

## Decoding the Spread of TB and its cures – Gasping for Breath

**M(Host) - Menaka Rao**

**Dr. ZU - Dr. Zarir Udwadia**

**Dr. KC- Dr. Kamal Chopra**

**Dr. YJ - Dr. Yogesh Jain**

**AB- Amitabh Bachchan**

This is a Suno India production and you are listening to Gasping For Breath.

**M(Host)** - If you go to Sewri TB hospital in Mumbai you can hear the winds bellow inside the wards through its almost wall-length windows. By early evening, the hoard of patients who come out during the day disappear. Built first as a sanatorium in 1919, the hospital has sprawling luxurious gardens. While the garden is welcoming in the morning, they seem eerie at night.

The hospital serves TB patients, often homeless or abandoned by their families. Its windows are covered with iron grills because this hospital has seen many patients trying to commit suicide- often succeeding.

This is where I first came face to face with the horrors of TB. Apart from its patients and staff, barely anyone else visits this hospital. Not even us journalists so much.

Then, In January 2012, a private doctor Zarir Udwadia called for a press conference and announced to the world that he had 12 tuberculosis patients with the worst strain of TB

**Dr. ZU-** “How many drugs was Salma resistant to ? 12. And how many drugs did we have to treat tb? 12. We called her totally drug resistant tb”

Salma is among the 4 lakh Indians who die of this disease every year. In 2017 there were approximately 28 lakhs TB cases in India. This accounts for about a quarter of the world’s TB cases.

So how did we reach here? How did the problem become so big?

I am Menaka Rao, a senior health reporter and the host of this podcast Gasping for Breath. I have, for years, written about Tuberculosis, met many patients and survivors and families. Through this podcast, I will try to bring to you the reasons why understand why the problem of TB refuses to go away. Not only that, it's become more virulent and more difficult to handle and now reached the proportion of public health emergency. In this episode, I shall explain how TB affects the body, and the history of how the disease was treated.

TB is caused by a bacteria called mycobacterium tuberculosis. It affects the lungs the most, but it can infect any part of the body. It is spread from person to person through the air. When people with lung TB cough, sneeze, or spit, they expel the germs into the air. Anyone

who inhales a few of these germs could get infected. It is not clear how long it takes for the disease to spread. However, the risks multiply if you are in, say, a crowded room. How the bacteria is fought by the body depends on the immunity.

Many famous people have died of this TB. This includes the poet John Keats, the writer George Orwell, writers Emily and Charlotte Bronte and even Mohammed Ali Jinnah.

This is Bollywood superstar Amitabh Bachchan sharing his story of contracting spinal cord TB and surviving it.

**AB-** 2000 me san 2000 me jab maine Kaun Banega Crorepati Shuru ki uss samay meri reed ki haddi me bahot dard hota tha aur wo kursi par baithne me takleef hoti thi, kuch investigation kiye aur pata chala ki mujhe Tuberculosis ho gya hai, uss detection ke baad uska ilaaj hua aur aaj mai TB se mukt hun.

In the year 2000, when i started Kaun Banega Crorepati i used to have severe pain in my spinal cord and I used to struggle to sit on the chair. After some investigation, i got to know that I have TB and after the detection, i took proper treatment and today i am free from this disease.

**M(Host)** - TB can infect anyone but some people are more vulnerable than others. Tb affects the poor, malnourished, especially those living in crowded areas the most. Those who are in a job if you are in a job that makes one's lungs weak, such as stone crushers or miners for instance, you are more likely to get TB.

When one looks at the history of TB, one realises that TB bacteria infected people who decided to settle down. In other words, wherever there have been signs of what is known as development, TB surfaced too.

The oldest evidence of TB is about 9000 years old in Israel's Atlit Yam. In this village, the archeologists found both humans and animals skeletons with tb lesions

Back then, people did not know what is it that was killing them. It was called white plague - its victims had a white pallor. It was also called r- or 'consumption' because the disease appears to eat the victim up from inside. Families, sometimes entire communities would be wiped out because of the disease. It horrified people so much that they believed that vampires killed their loved ones.

