



The CONTROL

(COgNitive Therapy for depRessiOn in tubercuLosis treatment)

to improve outcomes for depression and TB in Pakistan and

Afghanistan

Funded by: RIGHT3, NIHR

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“Naguman Refugee Camp Community Engagement Activity”

23rd & 26th July 2024

Afghan refugees are integral to the CONTROL study, with the CONTROL CEI team regularly engaging them in awareness initiatives. On July 23 & 26, 2024, community engagement activities were conducted at the Naguman Afghan refugee camp in Peshawar, KP, with female and male Afghan refugees respectively. The primary objectives of this engagement were to interact with the community within their natural setting, provide an overview of the CONTROL study, and discuss tuberculosis and mental health outcomes. Additionally, the activity aimed to introduce the concept of co-creation and art-based community engagement activities. This report will provide a detailed account of the community engagement activity held in both female and male hujras.

INTRODUCTION

Activity Aims & Objectives:

On July 23, 2024, a community engagement activity was conducted at the Naguman Afghan refugee camp in rural Peshawar. This initiative aimed to actively engage with the community to raise awareness about the CONTROL study, tuberculosis, and mental health outcomes, while also introducing the concept of co-creation to the community members. Additionally, the activity sought to address prevailing myths within the community and highlight the significance of art as a powerful tool for impact, particularly through community-driven creations for tuberculosis and mental health awareness.

Naguman Camp CEI Activity Plan:

Prior to the scheduled activity, the CONTROL CEI team convened a comprehensive meeting with the Community Advisory Board members to seek their invaluable recommendations. Subsequently, the research team conducted a site visit to the area, engaging with local hujra and elders to extend invitations to community leaders and members, and to finalize necessary logistical arrangements. Additionally, a distinct meeting was held with the female religious scholar to ensure her participation and involvement in the activity.



Female Hujra:

The designated female hujra for the activity was centrally located within the Naguman refugee camp, making it easily accessible for both community members and the research team. The hujra was spacious and well-maintained, accommodating approximately 35 to 40 female participants.



Facilitator:

For female hujra:

From the CONTROL CEI team, the session was facilitated by:

- Dr. Saima Aleem (CONTROL Communication Manager and Community Engagement Lead)
- Saara Khan (CONTROL Communication Officer and MEAL Manager for CEI Guiding Principle Pilot Project)
- Dr. Fatima Khalid (CONTROL Qualitative Researcher)
- Dr. Kanwal Safeer (Co-Creation Coordinator, CONTROL CEI Guiding Principle Pilot Project)
- Rida Zarkaish (Co-Creation Coordinator, CONTROL CEI Guiding Principle Pilot Project)

From the CONTROL study Community Advisory Board, Dr. Ghazala Yasmin joined the team for the said activity.

Participants:

The workshop was attended by 36 female participants, including an Islamic scholar (a teacher from the Madrassa) and local female residents.

Activity:

The activity commenced with the recitation of the Holy Quran by Rida Zarkaish.

Saara Khan welcomed all participants and explained the purpose of the visit to the community members. She provided them with an



information sheet and consent form for their participation in the CEI session.

All About Tuberculosis & Mental Health

Saara Khan discussed tuberculosis, including its signs and symptoms, precautionary measures, and common myths. The facilitator then provided information on mental health and common health issues, discussing the signs and symptoms of depression and anxiety. The female refugee shared their lived experiences.

As a clinical psychologist, Saara Khan shared strategies to overcome depression, anxiety, and stress, and how to manage life stressors effectively. depression, such as persistent sadness, disturbed sleep, changes in appetite, feelings of worthlessness, and suicidal thoughts. Participants shared their experiences with mental health issues, describing feelings of heaviness, anger, sadness, and the impact of grief on their daily lives. Saara encouraged them to seek both pharmacological and non-pharmacological treatments and to engage in activities that interest them to manage stress and depression. She conducted a deep breathing exercise with the participants to help them feel better and emphasized the importance of this practice.

The Lived Experience of Afghan refugees:

During the community engagement activity, the females were asked if they had heard of TB, to which the participants responded affirmatively. When asked if anyone in their households had experienced TB, several participants shared their experiences.

