

HAMARI AWAAZ

UNCHARTED VOICES



Visuals and perspectives on living with the stigma of drug resistant tuberculosis

A book by nine participants of the Photovoice study:

*Addressing stigma in people living with
multi-drug resistant tuberculosis in India.*

A research project conducted at the
Médecins Sans Frontières (MSF) clinic, Mumbai, India.

October 2020

“Don’t just tell me to be strong; understand that I need support and stand by me.”

According to the Global Tuberculosis Report for 2019 by the World Health Organization, India accounts for almost one fourth of the world’s TB burden, with almost 27 lakh cases reported in 2018. Even so, this deadly disease is rarely spoken about or discussed in public, because of the stigma associated with it since historic times. Thanks to frontline workers, government schemes and non-government organizations like Médecins Sans Frontières/ Doctors Without Borders, the battle against TB is being fought aggressively on all fronts. However, a major obstacle in ensuring successful treatment outcomes, is the lack of social support. To eliminate TB, it is important to eradicate the stigma. The Photovoice project is a very important tool to initiate a conversation about TB and the stigma surrounding it. It empowers the patients to speak up and share their stories.

The photos chosen by the nine brave women in the book connect us to the pain and anxieties faced by them as DRTB patients due to the changed behavior of those closest to them. This obvious and sub-conscious manifestation of stigma related to TB can be detrimental to a patient’s spirit and willpower to heal, whilst already dealing with side effects of TB medication and injectables. The book is a powerful reminder that in the fight against TB, empathy is the most valuable drug. As a DRTB survivor, I can say that the book provides valuable insights into what goes on in the mind of a person undergoing DRTB treatment. Hopefully, it can empower the doctors, healthcare workers or family members to provide the correct psycho-social support to help overcome the stigma and improve treatment outcomes.

- Jinisha Lodaya

Patient Activist

This is a powerful and tragic account of a group of brave women, and a disease that tore through the physical, emotional and social fabric of their lives. It is a privilege to have an insider's view to this deeply real and courageous testimony.

My lens is as a social scientist who researches people's experiences with tuberculosis, or TB, the world's leading infectious disease killer. In late 2019, I was proud to play a small part in an initiative where Tahiya Mahbub, a Photovoice researcher, and Taanya Mathur, Patient Support Manager in MSF Mumbai, engaged with nine women receiving treatment for drug-resistant TB – the most severe and challenging form of TB disease – in the city of Mumbai. In order to bring to surface a more multi-dimensional and authentic account, each of the nine women took a series of photographs representing their experience with drug-resistant TB and shared an accompanying narrative to portray what those experiences symbolized for them. The result is a magnified glimpse into deeply disturbing encounters with exclusion, discrimination, injustice, shame, fear and betrayal, from the people and structures in their life that mattered to them the most. The rawness of this unfiltered testimony is magnified through powerful imagery that, as someone who grew up in the city, is at once familiar, jarring and crushing.

When you read this book, you too will feel jarred and crushed. And you will feel enraged. Enraged that the advancements made in TB diagnostics, treatment and service delivery have done little to alleviate the stigma of TB diagnosis, treatment and service delivery; that the social 'side effects' of TB remain a low priority on national TB

agendas. This book will wake you up to an uncomfortable truth. So much of what is steeped in the story of TB is a story about disparity in power and privilege, and a story about the systemic failure to protect women (and men) affected by TB from being engulfed by the structural violence which places them at risk for the disease, and for the exclusion it subsequently invites.

I applaud these nine women, and the millions more who they might represent, for finding their voice to capture injustices in such a poignant way, and for displaying a remarkable resilience in the face of brutal adversity. I also congratulate the MSF team in Mumbai for delicately facilitating such an empowering medium to bring these elusive realities to light.

- Amrita Daftary

York University, Toronto

And also, a SoBo girl with some humility

The book 'Hamari Awaaz' is the result of the photos taken by nine women with multi-drug resistant (MDR) tuberculosis (TB) who participated in a foundational Photovoice study conducted by Médecins Sans Frontières/ Doctors Without Borders at its TB clinic in Mumbai, India. The book includes a display of patients' photographs on stigma as they experienced it in their daily lives.

