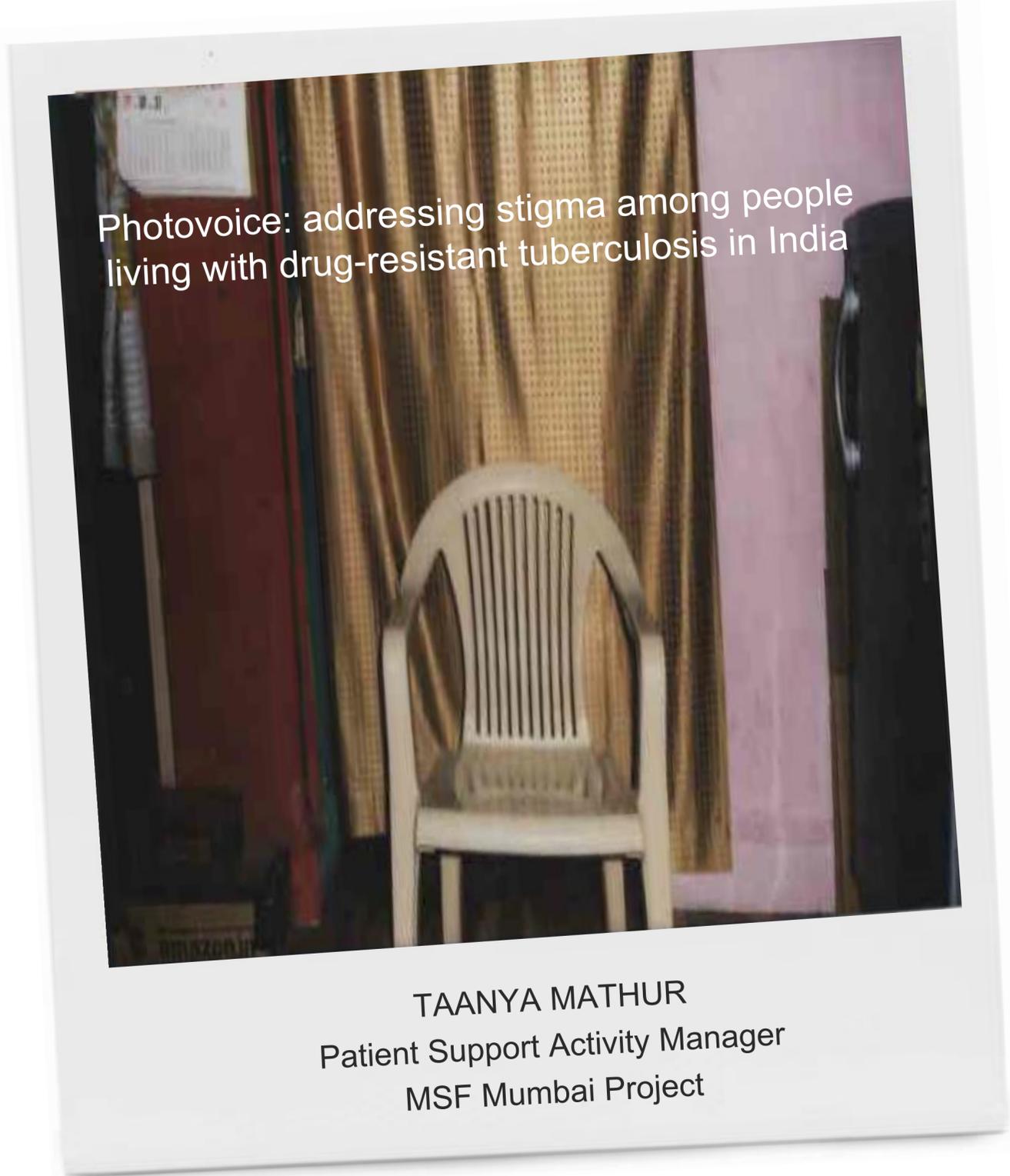


16-year-old Priya was just diagnosed with Drug Resistant Tuberculosis. Expecting support from her family, she was in for a rude shock when she was told:

‘This has happened to you because of the sins of your past life’

Conflict of Interest

The author has declared no conflict of interest.



