Tuberculosis Newsletter

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The Power of Patients Stories

Dr. Nibedita Rath, Scientific Director, Open Source Pharma Foundation, Bangalore

Storytelling is the best way to grab people's attention, and people who can tell the most compelling stories, stories about their lives, can command the most influence within their communities.

Stories are a powerful tool in engaging people that help in knowledge and experience sharing, and they possess the potential to influence quality improvement in healthcare. Sharing a survivor's experience during the journey of the recovery process can reflect upon improvements or problems in a clinical pathway. A good story has the power to motivate, encourage and engage minds in the right direction.

Sharing the stories of patients/ patient communities with different stakeholders and general audiences can effectively impact quality improvements and patient experience. In addition, it will help flow information among different sectors, raising awareness and connecting hearts and minds for a better outcome.

Tuberculosis, which continues to be a lifethreatening problem globally, knows no borders. It is a global health problem, and each year more than 5000 people die of TB globally. The stigma associated with TB is immense, which lead to delays in seeking treatment. Sometimes patients seek help after a prolonged period of self-medications. The social and economic impacts are disastrous, including poverty, stigma and prejudice. The stories of TB survivors from across the globe would throw light on their experience during their treatment and recovery phases, the difficulties they encountered during the treatment period. the social and psychological impact, including the importance of early diagnosis and compliance to the treatment duration. Their voice is a powerful tool to accelerate TB response and to achieve quality TB care.

The article by **REACH India** talks about how TB survivors and affected communities play a vital role in India's response to TB. In this issue, we are featuring a few TB survivors and TB Champions who are leading from the front to eradicate TB from the root. For <u>Chinmayee</u>, discovering that TB was a serious but treatable disease was only the beginning of her challenges. **<u>Tupeshwari</u>**prefers to keep to herself, but she is hard to miss. She has strong convictions and stands by them. Upendra Kumar is a tuberculosis survivor and Champion from Garhwa District in Jharkhand. has faced a lot of He stigma and discrimination from his family and neighbours and tried to keep his TB diagnosis a secret. "I want to tell people that they should not ostracize people affected with a disease. It's important to meet sick people and give them confidence"- This is what Poonam, an MDR-TB champion, says. "We have only one goal that we help people with TB in accessing the best treatment options available and help them to get cured", says TB survivor and TB Champion Abhishek Kumar.

Sharing the stories of patients/ patient communities with different stakeholders and general audiences can effectively impact quality improvements and patient experience. There is a greater need for advances in TB research and innovations. The current pandemic will change the future of drug discovery and development. There seems to be a paradigm shift in vaccine technology. The accelerated speed at which multiple vaccines have come up to address the current pandemic is overwhelming. Dr G Sitta Sittampalam talks about why enough has not been done for TB and other rare, neglected, and infectious diseases that kill millions worldwide. Article by Dr Rudrodip Majumdar talks about Covid induced pulmonary fibrosis and the possible linkage with tuberculosis infection.

"Lost in Translation": Vaccines and Therapies for Tuberculosis

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The supersonic speed with which the COVID-19 vaccines (mRNA and others) were developed, clinically tested, and delivered to the world was spectacular! So, the question is, why have we not done this for TB and other rare, neglected, and infectious diseases that kill millions worldwide? Indeed, a recent publication has asked the question, "Where are the RNA vaccines for TB?" (1).

Let's put this in context. In 1921, exactly 100 years ago, the first dose of Bacillus Calmette- Guérin (BCG)vaccine for TB was given to an infant in a Paris hospital (2). It's stunning that BCG is still the only approved vaccine[1] for TB today, which infects over 10 million and kills over 1.4 million people worldwide, which is estimated to prevent approximately 5-10% of preventable illnesses caused by TB (WHO, 2019, 3). Moreover, we still have only a few drugs and poor diagnostics, although Mycobacterium tuberculosis (Mtb) originated in Africa 70,000 years ago, and the complete genome was deciphered in 1998. The early 1900s were simple times with fewer regulatory, financial, marketing, and commercial hurdles.

The answer to the question of why we do not have more effective vaccines (and therapies) for TB to date is more complex. The sad truth is that the difficulties lie in translating new discoveries in the biology of the pathogen and the host's immunological response into the clinic. An elegant review in 2020 (4) addressed the issues related to TB and the development of new vaccines. However, a quick search in the literature revealed that mRNA and DNA technologies for TB vaccines were reported in 2004 (5) and again in 2010 (6) but were not pursued for development 2021[2], demonstrating the even in difficulty in the translational process.

Translational science and research[3] is a long hard jog that is mainly hidden from view but public has long been practised systematically in the pharmaceutical industry (7). It was an art and science with years of experience that was almost handed down from "Guru to Pupil" in the laboratory and the clinic. Only in the last 20 years since the sequencing of human genome, the discipline of translational science and research has gained attention in the public domain. Let us go through briefly the process of translating the basic science cited above from the lab to the patients.



Cover image of newsletter from Douglas Magno/AFP via Getty Images

It's the "Biology Stupid"

We use this term with some levity, but it is crucial.