Participant 1:

One participant recounted the harrowing experience of her 18-month-old daughter, who suffered from intestinal TB. She said, *“My daughter had a high temperature and a swollen belly, and despite taking medicines, her condition worsened. Tragically, my daughter passed away due to the illness. I personally also battled TB, enduring misdiagnoses and multiple doctor visits before a facility finally identified the disease through a shoulder fluid test. I medication for nine months and dealt with jaundice, which prompted me to seek further treatment in Afghanistan. There, I followed a diet of white rice, yogurt, and watermelon, which eventually led to my recovery. My two children who were born after her TB diagnosis were also diagnosed with TB when they were around three years old”*.

Participant 2:

Another participant shared her experience and mentioned, *“My grandson, now six years old, was diagnosed with TB at the age of two. Initially mistaken for an allergy due to symptoms like diarrhea, his condition was later correctly identified as TB, followed by jaundice. His TB was treated successfully, but he remained very thin and lean”*.

Additional respondents shared similar struggles with TB, describing prolonged high temperatures, multiple hospital visits, and the eventual diagnosis and treatment.

Participant 3:

One woman recounted her experience; *“I had chest (pulmonary) TB, which went undiagnosed for two months despite severe symptoms. I got relief finally after receiving the correct treatment and regaining the strength and energy to perform daily chores”*.

CEI team emphasized the importance of recognizing TB symptoms, which include a persistent cough for more than two weeks, high temperature, night sweats, body aches, vomiting, and significant weight loss. The participants were given awareness regarding how TB is transmitted through coughing and sneezing, highlighting the need for precautions like wearing masks or using handkerchiefs. Participants were urged to visit a doctor if they or someone in their household exhibited these symptoms to prevent the spread of TB.

Finally, Saara introduced a simple breathing exercise to help alleviate stress. She guided the participants through the exercise, emphasizing the importance of mental focus and positive thinking to achieve relaxation. The participants practiced the exercise together, acknowledging its potential benefits for their mental well-being.

Overview of Art-Based Activity:

The community members were given details regarding different art-based genres for community engagement and awareness. They were briefed about different visual, performing, and digital art mediums.



Flyer: A sample flyer, incorporating an animated cartoon alongside textual information about depression and tuberculosis (TB), was presented to the participants.

They were asked about their prior exposure to similar materials. Additionally, detailed informational posters were referenced. Participants were instructed to describe the visual content and interpret the depiction of the character on the flyer. One participant articulated that the

animated

character on the flyer. One participant articulated that the character appeared tense, which effectively conveyed the concept of depression.

Flipbook:

A flipbook was shared, featuring an example of a calendar with pictures on one side and information on the other. This format enables those who cannot read to understand through pictures. It was explained that the information could be written in any language, including Urdu, Pashto, Persian, and English, according to the area and its language.

Song/Audio/Caller Tunes:

The CEI team demonstrated the concept of music in raising awareness by drawing parallels with popular games like cricket and football or the famous COVID-19 awareness songs. When asked if they follow cricket, the participants confirmed that their husbands and children watch

the games, to which they were asked, "Have you noticed how cricket matches often feature uplifting and emotive songs that resonate with the audience?"

The participants were then asked, "*Do you remember the malaria advertisements featuring mosquitoes on TV?*" The participants replied, "Yes, like the Dengue mosquito advertisements."

The CEI team mentioned that "During the COVID-19 pandemic, there were awareness campaigns with ringtones in Pashto and Urdu, sharing information about symptoms." The participants shared their experiences, saying, "Similarly, with Dengue Awareness, we're informed about mosquitoes laying eggs in clean water during the morning or evening". The whole concept of this discussion was to give the females idea about awareness through music.

Role-Play/Drama:

The team introduced another genre, i.e; drama. The participants were asked, "Do you watch dramas?" They replied, "Yes, we all watch dramas, regardless of age." They were then asked, "Have you noticed how dramas often convey information through short videos, typically 1-2 minutes long?" The participants responded, "Yes, like advertisements we see."



Informative Videos: The females were shown an informative video to get clarity regarding the role of videos in community awareness. It was explained that there are various methods to disseminate information to people. However, visiting each household is challenging. If the information is not passed on to others, it is likely to be forgotten after a few days. Therefore, finding alternative ways to share information is crucial to reach as many people as possible.

Focused Group Discussion Proceedings:

Dr. Fatima Khalid and Dr. Kanwal Safeer started the Focus Group Discussion (FGD) with the participants, recording their responses.



The session was moderated by Kanwal and Rida did the notetaking for the activity. The participants were asked about their preferred methods of communication for receiving information. Participant 1 expressed a preference for direct, personal engagement, highlighting that the respectful presence of the team made the information-sharing process more effective. They noted that they rarely use mobile devices as their husbands provide only basic phones for calls,

limiting their ability to watch videos. Participant 2 shared similar sentiments, stating that direct communication builds trust and comfort. Participant 3 echoed this preference, appreciating the joy and peace brought by personal interactions.

