

The **VoICE** of CONTROL

Value of Integrated Community Engagement



Community Engagement Initiative (CEI) Activity with
Afghan Refugees on World Refugee Day
June 20, 2023



The CONTROL

(COgNitive Therapy for depReSSIOn in tubercuLosis treatment)

to improve outcomes for depression and TB in Pakistan and

Afghanistan

Funded by: RIGHT3, NIHR

Reference: NIHR201773

Executive Summary

On the World Refugee Day 2023, the team of CONTROL organized its fifth community engagement activity at the Khazana Afghan Refugee Camp in Peshawar. In line with the essence of the World Refugee Day, our aim was to cultivate a sense of inclusiveness among the Afghan refugees and to elucidate their importance for the CONTROL programme as a major stakeholder. We engaged with the Afghan refugee community on issues regarding their mental health, stigma and infectious disease like tuberculosis, and provided an orientation on CONTROL's scope of work.

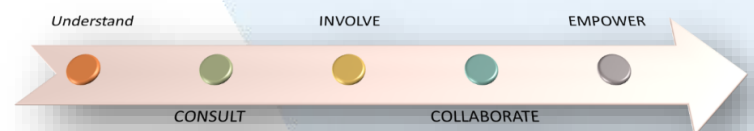
We conducted two engagement sessions, one each for males and females. The sessions were conducted at the community centres in accordance with the socio-cultural norms of the camps. This report will narrate the CEI activities in both female and male Afghan community settings.

About the VoICE of CONTROL

The VoICE (Value of Integrated Community Engagement) of CONTROL is a programme of interactive community engagement activities focusing on establishing strong linkages with community and patient groups in Khyber Pakhtunkhwa, Pakistan. The aim is to involve these groups in the design, conduct and dissemination of the research conducted under the CONTROL programme of research. 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.

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 Afghan CEI Activity

Report

Introduction

Activity background:

The fifth community engagement activity under the CONTROL project was conducted with Afghan refugees on 20th June 2023 at World Refugee Day 2023 at Khazana Refugee camp, Peshawar. The aim of the activity was to actively engage with the Afghan community, spread awareness about Tuberculosis (TB) and Mental Health multi-morbidity and dispel myths and misconceptions predominant in the community regarding both health issues.

The activity also aimed to identify potential members for CONTROL community advisory committee from Afghan refugees. 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.

Khazana camp CEI activity plan:

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

Prior to the activity, Afghan Commissionerate for Refugees at Peshawar was contacted for their approval of the activity and to assign focal person/ social mobilizer at the Khazana camp for overall coordination. Invitations were sent out to all the male and female members of the camp through an Afghan social mobilizer, who was also tasked to make the necessary arrangement at the community centers.

Female CEI meeting

Settings

With a population of twelve thousand Afghan refugees, comprising around 1300 families and 500 - 600 houses, Afghan Camp Khazana is a significantly populated area of Afghan refugees in the district Peshawar, which is located in one of the two target districts for the CONTROL programme of research. A community center located in the Afghan Camp Khazana was identified prior to activity and designated as the place for the meeting/activity. The community center was easily accessible to all the community members and research team.

Participants:

The workshop was attended by 20 Afghan females aged 18-60 years, and one Afghan female social mobilizer. Apart from the 20 adult participants, there were six Afghan teenage girls aged 12-17. Additionally, one Pakistani female participant who live in the camp, also attended the meeting.

Facilitator:

Dr. Saima Aleem (Communication Manager and Community Engagement Lead, CONTROL), Ms. Saara Khan (Communication Officer), Dr. Fatima Khalid (Data Analyst) facilitated the session with the female Afghan community members.

Workshop proceedings:

Opening of activity:

The activity started with the recitation of the Holy Quran by Dr. Fatima Khalid, followed by the introduction of the 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

Dr. Saima Aleem highlighted the Tuberculosis signs and symptoms, diagnosis, and safety measures. This was followed by group discussions with the participants and eliciting their views on tuberculosis and mental health in general. Dr. Aleem explained the facts and figures and talked about myths and misconception related to TB which prevails in Afghan community to spread awareness regarding TB.

Lived experiences of community:

Among the Afghan participants, there were three women who shared their thoughts regarding TB and mental health.

Verbatim as narrated by Afghan Participants:

Participant 1:

What problems does the Afghan community face?

“Our community faces a lot of problems. Especially shortage of electricity, Power outages are frequent, scarcity of drinking water and frequent flooding etc. Floods damage our homes, and we rebuild them. There is lack of education and awareness in our Afghan community. Apart



from it, we face a lot of problems while seeking medical health treatment, we face discrimination just because we are Afghan”.