With the sequencing of the human genome in the early 2000s, it became apparent that we are no longer closer to treating human illnesses. The sequence was a series of letters (A, T, G, C) that was like a computer code consisting of Os and 1s, with no information on the genes and effector proteins that carried out the functions of the cells. What was worse, even after identifying all 20-25,000 genes in our genome and expressed proteins, we still had to decipher epigenetics, posttranslational modifications in proteins, related changes in function, their expression patterns and distributions in diseased and normal tissues and organs. Not to mention the differences in the same genes and proteins in animal models and humans.

1 Three vaccines are in phase II a (MTBVAC) and Phase III (VPM1002) and M72 are in development.

2 Indeed several recent reports have also described the development of DNA and other vaccines with potential new targets in the alveolar macrophages, airway epithelial cells and neutrophils(4) in addition to the Mtb. The concepts in translation described above for mRNA will apply here as well. Note that addressing host cells takes us to host vs pathogen choices in Mtb infections which adds additional complexity in developing vaccines and therapies.

3 Translational science and research are distinctly different. The terms are extensively discussed in reference 7.



Image by Yale Rosen via https://www.flickr.com/photos/pulmonary_pathology/65 45176873

In the case of infections such as COVID-19 and TB, we must further elucidate the positive immune responses and the lack of it in the host. What are the adaptive, innate, and trained immune responses in the host? How does the pathogen circumvent these defenses? In a pandemic with an unknown pathogen, these complexities are urgent. In known pathogens like Mtb, these responses still can be complex based on responses in populations with various regional and genetic backgrounds related to age, sex and ethnic diversity. These hurdles can never be assessed when the first publications on the biology of the disease or pathogen become available. Much of this is known for TB (4). However, we still must navigate the biological complexity and variability in developing vaccines and therapies for diverse human populations with relevant geographic and economic realities.

In general, preclinical efforts to deconvolute basic and disease biology take approximately 3-5 years and costs about \$20-30 million dollars or more in the pharmaceutical industry. A costly affair that is generally beyond academic and non-profit organizations. Simultaneously with preclinical studies, toxicological and clinical trial approaches related to patient populations and regulatory considerations must be evaluated in a somewhat parallel fashion. A typical development paradigm and the accelerated program for COVID-19 illustrates the complexity of translational science and research in the graphic below.



Typical Vaccine/Drug Development Cycle: COVID-19 Exemplar

Note that the accelerated development paradigm developed for COVID-19 is remarkable and an exception during this pandemic than ever before- a perfect storm. The fundamental question is why we cannot repeat these achievements globally for the epidemic of neglected tropical diseases. The answer probably lies with the regional and global bureaucracies that do not play well together.

As biology is being addressed, there are other critical steps in translational research.

Now we need molecules that can become drugs

This is a special aspect of translational science and research that is somewhat hidden in the graphic above. Molecules, whether targets, assay reagents, drugs or vaccines are the real currency in the development of therapies and vaccines. Much work on making these molecules and owning them are the domain of the pharmaceutical industry and highly coveted. Many hundreds and even thousands of potential drug molecules (or vaccine candidates that involve DNA and RNA) must be tested before potential candidates are selected for clinical trials.

When we see a pill, a capsule, or an injectable medicine, we take it for granted. lt has an active pharmaceutical ingredient formulated appropriately to maintain efficacy, safety and stability. In the early days of drug discovery (the 1950s -1970s), many molecules of therapeutic value originated from plant extracts or were svnthesized painstakingly by biochemists, chemists, and pharmacologists. They are rigorously in animals tested and modified chemically or biochemically one to few molecules at a time to improve efficacy and reduce toxicity. In the last 25 years or so, High Throughput Screening (HTS), sophisticated bioanalytical instrumentation, libraries of medicinal chemistry compounds, and automation and information technologies have revolutionized the early discovery landscape, with the concomitant effect of increasing the cost of drug albeit discovery, increasing the efficiency of early discovery. Billions of virtual molecules and millions of small molecule libraries are currently available for computer-assisted drug discovery and biological testing in HTS and lead optimization laboratories. Valid disease targets must be identified (a difficult, albeit necessary step) and physiologically and pharmacologically relevant robust assays must be developed to test large libraries of molecules (8). Once active molecules have been identified in the initial screening, multiple batteries of assays are needed to validate their activities in disease pathways, bioavailability, pharmacokinetics, pharmacodynamics, and toxicity in animals and possibly in human tissues (preclinical development box in the figure). These studies are needed to move lead molecules to be tested in Phase I clinical trials that cannot be initiated without regulatory approval.

The hidden problem is a lack of understanding of translational science and research efforts that are required in the "valley of death" for many drugs and vaccine development.

Failure rates in the preclinical discovery and development stage can be large, with 1 in 100 to 1000 molecules advancing to regulatory applications. Note that if valid targets and pathways were not used in the initial stages of screening and lead optimization, the chances of success in very expensive clinical trials become limited increasing economic risk. In infectious diseases, there is double jeopardy since targets and pathways can come from either the infectious agent or the host tissues and immune system, or both, that need to be considered for finding therapies. This is indeed the case with TB. malaria and almost all infectious diseases.

