



GLOBAL COALITION OF TB ACTIVISTS (GCTA)
PRESENTS

MEN
&
STIGMA

CONVERSATIONS OF RESILIENCE
IN THE WAR AGAINST TB

FOREWORD BY MADHUKAR PAI

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We would also like to thank the brave men who shared their very personal TB journeys and re-lived their experience of suffering and stigma in the hope that others may be spared similar suffering. We laud you and your courage.

TEAM GCTA

About GCTA



The Global Coalition of TB Activists (GCTA) was conceptualised as a global platform to bring together affected community and ensuring that community is involved in all TB processes.

Since its inception in October 2013, GCTA has contributed significantly to the global TB agenda through its network of over 300 members affected by TB achieving a number of significant milestones along the way.

Vision

A world free of tuberculosis

Mission

To ensure that the voices of the TB-affected communities influence the global TB health agenda

Strategic Goals

- To amplify community engagement and strengthen the capacity of TB activists at national, regional and global levels
- To promote rights-based, people-centred TB response at all levels
- To advocate for increase in resources for TB research, community mobilisation and services
- To strengthen capacity of GCTA for improved effectiveness and efficiency

Foreword by Madhukar Pai

**Director, McGill International TB Centre,
McGill University, Montreal, Canada**



TB: No Man's Land

Women are disadvantaged in most areas of healthcare, and stigma is major concern for women. TB, however, is one condition, where all evidence points to a higher burden of disease in men, a consistent pattern of underutilization of health services, and generally poorer health outcomes in men.

Multiple systematic reviews have found that men are more than twice as likely to have active TB but are considerably less likely than women to be diagnosed and notified to national TB programmes. This represents a reversal of the usual pattern of disadvantage for women in use of health care. Understanding the sources of this gender imbalance is crucial to identifying and treating the missing millions of patients with TB globally.

TB is well known for interventions that are imposed from top-down, and for systems that are designed with the public health system in mind (e.g. DOT). TB services (e.g. National TB programs) simply do not seem to be convenient or anonymous for men, nor do they adequately address their fears and insecurities.

It is time for TB care to follow the principles of human-centered design, focus more on what people want, and align better with life circumstances. We need to understand men's needs in specific contexts, listen to what men are saying and not saying, and design multifaceted and synergistic interventions that are grounded in realities.

Unlike the HIV community, the TB community has not done a good job of harnessing the power of survivors and patient advocates. Thankfully, this is

changing. In this context, I see great value in this book *Men and Stigma* by the Global Coalition of TB Activists. It is timely because it helps raise awareness that men not only bear a higher burden, but also struggle to seek care and get adequate care.

The powerful stories of the male TB survivors in this book clearly illustrate the range of barriers they faced while dealing with TB. Their stories also provide valuable clues on how to overcome stigma and barriers, and how to design male-friendly TB services. It is important to make sure TB services are also female and child-friendly, and health systems do not need to choose between these.

I hope TB program managers, donors, and implementers read this book. If we want to end TB, then we need to worry about the missing men with TB, listen carefully to those who have lived experience and can make sure live-saving interventions reach those who need them the most.

Message from Mark Harrington

Executive Director, Treatment Action Group

Nelson Mandela was a TB survivor. After 26 years of imprisonment on Robben Island, Mandela developed TB. He described his experience at the 2004 International AIDS Conference in Bangkok, Thailand: "I was in jail when they took a specimen of my sputum and sent it to hospital. I was diagnosed with TB ... Fortunately we sent the specimen before there were holes in the lung... I underwent treatment and was completely cured." Mandela's example should inspire us all to fight the stigma associated with TB by being open about it and open to diagnosis, treatment and cure.



Mark Harrington getting arrested at the White House, in solidarity with the global and domestic struggles to end HIV, HCV, and TB.(2012)

Message from Blessina Kumar

CEO, Global Coalition of TB Activists



Greetings from The Global Coalition of TB Activists!

Working with TB survivors and affected communities, it has been crucial for us to understand the stigma associated with TB. This is one area everyone talks about, yet leaves unexplored the implications it has on the life of an individual. We do not talk enough about how big a challenge and barrier stigma can become.

We embarked on this journey last year, to understand stigma. Rather than making assumptions, we decided to hear the 'reality' from the survivors themselves. We started with the stories of women survivors. Several amazing women from across the globe shared their journeys with us—the journeys on the difficult path of overcoming not just TB but also the stigma associated with it. We often heard that it was not TB that killed people, but the stigma attached to it. That was very profound, coming from the TB survivors themselves.

This journey, we felt, had to continue, to discover the truth about stigma barriers. We needed to explore more. Our next book focused on stories of children and how stigma affected them and their caregivers. We looked at how stigma affects children who are often perceived to be protected from stigma. It was heart wrenching and many of us read the book and were moved to tears.

In all this, men were left out of our discussions and deliberations about stigma. Stigma does place a heavy load on women and children, and affects them differently. However, that does not mean that men do not face stigma. The casual understanding is that 'men are able to handle it'. Is this understanding true? We were not sure. So, we decided to explore how TB stigma affects men and we have uncovered some distressing stories that shook us and our assumptions.

This book, *Men and Stigma*, the third in the GCTA Stigma series, focuses

exclusively on men and the stigma they face. My hope is that as the previous two books have done, this too will open our eyes, touch our hearts and move us to action. At the UNHLM on TB last year we had great commitments from global leaders, and for these to be real, and actionable, they need to be unpacked and translated into the ground realities. Stigma is an enormous portion of that ground reality, which we bring and place before you. We ask decision makers, policy makers and donors to really understand and consider addressing stigma, so that it stops being an invisible barrier to finding people affected with TB, getting them a right diagnosis, putting them on treatment, and supporting them to complete the treatment.

Our dream of ending TB and finding the missing millions can become a reality if we remove this invisible barrier.

We now know for a fact that stigma does not differentiate. It affects everyone: women, children and men. This book is for all of us. We want to salute the brave men who shared their stories with us. A big thank you to friends and colleagues who have supported us in this journey and for their encouraging messages. I want to thank my team for working day and night on this.

We proudly present to you, *Men and Stigma*. Hope this will play a part in changing our TB response to a people-centered and rights-based one.

