Unmasking stigma and building resilience to deliver high-quality person-centered TB care

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Harvard Medical School & TB Proof

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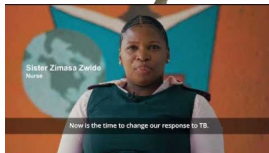
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Objectives

- To understand the drivers and manifestation of stigma experienced by people with TB

- To apply approaches such as human-centered design to develop stigma reduction interventions

https://www.youtube.com/watch?v=Il4a5_q_HD4
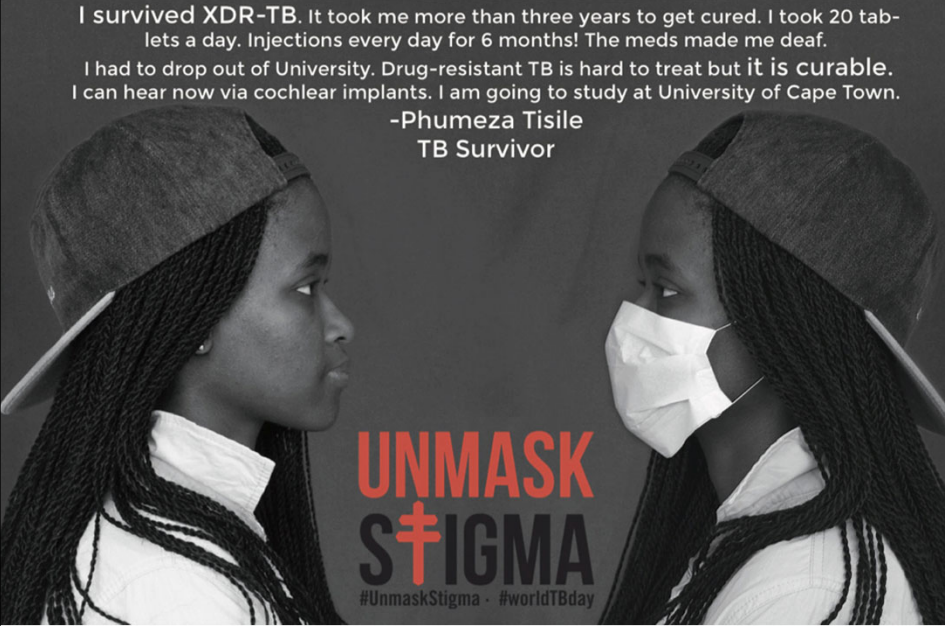
Image credit: University of Rochester Recovery center, IDEO Design Thinking

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www.unmaskstigma.org

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TB stigma

- Stigma: differences are linked to negative stereotypes leading to separation (us/them) -> status loss

- Stigma is a barrier to high quality TB care delivery

- Targeted stigma reduction interventions are needed but little known about optimal design / implementation

Link and Phelan 2001
Mitchell IJTLD 2017
Image credit: Paulina Siniatkina

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Impacts of stigma on TB care journey

Figure 1. Potential Impacts of Stigma along a Person's TB Care Itinerary or Trajectory (Artist: Retsu Takahashi).
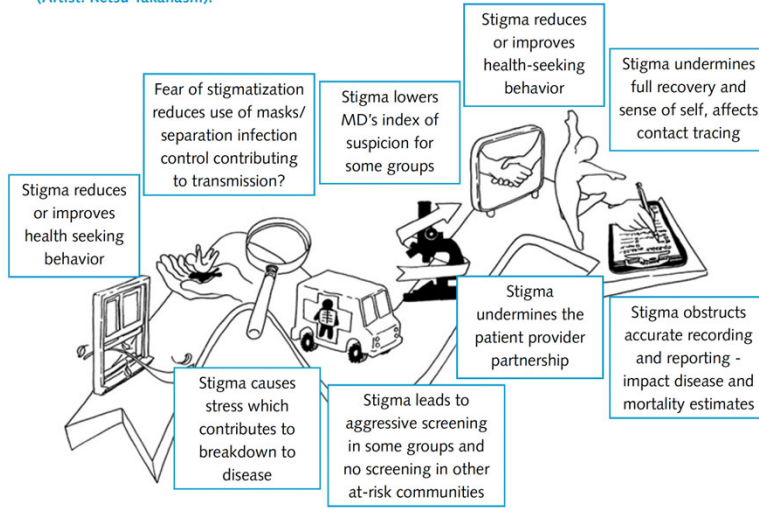
KNCV Stigma Measurement Guide