One last hurdle is the intellectual property and funding considerations on novel molecules and development technologies (drug formulations, manufacturing know-how/infrastructure). These issues are equally important and critical and should not be ignored since resolving these issues allow molecules available for clinical testing and eventually as medicines or vaccines for patients.



Tuberculosis-114 Countries Join Hands To Eradicate TB by 2030 - By Dr Garima, Lybrate

The big elephant in the room-Clinical Trials and Funding

Clinical trials are costly affairs mainly as it involves testing new therapeutic candidates in large populations of patients. Manv researchers focused on the basic biology of the diseases generally are unaware of the requirements in clinical trials to tailor their studies appropriately. The phase I clinical trials explore safety in healthy volunteers at pre-determined dose levels along with pharmacokinetic and dose-limiting toxicities. There may be exceptions in some trials that combine efficacy and safety in phases IIa and IIb trials with cancer patients. The number of patients is limited in Phases I and II (in the hundreds), but Phase III efficacy trials involve thousands of patients multiple clinical in centers, including diverse patient populations with age, sex and ethnic considerations. Ethical design and execution, patient selection and exclusion criteria, adverse event reporting are carefully monitored by both regulatory agencies and the sponsor of the clinical trials. Generally, the resources for clinical trials are in the industrial domain and requires close collaborations managed by well-financed private Clinical Research Organizations, academic medical centers. government research laboratories, regulatory agencies, and pharmaceutical companies. Traditionally these phases of clinical trials can last 5-10 years, depending on the disease and trial objectives and patient outcomes, costing several hundred million dollars.

Many hundreds and even thousands of potential drug molecules (or vaccine candidates that involve DNA and RNA) must be tested before potential candidates are selected for clinical trials.

There are, of course, clinical trials that can be carried out exploiting the potential of repurposing of medicines and vaccines with rich human exposure data that have already been approved for human use. Therefore, repurposing or repositioning these candidates for new indications, with potentially less preclinical and clinical development costs, have been pursued aggressively.

However, one should be careful, since many obstacles must be overcome to carefully justify the biological mechanisms that ensure efficacy and toxicity for the new indications in the targeted patient population, drug development and manufacturing costs, funding for clinical trials and intellectual property considerations. Nevertheless, there are very active efforts all over the world by many non-profits and in some cases by Pharma organizations themselves, summarized in a recent review (9).

A timely example is the use of the anti-diabetic drug Metformin repurposed for TB in a combination trial that has been funded by multiple organizations in India (10). It is known that Metformin, an AMPK modulator (adenosine monophosphate-activated protein) inhibits the growth of Mtb in host cells by controlling the autophagy pathway by augmenting the activity of anti-TB drugs. In this clinical trial, Metformin (1000 mg) is administered in combination with a standard regimen of rifampicin, isoniazid, pyrazinamide, and ethambutol. This is a classic example of enhancing both host response to the pathogen and exploiting the activities of existing approved drugs against the pathogen. More such efforts should be undertaken to tackle the epidemic of Neglected Tropical Diseases (NTD).



Circular map of the chromosome of M. tuberculosis H37Rv. Nature 393, 537–544 (1998)

Going forward

The hidden problem is a lack of understanding of translational science and research efforts that are required in the "valley of death" for many drugs and vaccine development (11). In many cases, failures occur during the lead optimization and preclinical development that involves efficacy and toxicity testing, not to mention failures in clinical trials that involve human genetic diversitv. In the current environment and available infrastructure, this effort can take 10-15 years. None of our graduate curricula is geared to include translational science and research for obvious reasons. The costs associated with preclinical and clinical studies and the lack of translational science and research expertise in the academic and non-profit research community is a serious problem worldwide. This gap requires urgent attention from governmental and nongovernmental funding organizations.

Note that the organizational structure and processes required (the science of translation) (7) and the research effort to convert discoveries in biology as medicines are enormous. The trick is to make the valley of death into a "valley of life" where we increase the probability of success, as we witnessed in the development of the COVID-19 vaccines. In addition, the clinical trial costs and timelines should be coordinated on a large scale to ensure safety and efficacy to demonstrate and clearly define patient outcomes that are economically viable. The timeline for vaccines for COVID-19 was just 1 year, with many hurdles in the translational pipeline that were overcome during this pandemic. The same can be achieved for TB and NTD epidemics in the next few years, and that's an achievable challenge. Today, biomedical advances in biology, chemistry and pharmaceutical sciences have the muscle to make this happen. However, there must be cultural, social, and political will to allocate the necessary resources and organizational structure to accomplish such an undertaking.

Simply put, there needs to be a focused effort from not only the citizens but also from the healthcare industries, affluent philanthropies, international NGOs with a sense of urgency for the epidemic of NTDs. Interestingly, the US government alone has spent over 1 billion dollars on seven targeted NTDs from 2006-2020 (12). With over 3 billion people affected by these NTDs globally, this is a pittance compared to what has been spent on the COVID 19 pandemic in 2020-2021.

