



The CONTROL
(COgNitive Therapy for depRessiOn in tubercuLosis treatment)
to improve outcomes for depression and TB in Pakistan and
Afghanistan

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Community Engagement Initiative (CEI) Activity on Tuberculosis and Depression

February 25, 2023

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Executive Summary

Fourth community engagement activity under The CONTROL Community Engagement Initiative was held on 25th February 2023 in Khalabat, Haripur, KPK to engage with community in their natural settings for project overview and to discuss Tuberculosis and common mental disorders. We conducted two meetings in total, one each for males and females. The meetings were conducted at the local hujras in accordance with the socio-cultural norms of the area. settings This report will narrate the CEI activities in the both female and male community setting.

About CONTROL's VoICE

CONTROL's VoICE (Value of Integrated Community Engagement), is a series of interactive community engagement activities to establish strong linkages with community and patient groups in Khyber Pakhtunkhwa, Pakistan.

At the very outset of CONTROL research programme, CEI was envisioned to establish a mutual understanding between patients, communities, community gatekeepers and influencers, civil society representatives and researchers regarding TB and mental health outcomes.

VoICE Aim:

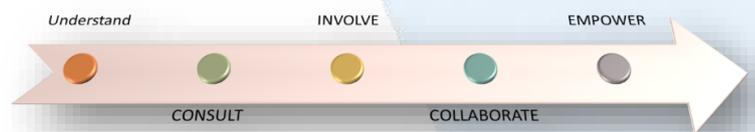
CONTROL's VoICE is guided by the aim to improve mental health and TB outcomes among TB patients of both Pakistani and Afghan origin in KPK and to ensure CONTROL's decision making at every step of the research process to be driven by insights from the community.

Community engagement spectrum

To establish an effective community engagement foundation, the CEI team is following the community engagement spectrum.

Under the CEI, a series of interactive information sessions at both urban and

rural settings are arranged to cater for variety of communities affected by TB and mental health issues and explicitly recognizing the valuable expertise and insights that people with lived experience offer.



Female Hujra Report

Introduction

Activity background:

The fourth community engagement activity under the CONTROL project was conducted at Khalabat, a small village in one of CONTROL'S target district, Haripur. The aim of the activity was to engage actively with the community, spread awareness about Tuberculosis (TB) and Mental Health multi-morbidity and dispel myths and misconceptions prevalent in the community regarding both health issues.

The activity also aimed to identify potential community advisory committee members for the CONTROL project. This advisory committee will guide the research team during all phases of the CONTROL programme and bring in the community perspective in our planning and decision-making.

Khalabat CEI activity plan:

The community engagement activity at Khalabat was planned as a parallel activity in both male and female hujras considering the socio-cultural norms of the area, and to ensure active inclusion of both male and female residents.

Prior to the activity, invitations were sent out to all the male and female members of the village through a local key-informant, who was also tasked to make the necessary arrangement for the male and female hujras.

Female CEI meeting

Settings

Khalabat is a thickly populated area in the district of Haripur, which is one of the two target districts for the CONTROL programme of research. A centrally located premises in the Khalabat village was identified prior to activity and designated as the female hujra for the meeting. The hujra was easily accessible to all the community members and research team. The meeting was held on 25th February 2023.

Participants:

The workshop was attended by around 20 local females aged 24-47 years, including female religious scholar, lady health supervisor (LHS) of the village along with local female residents, 01 Pakistani TB patient and 01 Afghan TB patient and their carers. Among the participants, four were teachers at primary and middle schools in the local community, two were lady health supervisor and a lady health visitor, three were self-employed (stitching clothes) and rest were all housewives.

Facilitator:

Dr. Saima Aleem (Communication Manager and Community Engagement Lead, CONTROL), Ms. Saara Khan (Communication Officer), Dr. Fatima Khalid & Ms. Mariyam Rahim (Research Associates) facilitated the session with the female community members.

