra Pulmonary
1 st Quarter	27	19	6	-
2 nd Quarter	35	27	6	-
3 rd Quarter	45	35	5	-
4 th Quarter	34	22	8	-
Jhirk (Control Area)				
1 st Quarter	13	9	3	1
2 nd Quarter	8	4	3	1
3 rd Quarter	6	3	3	-
4 th Quarter	4	1	3	-

The above table shows the number of sputum +ve and sputum –ve cases. As seen in the intervention group (Thatta), the majority of the cases seen were sputum +ve

while in the control group (Jhirk) equal distribution of sputum +ve and sputum –ve cases was seen.

Table 27: Sex Distribution of TB Patients in Intervention and Control Areas

Thatta (Intervention Area)	Male		Female		Total
	n	%	n	%	
1 st Quarter	21	77.7	6	22.3	27
2 nd Quarter	19	54.3	16	45.7	35
3 rd Quarter	25	55.5	20	44.5	45
4 th Quarter	16	47	18	53	34
Jhirk (Control Area)					
1 st Quarter	8	61.5	5	38	13
2 nd Quarter	6	75	2	25	8
3 rd Quarter	3	50	3	50	6
4 th Quarter	2	50	2	50	4

As seen in the above table in the control group (Jhirk), in the first and second quarter less percentage of female TB cases were detected i.e 38% and 25%. While in the third and fourth quarter the no of cases were too insignificant. In the intervention group in the base line first quarter 22.3% TB cases were females, but in the third and fourth quarter nearly 45 to 50% cases were females.

Discussion

The World Health Organization has estimated that the incidence of tuberculosis cases in Pakistan is 181/100,000 population and Pakistan ranks as the 6th country in descending order in the occurrence of Tuberculosis (1). Though 100% DOTs coverage has been achieved in the public health facilities, the over all case detection in the Sindh province remains at 37% (2). Tuberculosis in Pakistan is still regarded as a disease to be ashamed of, to be concealed and not to be disclosed to any one. The stigma associated with the disease results in fewer patients specially females reaching the health facilities, because they and their families generally try to hide the disease. These open cases result in further spread of the infection to the community.

Our study is aimed to address the issues related to stigmatization of tuberculosis at the community level through the infra structure of community based organizations. This study was conducted in two rural areas; Thatta and Jhirk, two Union Councils based in Taluka Thatta. The health awareness campaign related to tuberculosis was conducted with the help of NGO's and CBO's in the intervention area. The inherent stigmatization of tuberculosis was obvious in the results of the baseline survey. TB was considered a disease to be feared and chiefly associated with death. On hearing about tuberculosis both male and female respondents felt sad, got worried (60 to 80%). A previous study in Pakistan confirms these findings in which patients with tuberculosis considered it to be a disease to fear. (11). Long et al reported from Vietnam that TB patients specially TB patient suffering from tuberculosis could only think of death as a sequelae to tuberculosis (4). In Kenya the local terms used to describe tuberculosis emphasize the concept of a chronic fatal disease (12). Similar sentiments of sadness, anxiety and distress were expressed by respondents in a recent study from Pakistan (10). In the control and pre intervention results only 5 to 6% patients considered going to a doctor or starting treatment. After improving health awareness nearly a quarter of the patients considered starting treatment on hearing that they had developed tuberculosis. This is an important outcome indicator of the impact of health education, resulting

in improved case detection. Less fear and apprehension occurred post intervention with more patients seeking health care. The dangerous nature of tuberculosis was linked to the stigma associated with the disease and social isolation. Nearly 95% of males as well as females in the pre intervention and control group preferred to stay isolated because of tuberculosis. This took place secondary to the reaction of other family members including social boycott (esp. in female 58 to 60%) look down upon / hate (females 37 to 39%, males 56 to 60%), family members staying away (56 to 60%). In a study from Mexico City in TB patients, it was seen that 15% of patients expected rejection by the families (13). In a previous study from Pakistan similar results were obtained whereby 93% of TB patients said that they preferred to stay isolated (14). In a study in Philippines informants described TB as being shameful and “a bad mark on their family” (15). After health education nearly 50% of the patient said that they did not feel necessary to stay isolated from family and friends although they were suffering from tuberculosis. This occurred chiefly because of the change in the behavior of the family after intervention whereby social boycott decreased to 23% and feeling of hate was reduced to 29%. In fact 35 to 40% family members had started to give support for treatment. TB patients in the pre intervention and control groups had a number of misconceptions about tuberculosis, regarding marital relation, female infertility and complications during pregnancy whereby nearly 80 to 85% female and male patients agreed and strongly felt that tuberculosis strongly affects them. This also leads to the husbands divorcing their wives or families tending to break off engagement of unmarried female TB patients. Health awareness leads to a decrease in this perception about female reproductive issues being affected by tuberculosis with 40% of respondents agreeing to this. Similar results concerning stigmas of tuberculosis were expressed in a recent study from Pakistan addressing the issues of delay in seeking treatment (14).