INTRODUCTION

Research questions were:

1. **How do patients diagnosed with DR-TB, at a clinic in Mumbai, India understand and characterize their experiences of living with TB stigma?**
2. **What are the ways in which Photovoice methods can impact patients' experiences of sharing their stories of TB stigma?**

I have no, real or perceived, direct or indirect conflicts of interest that relate to this presentation.

WHAT IS PAR & PHOTOVOICE?

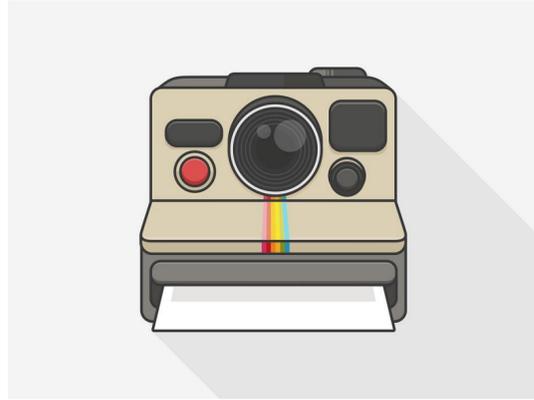
PARTICIPATORY ACTION RESEARCH (PAR): Alternative paradigm of producing knowledge wherein impacted groups of a particular phenomenon undertake collective study to understand and address it.

PHOTOVOICE is an innovative visual method wherein participants use photography to promote critical dialogue on topics of concern in order to reach policymakers and advocate for reform.

METHODOLOGY

- **MSF clinic in Mumbai: 140 MDR-TB patients (64% female).**
- **9 female patients participated; no male patients participated**
 - **Age range of 19-35 years**

Ethics approval was obtained from the MSF Ethics Review Board and a local ethics Body (Foundation of Medical Research)



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OUTPUT
(as per patient decision)

participants took photos and wrote optional entries to tell their stories of living with TB stigma



open, safe discussions

we as researchers were there to learn from them and we were there to navigate the process-it was their project and was about their stories and dissemination decisions

STUDY PHOTOS & STORIES



STUDY PHOTOS & STORIES



“...What to do, I had to adjust...”

STUDY PHOTOS & STORIES



“...They took everything away from me, one by one...”

STUDY PHOTOS & STORIES



"...It is like a partial disability..."

RESULTS & DISCUSSION

RQ 1: findings on stigma & coping

- **Life-altering stigma**
 - Loss (of self, voice, status, mobility)
 - Abuse (mental, social)
 - Distress (shame, isolation, suffocation and peril.)
- **Coping mechanisms**



"...There is only my emptiness here, and there is my loneliness..."