Since we live in a global village, addressing NTDs is an imperative that should be undertaken not just by one nation but on a global scale for TB and other infectious diseases that would probably get worse with changing economic and climate catastrophes that face us.

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Covid-Induced Pulmonary Fibrosis and the Possible Linkages with the Tuberculosis Infection: An Observation

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Introduction

Till August 30th, 2021, a whopping number of 21.75 crore people have been known to be infected globally by the novel coronavirus SARS-CoV-2, and 45.19 lakh people have succumbed to the ongoing COVID-19 pandemic [1]. Research has shown that progressive fibrotic lung disease is one of the possible consequences of pulmonary pneumonia induced by the novel coronavirus and is one of the most worrisome complications following the recovery from the COVID-19 [2]. Considering its importance and sensitivity in the human body, lung performance is a good indicator for understanding the host tolerance to infectious diseases [3]. Therefore, in lung functionality, the discussions revolving around pulmonary fibrosis are even more relevant.

Simply put, there needs to be focused effort from not only the citizens but also from the healthcare industries, affluent philanthropies, international NGOs with a sense of urgency for the epidemic of NTDs. Pulmonary fibrosis is a lung condition commonly associated with severe lung injury when the lung tissues around and between the air sacs (alveoli) become damaged and scarred. Fibrosis in the lungs leads to thickening of the tissue, and the stiff tissue results in improper functioning of the lungs. As the pulmonary fibrosis condition worsens, the shortness of breath experienced by the person suffering from it becomes more acute [4].

Since the scarring of the lung tissues can occur in the absence of a clear initial acute inflammatory phase and can manifest to an advanced stage without a clinically acute symptom, no inciting agent has been pinpointed yet as the pivotal cause of pulmonary fibrosis. However, the medical community broadly opines that the germination of pulmonary fibrosis is owed to abnormal wound-healing mechanisms following repetitive alveolar microinjury[5]. Activities like smoking, as well as the microaspiration of gastric content (a risk factor commonly associated with intubated critically ill Pneumonia patients who are unable to breathe on their own and need to be on ventilator support), and microbial infection are known to trigger the fibrotic response in the lung [6]. Even exposure to hazardous materials (e.g., silica dusts, asbestos fibers etc.) can lead to lung fibrosis[7].

Scarred lung tissues heavily restrict the supply of oxygen to the rest of the body. This eventually affects the right side of the heart. Pulmonary fibrosis can result in high blood pressure in the lungs, known as pulmonary hypertension. In severe cases, it can cause heart failure, resulting in the demise of the patient suffering from it [8].

Some of the symptoms that can indicate the signs of lung fibrosis include shortness of breath (dyspnea), fatigue (due to insufficient oxygen being supplied to the muscles), cyanosis (bluish skin in fair-skinned individuals), persistent dry cough, sudden and unexplained loss of body weight, aching muscles, and joints, as well as widening and rounding of the fingertips and toe-tips (also known as clubbing) [9].

Dr Sonve Danoff (MD, PhD), an Professor Associate of Medicine and the Co-Director of Interstitial Lung Disease / Pulmonary Fibrosis Program at Johns Hopkins University, from research experience her associated with 41 men and women with idiopathic pulmonary fibrosis, found that the patients on an average exhibited more than twice the amount of night-time sleep disturbances and about double the number of davtime episodes of drowsiness as compared to the people with healthy lungs [10]. Therefore, it is evident that pulmonary fibrosis affects the quality of of life the patients substantially.

It is noteworthy that pulmonary fibrosis is characterized by the replacement of normal lung parenchyma with collagenous resulting tissue, in architectural changes in the lung that are irreparable and largely irreversible [11]. However, specific anti-fibrotic and therapies drugs can sometimes help in improving the quality of life by alleviating some of the symptoms in patients whose lung function tests fall within certain limits [12]. For extreme cases, a lung transplant might also be required.

The medical community broadly opines that the germination of pulmonary fibrosis is owed to abnormal wound-healing mechanisms following repetitive alveolar microinjury.

Linkage between Tuberculosis (TB), COVID and Pulmonary Fibrosis

Pulmonary tuberculosis is known to be responsible for several respiratory problems in the long run, viz. chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, and restrictive lung diseases (i.e., the lung diseases that prevent the lungs from fully expanding with air) [13]. Particularly, a past record of pulmonary tuberculosis (TB) increases the risk factor towards developing long-term respiratory impairment in TB patients [13].

Published research indicates that the bacterium responsible for tuberculosis infection (i.e., Mycobacterium tuberculosis) latently resides in about 25% of the global population, and it may enhance the chances and severity of the SARS-CoV-2 (COVID-19) infection [14].

In a sample study comprising 36 COVID-19 cases from Shenyang, China, the tuberculosis history (both of active and latent TB) of the patients emerged as a key risk factor associated with the SARS-CoV-2 infection. The patients with active or latent TB exhibited greater susceptibility to SARS-CoV-2, and in those patients, the symptom development and progression of COVID-19 were rapid and severe [14].