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Stigma building cascade

Figure 2. A typical stigma-building Cascade (Link & Phelan)

KNCV Stigma Measurement Guide

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Conceptual model for TB stigma

Facilitators — Clinic set up, messaging

Drivers

Blame

Manifestations

- Anticipated — Fear of gossip/ repercussions
- Internal — Negative self perception
- Enacted — Loss of respect/ standing/ job

CASCADE OUTCOMES **Care seeking** **Treatment initiation** **Adherence** **Retention**

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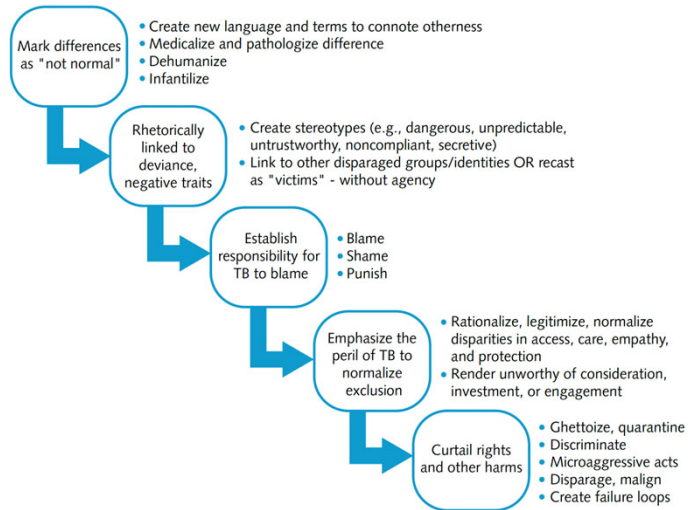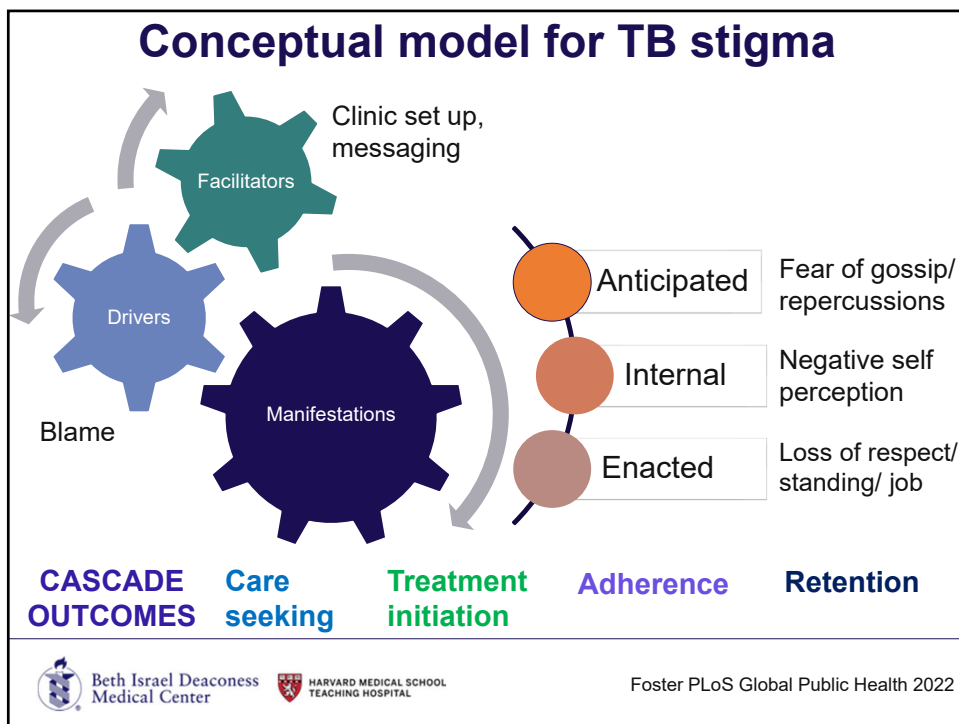
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Stigma scoping review findings