Workshop proceedings:

Opening of activity:

The activity started with the recitation of Holy Quran by Dr. Fatima Khalid, followed by the introduction of CONTROL project and team by Dr. Saima Aleem. This was followed up by the sharing the purpose and aims of the CEI activity

All about tuberculosis

Our team highlighted the signs and symptoms, diagnosis, and preventive measures for Tuberculosis. This was followed by group discussions with the participants and eliciting their views on tuberculosis and mental health in general. Our team then touched upon the facts and myths about TB and mental health issues, to spread awareness regarding these diseases, and address the misconceptions related to these conditions that prevail in the community.

An integral challenge associated with TB is that of the stigma associated with TB that not only impairs the quality of life and self-esteem of the patients, but also appears as a considerable barrier to both treatment seeking and non-compliance with the medications. For this reason, TB related stigma was discussed with participants.

Lived experiences of community:

Among the participants, there were two women patients; one Pakistani patient and the other an Afghan refugee patient. They both narrated their journey from diagnosis till recovery.

Participant 1:

Verbatim as narrated by patient:

Female Afghan Patient:

“I was diagnosed with TB four years ago, my family was not supportive, they did not use to sit with me or talk to me since I had persistent cough and fever. My family used to stay away from me, they separated their utensils and other belongings of the house, and they all started ignoring me. I was very worried and lonely at that time. I used to have terrible headaches, body aches, and fever most of the time due to this illness. I had to eat alone because my family used to think that the disease would spread by eating or drinking with me. I had a very bad time moreover, I used to overthink.”

How was the attitude of people living in your community towards you? Or did you notice any change in their behavior towards you?

“People in our community also started avoiding me like my relatives when they come to know that I am diagnosed with TB, their attitude was also not very welcoming towards me, they stopped visiting our home and told others too not to come near me. Due to the behavior of people, I was very depressed and I was always lost in deep thoughts about my illness and the behavior of people. During this whole process, my health deteriorated, and I started losing weight very quickly.”

Participant 2:

Verbatim as narrated by patient:

“I have three children, and I must take care of them as my husband is unemployed, I am the only bread earner at home because of these reasons my stress level is always increased. I caught a cold and had a persistent cough so I visited the hospital and got all my investigations done after which they told me that I am have TB. I started treatment for TB and was very particular about receiving all the medicines from the same hospital. This is my 6th month of the TB treatment.”

Did anyone from your family had TB?

“No one at my home or in my family had TB. Even I didn’t share with anyone in my family that I am diagnosed with TB. I took all the precautionary measures myself. I used to eat in separate utensils and washed them immediately once I was done with my lunch or dinner. I kept myself away from people. I avoided visiting people for the fear of spreading disease to them. Even I asked a health educator (lady health worker) if meeting people is an issue, I will stay at home all the time but she guided me that I have to cover my face while coughing or sneezing as then I can transmit TB to others”.

Who brings Medicines for you from the hospital?

“I bring my medicines myself because no one at home knows about my illness except my husband but since he is jobless so he spends day out in search of job”.

Did you get proper guidance or counselling at TB facility regarding TB and preventive measures?

“In the hospital, they did not guide me properly about precautions but I myself followed the instructions given to me by the health educator (lady health worker) and kept my distance from other family members. If my children call me to have lunch with them, I try to ignore them and say that I am not hungry now. I take my lunch or dinner before other family members and wash my utensils”.

“I am worried about my kids all the time; they are too young if something happens to me who will look after them? I am illiterate and I work as a maid in a colony. Since the time I got sick, I am even more worried about my kids. What if the get TB from me, what if the get any injury when I am away. These thoughts make me worry a lot. I always think if my treatment will be

successful or not. I initially used to think to ask doctor to inject poison in me to make me die so that I get free from this disease and worries”

Do you still feel this way or you are better now with the progression of your treatment?

“I took 5 months of treatment. I am fine now but still, sometimes I overthink, and I am under stress and hopelessness. Sometimes I also think that if my relatives come to know about my illness how they will react? These all thoughts make me worry.”

The patients 2 was accompanied by the lady health worker visiting their area. The team also asked her to share details regarding the 5 months journey of patients from the time of diagnosis till 5th month of treatment.