MDR-TB is resistant to most first line (drug sensitive) TB medications. Patients take treatment for 1 to 3 years. During this period, they face life altering stigmas - from enacted stigma or direct discriminatory actions from others, anticipated stigma or the fear of being discriminated, to structural stigma or institutionalized and systematic exclusion. The photos in this book illustrate the loss of voice, status, and mobility caused by this stigma, and the consequent internalized experiences of shame, distress, and peril faced by the recipients. Stigma may also affect their treatment adherence and re-integration into society once cured.

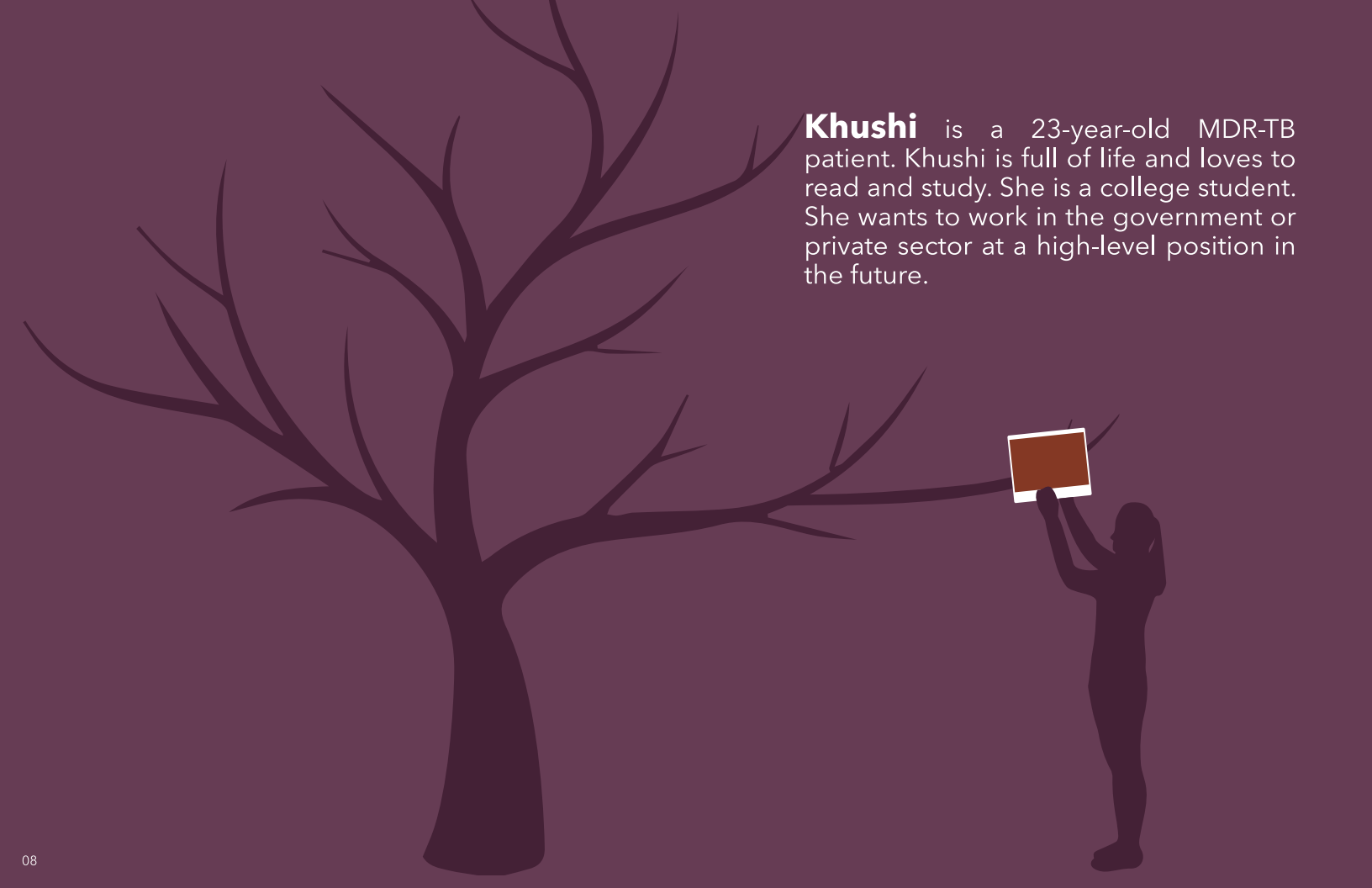
I took treatment for a while and then the doctor said that I was getting better, but I would have to take medicines till I become old. I asked for how long my treatment would last and he said, until 'you become old'. So, I got angry and stopped the medicines, then my TB, it relapsed. (Zeenat)

