The Curable Pandemic
TUBERCULOSIS

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1. INTRODUCTION

The deadly disease of Tuberculosis kills approximately 3000 people per day worldwide. It is one of the top 10 causes of death, and the leading cause from a single infectious agent. About one-quarter of the world's population has been infected by this disease.

Tuberculosis is one of the most prevalent, yet treatable, diseases in the world today. In 2018, an estimated 10 million people fell ill with tuberculosis(TB) worldwide. Eight countries account for two thirds of this total, with India leading the count, followed by China, Indonesia, the Philippines, Pakistan, Nigeria, Bangladesh and South Africa. The UN, in its Sustainable Development Goals, has set a target of eradicating the TB epidemic by 2030. (World Health Organization,2020)

Of the 10 million infected with TB in 2018, 26,90,000 were Indians. India also had the maximum number of drug resistant TB cases. Within India, the burden remains highest among low income and marginalised populations who often are at greater risk of exposure, whose cases go undiagnosed, and who face structural limitations when it comes to drug adherence.(Thacker, 2019)
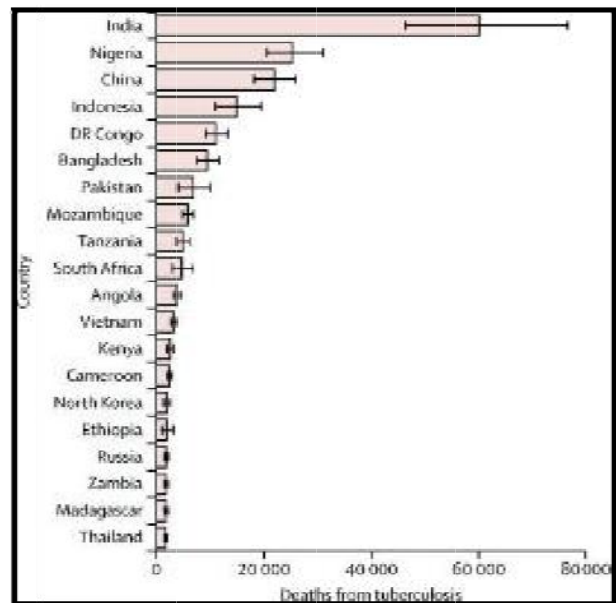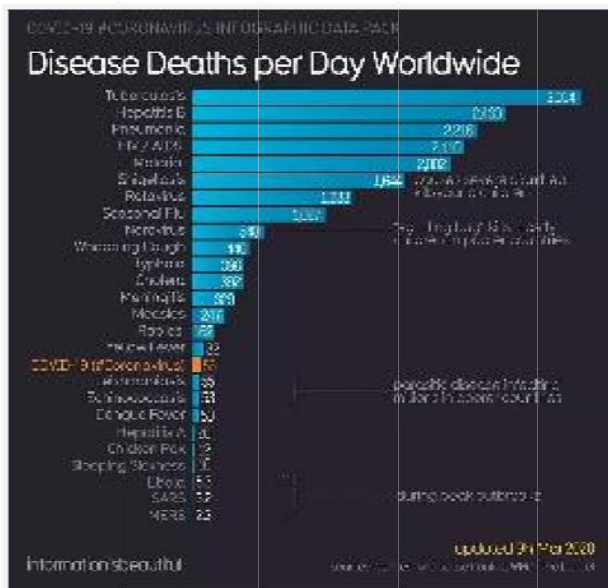

Image Source: Dodd et al., 2017

Personal background

I first heard the term Tuberculosis when a young woman who worked in my home was diagnosed with spinal TB. It started with an innocent back ache, and it continued to worsen over the months, until she was diagnosed with TB. We immediately helped her get the medical aid she needed in order to be cured - a minimum 6-month course of   antibiotics with strict adherence requirements.

The whole experience was a revelation for me. Before that, I had had an image in my mind of TB patients being bedridden with fever, constant fatigue, and coughing up blood. I had never imagined that someone whom I interacted with daily and who, except for a backache, seemed perfectly healthy, could not only have TB, but also be putting others at risk of contracting the disease.