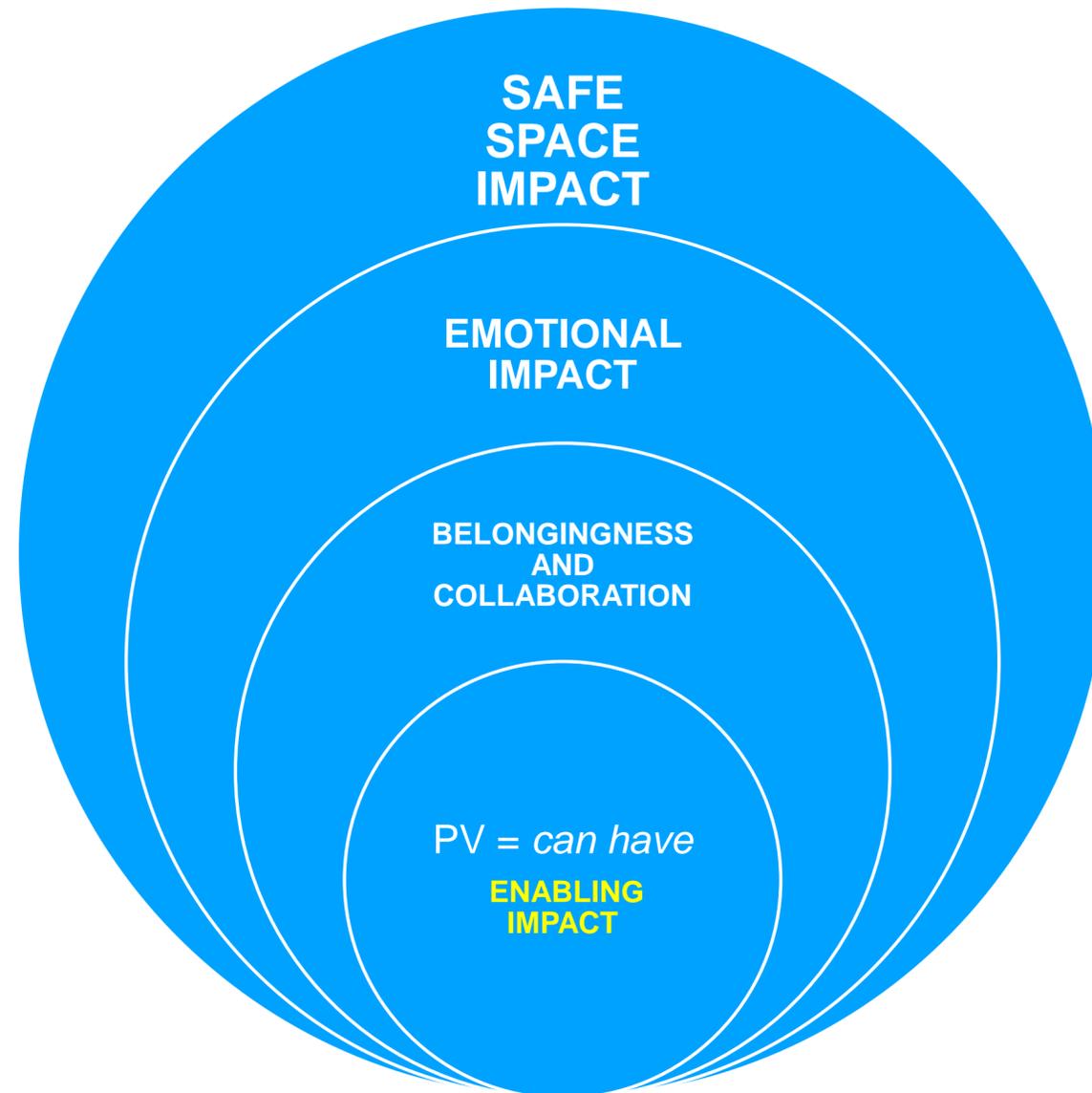
- Nishi



"...You should not lose courage..Tell the problem the Lord above is bigger than you...!"

-Mahera

RQ 2: HOW DID PHOTOVOICE HELP?



“Photovoice yes, it’s something new. It’s like a unique aspect that I have not come across before.” (Zee)

*“Photovoice was very important because for a year before this project, I felt that I was alone. **Who would I go talk to? Who can I talk to? We don’t talk to everyone that this has happened with me or this doesn’t happen with me.** But with the help of this project we had a discussion here and that felt good.” (Nikita)*

STUDY CHALLENGES

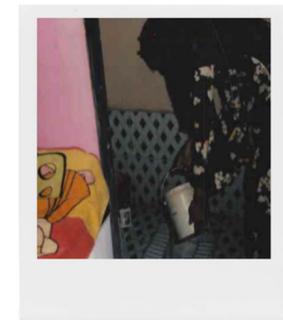
- Unable to recruit male participants for the study
- Participants found it difficult to understand the concept of “participatory action research”, or be considered “experts”
- Participant dissemination plans have been stalled or delayed because of COVID19



SELECTED RECOMMENDATIONS FROM PARTICIPANTS

- Use photos and project as part of patient onboarding
- Include family members
- Short term goals combined with longer term/final goals of treatment.
- Peer support should be set-up for new patients/intakes.
- Photovoice/visuals in counselling sessions.

MSF Mumbai has implemented or is in the process of implementing almost all the recommendations





The tree of life, conceptualised and designed by the 9 brave women to represent their journey

WE, THE PARTICIPANTS VOICE

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.

Find more details on the stories of the participants at: <https://www.msfindia.in/uncharted-voices-addressing-stigma-in-people-living-with-multidrug-resistant-tuberculosis-in-india/>