In 1990, archaeologists digging there found remains of skeletons inside coffins in complete disarray..like someone had rearranged them. The archaeologist, Nicholas Bellantoni found one coffin where the thigh bones were uprooted and crossed over the chest region. Bellantoni traced the graves back to one Ray family in which the father, Horace Ray and two of his sons died in quick succession. When another son fell sick the family members and community thought fell for the idea that the dead had become undead, zombie-like, like the dead had arisen from the grave and they were feeding off the blood of family members for nourishment. The family was so convinced with this theory that they exhumed the bodies of the already dead family members, burned them and rearranged the bones as a solution to this problem. Little did they know that it was a tiny bacteria causing TB. The son in the family died anyway. These beliefs continued because people did not know what caused TB.

It was only in the year 1882 that the first conclusive evidence of TB as an infectious disease was discovered. came in 1882. Robert Koch published his paper announcing the discovery of tubercle bacteria as the primary cause of tuberculosis. In 1882, it was estimated that one in seven people, at the time one in seven people died of TB.

**Recording** - “No Tuberculosis is not inherited, it is passed from one person to another.” This is an enemy, An enemy far more dangerous, an enemy that is severe, silent and deadly, an enemy that works in the back in the atmosphere of the tissues in the human body, particularly in the lungs.

**M(Host)** - At the time, however, sanatoriums were the only recourse to tuberculosis. Fresh air, heliotherapy or prolonged exposure to sunlight, good nutritious food, along with some light exercise had some impact in arresting the disease among the patients. Mass radiology was making it possible for patients to be diagnosed of TB early. In India, the British government at that time started paying attention to the problem only when the mortality of certain groups of people increased such as the army, prisons and police.

In 1914, Dr Arthur Lankester from the Medical Missionary Association of India investigated the extent of tuberculosis in India by travelling across India for two years. He noted there was an apparent increase of TB in the cities, particularly in Bombay, Calcutta and Madras Presidency. The high death rates were mostly in the areas where there were mills or factories such as Ahmedabad where more than 5 people out of 1000 were dying of TB.

Sanatoriums were popular in Europe and the US but were first built in India by Christian missionaries in Tilonia, Rajasthan. Later many others were built across the country such as in They were built in Madanapalle in Andhra Pradesh, Dharampur in Himachal Pradesh among other places.

One of the first TB dispensaries in the country was built in Mumbai in Kamathipura, a red light district. In 1918, a sanatorium was built in Bhoiwada hills-- now a suburb of Sewree in Central Mumbai. This is the Sewri hospital- where this podcast first began. Now a TB hospital is probably Asia's largest. It was then supposed to provide a judicious mix of exercise and rest. It has now parlour games and a library.

By 1944, biochemists and microbiologists Selman Waksman and his PHD student, Albert Schatz from Rutgers University, US were able to produce streptomycin from soil microbes. This drug was found to be effective against tuberculosis.

**Recording-** “In the 1940s, a small group of scientists working under improbable conditions in 4 countries pulled off an antibiotic miracle, a combination of drugs that promise to exterminate the greatest killer ever known to man.

**M(Host)** - Waksman who had a deal with the university Rutgers to receive 20% of the net royalties and in 1948 alone, his royalty payment was 124000 US dollars.

Streptomycin was barely available outside the US. Even postwar Britain had too few dollars to buy it. They could only afford to buy 50 kgs of the drug which was bought for a sum of 320,000 dollars which were distributed via randomised controlled trials. This was enough to treat only about 150-200 people. Only 50 people got the medicine during the trials.

Doctors then were besieged for this “miracle drug”. A black market emerged for this drugs. George Orwell became the first person in Scotland to be treated from TB. A bank account with proceeds of sale from his book Animal Farm provided the money for streptomycin. It is important to remember how such life saving drugs are often not widely available to everyone who is sick with the disease and this saga. This continues till date.

In countries such as India which got independence around the same time, there was no system of delivering TB care. India then had only 118 clinics and about 11,600 beds, it needed about 5 lakhs bed then.

A nationwide [survey](#) done by Indian Council of Medical Research between 1955-1958 showed that 400 per one lakh population had TB and about 5 lakh people died every year. This was the last TB prevalence survey done in the country.