Study	Population	Intervention	Stigma Domain	Framework
Acha, 2007	MDR-TB patients, Peru	Psychosocial support groups	Internal and Anticipated	Individual Interpersonal
Demissie, 2003	TB patients, Ethiopia	Support groups: TB clubs	Internal and Anticipated	Individual Interpersonal
Macq, 2008	TB patients, Nicaragua	Support groups: TB clubs	Internal and Anticipated	Individual Interpersonal
Bond, 2017	TB patients, South Africa	Household counselling	Internal and Anticipated	Interpersonal
Wilson, 2016	TB patients and households, El Salvador	Educational video post diagnosis to patients & family	Enacted	Interpersonal
Siegel, 2015	HCWs, South Africa	Stigma reduction campaign with informational posters	Anticipated	Organizational
Wu, 2009	HCWs, Taiwan	Educational workshop	Enacted	Organizational
Yassi, 2019	HCWs, South Africa	Participatory theatre	Enacted	Organizational
Balogun, 2014	General Public, Nigeria	Educational workshop	Enacted	Community

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TB stigma scoping review conclusions

- Few studies differentiated interventions by stigma domains and definition of stigma domains varied

- Wide heterogeneity in the approaches used to measure effect of stigma interventions

- Implementation outcomes were sparsely reported

- **Need for targeted context-specific interventions to address different stigma domains at different stages of TB cascade of care and at policy level**

Foster, Nathavitharana, et al, under review

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Community engaged research

- Communities should be centered in intervention design

- CER incorporates input from people who the research outcomes impact and involves people or group as equal partners through the research

- Peer research associates used for HIV, cancer research: no data on role in TB

Kaida Harm Reduction 2020

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TB stigma mixed methods study: South Africa

- TB survivor peer research assistants conducted:
- 93 community based stigma assessments and
- 25 in-depth interviews in Khayelitsha & Hammanskraal
  - 22 people with ≥ one TB episode and 3 caregivers
  - 8 had DR-TB
  - 6 had HIV

TB stigma mixed methods study results

Anticipated | **Enacted** | **Internal**

Stigma delayed symptom recognition
Stigma delayed initial clinic visit
Stigma delayed starting treatment
Stigma delayed seeking treatment support
Stigma delayed completing treatment
Stigma delayed seeking post-treatment care
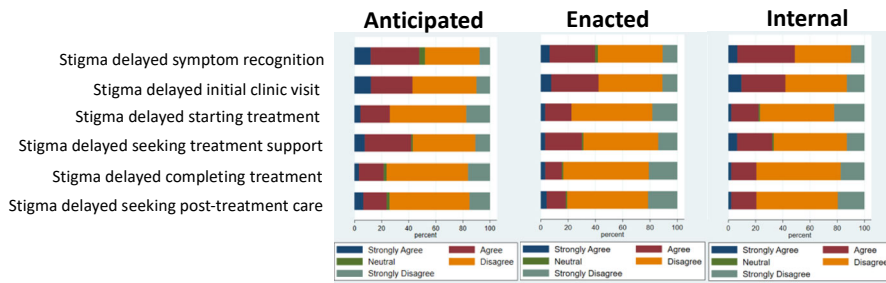
I probably got TB because I smoke, drink or do other careless things.
(47% Males agreed vs. 16% Females)

I have lost respect in the community because I had TB.
(13% Males agreed vs. 58% Females)