Rapid expansion of the DOTs programme was started in Pakistan from the middle of 2001. The Province of Sindh has achieved 100% DOTs coverage. However, the general population lacks awareness about the DOTs programmes as evidenced by interviews of community leaders where by only 7 to 8% females and 10 to 12% males in the control and pre intervention areas had heard about DOTs. After health education nearly 56 to 70% respondents answered in affirmative that they had

heard about the DOTs programme. Increasing awareness at the community level through the network of CBO's and NGO's helps in imparting the information about the DOTs programme. This ultimately results in improved case detection. Another important aspect brought forth during focus group discussions was that female patients are generally not allowed to visit the doctor or health center alone or with other females. They are only allowed to visit health facilities with male family members. This results in less females accessing health care for diagnosis and treatment of tuberculosis. Similar views were obtained from a previous study in Pakistan concerning gender perspective on tuberculosis (10). After health education a slight change was noted in the attitude where by female patients were allowed to visit the TB centers with elderly female members or close friends. Nearly 47% TB patients post intervention said that treatment of female TB patients was now possible versus 92% pre intervention felt that treatment of a female TB patient was difficult.

The impact of the health education campaign was manifest in the number of cases detected in the intervention and control group. In the first quarter that is in baseline 27 cases were detected in the intervention area and 13 cases in the Jhirk area giving an incidence of 21.6/100,000 in Thatta and 23.6/100,000 in Jhirk. Once the health awareness campaign started or substantial rise in the number of cases started taking place in Thatta nearby 35 cases were detected in the second quarter, 45 cases in the third quarter and 34 cases in the fourth quarter giving an incidence of 28/100,000 and 36/100,000 in the second and third quarter respectively. On the contrary in Jhirk (control area) the number of TB cases detected dwindled from 8 cases in the second quarter to only 4 cases in the fourth quarter, thus given an incidence of 14.5/100,000 in the second quarter to 7.2/100,000 in the fourth quarter. The health awareness created at the community level through the network of CBO's and NGO's helped in removing the perceived misconceptions in minds of the masses at the community level. The stigmatization of TB as a disease was highly manifest at the baseline survey both in control and pre intervention areas.

The beliefs and perceptions of the people represent the common prejudice against tuberculosis. It is very evident that a high degree of stigma is associated with the

disease and social isolation of TB patients leads to delay in diagnosis and initiation of treatment. This leads to further spread of infection in the community, as a result of which more and more people are afflicted with TB. This project aimed to produce behavioral change in attitude and behavior so that the stigma against tuberculosis was reduced. The intervention phase comprised of advocacy and awareness rising in the form of village community meetings with both male and females, removing their apprehensions and case identification in remote villages with initiation of treatment. As evident in the study females in the villages do not have access to health information related to tuberculosis through the media (newspapers, radio and TV). Even among male patients access to health information was limited. Very few community leaders had heard of the DOTs programme. In the Focus Group Discussion it was revealed that TB patients consult traditional healers (*Hakeems*) and local religious healers. The intervention not only reduced the stigmatization of the disease but also created an awareness about the existing DOTs programme, encouraging patients to be taken to the DOTs centers for investigations and treatment. A change in the attitude of the families encouraged patients to seek medical care rather than isolate and stigmatize TB patients.

Though this was a pilot project, it strongly demonstrated that in the masses TB is considered a highly stigmatized disease and TB patients do not seek treatment, rather hide the disease due to fear of social boycott. This community intervention effectively demonstrated that involvement of NGO's and CBO's as well as key community leaders not only reduces perceived misconceptions about TB but also improved the case detection rate. It is strongly recommended that the project be replicated in other areas of the country at the national level. The National TB Control Programme (NTP) should involve community based organizations to improve case detection rates through the DOTs programme.