I was not allowed to sit for my [higher secondary certificate] exams due to my TB and till today I remember the dates when I had gone to fill out the form and not allowed... those dates repeat every year. When I think about that I feel very, very bad. I wonder how will I get the job/profession I want. (Khushi)

It is the wish of the nine individuals who participated in this study that, through a visual display of their experiences, the issue of MDR-TB stigma can be openly discussed and addressed at health centres across Mumbai and beyond. It is their wish that through their photos, which render a glimpse into their personal lives, other patients, health care workers, relatives, communities and programme staff can learn about the risk and danger of MDR-TB stigma, be prepared for it, and eventually join hands to fight it.

The first section of the book displays up to two photos taken by each participant via polaroid cameras, which allowed for instant photo-production. These were the photos participants chose to share with the TB community, and provide a visual illustration of their life with MDR-TB stigma. Each photo is accompanied with a brief dialogue narrated directly by the participant upon reflecting on the visual, and a single word depicting the emotion it evoked for her. Where applicable, the researchers comment on the type of stigma depicted by participant's photo and her voice.

The second section of the book displays a group poem that was collectively decided upon and written by the participants. The participants wrote this poem as a tool to engage patients, family members, treatment supporters, health care workers, and community fellows – in other words, you – to spread awareness on the issue of TB stigma and engender a change in thinking for others affected by this disease.

A large, dark silhouette of a tree with many branches occupies the left side of the image. To the right of the tree, a smaller silhouette of a person stands, holding a tablet computer high above their head with both hands. The tablet screen is a solid light blue color. The background is a solid dark blue.

Khushi is a 23-year-old MDR-TB patient. Khushi is full of life and loves to read and study. She is a college student. She wants to work in the government or private sector at a high-level position in the future.



“[This is a picture of an empty bench]. When a person is, or I am treated less favourably on the grounds of illness and fear of becoming the subject of gossip I often isolate myself. To avoid infection of others and to avoid uncomfortable situations, I just like to keep myself separate. I feel this is self-discrimination where I feel unworthy, leading to a lack of self-worth, depression and abnormal behaviour. Although my family tried to pull me out from this situation... but because of my TB and treatment, high consumption of drugs makes me... I am more comfortable with isolating myself.”

This situation made Khushi feel alone.

TYPE OF STIGMA: **INTERNALIZED**

“[This is a picture of my academic books]. I have been suffering from tuberculosis since my HSC [Higher Secondary Certificate Exams]. That is since 2014. At that time, my board exams were to start. It was December, so we had to submit the forms for the board exams. My college authorities came to know I had TB. Once they found out, they did not allow me to appear in the board exam. They told me not to take it. Not because they cared and that I would need rest due to my health but because my college always had 100% results. The authorities were worried how my health could impact my performance on the exams and bring the cumulative college performance down. After so many arguments, the principal kept a condition that if I can clear the preliminary exams with specific percentage, only then can I appear in the board exam. I had insisted a lot that I have worked very hard and I want to take the exams. But they said you have TB if you go to the exam and then die there who will be responsible? They used such harsh words. And my parents told them nothing like that would happen and that they would be there with me. The authorities said that if she fails, the college reputation and result will be ruined.”

This situation made Khushi feel unfairly treated.

TYPE OF STIGMA: **STRUCTURAL**



Structural stigma describes the laws, policies, and institutional architecture that may be stigmatizing or alternatively protective against stigma. This includes societal level conditions, cultural norms and institutional practices that constrain the opportunities, resources, and wellbeing of stigmatized populations.

Nags is a 23-year-old MDR-TB patient. Nags is a student who loves to make friends and travel. She is talkative, easy going, and full of life.