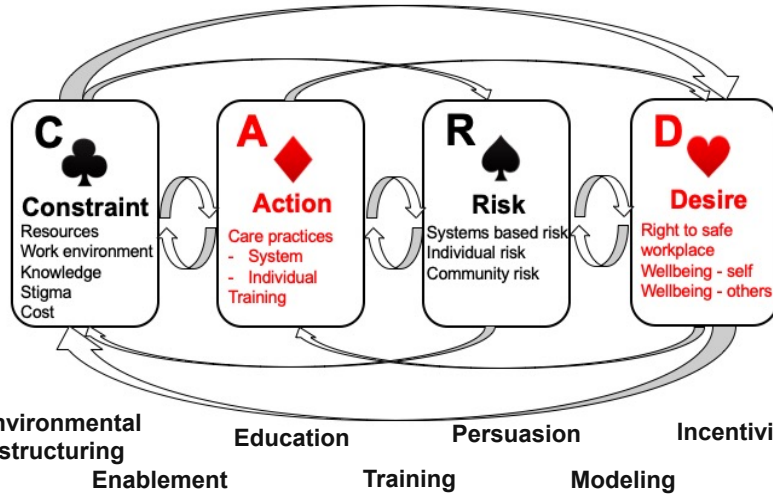In adjusted analyses, only rural versus urban residence was associated with higher stigma scores

Foster, Biewer manuscript in preparation

CARD framework developed from in-depth HW interviews & links to behavioral change strategies

C ♣ Constraint
Resources
Work environment
Knowledge
Stigma
Cost

A ♦ Action
Care practices
- System
- Individual
Training

R ♠ Risk
Systems based risk
Individual risk
Community risk

D ♥ Desire
Right to safe workplace
Wellbeing - self
Wellbeing - others

Environmental restructuring   Education   Persuasion   Incentivization

Enablement   Training   Modeling

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Nathavitharana PLoS One 2021

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Stigma findings according to CARD domain

CARD DOMAINS and Themes	Quotations
CONSTRAINTS – Intersectional stigma: HIV, alcohol use, gender	"If you lose weight then they assume that you have HIV. They would say you might have HIV and you should go and get tested." "He was drinking alcohol and he died." "Us male people, we are worse. We are embarrassed to go to the clinic and take treatment"
CONSTRAINTS – Socio-economic barriers and exacerbation of these due to TB	"I struggled when it comes to food and I am still struggling now because I am not working." "I don't have money, I don't have anything to eat. If I take these pills, they make me sick".
ACTIONS – Disclosure decisions varied depending on anticipation and experiences of enacted stigma	"[I did not tell my friends I had TB]. I knew that they were going to gossip about me." "I never told her [participant's girlfriend] anything - even today. We even broke up because I was ashamed what I would say."
ACTIONS – Stigma resilience demonstrated by understanding TB can affect anyone	"I didn't fear anything when it came to that [decision to seek healthcare], I just thought everyone can be infected by TB." "I was telling her that she [child with TB] is not the only one that has TB. There are a lot of people that have TB."

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Stigma findings according to CARD domain

RISKS – Anticipated and enacted stigma negatively impact engagement in care	"What is so and so going to say when I'm on the side of people with TB, who are taking the TB treatment?" "Once a person has started treatment we go around talking about them, saying that "So and so has TB". This person is even afraid to leave the house, to go to the clinic."
DESIRES – Counselling, including specific role for peer counsellors	"I never received any counselling." "I would say that they [counsellors] are needed, but should be someone who has experience of what you are dealing with, who has felt the pain you would be feeling like the side effects."
DESIRES – Education for communities, patients and health workers	"I listen a lot to the things being taught at the clinics. We could have a venue where people will be invited to be taught about TB." I said to the doctor "You educated people have a name saying 'default'. You're mistaken. I didn't default, I'm just not well".

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Foster, Biewer manuscript in preparation

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TB stigma interview conclusions

- Experiences illustrated impacts of anticipated, internal, & enacted stigma at different cascade stages

- Intersectional stigma: HIV, gender, substance use

- Stigma from health workers, lack of holistic support from health system plus stigma in community

- **Counselling can decrease stigma and promote person-centred care**

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Combining stories and science to make the world TB Proof

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Using HCD to develop counselling intervention

- Human-Centred Design (HCD), "is an approach that puts human needs, capabilities, & behaviour first, then designs to accommodate those needs, capabilities, and ways of behaving."