Further, if a patient who is already suffering from pulmonary fibrosis (due to COVID or any other triggering agents/diseases) contracts pulmonary tuberculosis, a grave situation can unfold. In such cases, it may be difficult to cure the tuberculosis infection of the patient, primarily owing to the reduced oxygen-carrying capacity of the lungs.

Therefore, during the ongoing pandemic, it is important to carefully evaluate the linkage between pulmonary tuberculosis and the fibrosis in the lungs induced by the extended aftereffect of COVID infections. It is also important to look at an integrated picture of such diseases instead of looking at each one in an isolated manner.

Possible Interventions

It is widely known that the risk of tuberculosis infection increases substantially for the individuals residing in unclean and crowded living conditions, as well as those suffering from poor nutrition. On the other hand, pulmonary fibrosis can get aggravated due to cigarette smoking and regular inhalation of chemicals or hazardous substances [8].

Further, it is noteworthy that most of the microbial infections are owed to the compromised immune system of the human body. The immune system becomes weak due to several reasons, such as old age, unhealthy and improper dietary habits, unhealthy lifestyle, chronic illnesses, high blood pressure and diabetes, continued stress, as well as smoking and other intoxications.

Therefore, a balanced diet, adequate amount of aerobic exercise and staying away from stress and negative thoughts are quintessential for maintaining a good quality of life. Furthermore, routine check-ups for chronic diseases, strict adherence to the treatment regime, proper social distancing, and a hygienic living condition would prove to be instrumental in ensuring an enhanced level of overall safety during these challenging times marred by the rapid spread of lethal contagious diseases.



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From TB Survivors to TB Champions

Reach, India

ΤВ survivors affected and communities are playing a vital role in India's response to TB. TB survivors are best placed to understand the struggles of people with TB and their families and can significant plav а role in complementing the interventions of the health system. In this issue, we are proud to feature profiles of TB survivor- Champions, from different backgrounds, with one thing in common - their courage to defeat TB and their determination to now play an active role in ending TB in India.

These stories have been shared by REACH (Resource Group for Education and Advocacy for Community Health), an organisation working with TB Champions across India and building their capacity through workshops and mentorship programmes. REACH is committed to providing these TB survivors with the skills necessary to become effective advocates and play a role in raising awareness about TB and addressing stigma. In short, they are transformed into TB Champions.

The training of the TB Champions featured here was a highlight of the TB Call to Action Project (2016-2020) supported by the U.S. Agency for International Development (USAID). In addition, REACH continues to work closely with TB Champions in Jharkhand, Odisha and Tamilnadu through the ALLIES Project, also supported by USAID, and in Bihar through the Challenge Facility for Civil Society initiative of the Stop TB Partnership.



Bouncing Back with Grits, Guts and Gumption

B Chinmayee, TB Champion, Ganjam, Odisha

B Chinmayee is a classical Indian dancer from Odisha. After she was diagnosed with TB in 2017, about of TB meningitis left her paralyzed in a hospital, and she subsequently suffered a miscarriage.

For Chinmayee, discovering that TB was a serious but treatable disease was only the beginning of her challenges. She also faced a lot of stigmas. Her husband and family were unsupportive, and she returned to live with her parents. "Delayed [TB] diagnosis made me paralyzed and shattered my dream to dance on a stage," Chinmayee said. However, with support from her father, she completed her treatment and was determined to lead a normal life.

In February 2019, she attended a capacity-building workshop for TB survivors organised by REACH. Since then, Chinmayee has been working as a TB Champion, supporting people with TB, including those seeking care in the private sector. Chinmayee centres her advocacy efforts on ending the stigma associated with TB. She has organised several awareness meetings and anti-stigma campaigns during local festivals and in her neighbourhood.

"I often glance through my old photographs in my bright and traditional costume, and that gives me a determination to dance again," she said. "I do try a few simple steps and have shared it with my TB Champion friends. Their encouragement motivates me to perform one day, especially on Mahisasurmardini, which depicts the powerful Goddess Kali killing the demon king Mahisasur."

I am not afraid of Tuberculosis now. TB is afraid of me.

In September 2020, addressing senior health officials at the launch of the TB Harega Desh Jeetega campaign in New Delhi, she spoke of her determination to end TB stigma and to dance once again., Chinmayee is today considered a role model for young women affected by TB, with her openness and courage.

Watch Chinmayee's story here: https://www.youtube.com/watch? v=Tl79p1sENqU



Outcast to TB champion - 22-yr-old rebuilt her life

Odisha woman who lost nearly everything to disease is now powering anti-TB campaign

ADITI TANDON

NEW DELHI, OCTOBER 8

Fresh from her excruciating struggle against brain tuberculosis, 22-year-old Chinmayi cannot stop smiling.

"I am not afraid of tuberculosis now. TB is afraid of me," says the young woman after the government recently named her a TB champion who will power India's anti-TB campaign starting this year.

Chinmayi's mission is cut out before her. She has to inspire lakhs of TBinfected persons like herself to report the disease and fight the stigma associated with it.