#ItsTimeforTB **Act Now!**



José Antonio Granillo Montes

*is a 61-year-old TB survivor from **Mexico**. He identifies as an activist in the fight against TB. His tryst with TB started when he was struggling with heroine and alcohol addiction. He managed to get the support he needed and was able to build a better life for himself. Today, he dedicates his time and life to ensure that others do not have to face the same stigma that he had to endure on his path to recovery.*

Overcoming Stigma with Knowledge[†]

GCTA: Thank you for taking the time to talk to us, Antonio. How long did it take for you to get your diagnosis?

Antonio: I was diagnosed with testicular TB in 1996. It took me a few months to get my diagnosis because I was using drugs back then. I was only 24 years old. That year, my life deteriorated more than ever before. I touched rock bottom. I used heroin and alcohol, and I was walking with gangs.

One day, I realised that one of my testicles was inflamed and had an infection with pus. I was ignorant and did not suspect that it could be TB. Instead, I took advantage of my condition and started to profit. I approached businessmen, neighbours and friends, and told them about my problem. They feared that I would show them my testicle, and hence, they would quickly agree to give me money. I saw my condition as a gold mine to get money for heroin, and I stayed like that for months. Fellow addicts saw me getting worse

and started discriminating against me. They told me to stay away from them. That is when I could not take it anymore. I went to a rehabilitation centre and the people in charge of the centre took me to the hospital. The doctor referred me to a urologist who told me to get a surgery at the earliest. After the operation, they sent a sample to pathology, and finally, I was diagnosed with tuberculosis.

I remember that my lungs were never checked. But the doctors told me that I have scarring on the lungs. I might have also had pulmonary tuberculosis. But, back then, they only focused on the tuberculosis in the testicles.

GCTA: After you were diagnosed, how long did it take for you to be put on treatment?

Antonio: Due to the addiction, it took a month to start my treatment. They first needed to detoxify me. My treatment lasted for approximately six months. It was very difficult for me because I had withdrawal symptoms like auditory and visual hallucinations.

I remember feeling nauseated and having bouts of vomiting. I struggled with the medicine. I did not like it. But after a month, my body adapted to the treatment. I also remember being scared by the colour of my urine because nobody had told me anything about that. Later, I understood that this was a typical side effect of the medicine.

GCTA: All this must have been incredibly difficult for you to endure. What are some of the factors that you think helped your treatment and recovery?

Antonio: I was abandoned even before I got sick. I came from trash. I had already lost everything—family, friends and even my dignity. I had nothing to offer. I am extremely grateful to the rehabilitation centre for what they did for me. During my treatment, I had the support of my colleagues in the rehabilitation centre. I had housing and food support. They even accompanied me to my medical evaluations and they also made sure that I complied with my treatment.

GCTA: Could you talk a little about your experience with stigma?

Antonio: Inside the rehabilitation centre, the staff treated me well, even when they found out that I had TB. But the residents rejected me due to

ignorance and lack of information about TB. Being a TB patient, I experienced stigma everywhere else. I was also dealing with my drugs and alcohol problems. I looked bad and people rejected me.

When I started my treatment at the health centre, I could see the difference in how the health personnel treated me, as compared to the other patients, only because I was in a rehabilitation centre. It seemed as if they believed that I was suffering as a result of my own deeds. But then, there are always exceptions. When they operated on me, I met a nurse who was humane and professional. But largely, I always felt rejected for being an addict and having TB. I feel that there is still a lot of ignorance and misinformation about tuberculosis.

Before I went to the rehabilitation centre, I was miserable. My self-esteem was very low. I thought that I was born to be a failure. I believed that I was born to stay under the influence of drugs, live behind bars, walk with gangs and be thrown in the trash. But when I entered the rehabilitation centre, I began to look for emotional stability with spiritual support. I learned to accept myself. I learnt to have values and principles and be accepting of my defects and virtues. Within seven months of being in the rehabilitation centre, people there realised that I

liked the health department. I liked talking to my colleagues and I also helped them during their treatment. Once, the person in charge of the health department, who supervised the treatment and accompanied residents to the hospital for their evaluations, was absent, and they asked me to take his place. This was after being in the centre only for seven months! That day onwards, I became interested in the problems of tuberculosis, HIV/AIDS and all other diseases.

At that time, six residents had tuberculosis. I started helping them in administration of intramuscular injections and intravenous treatments. I had spent many years injecting myself, and I clearly knew how to inject. Even though this sounds like a joke, it is true. I had taken the good out of the bad. Soon, I realised that I do not understand everything about TB, and that frustrated me. I wanted to return all that the staff at the rehabilitation centre had done for me, which is why I focused on continuing to help other people. I started asking for permits to attend training, symposia and workshops, all related to tuberculosis,

HIV/AIDS and hepatitis. I believed that gratitude ought to have been manifested in some way. It would have been very selfish of me to do otherwise. They helped me, took care of me, and that is how I became interested in doing the same for other people.

“I was abandoned even before I got sick. I came from trash. I had already lost everything—family, friends and even my dignity. I had nothing to offer.”

Now, I think life is wonderful. I have a different life and value everything that god has given me. I think that I have accepted my past

now. It does not affect me anymore. But I think there is a lot to do, and by sharing my testimony, I think I can help. All this has given me the strength to continue my work.

GCTA: As a TB survivor, what do you think needs to change in the TB response?

Antonio: Nationally, Tijuana still occupies the first place in tuberculosis incidence and mortality. It is the busiest border in the Americas, and the tuberculosis bacterium does not need a visa! Our authorities and society have made tuberculosis invisible. They see TB as a biomedical problem, but it is also a social, economic and human rights issue.

The Ministry of Health must understand that tuberculosis is a severe public-health problem in our country. There are some people who have access to health services, but there are others who are on the streets, who have been abandoned. I think we should be more sensitive and stop ignoring them. We have much more to do for people affected by tuberculosis, not only in my city or country, but also in America. We must awaken our authorities and be aware that tuberculosis still exists, and that it is a worldwide pandemic that kills millions. We need to commit ourselves to this struggle. Civil society, academics, scientists and politicians also need to join this struggle.

[†]*This interview was conducted in Spanish.*



Cecilio Sangama Ramírez is a 49-year-old TB survivor from **Peru**. His tryst with stigma pushed him to dedicate his life to fighting for the rights of people affected by TB.

Stigma at the Workplace[†]

GCTA: Thank you for taking the time out to talk to us. How long did it take for you to get your diagnosis? What were some of the challenges that you faced?