Lady health worker observation about the TB patient:

“I have felt a huge difference in her perceptions about the disease and life. We visit the household as per schedule of different campaigns or routine visits, when one day, she secretly asked me details about TB and how to keep her children safe from getting TB. When I asked her, she mentioned about being diagnosed with TB but she was so scared to tell it to anyone as in this community people avoid meeting or sitting with TB patients. When she was diagnosed with TB, she used to cry and was very hopeless about the treatment and her life. She was so worried that her 4 kids are so young and what will happened to them if she will die of TB. I consoled her, that you visit hospital and start taking proper TB treatment. I informed her that all medicines are available free of cost, and if you take treatment, so with time you will get better, and I also told her that TB is a disease with a cure so you don’t need to worry. I visit her regularly and she is Alhamdulillah taking treatment regularly. Me and other LHWs visiting her counselled her about her negative thoughts as initially she wanted to die but now, she is mentally stable. I can clearly see improvement in her attitude towards life and TB”.

Mental Health & Depression:

The importance of mental well-being, individual, social, and health related factors either protecting or undermining, TB related mental health stressors and coping mechanism were discussed in details with participants by Ms. Sara Khan. Special emphasis was laid upon the TB related stigma and both stigma and depression prevailing in local community was interactively discussed. Participants opened up their hearts and minds to not only discuss their personal experiences but shared the local myths and how their community reacts to these myths.

TB and mental health related stigma:

In lower- and middle-income countries, the shame and stigmatization associated with diseases and lack of social and emotional support leads to poor treatment and mental health outcomes. Stigma associated with both TB and depression was explained to participants in simplest possible way by taking daily life examples as reference for better understanding.

Lived experiences of community regarding depression

There was two participant who had experienced both anxiety and depression. One was on medication for last two years. Both shared their lived experiences.

Participant 3:

Verbatim as narrated by patient:

“As I always stayed depressed about my life, I think when a person is depressed, he or she stops talking to others and ignores meetups. I have strange feelings about people because they all are happy, and then I feel there is either something missing in me or wrong with me that I don't feel happy like others. These are my own feelings which I am sharing with you. God

forbids! Sometimes I am so depressed that start thinking about suicide. Recently my daughter got married so now I live alone at home. I don't have any other child so feelings of being alone are very painful for me sometimes. I do not visit relatives or friends; I feel better sitting alone and thinking about my life. I cry a lot when its evening times, as darkness and loneliness haunts me. I perceive things like this, I do not know about other people and how they feel when they are alone and hopeless”.

Participant 4:

Verbatim as narrated by patient:

“I am hypertensive, so mostly I am down and have health issues, but I feel I am also not fine mentally, like recently at two different occasions, I started mumbling words differently because I was under stress. I don't feel like visiting anyone or talking to people. When my kids watch TV in loud volume, I get irritated and want to sit in a separate room with no noise. On the other side, I think that these are kids, and they can make noise or can watch TV, and I must take care of them so I start feeling guilty over my actions. Sometimes I lock the main door of my house and go to some other room, I start thinking whether I had locked it or not, then I go back to check the main door again. Same thing happens when I am cooking in the kitchen, I keep going back to stove to check if it's on or I turned it off properly. I wash hands and then moments later I forget if I had washed my hands so I go back again and again to wash them. I feel like due to this all depression or my mental illness, I am losing my mind and my memory is becoming weak day by day. I do not have trust in my work, I feel like whatever I have done is wrong. Just to ignore all these thoughts most of the time I sleep. This is how I cope with my depression”.

Response of community regarding Tb and mental health:

Almost all the female participants mentioned that they all experience stress and anxiety owing to many reasons and requested the team to arrange frequent awareness sessions.

Another participant mentioned that the area she lives in comprised very poor households and TB was prevalent among locals there but due to lack of knowledge and stigma, people are reluctant to seek treatment and help.

She also mentioned that for young unmarried girls suspected of having TB, families don't take them for confirmatory tests for the fear of having difficulties in later stages regarding their marriage proposals and weddings as community doesn't accept such girls.

Regarding the awareness and guidance, they urged that people listen to information provided by the local lady health workers so they should be trained to convince people to seek TB treatment and also to give psychological support.

Recommendations:

Based upon the team's interaction with the community members and patients, it was unanimously agreed upon that local females strongly connect themselves with lady health workers visiting them. They don't discuss their health-related issues even with their family members but feel confident in talking to these lady health workers. They listen to their advices and follow them religiously.