This prompted me to begin learning more about Tuberculosis - its symptoms, causes, treatment, and implications for India's population. I researched statistics from government and medical bodies, and even interned with a private organisation working toward ensuring drug adherence for diagnosed TB patients. All of this has culminated in me launching a campaign to spread greater awareness about tuberculosis testing, and free/low-cost treatment options for those diagnosed with the disease.

Current TB Treatment Measures in place in India

In 2017, the Government of India launched a National Strategic Plan (NSP) for Tuberculosis Elimination (2017 - 2025). The stated goal of the NSP is to achieve a rapid decline in the burden of TB morbidity and mortality while working towards elimination of TB in India by 2025. (Central TB Division, Directorate General of Health Services, Min stry of Health with Family Welfare, 2017)

They aim to measure these indicators in accordance with the framework work mentioned in the table below.

Table 1: Results Framework (impact and outcome indicators and targets)

	Baseline 2015	Target 2020	2023	2025
IMPACT INDICATORS				
1. To reduce estimated TB Incidence rate (per 100,000)	217 (112-355)	142 (76-255)	77 (49-185)	44 (36-158)
2. To reduce estimated TB prevalence rate (per 100,000)	320 (280-380)	170 (159-217)	90 (81-125)	65 (56-93)
3. To reduce estimated mortality due to TB (per 100,000)	32 (29-35)	15 (13-16)	6 (5-7)	3 (3-4)
4. To achieve zero catastrophic cost for affected families due to TB	35%	0%	0%	0%
OUTCOME INDICATORS				
1. Total TB patient notification	1.74 mil	3.6 mil	2.7 mil	2 mil
2. Total patient Private providers notification	0.19 mil	2 mil	1.5 mil	1.2 mil
3. MDR/RR TB patients notified	28,096	92,000	69,000	55,000
4. Proportion of notified TB patients offered DST	25%	80%	98%	100%
5. Proportion of notified patients initiated on treatment	90%	95%	95%	95%
6. Treatment success rate among notified DSTB	75%	90%	92%	92%
7. Treatment success rate among notified DRTB	46%	65%	73%	75%
8. Proportion of identified targeted key affected population undergoing active case finding	0%	100%	100%	100%
9. Proportion of notified TB patients receiving financial support through DBT	0%	80%	90%	90%
10. Proportion of identified/eligible individuals for preventive therapy / LTBI s - initiated on treatment	10%	60%	90%	95%

Image Source: Central TB Division, Directorate General of Health Services, Ministry of Health with Family Welfare, 2017

The Indian government aims to achieve these goals through a Detect-Treat-Prevent-Build (DTPB) approach:

Explaining the DTPB Approach of NSP 2017-2025

DETECT	HOW DO WE DO IT?
Find all DS-TB and DR-TB cases with an emphasis on reaching TB patients seeking care from private providers and undiagnosed TB in high-risk populations.	• Scale-up free, high sensitivity diagnostic tests and algorithms • Scale-up effective private provider engagement approaches • Universal testing for drug-resistant TB • Systematic screening of high risk populations
TREAT	**HOW DO WE DO IT?**
Initiate and sustain all patients on appropriate anti-TB treatment wherever they seek care, with patient friendly systems and social support.	• Prevent the loss of TB cases in the cascade of care with support systems • Free TB drugs for all TB cases • Universal daily regimen for TB cases and rapid scale-up of short-course regimens for drug-resistant TB and DST guided treatment approaches. • Patient-friendly adherence monitoring and social support to sustain TB treatment • Elimination of catastrophic costs by linkages of eligible TB patients with social welfare schemes including nutritional support
PREVENT	**HOW DO WE DO IT?**
Prevent the emergence of TB in susceptible populations	• Scale up air-borne infection control measures at health care facilities • Treatment for latent TB infection in contacts of bacteriologically-confirmed cases • Address social determinants of TB through intersectoral approach
BUILD	**HOW DO WE DO IT?**