**Dr. Thakur-** Previously only 3 drugs were available when we were students of Masudhan Das, head of the department and he was very much TB minded because he was a pulmonologist, jaisa kaagaj main chaar pad bantata tha, ek sheet me pura ek kone me kewal 3 dawa likhi jaati thi streptomycin, 1 vial, ethambutol, isoniazid one tablet daily continue for 6 months both tablets - injection 60 days, that was total prescription and after 80 when he was practicing he was not mentally sound but he was again writing the same medicine and the cure rate was more than 50% because more than 50% person used to suffer from tuberculosis and they used to improve so that was the old treatment of TB.

**M(Host)** - There was a very poor public health system which the WHO and the Indian government conceded will not be able to handle anytime soon. At around the same two, two pronged solution was offered. One was vaccinating the entire population. The other was offering TB treatment at home, which is called domiciliary treatment.

Despite the advent of medicine, most patients were still treated in hospitals during the duration of their treatment. “Is that really necessary?” The WHO wanted to check, especially in India considering there where there were not enough beds to treat TB patients.

In 1956, the World Health Organisation, Medical Research Council of Great Britain, and the Indian Council of Medical Research conducted a landmark trial in Madras. The idea was to check if TB treatment taken at home is as good as TB treatment in the hospital or sanatorium.

They decided to have two wings of treatment - the one where the patients took treatment at home, and one where patients were housed in the sanatorium for a year.

Dr Yogesh Jain, who runs Jan Swasthya Sahyog, a community hospital in Chhatisgarh revisited this trail.

**Dr. YJ** - it was a very well done study supported by the British Medical Research Council that people who were treated in sanatoria or at home had equal rates of disease conversion and therefore cure in terms of whether their germs had died or not. They did not study what was their ability to return back to work that was not a part of the outcomes that they committed upon in this paper but the other smaller bits of data that came out from the study showed that people who were treated in a sanatoria especially the women they gained an average of 11 pounds weight that is 5 and a half kilos at least on in the duration of treatment they received whereas the women who were admitted who were in the domiciliary treatment at home who got home food and had to work while they were receiving treatment they gained a weight of lowly 2 pounds or 2 and a half pounds in that duration of treatment and as we know from our biomedicine also that the weight gain that you have are a good marker of you know your disease recovery and your ability to work later which is an important thing for all laboring people so while the men did not show a very significant weight gain difference in domiciliary versus sanatorial care. People who were in sanatoria obviously got a very defined and a high calorie high protein diet whereas in home the food even if you get supplements they would be shared between family members as well as the household laboring which is itself a calorie expenditure would continue given the gender distribution of laboring that happens in patriarchal societies like ours it clearly showed that women were at a disadvantage when they were treated at home with TB drugs but this differential was you know when you combine both men and women then it shows the weight gains were not different between men and between those who were treated at home or in the hospital. So for the next 50 years we included the generations of doctors have been trained to believe that domiciliary treatment is as good in fact and it has a social advantage of not disrupting families and situations at home and also allowing better privacy and you know confidentiality of care at home till the direct observation strategy of DOTS came in in the late 90s.

**M(Host)** - So while the scientists were keen to see the benefits and cost-effectiveness of the treatment protocol, it turned out - that is the disappearance of the bacteria. But, it had to turn a blind eye to how the person lives with the disease and after the disease.

At the same time, the Indian government with the World Health Organisation started the BCG vaccination programme in India. It was promised that the vaccine will reduce TB incidence by 80%. It was also cheap. It was the technological fix. It started in Madanapalle district in present day Andhra Pradesh. And the vaccine was produced in a lab in Guindy, outside Madras.

A former sanitary engineer from Madras, A V Raman, published editorials against it. This movement got momentum when freedom fighter and head of Madras state, C Rajagopalachari supported the campaign. Their argument was- we need to build our health and sanitation systems first- a technological fix won't do. Coming under pressure, The ICMR in 1968 conducted a trial in Chingleput area of Madras to test if the vaccine provided any protection against TB.

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At the end of more than 12 and a half years, it was found that the vaccine did not offer any significant protection against TB. However, the vaccine is still given at birth because it is supposed to provide protection against childhood forms of TB such as TB meningitis. During the trial, in 1960, the government also launched the National Tuberculosis Programme, this offered diagnosis at the district level and home-based treatment with streptomycin and pyrazinamide for about 18 months. The duration of the treatment changed over a period of time and was reduced to about a year. However, the logic of the programme was simple- if a person has symptoms of TB he or she will travel all the way to the district headquarters to be diagnosed and get treatment. The district TB centre should have X-ray and lab facilities including a doctor to treat tuberculosis. Dr Kamal Chopra, director of New Delhi Tuberculosis Programme was with the TB programme then.