Cecilio: I was 19 when I was diagnosed for the first time. It took me a week to get my diagnosis and begin treatment. The most difficult thing was not having enough resources to cover the several auxiliary tests, such as the chest X-ray, which were requested by the doctor. It was also quite complicated to obtain appointments and consultations with the doctor. The process was tedious.

GCTA: Were there any delays in accessing treatment? For how long did it continue?

Cecilio: My treatment was a nightmare because I did not know about this disease. The first time, I took the treatment for just four months. Then, I got sick again when I was 25 years old. This time, I completed my treatment. But then, I relapsed for the third time and was prescribed an

eight-month treatment. I could not imagine why I got sick again. At that time, no one had accurate information about tuberculosis. The staff did not give me any information and there were no organisations that would fight for the rights of those affected, provide information, and sensitise the community. To add to this, the system was extremely bureaucratic and I had to go through multiple steps to get into the TB programme.

It was a challenge for me to fight tuberculosis. From the beginning till the end, the treatment had many adverse effects. I had no appetite due to the medication. But the greater challenge was suspending all my daily activities to comply with the treatment. It was a struggle. Escaping this disease is really not a joke.

GCTA: Did you seek treatment in the private sector or the public sector?

Cecilio: I sought care in the public sector. In the private sector, they diagnose you quickly, but they do not

give you the medicines. In contrast, the government sector has a system for diagnosis and treatment. When I was on treatment, there was no concept of multisectoral responsibility.

GCTA: Did the treatment put a strain on your economic standing?

Cecilio: The first time I had TB, I did not feel the economic stress because my parents covered all the expenses. However, when I was diagnosed for the second and the third time, it was difficult to cover all the expenses of the treatment along with my household expenditure. Although the TB programme provides a basket of food, they only gave me two baskets in eight months. Also, some of the products were missing from the baskets. Even though there are free medicines for tuberculosis, the factor that restricts recovery in most cases is finance. During the treatment, many people have to stop working, despite being the only economic support of the family. Hence, when they feel even a little better, they start working again and stop going to the health centre for their treatment.

GCTA: Could you talk a little about

your experience with stigma?

Cecilio: When my friends came to know that I had tuberculosis, they started avoiding me. It was difficult to face such discrimination. I started feeling ashamed because of that rejection. Facing stigma at work was difficult. Several of my companions who heard about my diagnosis distanced themselves from me. But I had the support of my family, and little by little, I was able to overcome this barrier. This experience left an impact on my life and was a challenge in my recovery. However, it was after all this that my life took a 360-degree turn. Through my experience, I have been able to continue to help many people affected by

"I started feeling ashamed because of the rejection. Facing stigma at work was difficult. Several of my companions who heard about my diagnosis distanced themselves from me."

tuberculosis. I work to defend their rights and ensure that they have access to health services.

GCTA: How did you break the news to your partner? How did this impact them? Did your partner also face stigma?

Cecilio: I was in a dilemma about telling my wife that I had TB. I thought if I told her, she would leave me

forever. The impact was hard because I was the only person with tuberculosis in my family. However, I thank god because my wife did not abandon me during those difficult times and supported me throughout. She also suffered stigma but chose to live with me when many of my friends deserted me.

GCTA: What do you think needs to change in the global TB response?

Cecilio: We must raise awareness among our authorities, civil society, NGOs and other sectors. Tuberculosis is a public-health problem that causes deaths on a daily basis. All actions to combat TB must be focused on those who are affected.

[†]*This interview was conducted in Spanish.*



Ficard Ndayimirije belongs to **Burundi**, a country in East Africa. He describes himself as the son of a rural peasant, who had the chance to go to school because of which he is now working as a legal representative to fight against tuberculosis and leprosy. He is one of the people who have been affected by tuberculosis in Burundi.

When Stigma Seems Normal†

GCTA: Thank you, Ficard, for taking the time to talk to us. How long did it take for you to get your diagnosis?

Ficard: It took me two to three months to know I had TB. First, they thought that I had pleurisy. I was asked to get a sputum test, but I couldn't get it. But the X-ray confirmed that I have tuberculosis and I was put on treatment. The problem was that after high school, we had to go through military service (SMEO) and that is where I contracted TB. I was diagnosed while I was serving. I was sent home immediately and I returned to service after three months. But I took the treatment for six months.

GCTA: Were there any delays in accessing treatment?

Ficard: After the diagnosis, the doctors asked me to go to the healthcare centre closest to my house, and I was transferred to their care. After seeing the drugs prescribed to me, the head of the healthcare centre explained how I should take them. Since I had been to school, I was able to follow the advice. But no one warned me about

the side effects. I also did not have any particular counselling support.

GCTA: Did the treatment affect your economic standing? Was it free or did you have to pay for it?

Ficard: In Burundi, TB treatment is a bit expensive in the private sector. The treatment in the public sector has been subsidised and supported by the Global Fund, which is why many people seek treatment there. When you don't have a lot of money, you can't go to the clinics because there the tests and X-rays are expensive. My family, however, struggled for my nutrition and diet while I was being treated. My parents paid for my treatment. They hardly had any means to support me and were forced to borrow money.

GCTA: Apart from the economic hardships that you faced, were there other challenges?

Ficard: I would say, things like not having a person to accompany me to the health centre and no psycho-social assistance for TB

patients were restrictive to my recovery. **in the TB response?**

GCTA: Could you talk a little about your experience with stigma?

Ficard: When I was undergoing treatment, and was at home, I had my own room, a plate and a cup. The children could not approach me because I had the disease. These are the examples of the stigma I faced during that period. For two months, people did not approach me and I thought it was normal. Neighbours knew I had TB so they came home but didn't come near me. I stayed in my room. By the time I joined the military again, I had regained my health, and hence, my colleagues had the same behaviour as earlier. The stigma I faced was the reason behind creating my organisation so that I could intervene in favour of the TB patients who suffer deep stigma.

GCTA: So, as a TB survivor and an activist working to end stigma, what do you think needs to change

“For two months, people did not approach me and I thought it was normal.”

“We need to put more energy into supporting community systems so that communities can raise awareness and approach patients.”

Ficard: We need to put more energy into supporting community systems so that communities can raise awareness and approach patients. Even if there are few TB organisations in Burundi, they can still raise awareness. This is crucial especially because people in Burundi are afraid

to go to healthcare facilities and be diagnosed with TB. Presently, the community is raising awareness so that people approach the healthcare centres and are able to heal properly.