Kanwal then asked questions about how participants would retain and continue to access the shared information in the team's absence. Participant 3 acknowledged the lack of smartphones but expressed a willingness to continue communication through personal conversations. The majority of participants found watching dramas or advertisements mentally exhausting and mentioned that their husbands do not allow them to use mobile phones. When asked about alternative methods like TV or radio, Participant 2 mentioned the absence of these devices in their households. However, Participant 4 mentioned having a radio that can play voice notes from a USB drive, suggesting this as a potential medium for information dissemination.

Kanwal introduced the idea of using flyers, which could be explained to the participants by their educated children. The majority agreed that this method was effective and could be easily understood with assistance. Participant 5 emphasized the utility of flyers for personal reference and suggested that the team continue visiting their homes for discussions. When discussing the best times for gatherings, Participant 5 offered flexibility, suggesting that the team choose a suitable time and they would invite others accordingly.

The participants were then asked about the most effective methods for sharing information with those who couldn't attend the meeting. Participant 8 assured that they would share the information on depression and TB with absent community members by visiting their homes. Participant 2 confirmed their intention to disseminate the knowledge shared about the connection between TB and depression.

Kanwal inquired about the preferred format for presenting information, whether through more written content or images. Participant 3 requested comprehensive awareness materials in Pashto, noting that their girls study and understand Pashto better than Urdu. The majority agreed on the importance of using Pashto for written materials. When asked about combining information on TB and mental health into a single resource, the participants preferred having all information in one place, with flyers being the favoured medium.

Regarding visual preferences for the flyers, the participants preferred realistic human images over cartoons for clearer message delivery. Due to cultural sensitivities, the use of animations was agreed upon. The majority also preferred content in Pashto for videos. They requested detailed written documents in Pashto, covering where to find treatment and other essential information about TB and mental health.

Concluding Remarks:

Dr. Ghazala shared her lived experience of TB and mental health with patients and mentioned that she had been a CONTROL community advisory board member since the beginning of the project and she feels that before CONTROL's CEI initiative, no one included communities in the true spirit. She encouraged all female to be vocal for information seeking and playing their active roles.

Dr. Saima Aleem thanked all the female community members and Hujra owner

lady for opening their doors to the team and community members and allowing us to actively engage with all.



Group Pics of CONTROL CEI Team



Community Engagement Activity with Male Afghan Refugees at Naguman Camp

26th July 2024

Facilitator:

From the CONTROL team, the activity was facilitated by:

- Asad Ullah, (CEI Pilot Project Manager),
- Ihtesham ul Haq (CEI Pilot Project Community Engagement Officer Local)
- Ihsan Ullah (CEI Pilot Project Community Engagement Officer Afghan)

From the CONTROL study Community Advisory Group, the session was attended by:

- Asad Ullah
- Agha Sherin
- Farman Ullah

Workshop Proceedings:

Day & Venue

The community engagement activity was conducted on July 26, 2024, in Naguman Camp, located on the rural outskirts of Peshawar, Khyber Pakhtunkhwa (KP). This area is predominantly inhabited by Pashtuns, whose native language is Pashto. Naguman Camp is recognized for housing Afghan refugees, primarily daily wage laborers, under the administration of the Commissionerate of Afghan Refugees (CAR).

Participants:

The workshop was attended by 36 males residing in Naguman camp, their religious scholars, hujra owner along with CEI advisory group members.

Aims & Objectives of CEI Activity:

The aim of conducting this CEI activity in a natural setting and among the rural population was to understand their perceptions regarding TB and associated mental health outcomes, how they deal with TB patients and to address the myths prevailing in both urban and rural communities regarding TB and depression. Also, to ensure the community's active participation and support, the aim of this CEI session was to establish consensus on ART-based genres for community engagement and involvement.

Activity:



The activity was opened with the recitation of the Holy Quran by Ihsan Ullah. Later Ihtesham ul Haq introduced the CONTROL team and briefed the participants on the purpose of the activity, its aims and objectives, and how the community can help and contribute to the project.

