

Photovoice: addressing stigma among people living with drug-resistant tuberculosis in India

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What challenge or opportunity did you try to address?

Were existing solutions not available or not good enough?: Individuals with multidrug resistant tuberculosis (MDR-TB) undergo one to three years of treatment and face intense stigma.

Why does this challenge or opportunity matter – why should MSF address it?

We used a Photovoice intervention among patients with MDR-TB to explore their lived experiences of stigma and to gauge the efficacy of Photovoice as a tool to engage individuals to speak about it.

Describe your innovation and what makes it innovative:

Photovoice is a visual method requiring participants to use photography to voice, identify, represent, and reflect on their lived experiences. Compared to other interventions, Photovoice provides an innovative & interesting platform for sharing experiences and adds an extra aid for describing experiences.

Who will benefit (whose life / work will it improve?) and were they involved in the design?

This innovation is aimed at helping patients and healthcare providers understand the stigma around MDR-TB. The participants provided input during the study implementation process.

What objectives did you set for the project – what did you want to achieve and how did you define and measure success (improved service, lower cost, better efficiency, better user experience, etc.)?

This study utilised participatory methods to understand and address stigmatisation associated with MDR-TB at a specialised TB clinic in Mumbai, India.

What data did you collect to measure the innovation against these indicators and how did you collect it? Include if you decided to change the indicators and why:

Nine female patients were recruited from the MSF clinic in Govandi, Mumbai, between September and October 2020. Males were unwilling to join. Following orientation, we met with participants to understand their motivation and commitment to the project. Consent was taken and camera training was provided.

Participants were asked to take four photos of moments, issues, subjects, artifacts, stills, people (unidentifiable), or anything else that represented a form of stigma that they had personally experienced over two weeks. In addition, each participant attended three focus groups facilitated by the MSF clinic, during which 37 non-identifying images and 15 hours of narratives were collected. Participants were also required to attend one dissemination session.

How did you analyse this data to understand to what extent the innovation achieved its objectives?

Did this include a comparison to the status quo or an existing solution?: The photos were analysed thematically during the focus group discussions with the participants. The focus group transcripts were coded and analysed thematically.

Were there any limitations to the data you collected, how you collected it or how you analysed it, or were there any unforeseen factors that may have interfered with your results?

There was no male representation in this Photovoice project. Reasons provided by males for non-participation were primarily around the time commitment, however we suspect that it may also have been due to discomfort when discussing topics such as stigma.

What results did you get?

Results revealed that patients with MDR-TB face life altering stigma. Loss (of self, voice, mobility) was the predominant theme, in addition to abuse (mental and social), which caused distress such as shame, isolation, suffocation, and feelings of peril. Education (general or disease-related) did not correlate with non-stigmatising and compassionate behaviour from stakeholders. Married women reported stigmatisation from family members exacerbated by pre-existing power dynamics. Coping mechanisms, which started at diagnosis, included peer/family support, self-motivation, and resilience.

Comparing the results from your data analysis to your objectives, explain why you consider your innovation a success or failure?

Focus groups provided a safe space for participants to voice their feelings. Each and every photo gave the participants a chance to reflect on their own situation and that of others in the group.

To what extent did the innovation benefit people's lives / work?

Photo-sharing often led to in-depth conversations about shared experiences of stigma among the participants.

Is there anything that you would do differently if you were to do the work again?

Gender-specific orientation and focus group sessions may improve male participation. The study will need to be flexible with the time commitment required from the participants. Topics other than stigma can be explored using the Photovoice intervention, for example social difficulties related to TB treatment.

What are the next steps for the innovation itself (scale up, implementation, further development, discontinued)?

The results of this innovation have been used to improve the MSF counselling package including tools for routine implementation.

Is the innovation transferable or adaptable to other settings or domains?

The Photovoice intervention can be used in other settings to better understand patient perceptions.

What broader implications are there from the innovation for MSF and / or others (change in practice, change in policy, change in guidelines, paradigm shift)?

Photovoice helped participants connect and gave them focus and motivation to be part of a larger cause. Photovoice can be a vehicle for instances of joy, ownership, and creativity to strengthen patient voices for advocacy.

What other learnings from your work are important to share?

Improved support and attitude changes from family members and health care workers are needed to curb stigma. Patients were encouraged to provide suggestions and recommendations to reduce stigma and were included content planning.

Ethics

This study was approved by the MSF Ethics Review Board (ERB) and the Ethics committee of the Foundation for Medical Research, Mumbai, India.



Taanya Mathur

Taanya Mathur is a qualified psychologist and psychotherapist, with over seven years of rich experience in counseling patients of varying age groups and backgrounds, and providing them with therapeutic relief.

She has completed a MSc in Clinical Psychology from Christ University, Bangalore and is trained in Rational Emotive Behavior Therapy and Gestalt therapy. Taanya joined MSF in July 2017 as Activity Manager- Patient Support for MSF's drug-resistant tuberculosis (DRTB)/HIV project in Mumbai. She provides technical support to the patient support team, working with counsellors and social workers, for strengthening treatment outcomes of patients infected with DRTB and HIV by identifying the barriers in treatment and addressing their psychosocial needs. The project aims to develop and implement patient centered approaches which would eventually contribute towards policy and practices within the national TB program. Taanya is also engaged in different operational research projects to explore TB patients' emotional and mental health needs and to push for efforts to improve the care for them. As a part of this, she also presented in the Union Conference in 2018 to highlight the needs and the importance of patient centered care for TB patients. Along with the patient support team in Mumbai, she aspires to continue improving access of care for the vulnerable TB and HIV patients in Mumbai.