- We conducted focus group discussions using human-centred design
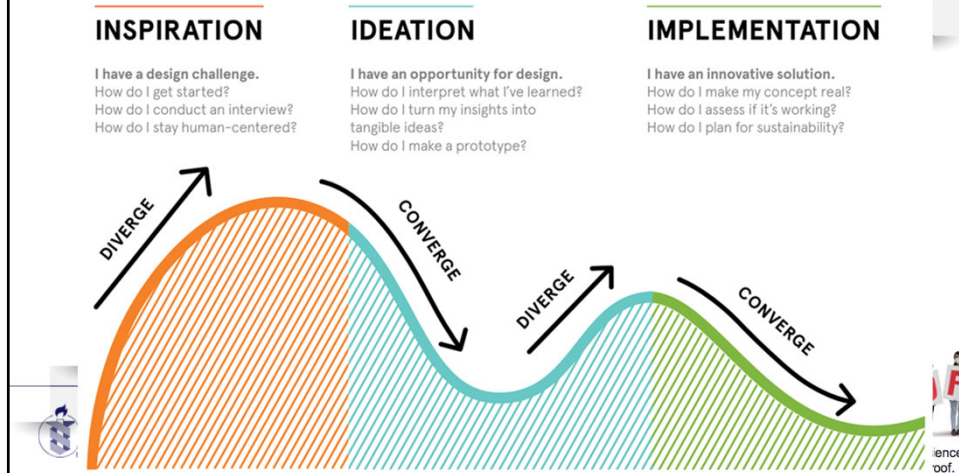
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Anticipated stigma about presenting for TB care

- 'To come here to [this clinic] for me its double the distance, but the way I was struggling, it made me attract the prying eyes'
- "When health workers [in uniform] come to you people already know you have TB or HIV"

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Internal stigma and fear due to TB diagnosis

- 'You are scared within yourself because of what is happening as it is the first time you are experiencing this

- 'You do not even have hope that you will even finish the year.'

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Enacted stigma from health workers

- "I was scared to be shouted at."

- "I am the one who should be advocating for this patient and make things better for the patient but instead it's me who makes the patient feel less of a human because they are infected with TB.
Remember TB is the airborne disease, it's not like you go and buy it in the shop; everyone can be infected with TB."

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Stigma compounded for those with DR-TB

- "When you are diagnosed with MDR you feel so small and like they have put you inside a tin, you are suffocating"

- "The nurses were fighting when it is time to do observations on that [MDR] ward, as if these people are serial killers, even when you get inside there they rush you."
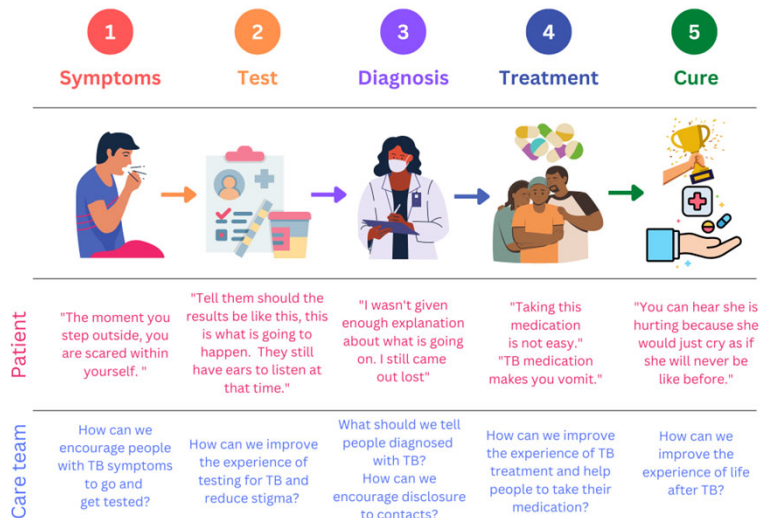
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Patient journey mapping to guide FGDs

	1 Symptoms	2 Test	3 Diagnosis	4 Treatment	5 Cure
Patient	"The moment you step outside, you are scared within yourself."	"Tell them should the results be like this, this is what is going to happen. They still have ears to listen at that time."	"I wasn't given enough explanation about what is going on. I still came out lost"	"Taking this medication is not easy." "TB medication makes you vomit."	"You can hear she is hurting because she would just cry as if she will never be like before."
Care team	How can we encourage people with TB symptoms to go and get tested?	How can we improve the experience of testing for TB and reduce stigma?	What should we tell people diagnosed with TB? How can we encourage disclosure to contacts?	How can we improve the experience of TB treatment and help people to take their medication?	How can we improve the experience of life after TB?