References

1. Global tuberculosis control. Surveillance, planning, financing.WHO report 2003.
2. National Guidelines for TB Control in Pakistan. NTP.MOH.GOP .
3. Eastwood SV, Hill PC. A gender focussed qualitative study of barriers to accessing tuberculosis treatment in the Gambia, West Africa. *Int J Tuberc lung Dis* 8:70-75 (2004)
4. Long NH, Johansson E, diwan VK, et al. Fear and social isolation as consequences of tuberculosis in Vietnam: a gender analysis. *Health Policy* 52:33-51(2000).
5. Johanasson E, Long NH, Diwan VK et al. Gender and tuberculosis control: perspectives on health seeking behaviour among men and women in Vietnam. *Int J tuberc lung Dis* 3:862-8 (1999)
6. Hudelson P. Gender differentials in tubeculosis: the role of socioeconomic and cultural factors. *Tuber Lung Dis* 77:391-400(1996)
7. Hudelson P. Gender differentials in tubeculosis: the role of socioeconomic and cultural factors. *World Health Stat Q* 49:115-9 (1996)
8. Bashour H. Gender differences in tuberculosis,prospects for better control in Syria. *Small Grants Scheme,97, 2002, WHO,Alexandria*
9. Kamil IM. Gender differences in utilization pattern and outcome of respiratory tuberculosis. *Small Grants Scheme,32, 2002, WHO,Alexandria*
10. M. Agboatwalla, G. N. Kazi, S. K. Shah and M. Tariq. Gender perspective on knowledge nad practices regarding tuberculosis in urban and rural areas in Pakistan. *East Med Health J.* 9(4):732-740 (2003).
11. Liefoghe. R, Michiels. N, Habib. S. Perceptions and Social Consequences of Tuberculosis patients in Sialkot. *Soc Sci Med.* 4:1685-1692 (1995).
12. Dinish. M., George. A, Chacko. K. Tuberculosis in Bombay: new insights from poor urban patients. *Health Policy. Planning* 12 (1): 77-85 (1997).
13. Arthur. J.R, Linda. C.G. Social and Cultural Factors in the successful control of Tuberculosis. *Public Health Reports.* 107: 626 – 36 (1992).

14. Agboatwalla. M, Kazi.G.N, Shah.K. Case-finding in tuberculosis patients diagnostic and treatment delays and their determinants in Pakistan. TDR WHO/EMRO (2004).
15. Nichter. M. Illness semantics and International Health: the weak lungs/TB Complex in the Philippines. Soc Sci Med. 38: 649-643 (1994).

Annexures

**The Role Of NGO's And CBO's In Neutralizing The Socio-
Behavioral Hindrances Leading To Stigmatization Of TB .**

Tuberculosis Patients

AREA CODE:

DATE: _ _ \ _ _ \ _ _

INTERVIEWER NAME:

INTERVIEWEE ID:

INTERVIEWEE NAME:

AGE:

SEX:

QUALIFICATION:

DESIGNATION:

ADDRESS:

HOME:

OFFICE:

OFFICE TEL:

- Q.1 What was your reaction when you were first diagnosed to have tuberculosis?
- Did you have difficulty accepting that you were suffering from TB ???
How many Doctors did you consult
Did you consult traditional healers ???
- Q.2 What was the usual reaction of your family when they found out that you had T.B?
Do they stay away from the patient ???
- Q.3 What was the usual reaction of your friends when they found out that you had T.B?
- Q.4 Are you single or married.
- Q.5 If single, Does this affects your chances of getting married?
- Q6. What was the reaction of your parents?
- Q7. What was the reaction of your fiancée
- Q.8 With whom should she share the information?
- Q9. Who should not be told?
- Q10. If married, What was the reaction of your husband?
- Q11. What was the reaction of your mother in law/ father in law?
- Q12. How did this disease affect you socially? Did People avoid meeting you?
- Q13. Do people usually avoid sharing food with you?
- Q14. How long does it take to completely cure the disease?
- Q15. When would you stop treatment?
- Q16. Would you stop treatment when you start feeling well?
- Q17. Would you take treatment as long as the doctor advises?
- Q18. Would it be possible for you to go to the nearest DOTS TB control center daily for 2 months and then as and when required to take medicines in presence of any health care provider?
- Q19. Do you feel ashamed of having TB?
- Q20. Do you have to hide TB diagnosis from others?

Q21. Are you compelled to live in isolation once diagnosed to have TB?

Q22. Has TB affected your work performance?

Q23. Has TB affected your family responsibilities?

Q24. Does TB causes infertility?

Q25. Does TB treatment causes serious complications during pregnancy?

Q26. Would you breast feed your child if you have TB?