Build and strengthen enabling policies, empowered institutions and human resources with enhanced capacities.	• Translate high level political commitment to action through supportive policy and institutional structures:
	  • National TB Elimination Board with 4 divisions instead of the current administrative set up at the national level - TB Elimination efforts to be implemented in a "Mission mode"
	  • National TB Policy and Act
	• Restructure RNTCP management structure and institutional arrangement:
	  • HR reforms to include unified state level contractual supervisory cadre (merger of STS/STLS) and dedicated staff for TB surveillance network in the country
	• Build supportive structures for surveillance, research and innovations, and a cafeteria approach of interventions based on local epidemiological situation
	  • Reforming STDCs and expanding the role of the Medical Colleges to include surveillance and as centers of excellence (COEs)
	  • Redefining the role of National institutes (NTI, NRTI, to encompass the burgeoning need for evidence to support policy advice
	• Scale up Technical Assistance at national and state levels.
	• Align and harmonize partners' activities with programme needs to prevent duplication

Image Source: Central TB Division, Directorate General of Health Services, Ministry of Health with Family Welfare, 2017

The implementation of this strategy is a daunting task in India, where decades of unrestrained transmission has left hundreds of millions of Indians with latent TB infection. Other challenges facing the successful eradication of TB in India include: delayed detection and treatment; lack of access to TB treatment; difficulty in completing treatment; lack of knowledge and information

about TB that can lead to stigma, discrimination and delayed diagnosis and/or treatment; stigma and discrimination that can prevent people from seeking care and diagnosis; misunderstandings and myths surrounding TB, including the belief that it is "untreatable"; weak political support for TB programmes; and insufficient funding for TB programmes.

Further, a significant proportion of the Indian population suffers from other risk factors for TB, including malnutrition, diabetes, indoor air pollution from cook stoves, or smoking. Growing urbanisation further facilitates the transmission of the disease as people live in close quarters and communities, and infectious TB can easily be spread through families, or entire communities.

The most overwhelming challenge India faces when it comes to TB control is delayed diagnosis and inadequate treatment, with one-third of patients lost between seeking care, and achieving a successful cure. The burden of multidrug resistant (MDR -)TB and extensively drug resistant (XDR-)TB worsens patients' ability to seek treatment, as those who are detected with MDR- and XDR-TB must endure long, toxic and costly treatments. Although India has managed to scale up basic TB services in the public health system, the rate of TB decline is still too slow to meet the 2030 ustainable Development Goals (SDG) and 2035 End TB targets.

Spreading Awareness

One of the challenges facing TB treatment is that patients often hesitate to seek treatment or deny their condition altogether because of the social stigma attached to tuberculosis. According to NFHS-4, one in every five men and one in every six women would prefer to keep the TB positive status of a family member a secret.

This can be combated, however, through mass awareness campaigns like 'TB Harega Desh Jeetega', through which the Indian government launched 25 National TB Prevalence Survey vans to carry out a countrywide awareness survey. (Government of India, Ministry of Health and Family Welfare, 2019) The three pillars of the campaign include a clinical approach, a public health component and active community participation. Other supporting elements were private sector engagement, patient support, and political and administrative commitment. (Prasad, 2018)

Along with the 'TB Harega Desh Jeetega' campaign, the government has also adopted an approach they call ACSM: advocacy, communication and social mobilisation in order to reach the national goal of eradicating TB by year 2025. This is done by improving case detection and treatment adherence, combating stigma and discrimination, empowering people affected by TB and mobilizing political commitment and resources for TB. (Bakshi, 2019)

Advocacy: Advocacy aims to ensure that governments remain committed towards implementing TB control policies and focus on influencing policy-makers, funders and international decision-making bodies. There are three different types of advocacy such as policy, media and programme advocacy, all intended towards influencing a large portion of the society and enforcing certain sets of rules.

Communication: Behaviour-change communication aims to alter knowledge, attitudes and practices amongst society and it frequently informs the public of the services that exist for diagnosis and treatment along with notifying the public about information on the disease.

Social mobilisation: this aims to empower TB patients and the affected community to achieve timely diagnosis and treatment completion, especially among families of TB patients. It also brings together members of the community to spread awareness about the cause, along with empowering those who suffer from this disease.

Treatment & Drug Adherence

Adherence to prescribed drug regimens is a crucial element in the fight against TB, because non-adherence to anti-TB treatment might lead to an increased risk of drug resistance and a prolonged infectiousness, in addition to relapse and death. Furthermore, adhering to the medication for 2 weeks makes the patient no longer contagious. Quoting the words of Mr. Nakul from 99dots, a private initiative to ensure TB medication regime adherence – "Challenges facing drug adherence include the long duration of the drug course; the negative side effects of the drugs; the fact that many people forget to take their medicine according to their prescribed regime."