Burundian society puts too much pressure on people with TB because there is no nutritional support like the one for HIV patients. There is only one centre that supports TB patients. In other centres, patients take the drugs and go home. But

now, our organisation has started advocating for the human rights of people affected by tuberculosis. People are beginning to integrate human rights into the health system, especially for tuberculosis.

At the governmental level, community health workers try to raise awareness among people who are suspected of having TB. They also work to get drugs for TB patients who do not have enough strength to reach the healthcare centres. Community interventions like these need to be supported so that they can raise awareness about TB diagnosis and testing, especially among the most vulnerable. On the other hand, patients need company. If left alone, they will lose the will to continue and will give up the drugs, and therefore, will not be cured. In addition to the treatment, follow-up is equally necessary. The patients need visits, nutritional support and transport because sometimes the health care centres are far away.

[†]*This interview was conducted in French.*



Ganesh Acharya, a TB survivor from **India**, almost lost his life due to the stigma and neglect he faced at the hands of care providers and medical practitioners. He is now committed to ensuring that no one else is made to go through the same plight that he had to endure.

Stigma at Health Facilities

GCTA: How long did it take for you to get diagnosed? What were some of the challenges in getting the diagnosis?

Ganesh: I was diagnosed twice. The first time, I was only 16 years old. It was not easy to get a diagnosis. I had to visit multiple public and private clinics. We had to go from practitioner to practitioner to get a cure for TB. Finally, I was shifted to Mumbai and I was admitted to a government hospital which is where I started my treatment. The second time I was diagnosed with TB was in 2003. This time I had to struggle with getting access to proper nutrition to take my medication on time because I was stigmatised and could not hold a job. That was a harrowing experience in itself.

GCTA: How long was your treatment? Did you face any delays in accessing it?

Ganesh: After I was admitted to the government hospital in Mumbai, at the age of 16, it took them six more months to run additional tests,

including X-rays and sputum tests, to ascertain my condition. This became a challenge because I was HIV positive. Finally, after six months of being on a makeshift cot, I was put on treatment for TB. This treatment took a total of five months. So, I was in the same hospital for 11 months in total. I could not go back home because my family did not want me there, so I had to stay at the hospital. The second time I was diagnosed with TB, I underwent treatment through out-patient services at a public provider.

GCTA: That must have been very difficult for you. Could you talk a little about how the treatment impacted you?

Ganesh: I had horrible side effects due to the treatment. I would have unbearable bouts of vomiting and joint pain. I could not sleep and felt extremely restless. I also had suicidal tendencies. This was only one aspect of it. I was also stigmatised so much that I could not access a loaf of bread or eggs from the corner store near my house because they did not want to sell supplies to me. So, I had to travel

to the shops far away from my house to even get bread. All this got to me and I started isolating myself. It took a toll on my mental health. I could not express my pain because I could not bring myself to share it with my friends.

GCTA: What was the difference between seeking treatment in the private sector versus the public sector?

Ganesh: Both the times when I had TB, I sought treatment in the public sector. But once, in 2012, my immunity was severely compromised due to HIV, I decided to go to a private practitioner and seek IPT. There is a huge difference in service delivery in the private sector as compared to the public sector.

Though stigma is present everywhere, I believe that in the private sector the service providers deal with TB with some urgency. They are quick to render treatment. The public sector is not that keen on providing the treatment. However, accessing treatment in the private sector can be economically taxing for many. I have even had private practitioners telling me that I should not visit their clinics

because I have had TB twice.

GCTA: While you had all these obstacles in your way, what are some factors that were helpful in your treatment and recovery?

Ganesh: I was extremely disheartened while I was on treatment. My sister was the only saving grace I had. She constantly provided me with moral as well as financial support. My friends from HIV and TB support groups were also a key factor in keeping me afloat and keeping me from taking my own life. One friend even gave me space to stay in his house after I was thrown out of my accommodation. But then, I was also alienated by many peers and friends. Some of them still do not talk to me.

“The second time I was diagnosed with TB, my landlord threw me out of the house because they were afraid that I would infect the others living in the building.”

GCTA: In your opinion, what were some of the factors that were restrictive to your treatment and recovery?

Ganesh: The first time I was diagnosed with TB, I had to drop out of school in order to seek treatment. The second time around, I lost my job and was thrown out of my accommodation because people were scared of me.

These issues added to the burden of trying to recuperate from TB.

GCTA: Could you talk a little more about your experience with stigma?

Ganesh: I had multiple trysts with stigma right from my first diagnosis when I was only a teenager. By this time, I had already known that I am HIV positive and with the TB diagnosis I started to feel that I am a burden to my family. Some family members said that my parents were wasting money by investing in my treatment because I am going to die very soon. This was very difficult for my family.

Then, at the Mumbai hospital, the staff tagged me as an 'extremely infectious patient' and they would tell each other to maintain their distance from me. In fact, I was not even provided a bed. I was just given a makeshift cot that had bloodstains on it and it was placed in a corner near the washroom. No one frequented that area. They did not want to give me a proper bed because they were scared that they will not be able to allocate the bed to anyone else after that.

I started lying and hiding my name. When doctors would come and visit

me, I would not tell them my real name. Instead, I would tell them that my name is Jimmy so that they would at least look at me and treat me. I did this because I noticed that when I told people my real name, they would not bother giving me any medications or even a saline water drip. I was just left on that makeshift cot to die. I was suicidal at this point. Finally, a women's

"I was extremely disheartened while I was on the treatment. My sister was the only saving grace I had. She constantly provided me with moral as well as financial support."

group that used to frequent the hospital with nutritional aids for the patients, noticed me. I was extremely frail and weak by this time and looked like I was perhaps merely 12 years old. These were

the first people who talked to me in the hospital. These women spoke to the doctors on my behalf and demanded that I be started on the TB treatment and given a proper bed in the ward. I had struggled for six months on that makeshift cot! For six months, I counted each passing day as my last, before these women stepped in and demanded I get treatment. The situation had become so bad that I could not even get up from the bed to go to the washroom, but the ward help would refuse to clean out my bedpan or provide me with any assistance. They did not want to tend to me at all.

The second time when I was diagnosed with TB, my landlord threw me out of the house because they were afraid that I would infect the others living in the building. They were so scared of me that they asked the local politician to assist them in using muscle power to get me out of the house. I could not go out and buy a loaf of bread during the last week of my stay in the accommodation because people refused to sell bread to me. All this impacted my mental health deeply and I started stigmatising myself. I isolated myself from everyone. I did not want to talk to anyone or have any connections with my peers and friends. It was a horrible experience.