TB Stigma

Strongly agree=0	Agree=1	Average=2	Do not agree=3	Do not agree at all=3
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- Do you feel ashamed for having TB?
- Do you have to hide TB diagnosis from the other people?
- Does TB effect relation with the others?
- Is TB very costly due to long duration of the disease?
- Do you prefer to live isolated since you got TB diagnosis?
- Does the TB affect your work performance?
- Does TB affect marital relation?
- Doe TB affect family responsibly?
- Do you thing there is less chances of marriage due to TB diagnosis?
- Does TB affect your family relations?
- Does TB cause female infertility?
- Does TB leads to serious complications during pregnancy?
- Does TB affect breast feeding?
- Does TB affect pregnancy outcomes?
- Is a girl unable to decide for getting TB treatment?

Key Informant Interviews

(Community Leader)

AREA CODE:

DATE: _ _ \ _ _ \ _ _

INTERVIEWER ID:

INTERVIEWER NAME:

INTERVIEWEE ID:

INTERVIEWEE NAME:

AGE:

SEX:

QUALIFICATION:

DESIGNATION:

ADDRESS:

HOME:

OFFICE:

OFFICE TEL:

- Q1. In your opinion who is more prone to tuberculosis? why?
- Q2. What is the usual reaction of people when they find out that their family member has T.B ?
- Q3. What is the reaction when people they get tuberculosis ?
- Q4. Is this reaction different when the patient is a female ? why ?
- Q5. What happens when an unmarried girl gets tuberculosis? Does this affects her chances of getting married?
- Q6. What is the usual reaction of her parents?
- Q7. What is the usual reaction of her fiancée?
- Q8. What happens if the woman is married?
- Q9. What would be the reaction of her husband?
- Q10. What is the usual reaction of her mother in law?
- Q11. What is the usual reaction of her father in law?
- Q12. How does this disease affect the patient socially? Do People avoid meeting them?
- Q13. Do people usually avoid sharing food with them?
- Q14. How long does it take to completely cure the disease?
- Q15. When should a patient stop treatment?
- Q16. Should the patient stop treatment when he starts feeling well?
- Q17. Should a patient take treatment as long as the doctor advises?
- Q18. Have you heard of DOTS programme for the treatment of tuberculosis?
- Q19. Would it be possible for a patient to take medication in presence of a responsible person daily/ twice weekly? What in case of women?
- Q20. Would it be possible for a patient to go to the nearest health facility and take medicines in presence of any health care provider? What if the patient is female?
- Q21: Would the family of a patient allow someone responsible to visit their house to give medications daily? Twice weekly? What if the patient is female?

The Role Of NGO's And CBO's In Neutralizing The Socio-Behavioral Hindrances Leading To Stigmatization Of Tb

Focus Group

AREA CODE:

DATE: --\-- \--

FACILITATOR NAME:

RAPPOTUER NAME:

OBSERVER NAME:

NO. OF PARTICIPANTS:

- Q. 1. When you hear about tuberculosis what is the first thought that's comes in your mind?
- Q. 2. Which people get this disease? Why?
- Q. 3. Are there any factors predisposing to tuberculosis? What are they?
- Q. 4. After how many days of persistent cough would you consult a health care provider?
- Q. 5. If you had persistent low grade fever after how many days would you consult a health care provider?
- Q. 6. If you know some one has tuberculosis would you stop meeting her/him Socially? Why
- Q. 7. Would you eat with a person who has tuberculosis? Share eating utensils?
- Q. 8. Are there any cultural beliefs regarding causes of tuberculosis?

- Q. 9 Are there any cultural beliefs regarding management of tuberculosis?
- Q.10 How would parents feel if their unmarried engaged girl develops TB?
- Q.11 How would her prospective in laws feel? Would they accept her anyway?
- Q.12 If a married woman/man gets TB how would her spouse react?
- Q.13 If a married women gets TB how would her mother in law feel?
- Q.14 How do friends and relatives react when they find out that a person has TB. Do they stay away from the patient ???
- Q.15 What is the reaction of working colleagues, when they find out that a person has TB, Do they stay away from the patient ???
- Q.16 Are women generally allowed to visit any health care provider with friends?
- Q.17 What if they are unmarried?
- Q.18 In your area where do people suffering from T.B usually go for treatment??? Do they have more faith on the medical system or on traditional healers ???
Do patients prefer going to the Public TB Control Centers or do they go to the private sector ???
- Q.19 Would female TB patients be allowed to visit TB treatment center daily to receive medications?
- Q.20 How long should a patient take treatment for tuberculosis
- Q.21 Is the treatment usually completed as advised by the doctor?
- Q.22 Is there a difference in duration of treatment if the patient is a girl?
- Q. 23 Are there any local organizations who provide guidance to TB patients ???