"[This is the picture of empty seats on a metro train]. When I was very sick, I had to go to different hospitals, sometimes to Ghatkopar and sometimes to Sakinaka. At that time, I used to have difficulty in breathing, due to the dusty soil, so I used mask to cover my face. Once, I was going to the hospital and I had to travel by metro. I had a face mask on. Just one seat was empty as I boarded the metro train. I sat there. A man was sitting on the seat next to the empty one. When I sat down, he immediately saw me and got up. Then he stood away and started staring at me. He continued to stare at me. At that time, I felt bad and at the same time, I started getting angry and question why this man ran away like this while I was wearing a mask. This was a very nasty experience for me, it was my first experience. It was a very bad experience. I will always remember this incident. People make a patient weak by doing this."

This situation made Nags feel anger.


TYPE OF STIGMA: **ENACTED**

"[This picture is of the dining table of my house]. Here we all used to sit and eat food. But since I came to know that I am a patient, I started to sit alone at the table and have dinner. Everyone else started eating together, separately. It was painful for me. But somewhere I understood that it is better for me and for my family members. I tried to take this experience in a positive way. This made me feel less bad. This picture makes me feel pain but it was important for me somewhere, the pain."

This situation made Nags feel dangerous.

TYPE OF STIGMA: **INTERNALIZED**



A dark silhouette of a person stands at the bottom right, holding up three Polaroid-style photographs. The photos are orange, green, and brown. Behind them is a large, dark silhouette of a tree with many branches. The background is a solid dark purple color.

Nishi is a 27-year-old MDR-TB patient. Nishi is married. She has a daughter. She is outspoken and brave. She speaks about difficult topics with confidence and openness.



“[This is a picture of my room]. In this photo, there is a room that is completely empty. There are some things in there that only fulfil my daily needs. And to tell you what is really happening in this room, is that there is only emptiness here, and there is my loneliness. Apart from this there is no companion that I have. I used to be alone all day so I took up a job. In the hustle and bustle of the day, I forget about what has happened with me. But when night comes, I am alone in my room, I feel very lonely. And the biggest reason for this situation of mine is my illness.”

This situation made Nishi feel solitary.

TYPE OF STIGMA: **ENACTED**

“[This is me putting water in the bathroom]. Naturally everyone goes to the bathroom in the morning but no matter what happened, I did not have the permission to go to the bathroom until everyone’s breakfast was done. Once everyone had eaten and gone out for work, I could go to the bathroom. After that, I would have to put 3-6 buckets of water and Dettol [cleaning agent] properly and only after I washed the bathroom that way, was I permitted to enter the hall or my room...[so, my urge, I had to] keep controlling it from 6 am to 11 am. Anyhow, I had to control it. So much that I would have issues with my stomach. But what could I do, I had to adjust.”

This situation made Nishi feel dehumanized.

TYPE OF STIGMA: **ENACTED**



Zeenat is a 26-year-old MDR-TB patient. Zeenat is quiet and demure but engaged and bright. She is married with two children.





"[This is a picture of my mother-in-law]. For 2.5 years I took treatment in the private hospital and at that time, my in-laws threw me out of the house. My mother-in-law also took my children away from me. One son and one daughter. They threw me out and then I was in my maternal home."

This situation made Zeenat feel disgust.

TYPE OF STIGMA: **ENACTED**


"[This is a picture of my sewing machine]. This is my machine and I would stitch my clothes and others' clothes with this and earn for myself. Since I got TB, my mother in law took it away from me. Since then she isn't giving it back to me. I have been asking her for it so much. I don't have any other talent but with this I can earn for my home. But she says she will not give it. She is saying that it is not yours. It is my son's. So, my husband had bought that machine for me. Since I got TB, they just started taking everything away from me-one, by, one."

This situation made Zeenat feel anger.

TYPE OF STIGMA: **ENACTED**



Enacted or experienced stigma reflects the range of stigmatizing behaviors, messages, and effects that are either directly experienced by the person with TB or their families and/or that drive others to acts of discrimination, rejection, or isolation.