What difficulties are faced by the Afghan community face while seeking treatment in a hospital?

Participant 2:

“We face a lot of problems while seeking treatment. Doctors do not pay attention to us and says that you people do not have Pakistani CNIC card if you had Pakistani CNIC card, we would be able to get free treatment. A year ago, my daughter eye got badly injured. When we went to hospital X, we were not allowed to admit her. We were so worried, someone helped us, “Khude de aghe madad uki” (God bless him), and then we were allowed to admit her. We



showed the card to the faculty in hospital; then we admitted her in the ophthalmology department and her eye got operated on. So, this happened to us last year, just because we don't have citizenship here, we face so many difficulties”.

Did anyone from your family have TB or have seen any TB patients?

Participant 3:

“Yes, my grandmother and uncle had TB”.

How was the attitude of family members towards her?

“When my grandmother was diagnosed with TB a few years ago, her complexion was getting dark. She had fever and cough. We came to know that she had TB. My mother used to take care of my grandmother. Our behaviour was good towards her. My mother used to take care of her diet and gave her clean clothes and medicine on time. My father and my mother had an incredibly special attachment to my grandmother. Therefore, everyone took good care of her. We separated her utensils, followed all the SOPs. Despite of all the care, my grandmother used to think about her illness and was afraid of dying. She got really worried that how did it happen? whether she would get better or not. However, her health was getting better when she started taking her medicine. Alhamdulillah (Praise be to God), she got better after completing her TB treatment”.

How was the attitude of people living in your community towards her?

“I do not know much about the attitude of people in our community towards her. Some people used to comment about TB, that it never gets better and its contagious so keep her away from others, separate her utensils. She should not touch other’s clothes or cook anything. However, we were very supportive and took good care of her. We followed all the SOPs”.

Mental Health & Depression:

Ms. Saara Khan, being a clinical psychologist focused on the importance of mental health, how we can handle stress related to different situations, and make healthy choices. TB related mental health stressors and coping mechanisms were discussed in detail with participants. Special emphasis was laid upon the mental health problems prevailing in Afghan refugee community.



Participants shared their experiences and discussed issues in detail.

Afghan refugees and stigma:

A major barrier associated with TB and mental health is that of the stigma. In the Afghan community the problem of stigma is further compounded by the issue of marginalization, resulting in lack of optimum care for their conditions, low self-esteem and impaired quality of life. Additionally, cross-cutting issues like gender-based violence, gender discrimination and a general lack of education all affect the mental health and disease outcomes. We solicited information that would help us understand the issue of Stigma and discrimination from the perspective of the refugees. We then proceeded to explain to participants how to avoid stigmatization and how to deal with it, through real life examples as reference for better understanding.

Lived experiences of community regarding depression

Among the participants, there were three Afghan women and one Pakistani local woman who narrated their stories of depression and other mental health issues.

Verbatim as narrated by participant

Participant 4:

“It happens to me most of time, sometimes you don’t feel like talking to anyone and I think about ending my life. Sometimes I am so depressed that I start thinking about suicide and then I ask people to pray for my death as there is no meaning of this life. I think I am under stress, or some tension is going on in my life, but I don’t know the reason behind my sadness”.

Participant 5:

“I got married when I was very young. I have seven children; my elder son takes drugs and my husband too and he does not work. While my other son works in a vegetable shop. Our financial condition is not good. I spend my whole time thinking about life. I struggle with the household chores and have difficulty in concentration”.

Participant 6:

My name is X and I have six children. I am Pakistani citizen but I live in this refugee camp as my house is within its boundary. When I heard that there will be a session here, I wanted to participate in the session to share my problems with you people. I always stayed depressed about my life; I lost my husband in a bomb blast 11 years ago. There was no one to support me. There was no hope, I had the toughest days of my life when I was all alone. I used to miss my husband and cry all night. My mother used to support me financially and is still supporting me. I got married again 4 years ago; I thought I would have a good life. This was when I was

*going to make my life come together but my second marriage was a disaster, forever threatening to break and destroy my mental peace. My second husband doesn't work. He is always at home and does nothing. His behaviour is not good towards me. I feel so lonely and depressed. I always think about the future of my children and my life, it makes me tense. I overthink and is very painful for me sometimes. Now, I have accepted my destiny and living my life as now I feel **Life demands compromises**".*

Participant 7:

There was one Afghan female participant who wanted to talk to the team at the end of session as she wanted to keep the conversation confidential and didn't want to share with her Afghan fellows. The team talked to her at the end of the session keeping the privacy and confidentiality intact.