GCTA: As a TB survivor and as a TB activist, what do you think needs to change in the TB response?

Ganesh: We need to prioritise TB. It has been 100 years since we have discovered the cause of TB, and yet, we do not have a vaccination for it. TB keeps slipping off the global agenda and people continue to maintain their silence.



Jaime Ernesto Argueta is a 54-year-old TB survivor from **El Salvador**. TB and stigma weighed heavily on his life. He ended up losing his family and his livelihood while fighting the disease. Since his recovery, he has dedicated his time to defend the human rights of those affected by TB.

Guilt, Fear and Rejection: By-products of Stigma[†]

GCTA: Thank you, Jaime, for taking the time to talk to us. How long did it take for you to get your diagnosis? Did you face any challenges?

Jaime: In 1997, when I was working on an agricultural project in some rural communities, I noticed that I had started feeling tired and weak. I, however, did not give much importance to these symptoms. I thought it was a result of the work. Then, the night sweats started and I continued getting worse each day. I did not know anything about tuberculosis. A doctor diagnosed it as a respiratory tract ailment and prescribed a treatment. Although I complied with the treatment, my health did not improve. Then, I began to lose weight and suffered frequent bouts of fevers. I went from one doctor to another. I even started looking for alternative medicine, but nothing improved.

I was in despair. My family and my wife's family thought that this was some kind of witchcraft. I too believed this and met all kinds of charlatans. Around that time, a swollen bump appeared near my collarbone. The biopsy results showed that I had

lymph node tuberculosis. Before the results came out, they told me that it could be some kind of cancer or AIDS, so I was relieved when they told me it was tuberculosis. I thought, well, tuberculosis has a cure. My employer was astonished when I told them and they told me to take some time off. I soon commenced my treatment and started feeling better.

While I was at home, I found out that my employer had asked my colleagues to undergo tests for tuberculosis. When I returned after two to three weeks, I was told that I could not continue working there. They cleared my dues and fired me. It was a very difficult and complicated situation for me. In the beginning, I was happy thinking that it was merely tuberculosis, but then I had to face much more rejection than I would have faced had it been any other type of illness.

I was unemployed for a few months. I interviewed with another international organisation where the entire interview was related to my TB diagnosis. My previous employer had told them about it. They eventually did not hire me, despite knowing that I fit the profile for that job. After two or

three months, they offered me another job for two months, with possibilities of extension. I accepted it.

GCTA: Could you talk a little about your treatment? How long was your treatment? Did you face any delays in accessing it?

Jaime: The first time I got sick, it took me nearly six months to start the treatment. This is because the tuberculin test never reacted and the lungs always appeared clean. Despite knowing that I have tuberculosis, they did not test me for HIV. It was a taboo. I was, however, eventually diagnosed with TB-HIV coinfection.

The doctors did not explain anything about the treatment. Neither did they tell me how long the treatment would last, nor did they talk about the adverse effects. I went to the hospital and they simply gave me medicines to take at home. The treatment, eventually, took 10 months. When I used to ask the doctor about the duration of the treatment, he always told me one more month. That's how the months went by, until one day he just told me to stop.

Even after completing the treatment, I felt exhausted and was losing a lot of weight. I conveniently attributed this to tuberculosis. My recovery was extremely slow. Four months after I finished my TB treatment, I started

feeling sick again. I could neither eat nor drink. At this point, I was diagnosed with a fungal esophagus infection. I thought, this too, was due to tuberculosis, until I was hospitalised and tested for HIV.

When I was diagnosed with HIV there was no treatment in the country. I had less than 20 CD4 count. The viral load test was not available in the country. I spent my time going in and out of hospitals. I got sick with cryptococcal meningitis, esophageal candidiasis and toxoplasmosis. However, when I had all these opportunistic diseases, I wanted to live, but something different had happened with tuberculosis. It took away my desire to live.

In the year 2001, I again started having frequent fevers and that feeling of hopelessness set in. I insisted that I had tuberculosis, but the doctors kept telling me that I did not. I was hospitalised for 29 days and I kept losing weight by the day. I measured six feet but weighed less than 100 pounds. I couldn't walk. I was like skin attached to a skeleton without any muscle mass.

Finally, I was shifted under the care of another doctor who decided to give me anti-tuberculosis treatment. I was taken aback when, without explaining anything, they put in a nasogastric tube. I thought they would feed me

like that because of the weakness, but to my surprise, they instead administered the medication through the nasogastric tube. That moment was extremely traumatic because I was willing to take my treatment on my own. This carried on for a couple of weeks. Although there was no evidence that I had tuberculosis, I was recovering with the anti-tuberculosis drugs.

In total, I was hospitalised for approximately two months. I was given food orally. It was extremely painful to swallow while having a nasogastric tube. Had they told me that it was only to fulfill the treatment, I would never have allowed them to put it on me.

GCTA: That must have been a really traumatic experience for you. Would you tell us about the biggest challenge you faced during your treatment and recovery?

Jaime: The ignorance on the part of the health personnel was the biggest challenge. I consulted general practitioners and pulmonologists, but none of them realised that I had extra-pulmonary tuberculosis. The diagnosis of extra-pulmonary tuberculosis and not being offered a test for HIV were two of the

greatest challenges. Even now there are many hurdles for diagnosing extra-pulmonary tuberculosis in people living with HIV. Also, while I was on treatment, I had nausea, anxiety and panic attacks. Nobody ever informed me about these adverse effects. I am still taking treatment for peripheral neuropathy. My fingers and the soles of my feet are numb and that makes it difficult for me to walk.

GCTA: Did the treatment also put a strain on your economic standing?

Jaime: The two times I got sick, I lost my job. My wife had to travel to the United States for work. She took the responsibility of the household till I recovered. But when I fell ill for the second time, I lost everything. I lost my family, my home, my belongings, everything. My wife migrated to the United States, along with our two daughters, and never returned. I had no option but to return to my mother's house. I was a wreck and I survived all this only with the support of my brothers. They took care of all the expenses and gave me shelter. It was more difficult to say that I have tuberculosis than to disclose my HIV diagnosis. People discriminated more when they found out that I had

"I had to face much more rejection than I would have faced had it been any other type of illness."

tuberculosis. Family support was fundamental to my recovery.

GCTA: You mentioned how it was more difficult to share that you had TB rather than sharing your HIV status. In light of that, could you talk a little about your experience with stigma?