A stylized illustration on a dark purple background. A large, dark silhouette of a tree with many branches occupies the left and center. A small, dark silhouette of a person stands at the base of the tree, reaching up to hang a blue photo on a branch. To the right, a horizontal branch holds four more photos in a row: a green one, an orange one, a light green one, and a brown one. The photos are simple colored squares with white borders.

Mahera is a 21-year old MDR-TB patient. She loves her family fiercely, is outspoken and righteous. She is a college student who believes in fairness. She takes pride in her academic and sports-related achievements.



"[This is a picture of an empty chair where my relative used to sit]. There was a relative of mine who would visit us frequently. He was my uncle and he would visit 2-3 times a month. He would come with his wife and children. And since I got TB, my skin colour changed a little and he would keep asking what has happened? I didn't tell him. Then one day, I don't know from where and what, he suddenly found out that I had TB. Since then he stopped coming home. I had a very good bond with him and he was like a friend, it was that good our bond. But he stopped coming..."

This situation made Mahera feel abandoned.

TYPE OF STIGMA: **ENACTED**

"[This is a picture of my certificates and medals]. People generally give up on their studies, hobbies, other activities once they are diagnosed with TB. But I never let this disease stop me from participating in various sports events in school and college. Despite my health condition, I worked hard to earn these certificates and medals. I never stopped and no one should ever stop only because they have TB."

This situation made Mahera feel motivated.

TYPE OF STIGMA: **N/A**



Nikita is a 21-year-old MDR-TB patient. She lives with her stepmom, her father and her two siblings. Nikita has a very close and special relationship with her father. She is emotional and vivacious with a contagious smile.





"[This is a picture of the calendar and watch in my room]. When I had my TB operation, I used to sleep in my room. Lying down, I would always stare at that calendar and watch. I used to feel very sad and terrible, actually. I had lost one whole year due to my operation. So, I used to stare at the clock and the calendar and ask myself when my bad time would be over and I would be able to live again, normally, like before."

This situation made Nikita feel stagnant.

TYPE OF STIGMA: **INTERNALIZED**

"[This is a picture of a blanket in my room]. You can see a blanket in this picture. This is my blanket. My mother used to intentionally keep my blanket in a corner, separate from blankets of the rest of the family. She used to do this because I had TB. But I still ask myself why my mother did that to me? It still hurts me."

This situation made Nikita feel discriminated.

TYPE OF STIGMA: **ENACTED**



Salman is a 41-year-old MDR-TB patient. She is married and has two adult sons. Salman is effervescent and loves to talk. She is business minded.





"[This is a picture of my closed shop]. When I did not have TB, we would all sit in this shop, my mother in-law as well. Even when I had a cough I would sit there, I didn't know that I had TB. When I got to know, after the check-up that I have TB, I stopped going. I would be taking the municipality medicines and that would cause me a lot of pain. So, because of my TB I could not go there. And they [in-laws] would feel that she does not come to the shop and work so why to give her any money? They stopped giving money. Like I told you before, I was of no use to them."

This situation made Salman feel worthless.

TYPE OF STIGMA: **ENACTED**

"[This is a picture of my mother-in-law]. Because of my mother-in-law, I went through a lot of pain in these two years. The things she did with me I feel she shouldn't have done. Because I gave 25 years of my life to them. And they treated me like an outsider. I always considered my husband's mother as my own. Because my mother passed away when I was young. So I would even call her mummy and consider her my mom. I never differentiated. They did it because I was ill, and of no use. Like when a person falls ill they can't do any work... can't do anything. My mother in-law didn't support me at all. I felt like she should have supported me. She doesn't support and then stops giving me money as well. I couldn't take the municipality medicines so I had to go to private but the medicines there were very expensive. And then there was no money to run the house so I stopped taking my medicines. And my mother-in-law has said a lot of things to me. She would say, this disease...that my father gave it to me as a gift in my wedding. Whereas no one gives anyone an illness. The lord above gives it. She would say a lot of things that would sting. So, because of this once I overdosed on sleeping pills."

This situation made Salman feel discarded.

TYPE OF STIGMA: **ENACTED**



Zee is a 34-year-old MDR-TB patient from Kenya. Zee is friendly, talkative, and creative. She is emotionally perceptive and articulate. She wants to help others all the time.