Verbatim as narrated by participant:

"My name is A, when I got engaged, my in-laws demanded dowry, but my parents couldn't afford it. Hence, my father became a heart patient, and my mother is already a heart patient. Due to these circumstances, I got depressed and still in depression. I feel life, being a refugee, is very tough. People from our own community get mean when it comes to marriages and dowry. I have a request if you people can help us in this crisis. I would be very grateful to you as we need your help".

Response of community regarding TB and mental health:

Almost all the Afghan female participants mentioned that they all experience depression and stress. These mental health issues can be attributed to their displacement due to the war on terror and the general instability in Afghanistan over the last decades. This is further compounded by the general issues of marginalization that refugees face in settling down in new

environs. Almost all the females had this narrative that even back home for young female having TB, life gets tough and it ultimately leads to depression.

Recommendations:

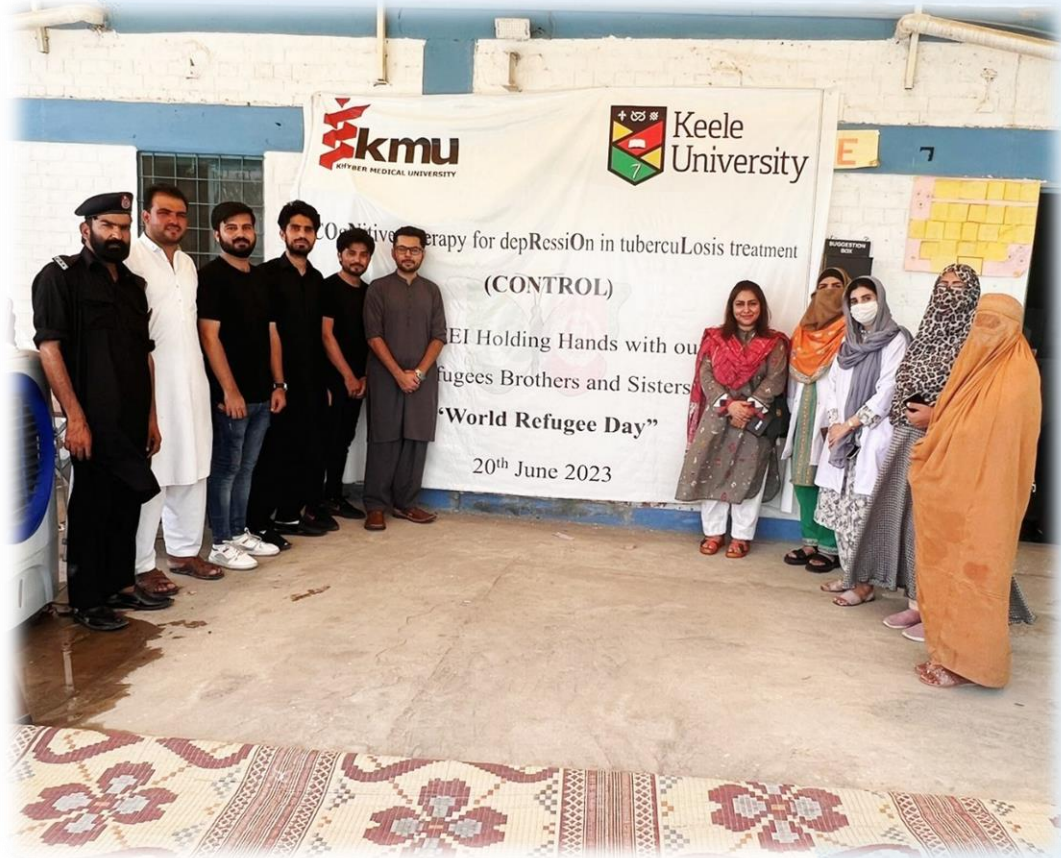
Afghan refugees' community need support and care, they need regular awareness sessions to understand the details of available treatment options for TB and mental health.

There should be a mechanism to equip them with appropriate coping mechanism as they constantly face violence within family, discrimination and stigmatization being inferior to male members of family.

Conclusions:

The participants shared their feedback regarding the information presented to them during the activity and session was concluded with the vote of thanks. Moreover, an Afghan social mobilizer was selected to join research user group (RUG) and the team decided to take him on board.

The Control team members



Group picture of Facilitators with Team CONTROL

Team members:

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

Male Afghan CEI Activity

Report

Introduction

Settings

With a population of twelve thousand Afghan refugees, comprising around 1300 families and 500 - 600 houses, Afghan Camp Khazana is a significantly populated area of Afghan refugees in the district Peshawar, which is located in one of the two target districts for the CONTROL programme of research. A community center located in the Afghan Camp Khazana was identified prior to activity and designated as the place for the meeting/activity. The community center was easily accessible to all the community members and research team.