Within India, the use of Directly Observed Therapy (DOT) in the public health sector has yielded high treatment success. However, direct observation introduces its own set of challenges, including the cost and logistical limitations of asking patients and providers to undertake each treatment in person. It is also challenging for healthcare workers to ensure that doses are taken in an accurate and timely way.

In order to overcome these challenges and maximize drug adherence, the Government of India has set up several initiatives, including a "Care Cascade Check", in which regular monitoring is undertaken through review meetings and onsite checks. They have also committed to ensuring that all patients - across both public and private hospitals and clinics - receive free of cost TB

care. The government has also set up e-Nikshay, a digital platform and surveillance system that monitors the treatment of TB patients, and sends them notifications to further ensure drug adherence. The Nikshay platform is being used across both public and private sector settings, and enables tracking of all notified TB patients across TB care cycles, geographies, transfers and referrals.

Upon diagnosis, each patient is notified under the Nikshay platform, and enrolled for ICT enabled treatment adherence support. Treatment information is further updated regarding the regimens, dosages, adherence mechanism and benefit schemes chosen. Accordingly, timely alerts and feedback mechanisms will get initiated through e-Nikshay. The platform empowers staff with daily information about their patients' adherence and allows them to use differentiated care to counsel those patients who need it the most. Similarly, patients are empowered to take their medication independently, and receive immediate outreach if they start to waver in adherence.

In addition to the e-Nikshay platform, the NSP also proposes other Information and Communication Technologies (ICT) to support adherence, including a mobile app based "Pill-in-Hand" adherence monitoring tool; the option for patients to receive remote follow-ups via Interactive Voice Response (IVR) or SMS reminders; specially designed electronic pill boxes or strips with GSM connection and pressure sensor that can be used to monitor the pill consumption by tracking the weight of the remaining pills; and a Short Messaging service (SMS) gateway to be made available by which the patient can report day to day events like pill consumption, minor side effects or his need for help through simple and shortcut SMS templates.
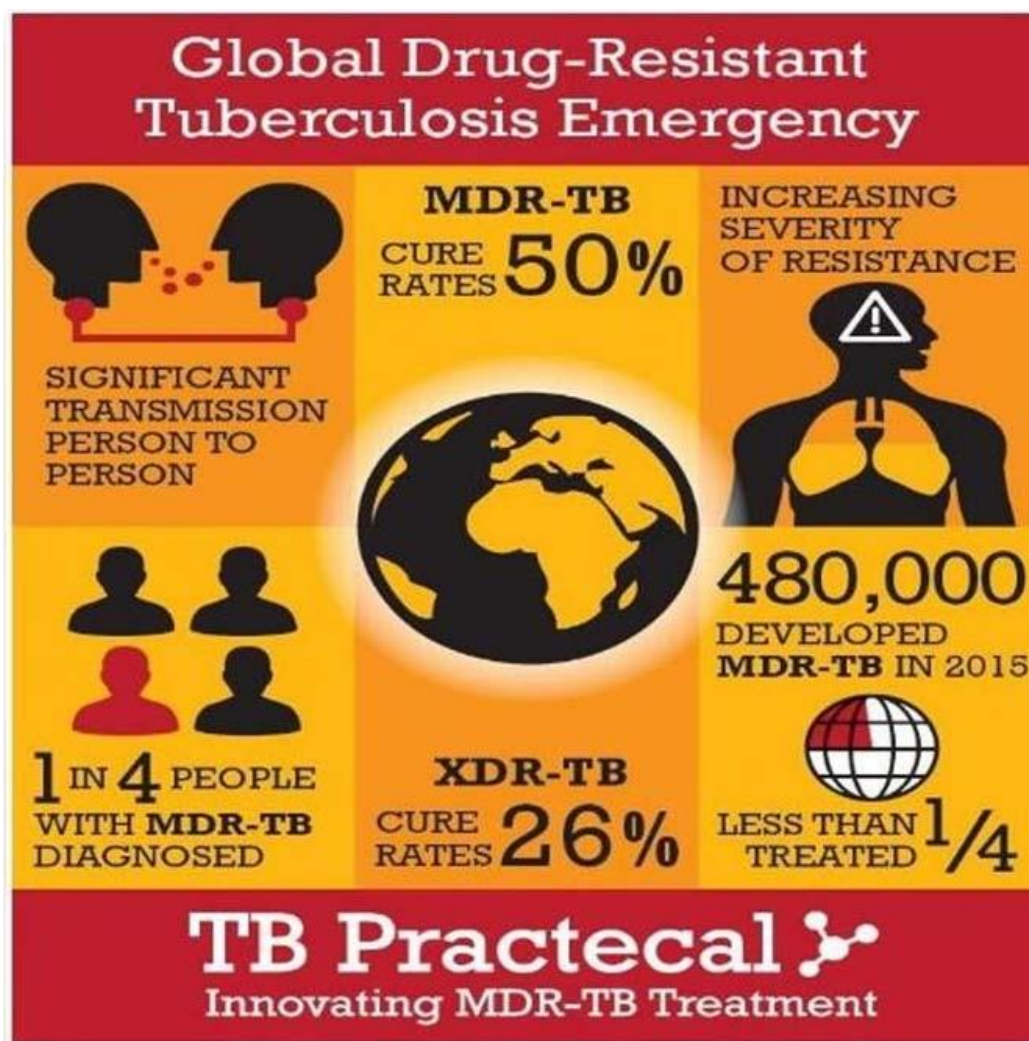
(BMC, 2015)