"Chinmayi's resilience against TB is already inspiring patients across Odisha," says Dr Sangeeta Sharma of the National Institute of Tuberculosis, who has been involved with the girl's treatment since initial years of detection of her disease.

It was 2016 when Chinmayi, a bright college student in Odisha's Berhampur, was detected with brain TB, a rare and extremely painful form of



TB champion Chinmayi with her father in New Delhi. TRIBUNE PHOTO

Had it not been for my father, I would be dead by now. In past six months, I have encouraged over 100 TB patients to strive against the disease Chinmayi, TUBERCULOSS OWNROW

the disease caused by bacterial infection.

"The first casualty was my unborn child as I had a painful abortion. The second casualty was my marriage. My husband didn't think twice before abandoning me after he learnt that I had been detected with brain TB. The disease caused severe paralysis. Within days of detection, my life as I knew it had ended. The stigma was more painful than TB," Chinmayi told *The Tribune* in an interview after the Ministry of Health celebrated her victory over TB at a recent event in the capital.

Three years down the line, Chinmayi is back to her feet and is learning to dance classical forms again. She credits her father — also her dance guru — for the turnaround and survival.

"Had it not been for my father, I would be dead by now. But here I am today, standing before you as a TB champion. Over the past six months, I have encouraged over 100 TB patients to strive against the disease

PAINFUL STRUGGLE

In 2016, Chinmayi, a bright college student in Odisha's Berhampur, was detected with brain TB, a rare and extremely painful form of the disease caused by bacterial infection

Her first casualty was her unborn child as she had a painful abortion. The second casualty was her marriage as her husband abandoned her after he learnt that she has been detected with brain TB

Three years down the line, Chinmayi is back to her feet and is learning to dance classical forms again and abandonment that comes with it. Wherever I go as a governmentappointed TB champion, I urge to people not to isolate patients and to be supportive. Care is the key in TB treatment," said Chinmayi.

Brain TB, experts say, is so painful that patients often speak of cutting their head off and keeping it aside.

Chinmayi endured that pain as she battled a drug resistant form of TB for which the only treatment available until a month ago was a series of painful injections.

India this month launched oral treatment regimen for drug-resistant TB which will not be painful and will raise the treatment success rate from 40 per cent at present to around 70 per cent.

India has the highest burden of TB, the most fatal communicable disease in the world with 27 per cent global new cases coming from India alone.

The government has committed itself to eliminating TB by 2025, five years ahead of the UN Sustainable Development Goal Target of 2030.



A Determined Fighter for the Community

Tupeshwari Devi, TB Champion, Giridih District, Jharkhand

Tupeshwari prefers to keep to herself, but she is hard to miss. She has strong convictions and stands by them. Tupeshwari is the president of a local political party in Dumri block and is active in community work. She is the mother of two children who are 20 and18 years old. Her husband runs a furniture business in Goa.

In 2012, Tupeshwari was diagnosed with TB. Initially, she had a cough and cold, and she consulted а private physician. He prescribed cough syrup, which she took for 15 days. As she continued to cough, she consulted another private doctor in Giridih. He asked her to get a chest X-ray but did not give her a clear diagnosis. But her health didn't improve. A few days later, Tupeshwari had a fever. "I was losing weight and felt weak. I did not know what to do. There was no one to help," Tupeshwari says. "My children supported me until my husband returned from Goa," she recollects.

Tupeshwari's condition worsened. She continued to go from one doctor to another, one of whom prescribed 23 injections and medicines for 15 days, which cost her Rs 5000, more than she could afford. Tupeshwari eventually went to the local PHC, where she was diagnosed with TB. "I usually prefer to go to private doctors, but this time I went to the PHC and took treatment for TB without a break," she says. She was declared cured after six months.



People should not stop interacting with those affected by TB. The disease will not spread if the right precautions are taken.

"The first time a doctor said I had TB, I felt terrible and started crying. The doctor said there was no need to worry and that I would be cured if I completed the course properly," Tupeshwari recollects. Tupeshwari's family was very reassuring. Her husband wanted to ensure that she was cured at any cost, even if it meant selling land to meet the treatment expenses. For over four months, he stayed with the family and gave her all the support and help she needed. "My husband tried to convince me that I would be cured, but I was sceptical as others in the family had died of TB. I was worried about what would happen to my children if I died," she says.

Today, Tupeshwari works as a TB Champion, having participated in a capacity-building workshop for TB survivors in 2018. She tries to help people in her area with early diagnoses. "I use the information I have to create awareness in the community. People will not die because of TB if they are diagnosed in time and take the medicines regularly," she says. Tupeshwari is also determined to reduce stigma in the community. "People should not stop interacting with those affected by TB. The disease will not spread if the right precautions are taken," she says emphatically.

As a member of both the state and district TB forums, she raises key issues affecting people with TB. In a social media campaign for Women's Day, Tupeshwari said, "When I support one woman with TB, and she supports 20 others, especially women, this movement will grow, and more people who earlier felt stigmatised would then feel cared for."