For future community engagement activities, to get connected to community at deeper level and to spread awareness regarding TB and Depression, taking LHWs and LHVs on board can strengthen the CONTROL's CEI.

Team members:

- Dr. Saima Aleem (Khyber Medical University)
- Dr. Fatima Khalid (Khyber Medical University)
- Ms. Saara Khan (Khyber Medical University)
- Ms. Mariyam Rahim (Khyber Medical University)

Male Hujra Report

Introduction

Male CEI meeting

Settings

Khalabat is a thickly populated area in the district of Haripur, which is one of the two target districts for the CONTROL programme of research. A centrally located premises in the Khalabat village was identified prior to activity and designated as the female hujra for the meeting. The hujra was easily accessible to all the community members and research team. The meeting was held on 25th February 2023.

Participants:

The workshop was attended by around 25 local males aged 28-55 years, including male religious scholar, area counsellor, local residents, TB patients and their family members. The participants belonged to different socio-economic group and varied in terms of education. Among the participants, few were local shop owners and shop keepers, teachers, drivers, and govt servants.

Facilitator:

Dr. Safatullah and Mr. Muhammad Ishfaq facilitated the session with the male community members.

Workshop proceedings:

Opening of activity:

The activity started with the recitation of Holy Quran by Mr. Ishfaq, followed by the introduction of CONTROL project and team by Dr. Safatullah. This was followed up by the sharing the purpose and aims of the CEI activity

All about tuberculosis

Our team highlighted the signs and symptoms, diagnosis, and preventive measures for Tuberculosis. This was followed by group discussions with the participants and eliciting their views on tuberculosis and mental health in general. Our team then touched upon the facts and myths about TB and mental health issues, to spread awareness regarding these diseases, and address the misconceptions related to these conditions that prevail in the community.

An integral challenge associated with TB is that of the stigma associated with TB that not only impairs the quality of life and self-esteem of the patients, but also appears as a considerable barrier to both treatment seeking and non-compliance with the medications. For this reason, TB related stigma was discussed with participants.

Lived experiences of community:

Both elder and young males actively participated in the session and shared their lived experiences. Among the males, there was a positive attitude towards the male TB patients and even while interacting with them on regular basis.

The carer of a TB patient was among the first ones to share his own experience. He was well-educated and considered TB as a regular treatable disease.

Verbatim as narrated by carer of TB patient:

Participant 1:

“My father had TB. He used to have severe fever, used to sweat a lot, and faced persistent cough during the disease. We took him to many places for treatment including traditional healers. We didn’t get afraid that much because TB is common now and there are lots of facilities now regarding TB treatment. My father also didn’t face any difficulties in taking medicines or any other mental health issues. Though my father did face anger issues. Before the disease, my father didn’t have anger issues that much. Besides anger issues, he is all ok with everyone.”

Among the males, the knowledge about TB and its treatment was satisfactory. After the initial round of presentation of information by Dr. Safatullah, the participants were more open to discuss details.

Participant 2:

“Now we don’t get afraid of telling people about someone who is dealing with TB. In earlier times people were not aware of TB that much and used to be afraid of it because it didn’t have any proper treatment. But now we see TB has become a treatable disease in Pakistan. In the whole world, there are 2-3 countries including Pakistan and Afghanistan where TB is still present but its ratio is decreasing with time.”

In the community engagement activity, involvement of religious scholar from local community holds a substantial value as being predominantly Muslims, the community has faith in Allah and to strengthen that faith, they follow local religious scholars.

The team had invited the local religious scholar to share his perspective of disease and cure and also to enlighten the community from the teachings of Holy Quran and Sunnah. This helps

the people to understand that disease or health related issues have no link to stigma and isolating patient can make the treatment outcomes even worse.

After initial discussion, the religious scholar mentioned:

Participant 3 (Religious scholar):

“Treatment of every disease is present in Pakistan and in other parts of the world too. But talking specifically about the cutting off from the world (Talking about Mental problems), the solution is one should get closer to Allah himself and Allah will provide him success in this life and afterlife too. In diseases, treatment is a must thing as it is sunnah but with that, if we establish a spiritual relationship with our religion too then we by the grace of Almighty Allah we can get out of these difficulties too. For mental problems, one should start practicing religious practices alongside medical treatment. One should recite Quran as Allah himself has mentioned in Quran “Quran itself is a healing”. So, by reciting Quran one would get mental satisfaction, perform the prayer, and kneel to GOD. These practices will help you in fighting disease and mental stress too. We say that “The satisfaction of hearts is in the remembrance of Allah”, pray two rakat nafal and Allah will remove all the problems”.