Image Source: Medecins Sans Frontieres (https://www.msf.org.uk/phase-ii-iii-clinical-research)

Public-Private Partnerships for Monitoring & Implementation

The monitoring and implementation of TB treatment in India is a gargantuan effort. Therefore, the government has also turned to the private sector, to help support in this endeavour.

99DOTS

99DOTS is one such private initiative that the Indian government has partnered with. 99DOTS offers a low-cost approach for monitoring and improving TB medication adherence. Using 99DOTS, each TB patient receives an anti-TB blister pack wrapped in a custom envelope, which includes hidden phone numbers that are visible only when doses are dispensed. After taking his or her daily medication, the TB patient must make a free call to the hidden phone number, to document that the dose has been taken. 99DOTS patients also receive a series of daily reminders via SMS and automated calls to take their medication. Missed doses automatically trigger SMS notifications to care providers, who follow up with personal phone-based counseling with the patient. This allows the DOTS methodology to still be in place, while substantially reducing time and cost constraints. 99DOTS has been integrated with the government's e-Nikshay patient management system, to help track and visualize data regarding patient adherence. (99DOTS, 2018)
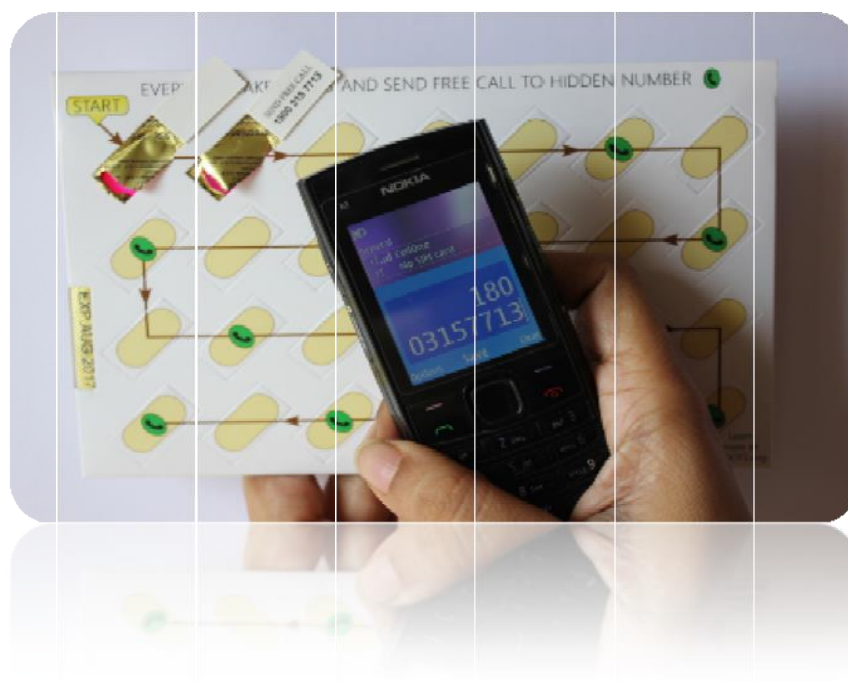
99DOTS patients give a free call on the telephone number provided to report taking their dose of TB medication