Finding the Hero Within

Upendra Kumar, TB Champion, Garhwa District, Jharkhand

Upendra Kumar is a tuberculosis survivor and Champion from GarhwaDistrict in Jharkhand. In 2015, Upendra first developed symptoms of TB. He faced a lot of stigma and discrimination from his familv and neighbours and tried to keep his TB diagnosis a secret. "I remember - I had been coughing for some time, and I thought it was a normal cough," he recollects. Although his health didn't improve, he did not tell his family as he thought they would get worried. Upendra happened to meet a health worker in the neighbourhood, and they discussed his condition. On the health worker's advice, he went to the Primary Health Centre (PHC) in Ramna, where he was eventually diagnosed with TB.

Upendra was devastated and started panicking. "I am the eldest in a family of ten siblings; I didn't know what to do. I had to look after the family, but my ill health did not allow me to work," he says. Upendra did not tell anyone except his wife about his TB diagnosis. For the first 45 days, he experienced severe side effects of the medicines. "The doctor and the health worker were helpful. There were meetings at the PHC every 15 to 20 days, and instructions were given about the treatment. We were also given an allowance to get nutritious food," he says.

After three to four months, Upendra felt his brothers had come to know about his diagnosis. "I did not tell them, but from their behaviour, I realised they knew. They must have been worried that they might also get TB," he says. He also recalls that when people in the neighbourhood realised that he had TB, they did not want to be around him. Finally, Upendra completed the sixmonth-long treatment and was declared cured.

In 2018, Upendra attended a capacity-building workshop for TB survivors organised by REACH, a non-profit organisation. He learned to work as a 'TB Champion' at the workshop, supporting people with TB and sensitising communities about the disease. Since then, he has helped nearly 500 people with TB and has transformed from a shy and reserved person into a vocal and committed TB Champion.

As a TB Champion, he has conducted many meetings to raise awareness about TB. "I educate people about the symptoms of TB. It is important to be tested for TB if there are symptoms. One should not be misled by the advice of quacks as it happened to me. Those diagnosed with TB should take the right dosage of medicines and on time. This way, we can make Jharkhand TB-free," he savs.

In 2020, when the COVID-19 pandemic hit the country and lockdowns were in place, several people with TB did not know how to get their medicines as they could not come to the TB centre. At that time, Upendra stepped up to the challenge and delivered medicines at the doorsteps of people in his block, ensuring he maintained COVID- appropriate behaviour.



With a total of over 400 survivors across Jharkhand

"During my visits, I would tell people to wear masks and wash hands frequently. Now that vaccines are available, I encourage people around me to take them to prevent falling severely ill with COVID-19. So far, I have personally ensured that over 200 people, including my family members, take the vaccine," he says with pride.

Upendra is also the President of Jharkhand's survivor-led network TEJ (TB Elimination from Jharkhand) and a member of the TB Forums at the state and district levels. He dreams of a future free of discrimination against people affected by TB. Watch this film on Upendra's journey as a TB Champion.

When Everybody Gave Up, She Stood Strong and Fought

Poonam Kumari, TB Champion, Jamui District, Bihar

Poonam is chirpy and charming with childish innocence. Unfortunately, in 2014, Poonam was diagnosed with TB and then almost a year later with MDR-TB.

At first, accompanied by her mother, Poonam went to a doctor in her village but could not get a clear diagnosis. Over the next few months, she visited multiple doctors, who asked for many different tests, but had no conclusive outcome.

As her health further deteriorated, she was taken to Patna and was diagnosed with TB. She began treatment but started to experience severe side effects. She says she felt there was no option but to give up the medicines after a few days. At the suggestion of a neighbour, Poonam was taken to another hospital in Patna where she underwent a test that confirmed MDR-TB.

"When I was diagnosed with TB, I did not think it was a dangerous disease. We got to know about its seriousness only after talking to several doctors. We contacted at least ten doctors," she explains. She was worried about the expenses needed for treatment but was relieved to learn that she could avail free treatment in the public sector. "We couldn't have afforded treatment in the private sector; that might have cost us a lot of money. My father needs to support the education of my brothers as well," she says.

Most of Poonam's extended family stayed away from her. She was disappointed that even her cousins maintained a distance; Poonam says she was very disturbed by the harsh and discouraging words her relatives used in conversations with her parents. "They would even say things like, there was no point in consulting doctors and taking medicines. It was better to let me die. My father was also disturbed, but he convinced me that things were not as bad as the others were suggesting and asked me to trust him," she says. "My parents and brothers were very supportive. They didn't make me feel like I was going to die."



"I know what it feels like, so one shouldn't get worried and go down that difficult path. It is important to remain positive."

Poonam's friends also stood by her, and there was no deficit in their love and affection. They used to check on her constantly whether she was taking medicines regularly. She also says that her fiance looked after her. "During the hard times, I got to know who would stand by me when I needed help," Poonam says.

Today, she is a trained Auxiliary Nurse Midwife (ANM) and is pursuing BSc in Nursing from MGM College, Patna. She also works part-time at a private hospital to support her education.