Jaime: I was dismissed from my job. My employer also revealed my diagnosis to the organisation where I had applied for another job. My community rejected me. Many people stopped coming to my home. There was no solidarity. People in the community would say things like, "In that house, they have tuberculosis." I also began fearing that I will infect others. My daughters were very young and they were looking for my love as a father, but I did not allow them to come near me.

I felt guilt. I started blaming myself for everything bad that was happening to my family. I think that my wife decided to go to the United States not only because of the economic issues but also to avoid the stigma and rejection. I felt I was lesser than other people and it only got worse after my HIV diagnosis. However, it was always harder for me to say that I have tuberculosis, than

to say that I have HIV. That is the case even today.

GCTA: What do you think needs to change in the global TB response?

Jaime: There needs to be a political will to eradicate tuberculosis. This will allow all government stakeholders to take action to control it. It is not just the duty of the Ministry of Health. This also has to do with ministries of work, education, armed forces, etc. If all of us work together, we can stop tuberculosis. We also have to work on improving living conditions. Marginalisation and exclusion due to poverty make people more vulnerable to contracting tuberculosis. We must work to eradicate that. People who have access to basic health services will be able to contribute to eradicating tuberculosis.

Finally, I would say, the stigma and discrimination associated with tuberculosis is one of the greatest pressures that a person can feel. Tuberculosis takes away a person's desire to live. The added burden of stigma and discrimination can lead to death. We all need to come together to overcome the stigma and discrimination associated with tuberculosis.

[†]*This interview was conducted in Spanish.*



Jeffery Acaba, a TB and HIV activist from the **Philippines**, recounts how his journey to receive proper care was marked by multiple hurdles such as difficulty in accessing medication through the public health facilities. He stands testament to the fact that many still struggle to get access to care and treatment due to economic barriers.

Stigma: A Challenge to Daily Life

GCTA: Thank you for taking the time to talk to us. How long did it take for you to get your diagnosis? What were some of the challenges that you faced?

Jeffry: In 2011, I got myself tested for HIV because my partner at the time indicated that I should do so. But I never went back to get my results because I was scared. There was a stigma around HIV and those working on it. I was already an HIV activist, and hence, I was sceptical of the community branding me as a person who does not walk the talk.

Then, in 2014, I started feeling really weak. I could not even get up from the bed. I also started having severe night sweats. It was as if a pail of water was emptied on me. My mother also noticed that I was rapidly losing weight. That was the first marker for me. So, I pushed myself and got myself tested in a private clinic. Though my X-ray and blood tests came back negative, the doctor asked me to wait to get my sputum test results. It

took two weeks to get the results. It came back positive. We did not have the GeneXpert during those times. Following this, I was immediately put on treatment for TB. Within two weeks of being on my TB treatment, I also started my ARV because the doctor informed me that I had advanced HIV.

GCTA: How long was your treatment? Were there any delays in accessing it? If yes, why so?

Jeffry: My doctor gave me two weeks' worth of medication for the intensive phase of the treatment, but the third week onwards, I was asked to go to the nearest health centre in the village. This is because TB treatment is free in the Philippines. The village health centres work from 8 a.m. to 5 p.m., but they only tend to TB patients from 8 a.m. to 9 a.m. They do not want TB patients to meet with their other clients such as pregnant women and babies. They fear that we will infect the others. On my first day at the health centre, I missed the time slot. I had just finished two weeks of intensive treatment

and I was having terrible side effects. Also, the nurse refused to give me my medication. I was feeling dizzy and light-headed. I decided to procure it through alternate routes. So, I went back to my private practitioner. My doctor told me that I can buy the drugs over the counter. So, I proceeded to buy medication for one month. Had I not had the money to pay the private practitioner, I would have had no choice but to be in the public sector.

“I constantly felt weak, exhausted and scared while I was on treatment because I was always under the threat of getting TB again.”

private sector and the public sector?

Jeffry: Accessing the public sector means that you have to have a lot of patience. They cater to 5000 patients each day. You have to find the time slot that is dedicated to your ailment. If you miss that, you do not get to see the doctor. Access to the village centre might also not be easy because of the travel. That is why I chose to go to a private clinic.

GCTA: What were some of the challenges related to the treatment?

Jeffry: I would feel really weak and I could not even get up from my bed. I remember that I used to have really dark urine. The private practitioner I was seeing had already told me to expect this, so it helped me cope. But I would have to spend some time to clean the toilet out after using it because I did not want my family members to know that I had such a dark urine discharge. I was afraid that my family members will worry about me.

The nurse at the village health centre told me to come the next day when I was expecting to get my next dose. Things like this could cause an MDR strain to develop in a person’s system. On the other hand, the private practitioner even has virtual sessions. I could talk to my doctor over online messages about my side effects. She would respond right away. But of course, I had to pay for the additional consultation. I did not mind that because she was friendly, and so was the staff at the clinic. They always call patients by appointment, so I have probably seen only 10 people there at a time. On the other hand, at the public health centre, there would be a long queue at 9 a.m. The patient

GCTA: What was the difference between seeking treatment in the

burden is very high at the public health centre.

GCTA: What are some of the factors that helped your treatment and recovery?

Jeffry: Being a part of an activist group in the health sector was really helpful. My friends also really came through for me. They were very supportive throughout my treatment. I believe that a constant access to my doctor was also very helpful. And then, personally, I had a positive outlook that kept me going. One has to fight to be able to stay away from self-victimisation.

GCTA: What are some of the factors that were restrictive to your treatment and recovery?

Jeffry: I constantly felt weak, exhausted and scared while I was on treatment because I was always under the threat of getting TB again. Without the assurance of protection through IPT, I would have probably lost hope and stopped my treatment.

GCTA: Could you talk a little about your experience with stigma?

Jeffry: I specifically remember one incident. This was while I was in the intensive phase of my treatment and I was wearing a mask. I got onto a minivan

to go for my doctor's appointment. People in the van immediately started staring at me. So, to avoid them, I went and sat down in the last row of the van. Two girls boarded the van after me and I could see that they wanted to sit in the last row but as soon as they saw me sitting there, they changed their mind and instead sat in the row in front of me. Slowly, all the seats in the van were taken except the three seats right next to me, and these vans don't move till all the seats have been filled. So, I could sense the uneasiness in the people. Finally, I just told the van operator that I will pay for the seats next to me as well.