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Core FGD findings: counselling, messaging

- Counselling is an identified gap: "we need to empower the patient because they are the ones who will go and face the community"

- Counselling should involve families to dispel myths re: infectiousness and provide support

- "You don't hear about so and so who survived [only who died]" Message from TB survivors can help emphasize TB is curable and can happen to anyone (not just PWH)
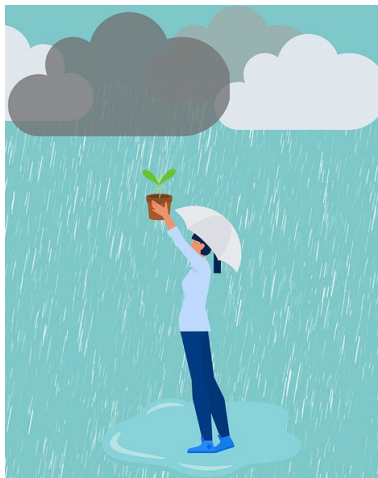
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Core FGD findings: resilience

- "I'm not hiding my medications." "I have to live for myself"

- "Today it's me, tomorrow it's you" (TB can happen to anyone)

- Support from families and health workers can help

- Role for counselling
- Support groups/clubs

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Core FGD findings: how HWs can destigmatize TB

- Improve understanding & empathy by learning from TB survivors

- Recognition of the particular challenges in the first few weeks 'People with TB are not the same, they are stubborn and get angry'

- Knowledge re: infectiousness

- Longitudinal stigma-free care-including pre-diagnostic counselling 'they still have ears to listen' and response to 'default'

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Core FGD findings: empowering communities

- Improving knowledge about TB and making testing available through approaches such as imbizos

- Consideration for children e.g. how to manage care around school and minimize impact, add learning about TB to school curriculum