"I want to tell people that they should not ostracize people affected with a disease. It's important to meet sick people and give them confidence. People with TB should take their medicines regularly. I know what it feels like, so one shouldn't get worried and go down that difficult path. It is important to remain positive," she says confidently.

"A person who was admitted along with me in the hospital, Abhishek Kumar, told me he received an invitation to join a capacity-building workshop for TB survivors. I joined the workshop and subsequently enrolled in a mentorship programme. As a TB Champion, I raised awareness about TB, supported people with TB and worked to ensure a stigma-free village," she recalls.

Today, as a member of TB Mukt Vahini, a survivor-led network, Poonam inspires other TB survivors to join the network and support TBaffected communities.

"Recently, I have joined a group of TB Champions from TMV who are providing tele counselling support to people with TB on treatment during the pandemic. Two of the biggest challenges they face are the inability to get their medicines on time and to avail of the benefits of the Nikshay Poshan Yojana. So we collect the information and pass it on to the TB programme staff in our area and see that their problems are resolved. We hope this way; we can reach out to hundreds of people with TB and become a part of their journey to cure," Poonam signs off.



During the first COVID-19 lockdown, people with TB on treatment faced challenges in getting their medicines.

Bold and Brave Survivor, Now A Dynamic Young TB Champion

Abhishek Kumar, TB Champion, Vaishali District, Bihar

MBA professional and TB survivor-Champion Abhishek Kumar hails from Vaishali in Bihar. He is an entrepreneur who runs a mobile and online ticketing shop with his father in his village. He was diagnosed with MDR-TB in 2014 when he was working as a banquet sales executive at a hotel in Bangalore. During a regular check-up, a chest X-Ray detected an infection in the lungs, and he was subsequently diagnosed with TB. He returned home and approached a doctor at a private hospital, who started him on treatment.

But Abhishek's health did not improve, and he was eventually asked to begin treatment for drug-resistant TB. "Within a day or two of starting the medication, my heartbeat increased abnormally. I was not able to sleep either," Abhishek recalls. Abhishek then decided to consult doctors at a major health facility in New Delhi and travelled there. "Doctors at the hospital said that it was a mistake to have started treatment for MDR-TB without doing the right tests," he says. At the hospital, doctors started him on Category II medication. He was then referred back to the TB centre at Hajipur, where he continued his treatment for three months.

However, his symptoms persisted, and there was no visible sign of improvement. In June, Abhishek went to the government hospital again and this time, he was diagnosed with MDR-TB. The treatment went on for 27 months. and in all, Abhishek was home for 37 months. "I was bored at home as I was not used to staying in my house for that long. I had been away from home for eight to ten years," he says.

A few months after starting treatment for MDR-TB, Abhishek experienced some side effects. "I was giving a tough time to my friends and family. I was not even able to have а normal conversation with them because of my disturbed state of mind," Abhishek says. He distinctly remembers an incident from December 2015 when some friends came home to visit. "I did not behave properly with a friend. I even assaulted him. Seeing this, my family was forced to lock me up in a room," Abhishek recollects.

In January 2016, Abhishek attempted to take his life. "My mother saw me and cried out loud. Other family members came rushing and, they saved me," Abhishek says. His family took him back to a doctor, who helped him manage the side effects. As a result, his mental health gradually improved. However, Abhishek points out that the delay in getting a precise diagnosis makes it much more difficult for a person who is affected by TB. In 2018, Abhishek attended a capacity-building workshop for TB survivors and has since steadfastly worked to provide psychosocial support to families affected by TB. He has advocated with key local stakeholders, including MLAs. PRI members. ASHA workers. SHGs and schoolteachers. He is a founding member of Bihar'sTB Survivor-led Network 'TB Mukt Vahini' (TMV) and has persuaded over 20 other survivors to join the network. His efforts led to the launch of a weekly counselling centre at the Hajipur District TB Cell, with guidance from the District TB Officer. As a TB Champion and TMV member, Abhishek vows to share his experience and knowledge of TB at health facilities. He also has plans to start a nutrition bank with other TB survivors to provide adequate nutritional support to people affected by TB.

During the first COVID-19 lockdown, people with TB on treatment faced challenges in getting their medicines. "To ensure that they didn't miss a single dose, I spoke to the health facility near me and helped many people get their medicines on time", says Abhishek.

Watch this film on Abhishek's journey as a TB Champion and this message for the 51stUnion Conference during a Community Connect session.

> We have only one goal - that we help people with TB in accessing the best treatment options available and help them to get cured.

> > TB से ग्रसित लोगों के लिए हमारा एक ही उद्देश्य है - कि हम उन्हें बेहतर से बेहतर इलाज उपलब्ध करा सके और उन्हें स्वस्थ करा सके.

> > > ABHISHEK KUMAR TB Survivor, TB Champion and Member, TMV

TMV is a TB survivor-led network based in Bihar that is supported by REACH through Challenge Facility for Civil Society



EACH

ing the fight against TB





Stop TB Partnership







For more information regarding this newsletter or to contribute, please contact **Nibedita Rath** nibedita.rath@ospfound.org or visit <u>www.ospfound.org</u>

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