Even after you are cured, you are tagged as someone who has had TB and people never look at you in the same way as they used to. They are constantly sceptical. A friend recently told me that he cannot find a job because he is an MDR TB survivor and that really impacts a person's sense of self.

GCTA: How did you break the news to your family? How did they respond?

Jeffry: I got my diagnoses for TB and HIV together. I told my mother about it soon after going on treatment. She was more disturbed by the diagnosis of TB than the diagnosis of HIV. It was

maybe because she also suspected that it was TB that claimed my grandmother's life, so she was really shaken up by the news. I remember, in 2004, a week before my grandmother died, she was constantly coughing and she had really thick phlegm due to that. She was never diagnosed. But now I suspect that maybe she was positive for TB and I got it from her.

When my father came to know about it, his primary advice to me was, "Finish your treatment. Don't let it be incomplete."

I never really had a conversation with my siblings about TB. I knew they had noticed the boxes of my pills around the house but we never really talked about it. But once I was done with my treatment, in 2017, I finally asked them to get tested as well.

GCTA: As a TB survivor, what do you think needs to change in the TB response?

Jeffry: First, let me talk about the TB response in the Philippines. We need to update our health systems. It cannot just be about giving treatment; it needs to be more holistic. Even if TB DOTS is readily available in every village in the Philippines, every health centre works differently. It will be great

if the government reviews how these centres actually work at the village level and provide dedicated health staff. The first two months of the treatment are crucial and most people have the most severe side effects during that period. Unfortunately, right now, the same staff tends to all the patients in the health facility, and hence, they are extremely overburdened and do not have the time or patience to counsel the patients.

We also need to bring changes in the guidelines on TB and HIV treatment. People with TB are not encouraged to have an HIV test in the Philippines. It is a challenge because this might lead to people falling through the cracks and getting re-infected. This also opens up possibilities of drug resistance. Additionally, the government needs to create systems where people who have experienced stigma can seek counselling, support and legal aid. Having TB can have a catastrophic impact and we need to build robust systems that go beyond just rendering treatment and truly provide support for people to get back to their normal lives after treatment. Health providers still believe that if you are cured of TB then you are completely fine, but that is hardly ever the case. TB and the

"There is a serious lack of information about the gravity of the situation, especially in TB high burden countries."

stigma around it affect a person's sense of self and confidence. This issue goes unaddressed in the response today. We need to integrate a support system within the existing health care system to combat these catastrophic costs.

TB high burden countries. People have become numb and complacent about protecting themselves. We need to change this.

At the global level, the TB community needs to work as one and TB survivors need to be at the front and centre of the TB response. TB survivors are professionals with talent. They can offer so much more than just being peer supporters to make the TB response better. The governments need to be supportive of this and the donors need to put their money in the right responses.

We also need to actively invest in creating better health-seeking behaviour amongst men. The society often expects men to be strong and they are expected to perform that role in the society. Hence, often, seeking medical care is seen as a sign of weakness and shame. My father and I, for instance, would have conversations about him feeling ashamed to see a doctor.

Another aspect that needs investment is awareness generation around IPT for PLHIV. Many of my peers do not want to undergo IPT as they see it as an additional medication. There is a serious lack of information about the gravity of the situation, especially in



Reverend Maxwell Kapachawo, from **Zimbabwe**, is a TB survivor and a person living with HIV. His story brings forth the irony of how stigma and discrimination also thrives in places of worship.

Stigma in the House of God

GCTA: Thank you, Reverend Maxwell, for taking the time to talk to us. How long did it take for you to get your diagnosis and what were some of the challenges that you faced?

Rev. Maxwell: I was diagnosed with pulmonary TB, twice. It was not easy to get a diagnosis, especially for the second time. I am a person living with HIV, and hence, my sputum tests came back negative four times. All this while, I would have horrible night sweats and my stomach bulged out for no apparent reason. The doctors were concerned and they said that I have fluids in my stomach. They advised me to visit the central hospital to get them drained, but they were unable to tell me the reason behind this. Then, finally, a senior doctor said that this was TB. I was shocked at his claim because my stomach was just swollen, it was not painful. But then, I decided to visit a mission hospital that was almost 100 kilometres away from town. That is where I got a chest X-ray done, and that is how I was diagnosed with TB. Reaching the hospital was also a challenge. A friend offered his car while another pitched in money

for fuel. Without the senior doctor's advice, I would have missed a key treatment point as they would have just drained the fluid in my stomach and sent me home.

GCTA: That must have been very tough for you to undergo. How long was your treatment? Did you have to face challenges while accessing the medications?

Rev. Maxwell: It is not easy to get TB treatment in my country. This has cost me a lot in my personal life. I lost my wife due to late diagnosis and delays in treatment. We had the same struggle with her. She had her sputum tested five times and it came back negative all five times. Then, a friend, who is a doctor now, recommended that we do a chest X-ray. That is how she was diagnosed. Only from the chest X-ray did we come to know that she had TB. After we got her X-ray, we went to the hospital and they told us that all the doctors had gone for a workshop. This was a Wednesday. It was recommended that she immediately be put on treatment. But, we had to wait till Monday for the doctors from the central hospital to

be back. Following this, she was only on treatment for two weeks and she passed away. She could not make it. I lost her. Losing someone to something treatable is extremely painful.

For me, the treatment journey was terrible. It was extremely hard to cope with the pill burden. When I relapsed, I was put on injectables for 60 days and that added to the pill burden. I would have to get an injection every day along with my HIV and TB medications.

The treatment was an issue for my mother as well. It was extremely difficult to access medications for her. We could not even get a month's supply at a time. We had to go from one health centre to another, just to access a week's worth of medication. This was a challenge for my mother who is 80 plus. She had nursed and given palliative care to my niece who had MDR-TB. This is how she contracted TB. I used to take my niece to the clinic every day for injections, and struggled to get her oral medication.

We were told that the drug stock-out is a global issue and all across the world people are facing a drug shortage, but

we are not sure about this. This was not the case when I was on treatment in 2006 and 2010. Even today, the situation has not gotten much better.

GCTA: Your mother and your wife sought care in the public sector while you visited a missionary hospital. What are the differences between seeking care in the public sector and the private sector?