All about Tuberculosis

Ihtesham ul Haq and Asad Ullah provided a comprehensive explanation of the signs and symptoms of tuberculosis (TB), detailing that symptoms include a persistent cough lasting two weeks or longer, chest pain, and coughing up blood or sputum. Other symptoms of TB disease

were also covered, such as weakness or fatigue, weight loss, lack of appetite, chills, fever, and night sweats. In addition to discussing the types of tuberculosis, they elaborated on various precautionary measures for patients, caregivers, and those interacting with TB patients.

They emphasized the importance of these precautionary measures to ensure the safety of both patients and caregivers. They also addressed prevalent myths within the community, highlighting the need for myth-busting to raise awareness and alter attitudes towards TB patients. This, in turn, can contribute to reducing poor mental health outcomes associated with

TB Lived Experiences of Community:

Among the participants, three males had Tuberculosis patients at their homes, and they narrated their journey from diagnosis to recovery.

Participant 1:

Verbatim as Narrated

Living as a daily wage laborer in Naguman Camp, as an Afghan refugees, presents numerous challenges. Being a refugee already meant limited access to healthcare, financial instability, and social stigma. When my father contracted TB, these issues became even more obvious. My father initially showed symptoms of TB, such as a persistent cough, fever, and chest pain. Access to healthcare facilities was already a struggle due to our refugee status, and the



added burden of TB made it even more difficult. The cost of medical treatment was a significant financial strain, as my daily wages barely covered our basic needs.

The stigma associated with TB in our community also added to our hardships. Neighbors and even some family members distanced themselves, fearing contagion. This social isolation was particularly hard on my father, who felt not only physically weakened but also emotionally abandoned. As the only breadwinner, I often faced exhaustion and stress.

Participant 1 also highlighted the psychological impact of TB on both his father and him. The fear of the disease, coupled with the financial strain and social stigma, led to anxiety and depression. Despite these challenges, he ensured the completion of his father's treatment.

Participant 2:

Participant 2 shared the details of his two-year-old daughter being diagnosed with extrapulmonary tuberculosis (TB), which affected his life. He mentioned, "The diagnosis of extrapulmonary TB brought about a series of challenges. My daily routine was significantly disrupted as I had to take my daughter to multiple medical appointments, often waiting in long lines at healthcare facilities that were already overburdened. Initially, I had issues due to my refugee status and then being a shopkeeper, each day spent at the hospital meant a day without income, adding financial issues. Emotionally, the experience was exhausting. I had many sleepless nights about my daughter's health and future. The stress of managing her medical care, combined with the need to continue working to support my family, created an immense emotional burden. Stigma surrounding TB meant that some community members distanced themselves from my family, fearing getting the disease despite the non-pulmonary nature of her disease. This isolation further added to my emotional distress, as I felt both unsupported and misunderstood by my community.

Response of Community Regarding Art base CEI:

In the next half of the discussion, Asadullah, presented an overview of art-based strategies, emphasizing the advantages of using art to improve awareness and engagement. Art-based strategies can help to make complicated problems more accessible and memorable, as well as build a stronger emotional connection to the issue. He mentioned that there are potentially five or six different types of art-based approaches, including visual, performance, and digital art. He displayed different art-related items, including books, banners, flyers, and videos. In addition to that, he also presented a two-minute animated short video about depression, which the participants found both enjoyable and informative.

Verbatim as narrated by the community representative:

"While the video was interesting, I don't think this method is effective for reaching our community since many of us don't have access to smartphones, and also, the women in our community don't use them. (All participants agreed with the statement)"

Islamic scholar said that booklet or flyer is ok as banners could be torn by children and will have no benefit and most of the participant got agreed".

Community Feedback of Art Genres:

Most of the participants choose the booklet and said that it will be easily understandable if you translate it into Pashto and Urdu language. They also said that it would be good if instead of animation real pictures of the TB and anxiety persons were used.



During the session, the moderator asked participants to share their observations and what they learned from the video presented. Participant 1 found the video engaging and informative, noting how it

illustrated the impact of financial struggles, family problems, and illness on a person's mental health, leading to depression. However, Participant 2 pointed out that while the video was interesting, it might not be effective for reaching their community due to limited access to smartphones among the women. All participants agreed with this sentiment, and the moderator encouraged them to share their views on effective communication methods.

When discussing the most beneficial ART-based communication methods, Participant 1 suggested booklets and radio, receiving agreement from the others. Participant 2 proposed banners, as they can be explained by others to the uneducated members of the community. An Islamic scholar, Participant 3, supported booklets over banners, expressing concern that banners might be torn by children or rain. Participant 4 recommended cartoon-like videos in

The participants outlined the benefits of ART-based activities, emphasizing awareness of diseases and ensuring patients reach the correct healthcare centres on time. When asked about future participation, all participants expressed a willingness to engage warmly and to gain new information.