**Dr. KC-** District me aate hi us patient ka X-Ray ho jata tha, small film chote chote X-ray hote the alag se camera hote the ab normal X-ray hote hain usme 13-12 ka film hota hai wo chota roll hota hai wo film ki tarah chalta rehta tha toh ek ek krke nahi krna padta tha aap 40,50 X-ray kar sakte ho usme, bilkul roll ho jata tha jaise photo ki film nahi hoti thi? Uss type ka hota tha matlab basis of diagnosis was X-ray.

As soon as the patients come to the district, we used to get their X-rays done. Earlier there were small rolls and small films with which 40-50 X-rays were done and it was the only basis to diagnose TB.

**M(Host)** - As indicated in the Madras trial, the WHO and the Indian government was convinced that the treatment could be given at home. The patient then becomes responsible for taking the treatment.

**Dr. KC-** Treatment ke liye kya karte the domiciliary treatment dete the- domiciliary treatment means -patients ko dawayi dete the- mahine bar ki aur tum ghar baith ke dawayi khao. Ek unka card bana dete the. Treatment pehle do saal tha phir 18 mahine hua phir 1 saal. injections woh 90 dete the, 90 injections are very famous- koi purana patient hoga unse pucho 90 teeke lage toh theek ho tum. Har mahine patient dawayi lene aata tha. Suppose woh nahi aaya phir ek week ke baad DTC jana padta tha. District TB centre. DTC main card bana hotha tha aur phir usko ek card dedete the ki aap ki dawayi due aap khaane nahi aaye.

Earlier we used to give domiciliary treatment to patients wherein we used to make a card and give them medicines for a month. The treatment was for 2 years then 18 months and then 1 year. 90 injections were very famous back then, ask any old patient he will tell you, you are fine if you completed the course of 90 injections. And, if the patient missed the dose he had to go to the DTC ( District TB centre) after a week where the card was maintained mentioning you missed the dose because you did not come.

**M(Host)** - This programme was reviewed in 1991 by the WHO and other agencies and was considered a failure.

**Dr. KC-** humara basis of diagnosis jo tha x ray tha. Ab x ray main koi bhi shadow specific nahi hain. Kai baar pneumonia tb lagta hain or tb pneumonia. Kai baar pneumonia cancer lagta aur cancer tb ke tarah. We say there is no specific shadow of TB. with the result 30% of cases were over diagnosed. Toh overall jo kehte the 1/3 rd patients hi diagnose kar pathe the.

**M(Host)** - what is most indicative of the failure of the programme is the blind belief in the medical technology, mainly chemotherapy and ignorance of the sociological aspects of TB. The National Tuberculosis Institute was one of the institutes that was conducting sociological research. One particular [study](#) of 1963 based in Tumkur district of Karnataka clearly stated that the programme was far from a “magic bullet” for controlling TB. The success of chemotherapy itself was dependent on the improvement in socio-economic conditions.

While some patients who dropped out of treatment could not come to the city every month; some had a precarious arrangement of sometimes sending their relatives to the TB centre to collect pills. Others lost their cards. Some faced rude health workers. Some were told the pills won't work without a diet and just stopped treatment as a result. Some moved to districts that had no coverage for TB treatment.

The initial optimism for a technological advancement that will resolve the TB problem no longer held true. Unfortunately, like all evidence indicated, including the Madras trial, TB was a problem that could only end if overall health systems improved, there was no easy fix to this problem.

**Dr. YJ-** One lesson we could draw is that it is better to have no program than to have a bad program but certainly the third situation is what we should aspire towards have a program that when people are taken on for their illness then the people seek treatment seek diagnosis and treatment then it is a system's responsibility to ensure that they finish the treatment it is not alone the patient's responsibility and i would say i would underline the message to seek treatment is a responsibility of a person who is sick but to ensure that they continue treatment and complete the treatment and return back to work and if any relapses happen even to pick them up is the responsibility of a system that aspires to you know to manage people with tuberculosis rather than leave it and to the person who is suffering to ensure his or her own treatment i would say instead of you know the system blaming the people for defaulting on treatment, the system should not be fault on people who have sought care for them.