“[This is a picture of my feet]. The picture did not come out perfectly because the light is dim but what I am trying to portray from this photo is that this particular medicine that we take, it affects the feet. And the chances are that it has damaged 70% of the nerves of the feet which makes it difficult to walk. If I had to start over probably I would have not accepted to take this medicine in the first place. Maybe if I was told that this problem, this medicine would have such severe side effects like this, I would have refused to take it. Because sometimes to live with a certain kind of side effect will have a negative impact for the rest of your life. I felt like uhh you know my world is like collapsed in a way because I felt like I wasn't myself the way I was before. I felt like I am different now. I felt almost half-disabled, in a way you know, I would feel like someone who cannot walk at all. Okay at least I cannot compare with them, but I felt like I could relate with them somehow. It is like a partial disability.”

This situation made Zee feel regret.

TYPE OF STIGMA: **STRUCTURAL**

“[This is a picture of my covered face]. This is to depict that when I had TB and I would want to go out to a public place or mall or anywhere this is how I would dress up to hide my identity because I would not like to wear a mask to make it obvious that I was suffering from something. And I thought this would be a good cover and it is also very common. Most girls wear such coverings, especially those who are riding motorbikes. You know to prevent dust from entering their mouth or to cover their face or so it was like a kind of an escape for me not to reveal my identity so it wouldn't be so obvious that I was suffering from a disease. So, this is the kind of, as you can see, very different from what I currently wear. So, nobody can identify who I am. So, I could feel comfortable wearing this and not be known who I am in a public place. So, yes.”

This situation made Zee feel shame.

TYPE OF STIGMA: **ANTICIPATED**

Anticipated stigma (perceived stigma) is the worry that one will be devalued after a TB diagnosis. For the person with a TB diagnosis, this is the fear that the stigma against the person will be so bad that it affects treatment. It may delay people from returning for care, or impact adherence to the prescribed drugs. Whether or not stigma actually occurs, anticipated stigma may interfere with health care seeking and treatment adherence.



Chary is a 36-year-old MDR-TB patient. She was and continues to be a nurse at a public hospital in Mumbai. Chary has a doting family, her husband and two daughters. Chary loves to make new friends and is a leader at heart.





"[**This is a picture of my uneaten food**]. At the beginning of my treatment, after the lymph node was exchanged, the doctor in the public sector. He gave me the wrong treatment. Wrong treatment means without drug susceptibility test¹. He did not do the drug sensitivity test and just started the medication and drugs. So, because of that I had an allergic reaction. Four months ago, I was in a very bad condition. I was mentally very disturbed. I was unable to eat as it would hurt to swallow and my jaw was locked so I couldn't even open my mouth. For six months I was on liquids."

This situation made Chary feel helpless

TYPE OF STIGMA: N/A

¹ Drug Susceptibility Test is a test done for all MDR-TB patients to determine which of the TB medications are effective in order to design a working treatment regimen.

Definitions of the different types of stigma are derived from the *TB STIGMA MEASUREMENT GUIDANCE*, Mitchell EMH & Macias K (eds.). Challenge TB, USAID Jul. 2018.

POETIC ILLUSTRATION OF LIVING WITH MULTI-DRUG RESISTANT TUBERCULOSIS

HAMARI AWAAZ

खुद पर लगी जंजीरों को तोड़ना है,
एक बार फिर से खुलकर जीना है मुझे ।
चीजों को लेकर डराया गया, बाँधा गया, चुप कराया गया मुझे,
जो मैं पहले ना थी वो भी बताया गया मुझे ।

दे के अपना नाम, बे-सहारा किया गया मुझे,
जो पहले नहीं हुआ वो करवाया है लोगो ने ।
देख के अपनी कमजोरी को दुनिया से खुद को छुपाया है मैंने ।
जो मैं पहले ना थी वो भी खुद को बनाया है मैंने ।

मेरे शौक, मेरी खुशियों को परे हटाया है,
कह के तुम अलग हो मुझे खुद से दूर भगाया है लोगो ने ।
इस एक बीमारी के कारण मुझसे दूरी बढ़ायी लोगो ने,
ये कर के मुझे खुद की ही नज़रों में गिराया है लोगो ने ।

मैं शांत हुई, उदास हुई, कमजोर हुई,
अब इस कमजोरी को अपनी ताकत बनाना है मुझे,
एक बार फिर सबकी बंद आँखों को खोलना है ।
खुद पे लगी जंजीरो को तोड़ना है मुझे,
फिर से नयी जिंदगी जीनी है मुझे ।

ENGLISH TRANSLATION OF THE POEM

HAMARI AWAAZ

The chains on me have to be broken.
I want to live freely again.
Made to be scared of things, tied up, and shut up.
I was also told what I was not before, how I had changed.