Participants:

The workshop was attended by 20 refugee males aged 28-55 years, including a male religious scholar, area counsellor, refugee residents, TB patients, caregivers and their family members. The participants belonged to different socio-economic group and varied in terms of education. Among the participants, few were shop keepers, teachers, drivers, and community workers.

Facilitator:

Mr. Asad Ullah, Mr. Hassam ul Haq, Mr. Ihtisham ul Haq and Mr. Zeeshan Khan facilitated the session with the male community members.

Workshop proceedings:

Opening of activity:

The activity started with the recitation of Holy Quran by the religious scholar, followed by the introduction of CONTROL project and team by Asad Ullah and Hassam ul Haq. This was followed up by the sharing the purpose and aims of the CEI activity

All about tuberculosis

Facilitators 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. Some of the participants also shared their lived experiences.

One significant challenge related to tuberculosis (TB) is the presence of stigma, which negatively impacts the patients' quality of life and



self-esteem. Moreover, it serves as a significant barrier to seeking treatment and adhering to medication regimens. Hence, the issue of TB-related stigma was addressed during discussions with the 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.

A TB patient was the first participant who shared the lived experience of TB. He was well-educated and considered TB as a regular treatable disease.

Verbatim as narrated by carer of TB patient:

Participant 1:

“In Hospital X, I received treatment for tuberculosis (TB) approximately 10 years ago. Throughout the treatment, I would visit the hospital every month to collect medicines, and my weight was checked during each visit. After 9 months of medication, the doctor informed me that I had fully recovered. Initially, when I was diagnosed with this disease, I experienced extreme fatigue and significant stress. Although I couldn’t eat anything, but by the grace of God, I regained my health after completing the treatment. My entire family was aware of my TB diagnosis. The doctor advised me to separate the utensils I used for eating and drinking to prevent transmission of the disease to other family members since TB is highly contagious. Taking the medication during the treatment was quite challenging, but I had to adhere to it as the doctor emphasized the importance of not missing a single day. Failure to comply would nullify the entire treatment process, necessitating a restart from the beginning. People would visit my house to inquire about my health, but they would maintain a distance and refrain from coming close to me. Due to the social stigma surrounding TB and the fear of contracting the disease, people avoided visiting me, which saddened me greatly. However, once I recovered, those same individuals resumed sitting and eating with me, just as they had done before I contracted TB.”

The male participants demonstrated satisfactory knowledge regarding TB and its treatment. Following the initial presentation of information by Mr. Asad Khan, the participants became more receptive to engaging in detailed discussions and shared their thoughts more openly about TB.

Participant 2:

“To address mental health challenges effectively, it is essential to possess the necessary skills for treatment. Once equipped with these skills, healthcare professionals can then transfer their knowledge to patients, enabling them to better cope with these issues.”

The participation of a religious scholar from the local community carries significant importance in the community engagement activity. Since the majority of the Afghan refugee community members are Muslims, they place their trust in Allah and rely on the guidance of local religious scholars to strengthen their faith. In this context, the team had extended an invitation to a local religious scholar to provide insights on the topic of disease and healing, drawing from the teachings of the Holy Quran and Sunnah.

This effort aimed to help individuals understand that diseases and health-related issues are not associated with stigma, and isolating patients can have adverse effects on their treatment outcomes. After initial discussion, the religious scholar mentioned:

Participant 3 (Religious scholar):

“As Muslims, we all believe that every illness has a cure. We should support one another and redirect patients' focus from their illness toward a more positive treatment approach. We firmly believe that every illness comes from Allah, and He holds the cure for every ailment. Today, during my visit to a hospital, I witnessed numerous instances where Muslim brothers were avoiding each other to minimize the risk of disease transmission. At that moment, a thought crossed my mind: If you cannot assist your fellow Muslim brother, then what is the purpose of our lives? We should believe in Allah that he is the one who tests us with these kinds of illnesses and he is the one who has the cure.”

A social community worker who was working in the camp and providing medical assistance to the patients was also present. He also shared his thought regarding the mental health-related issues prevailing in the community.

Participant 4:

“When individuals fall ill with TB or other diseases, they often experience a range of mental health issues. Additionally, during catastrophic events like floods or earthquakes, people undergo significant stress, which can lead to various mental health challenges. In such cases, we direct these patients to a psychologist for assistance. At our camp, we have a female doctor specifically assigned to TB patients. She provides care and oversees their treatment. If a patient exhibits TB symptoms, they are referred to the nearby hospital in Nahaki, where tests are conducted. If diagnosed with TB, the patients receive further treatment, which is entirely free of cost.”