- Infectiousness is a major concern 'even if you are at a distance, it's like you will infect them'
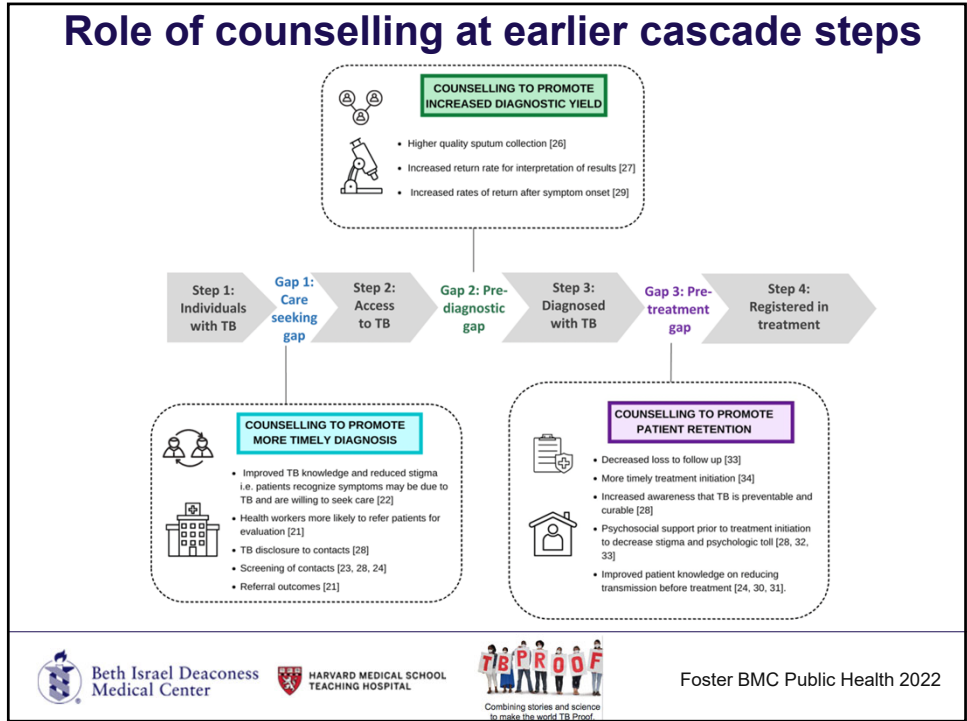
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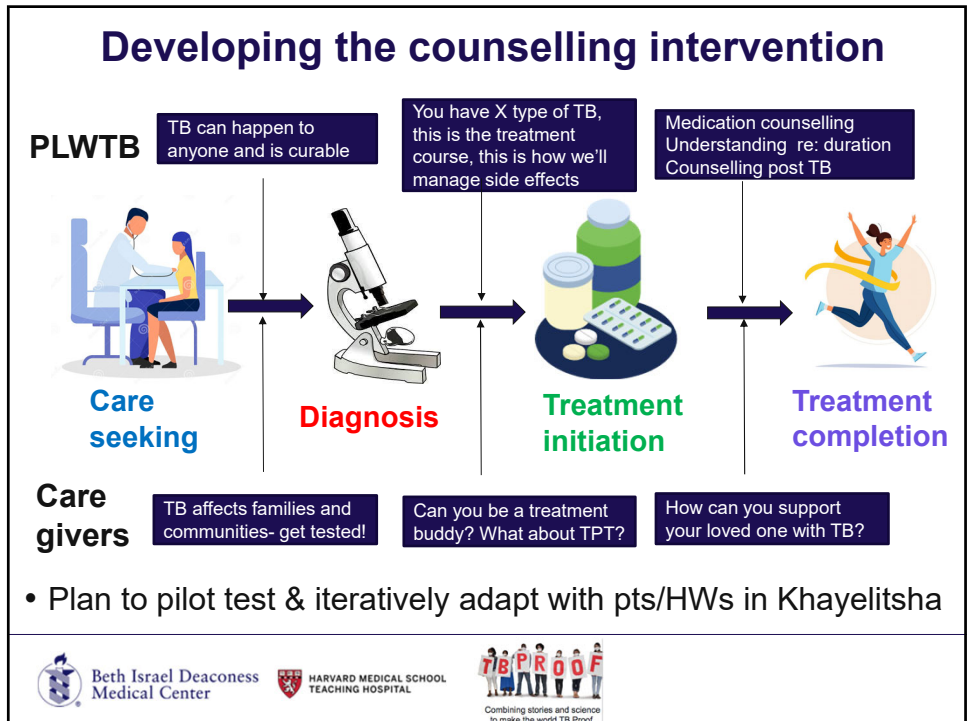
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Role of counselling at earlier cascade steps

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Developing the counselling intervention

PLWTB

TB can happen to anyone and is curable

You have X type of TB, this is the treatment course, this is how we'll manage side effects

Medication counselling Understanding re: duration Counselling post TB

Care seeking   **Diagnosis**   **Treatment initiation**   **Treatment completion**

Care givers

TB affects families and communities- get tested!

Can you be a treatment buddy? What about TPT?

How can you support your loved one with TB?

• Plan to pilot test & iteratively adapt with pts/HWs in Khayelitsha

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Impact of respiratory isolation on stigma

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Approach to TB stigma intervention design

Targeting *Drivers* of Stigma
- Blame
- Misunderstanding
- Prejudice
- Lack of awareness
- Fear of infection

Policy Level
Laws; Policies; Policy language; and programmatic documents

Community Level
Information; Skills building; Policies; Codes of conduct; and Engagement with people and households affected by TB.

Interpersonal Level
Information; Skills building; Health worker training

Individual Level
Support groups; Counselling; Skills building; and Coping Mechanisms. Integration of TB care with mental health services

Targeting *Manifestations* of Stigma
- Internal
- Anticipated
- Enacted

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Pathways to impact of TB stigma intervention

Fig. 2 Pathways to impact of TB-stigma interventions

Nuttall Infect Dis Pov 2022

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Conclusions

- Stigma is a pervasive and nuanced barrier that impacts all stages of TB care

- Stigma intervention design needs contextual insight and survivor engagement to understand resilience drivers

- Need to couple stigma reduction as part of multicomponent strategies

PEOPLE WITH TB NEED SUPPORT NOT STIGMA

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Thanks

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