Even after giving me your name (from husband, father), you have made me helpless.
People have done to me what was not done before.
By seeing my own weakness, I have hidden myself from the world.
Whatever I was not before, that too I became.

My hobbies, my happiness - were all shoved aside.
By telling me I am different, people have driven me away from myself.
Due to this one disease (TB), people have distanced me from them.
And by doing this, people have made me fall in my own eyes.

I became silent, sad, and weak.
Now, I have to make this weakness my strength.
I have to open everyone's eyes once again.
I have to break the chains on my own.
I want to live a new life again.

USE OF BOOK IN THE CLINIC / COMMUNITY / HOSPITALS

HAMARI AWAAZ

The Photovoice research study, which this book is based out of, was an attempt to elaborate upon patient experiences of MDR-TB who have faced stigma by involving the participants as experts of stigma. It was different from other traditional studies with patients which are normatively top-down. Herein, patients were asked to capture photographs of their experiences and were also invited to actively discuss their photos as representations of their experiences through group sessions and give suggestions for dissemination.

This book is a representation of that bottom-up research value, in that it is the participants photos and voices that are on display to be used as the participants have decided to create awareness around the topic of TB stigma for future patients, family members, and the larger TB community.

The objective of this book is to provide health care workers, patients, community members with a view of the experiences of a patient from the patients' lens, both literally and figuratively.

As spoken directly by the patients themselves, very powerfully, below:

We created this book through the Photovoice project conducted at the MSF clinic. This book for us, the participants, was an amalgamation of our conversations around our joint experiences of TB stigma as displayed visually in our photos. What we want to achieve with our photos and stories for the larger TB community, the patients, the families, and anyone reading this book is to start having openly the very difficult conversation of TB stigma.

FOR the patients, who are reading this book, specifically, we want you to understand what to expect to go through if you contract tuberculosis. We hope you feel encouraged and resilient.

FOR the families and caregivers of the patients with tuberculosis through this book, we want you to reconsider what your actions (out of fear and misinformation) might mean for the TB patients and how detrimental your negative actions may be to their identity as individuals. We want to encourage you to also be aware and try to work together, with your daughter, daughter-in-law, sister, niece, aunt, mother, or friend, on how to diminish the pain points for TB patients in your lives. We want you to always ask yourself, "Is my behaviour helpful and if not what can I do to help, and not deliberately hurt a loved one?"

FOR the larger TB community - the doctors, counsellors, policy makers, and non-government organization workers we wish for this book to be a tool for your use in any given setting that creates more awareness on the kinds of stigma we face. We want you to start and keep the conversations going so that stigma can be mitigated and better managed. We hope, that through you, our pain is translated into something meaningful for a larger and better cause that aids anyone who is or will face what we already have.

The visuals, stories, poems and messages have all been included to stir conversations between any cohort of people on the difficult topic of stigma. This book is hopefully an agent of change, even if in the smallest way possible, in the lives of individuals inflicted with MDR-TB both directly and indirectly.

A big congratulations to everyone who helped bring this book to life. Most importantly, with much affection, a heartfelt gratitude, to the nine brave women who led this study and lent us a glimpse into their lives.

Khushi

Zeenat

Salman

Nags

Mahera

Zee

Nishi

Nikita

Chary



Photo credit: Taanya Mathur

A tree was specifically chosen by the participants as a way to metaphorically illustrate the stigma rooting out of their lives with the branches reaching out to the community, with the fruits of their labor, their photos, showcasing their stories.

A big **THANK YOU** to the entire MSF Mumbai team and the Photovoice research team for making this study and book possible.



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