Mental Health & Depression:

In the second half of the session, the speaker talked about mental health problems in general and specifically about depression. They discussed the signs and symptoms of depression using examples from everyday life. These examples were used to explain how people might feel ashamed or embarrassed to ask for help, thinking it shows a weakness in their character. Additionally, some people believe they can't change their situation, which can prevent them from seeking the support they need.

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 experiencing severe depressive symptoms due to a few unavoidable circumstances, and the behavior of people around him contributed to his feelings of depression and sorrowful thoughts. He expressed that people stopped visiting him and ceased communication, which further saddened him. During the discussion, participants emphasized the importance of providing motivation and support to those battling the disease, and avoiding language or actions that may make them perceive it as a terrifying condition, which could lead to depression. The religious scholar also shared a religious perspective on treatment, emphasizing the significance of having faith in the chosen treatment approach.

Participant 5:

“Mental health issues pose significant dangers, emphasizing the need for awareness campaigns to address them. Unfortunately, people often lack awareness regarding the detrimental impact of these issues, which can ultimately prove costly for those experiencing them in the long run. However, if mental health issues are addressed promptly, individuals can regain control of their lives and return to their normal routines. Tension and stress negatively impact productivity, underscoring the importance of timely treatment. It is crucial to note that if mental health issues are left unaddressed and escalate to their peak, individuals may even attempt suicide.”

Participant 6:

“It is important to speak to the patient in a gentle and comforting manner, avoiding any indication that people around them hate them because of their illness. Our goal should be to make the patient feel loved and supported, preventing negative thoughts associated with their condition. Despite the severity of the disease and the lack of a cure in the past, we should convey to the patient that it is just like any other manageable illness. It is distressing when people develop hatred towards individuals with TB, and we should consider the impact this

behavior has on the patient's self-esteem. Therefore, such patients require compassionate care and understanding. We also acknowledge that illnesses are from Allah, and He holds the cure, as mentioned in the Quran. Our role is limited, and Showing hatred towards the patient will not contribute to their recovery.”

Response of Community Regarding TB and Mental Health:

The team found the community's response encouraging, as they began to address misconceptions surrounding depression as the session moved on. It became evident that mental health is just as vital as physical health. People came to understand that mental well-being is important at every stage of life, from childhood to adulthood.

By discussing common mental health disorders and their symptoms, participants became aware that when mental health deteriorates, it can make individuals more susceptible to certain physical health issues.

Conclusion:

Community members actively joined the session and offered their wholehearted support to the research team and anyone facing TB or mental health issues. The male participants expressed thanks to CONTROL CEI team to take time out to visit them and listen to their narrative as they need utmost guidance to address their issues more effectively.

They also recommended organizing regular sessions to increase awareness about this disease. It was suggested that people should be trained on how to care for patients within families, and the community should offer support to all such patients and their caregivers.

Team members:

- Mr. Asad Ullah (Khyber Medical University)
- Mr. Hassam ul Haq (Khyber Medical University)
- Mr. Ihtisham ul Haq (Khyber Medical University)
- Mr. Zeeshan Khan (Khyber Medical University)

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

COMMUNITY ENGAGEMENT INITIATIVE

Date: 20th June 2023

Area: Khazana Camp Peshawar, KP.

Time slot	Topic / title	Resource person
01:00pm – 01:05pm	Recitation of Holy Quran	Mr. Hessam ul Haq (Male side) Dr. Fatima Khalid (Female side)
01:05pm – 01:15pm	Welcome note and Introduction of participants	Dr. Saima Aleem (Female side) Mr. Ihtisham ul Haq (male side)
01:15pm – 02:00pm	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.	Mr. Asad Ullah (Male side) Dr. Saima Aleem (Female side)
02:00pm – 03:00pm	Lived experiences of community Moderated by Dr. Fatima Khalid	
03:00pm - 03:45pm	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.	Mr. Hessam ul Haq (Male side) Ms. Saara Khan (Female side)
03:45pm – 04:00pm	Speech by the community representative (social mobilizer)	Afghan Male Social Mobilizer (Male) Afghan Female social mobilizer (Female)
04:00pm - 04:15pm	Speech by the religious representative (Imam Masjid)	Imam Masjid (Male side)
04:15pm - 04:30pm	Vote of thanks	Dr. Saima Aleem (Female Side)

		Mr. Zeeshan Khan (Male side) Dr. Saima Aleem (Female side)
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