Mental Health & Depression:

The facilitator in the second half of session discussed the mental health issues in general and depression in particular. The facilitators discussed the signs and symptoms of depression. He gave examples from everyday life that were used to explain the stigma associated with TB, mental health, and its consequences. The unwillingness to ask for assistance, the belief that doing so reveals a personality flaw, and the belief that one cannot change one's circumstances can all hinder people from getting the right support.

Lived experiences of community:

The community had very little knowledge about mental health & depression. They mentioned about approaching faith and spiritual healers whenever they feel down or in distress.

One participant mentioned having severe depressive symptoms due to few unavoidable circumstances and people around him used to stigmatize him and labelled him as a mad or crazy person. A similar story was narrated by another participant, who witnessed and narrated his friend's tragic incident of his wife leaving him because of this disease. The religious scholar also shared the religious perspective of the treatment and having faith in whatever treatment they are getting.

Participant 4:

"The question of mental health which you asked was spot on. It is the members of the patient's family who makes the patient more ill. My father has TB but we haven't eaten separately from him for even a single day. He doesn't even feel like he has TB. Humans have the capability of fighting disease with their mental capability. About the prayer, I was reading somewhere that an American scientist has discovered that when someone goes into kneel down position then the brain works more efficiently. But if your mental condition gets disturbed then not only TB but thousands of more diseases will attack you."

Response of Community Regarding TB and Mental Health:

The response was encouraging for the team as community opened up on the misconceptions regarding depression. They came to know that mental health is as important as physical health. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

The narration of common mental health disorders and symptoms made the participant realize that poor mental health outcomes make the patient more vulnerable to certain physical health problem.

Conclusion:

Community members actively participated in the session and offered their complete cooperation to the research team as well as to anybody around who has TB or mental health difficulties. The male participants expressed their gratitude to Khyber Medical University and the CONTROL research project team.

They suggested that such sessions should be arranged on regular basis to make people aware about this disease. People should receive training on how to take care for patients in families and how the community may help all such patients and their caregivers.

Team members:

- Dr. Safat Ullah (Khyber Medical University)
- Mr. Ishfaq Azeemi (HOPE Project)
- Mr. Zeeshan Khan (Khyber Medical University)

**COGNITIVE THERAPY FOR DEPRESSION IN TUBERCULOSIS
TREATMENT
(The CONTROL Project)**

COMMUNITY ENGAGEMENT INITIATIVE

Agenda: CONTROL community engagement initiative

Date: 25th February 2023

Area: Khalabat township, Haripur KP.

Time slot	Topic / title	Resource person
11:00am –11:05am	Recitation of Holy Quran	Mr. Ashfaq (Male side) Dr. Fatima Khalid (Female side)
11:05am –11:15am	Welcome note and Introduction of participants	Mr. Ashfaq (Male side) Dr. Saima Aleem (Female side)
11:15am –12:00pm	Infectious disease burden in Pakistan (specifically TB) and in Khyber Pakhtunkhwa. Aim & objective of the Community Interaction, importance of community engagement in improving healthcare delivery and access.	Dr. Safat Ullah (Male side) Dr. Saima Aleem (Female side)
12:00pm - 12:35pm	Overview of mental health disorders in chronic diseases and TB Mental health disorders prevention and treatment, role of community in advancement of research and project specific research activities.	Dr.Safat ullah Ms. Saara Khan
12:35pm – 12:45pm	Speech by the community representative (cousellor)	Local cousellor (Male) Local cousellor (Female)
12:45pm - 12:55pm	Speech by the religious representative (Imam Masjid)	Imam Masjid (Male side) Hafiza (Female side)
112:55pm - 01:00pm	Vote of thanks	Mr. Ashfaq (Male side) Dr. Fatima Khalid (Female side)