When the moderator inquired about the effectiveness of role plays or drama versus booklets for disseminating information, half of the participants agreed to booklets, while the other half argued that role plays, or drama offer only temporary benefits to those in attendance. Booklets, they agreed, provide lasting value. To ensure the information reaches every person and home, Participant 1 suggested distributing flyers that could be shown to others.

The CEI team extended thanks to every member of the refugee camp for taking time out to attend the session and for their feedback.

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

Community Engagement Initiative CEI NIHR Pilot

Agenda: CONTROL Community Engagement initiative

Date: 23rd & 26th July 2024

Area: Naguman Camp, Peshawar

Male and female parallel in two different houses (Hujras)

Time slot	Topic / title	Resource person
11:00am-11:05am	Recitation of Holy Quran	Dr. Ihsan Ullah (Male side) Ms. Rida Zarkaish(Female side)
11:05am-11:15am	Welcome note and Introduction of participants	Mr. Ihtesham Ul Haq (Male side) Ms. Kanwal Safeer (Female side)
11:15am-11:25am	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. Ihtesham ul Haq (Male side) Dr. Saima Aleem (Female side)
11:25am-11:35am	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. Asad Ullah Ms. Saara Khan
11:35am-11:45am	Lived/shared experiences from CEI advisory group	Mr. Asad (Afghan representative) Dr. Ghazala Yasmin
11:45am-12:15pm	Introduction to art-based CEI i.e., performance art, visual art and digital art	Mr. Asad ullah & Mr. Ihtesham Ms. Saara Khan & Ms. Fatima Khalid
12:15pm-12:45pm	Participant feedback on each sample	Mr. Ihsan ullah & Mr. Asad Ullah Ms. Fatima Khalid & Ms. Kanwal Safeer

12:45pm- 12:55pm	Speech by the community representative (cousellor)	Local cousellor (Male) Local cousellor (Female)
12:55pm- 01:05pm	Speech by the religious representative (Imam Masjid)	Imam Masjid (Male side) Alma (Female side)
01:05pm- 01:15pm	Vote of thanks	Dr. Asad Ullah (Male side) Ms.Tuba (Female side)

Budget Utilization

CEI ACTIVITIES						
Costs head	Description	No of participants	Amount per person	Total Amount in PKR	Total Amount in GBP (@ 353 PKR/GBP)	Dated
Community Advisory group meetings						
renumeration	Post Naguman's activity me	5	5000	25000	70.82152975	30-Jul
Refreshment	Refreshment for Advisory gr	1	3800	3800	10.76487252	30-Jul
	Subtotal			28800	81.58640227	
CEI sessions Naguman Camp (Afghan Refugees)						
Printing	Information sheets, consent	1	2000	2000	5.66572238	15-Jul
Refreshment	Day 1: Refreshment for fem	1	5870	5870	16.62889518	23-Jul
Renumeration	Day 1: Female Participants re	35	500	17500	49.57507082	23-Jul
renumeration	Renumeration for Huja/hos	1	10000	10000	28.3286119	23-Jul
renumeration	Day 1: Renumeration for fee	1	5000	5000	14.16430595	23-Jul
renumeration	Day 1: Renumeration for fee	1	5000	5000	14.16430595	23-Jul
renumeration	Advisory group members	3	3000	9000	25.49575071	23-Jul
Transport	Transport cost (including ren	1	22000	22000	62.32294618	23-Jul
	Subtotal			76370	216.3456091	
renumeration	Day 2: Male Participants ren	30	500	15000	42.49291785	26-Jul
renumeration	Day 2: Male religious schola	1	5000	5000	14.16430595	26-Jul
Refreshment	Day 2: Refreshment for male	1	7000	7000	19.83002833	26-Jul
renumeration	Day2: Renumeration for fee	1	10000	10000	28.3286119	26-Jul
renumeration	Day2: Renumeration for fee	1	5000	5000	14.16430595	26-Jul
Stationary	Envelops for cash payments	35	5	175	0.495750708	26-Jul
renumeration	Advisory group members	3	3000	9000	25.49575071	26-Jul
Transport	Transport cost (including ren	1	22000	22000	62.32294618	23-Jul
	Subtotal			73175	207.2946176	
	Total			178345	505.2266289	

Approved and Signed by:

20/7/2024
30/7/2024