Image Source: 99DOTS

The Clinton Health Access Initiative (CHAI)

Clinton Health Access Initiative (CHAI) is supporting the Revised National   Tuberculosis Control Program (RNTCP) in increasing patient access to quality drugs and diagnostics in both the public and private sector. They are doing that through collaborating and supporting the program in scaling up using data driven insights on areas such as sample collection result delivery process analysis, and stock management. CHAI has, further, initiated the project "Initiative for Promoting Affordable and Quality TB tests" (IPAQT) in 2013. IPAQT aims to promote use of WHO-endorsed tests (sputum microscopy, culture, GeneXpert & line probe assay) at affordable prices through an agreed upon ceiling price and by building awareness among health providers, private laboratories, and patients.(Central TB Division, Govt of India, 2017)

CAREDOSE

CAREDOSE is a private medicine management company that, in collaboration with the Indian government, has launched a TB Medicine Adherence Tracking initiative. Quoting the words of Ms. Gauri Angrish, Co-Founder and CEO of CAREDOSE - "Our process involves a "smart dispenser": an ICT-enabled TB treatment box, which ensures and tracks real-time medicine adherence

in TB patients". A patient's monthly medicines are pre-organized and labeled by dose, and then auto-dispensed as per their prescription. Once the patient tears the dispensed dose, the adherence is communicated in real time, along with a timestamp. If a patient does not take the dose on time, then actionable alerts are sent to healthcare supervisors. Their process differs from other tracking systems in that it sorts the medicine for the patients, requiring less effort from the patients' side to consume and track adherence and also aims to aid and support adverse drug reactions, which are common for patients on TB medication.

Community Based Awareness Campaign

Post interning with CareDose, I wanted to contribute further and spread awareness about TB, its symptoms and its cure. I decided to do this by adopting the same model used by the government in its ACSM approach, specifically focusing on the communication aspect of it.

Effective behavior-change communication and messages need to convey more than just the medical facts as, on their own, these facts do not necessarily motivate people to visit a TB clinic or complete their treatment. The messages must also explore the reasons why people do or do not act on the information they receive, then focus on changing the actual behaviour by addressing the causes identified – social norms or personal attitudes, for example.

To implement this type of messaging, I visited several local hospitals and markets, where I distributed informational flyers that outlined the symptoms of TB, the steps to seek help, and the critical importance of drug adherence. The main aim of doing so was to combat the social taboo around T   (which prevents people from seeking treatment) while also informing people on how to get help so that they don't infect others.

TB Leaflet

Eradicating Tuberculosis

While the Indian government's goals to eradicate TB by 2030 are admirable, in order to realise these goals, they must commit to greater education, awareness, and public-private partnerships to carry out the work on the ground.

Interestingly, there are also a number of tactics that have been employed to slow and prevent the spread of the novel coronavirus, that can be used in a similar way to prevent the contraction and spread of TB. These include self-isolation for a 2 week long period while a patient is still infectious, covering of the mouth every time the person sneezes or coughs, regular washing of hands, and following the social distancing norms by working from home for people who are known to have the disease.

The greatest challenge to be overcome, however, is de-stigmatizing society against Tuberculosis. This can be done through the government, alongside the private sector, running campaigns to spread awareness on how TB is not a lifelong threat. In fact, if one adheres to the treatment regime, he or she will be un-infectious in a mere period of two weeks. This is an important first step in getting people to actively seek treatment. For it is only when people are willing to admit that they have TB and seek treatment, that we can begin to see progress towards the goal of making our country and our world TB free.

Image Source: Collaborative TB Strategy for England

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