Rev. Maxwell: The biggest challenge that we face as a country today is to be diagnosed correctly. And now we have the added challenge of being able to access the medicines. This is especially the case with high-burden health facilities. Central hospitals are overwhelmed with patients and there is a disproportionate distribution of patient load across the health facilities in the country. It has come

“It is not easy to get TB treatment in my country. This has cost me a lot in my personal life. I lost my wife due to late diagnosis and delays in treatment.”

to a point where people are asked to come to the health centre every day, swallow their pills and go home. That is the issue with the public sector.

Now, if you talk about the mission hospitals, it is a mammoth task for the doctors and clinicians at the public hospitals to even be able to say that we have picked up TB in your system.

You might even access a big hospital for diagnosis but you will not get an X-ray because they will tell you things like the chest X-ray machine broke down two months ago, and hence, they cannot give you an X-ray. But in a private sector hospital, you can get the diagnosis the day you visit the hospital. But then, missionary hospitals can be as far away as 100 kilometres, as was the case with me. Hence, access to the care facility itself becomes a challenge. But once you have the diagnosis, it is easier to get access to treatment at the nearest health centre.

GCTA: Speaking of treatment, what are some of the challenges of the treatment?

Rev. Maxwell: As you start taking the medication, the first side effect that hits you is loss of appetite. Whatever you put in your mouth, it is tasteless. The medicines, however, cannot be swallowed without having a meal. But eating anything also meant having bouts of vomiting. I also had rashes all over my body. It was extremely itchy and painful. I had marks all over my face and my body. This did not go unnoticed by my community, and people started talking behind my back and stigmatising me. So, I decided to

stay away from people, and months of inactivity caused my legs to swell up and made it impossible for me to walk. When you tell the doctors about this, they do not understand. All they do is prescribe more medication to combat the side effects. They do not understand the effect this has on your life. All this while, you just keep telling yourself that it will get better, and you just soldier on.

“I would tell myself things like, ‘You are not going to make it, my friend. Why don’t you just die?’ ”

GCTA: You touched upon how the side effects also added to the stigma. Could you talk a little about your experience with stigma?

Rev. Maxwell: First and foremost, it was enough for some of my family members, who were not aware, to isolate me as soon as they heard about my TB treatment. At the community level, people started pointing fingers at me because in the community the common belief is that TB is equivalent to HIV. They think that one cannot go on TB treatment without having HIV. So, when a person like me, who is openly living with HIV, is diagnosed with TB, this reinforces their belief and gives them a chance to talk behind the person’s back and isolate them from the community. People do not wish to see you or meet you. Because I am

a pastor, people would come to visit me but they would not enter my room. They would stand outside, and I, in my fragile state, barely being able to walk, had to get up and go out to meet them. I had turned extremely dark due to the side effects of the medication. That further cemented their belief that I had done something wrong to deserve this punishment from god. People would even discuss if I would make it or not. I felt like an outcast in my community.

During the Holy Communion, on Sundays, I saw people hesitating to give me their hand. You think to yourself that this Sunday I am feeling better and I will somehow gather the strength to go to the church, but there you are stigmatised by your community. So, all in all, it means that you cannot go to the Holy Communion. Why? Because you are a TB patient. It breaks your heart. Most of the time what kills people is not the disease but how our communities view us and treat us after they come to know that you have TB. Living in isolation is worse than living with TB. I was denied association and company. You do not choose this. It is what is chosen for you by the community. They do not want to have anything to do with you because, in their eyes, you are already moving to the grave. You are already dead to them.

That is the worst part of the stigma

that I have faced. You are blamed for having the disease and that turns into self-stigma. I felt pity for myself. I would tell myself things like, "You are not going to make it, my friend. Why don't you just die?" I contemplated suicide many times just to get out of the situation. If it wasn't for the immediate support that I used to get, especially from my wife, I would have been a dead man.

GCTA: You mention that your wife was a huge support for you. Did she also face stigma?

Rev. Maxwell: My wife was a huge support for me, but unfortunately I lost her to TB. She faced double stigma—due to my being HIV positive and then due to my TB diagnosis. It was very hard for her. The community would say such horrible negative things behind our backs. Hearing those things, you think that it would be better if you were dead because your community has already taken you to be dead. Her support was the biggest conducive factor for my recovery though.

GCTA: What do you think needs to change in the global TB response?

Rev. Maxwell: I feel, not much advocacy has been done around TB. People in our communities have very little knowledge about it. The biggest

message that needs to go out is that if you have TB, don't worry. It is treatable and it is different from other diseases (like HIV), which are only manageable, but TB is treatable.

To those people who are involved in manufacturing these medicines, I would like to say, please work to lessen the pill burden. It is great that we have been able to make some improvements here. But still, pill burden is the biggest challenge to most people who happen to be in need of treatment. The time frame of the TB treatment is too long. That has created the greatest number of defaulters. If we can have something that will curb this prolonged treatment, I am sure we will see TB being eradicated globally. Because remember, these medicines add toxins to our bodies and it is very difficult to undergo such a long treatment.

Another thing is that, though TB medications are available for free in the public sector, do we have enough clinicians who can prescribe these medications and provide care? We do not. And that is the reason why so many people go without treatment and care. The human resource available to attend to this problem is disproportionate as compared to the patient load. We need to invest in health facilities as well.

Also, TB has never been seen as an

issue for the richer economies. People have only thought of it as something that exists in third world countries, where there is a lot of poverty. But we need to change this perception. TB can affect anyone, and it has to be a global fight.

Look what has happened with other issues like HIV. We have seen immense change there. This is why we see the change in the way people talk about HIV. People do not talk about TB in the same way because they do not have the support to combat the disease. People are still living with many myths and misconceptions about the transmission of TB because there is a lack of knowledge. If we commit to advocating for TB, we can make a huge change globally. We can imagine a future where people will be able to live with dignity, unlike the current scenario where the treatment itself is burdensome, the time frame of the treatment is a challenge, and even the machines for diagnosis are not up to the mark. This is why TB has taken a toll on many lives in third world countries. Global advocacy is required to change the face of TB.



Meas Sambath is a TB survivor from **Cambodia**. He is also a person living with HIV. His lived experience with stigma motivated him to fight for the rights of the affected communities. Now, at the age of 63, it is what he continues to do through the District Network of People Living with and Experienced TB (DNPET) in the Siem Reap Province of Cambodia.

Counselling to Counter Stigma

GCTA: Thank you, Meas, for taking the time to talk to us and sharing your story with us. What was your biggest challenge in getting diagnosed and starting treatment?

Meas: It took two weeks for me to get a diagnosis before being put on treatment for eight months. This was primarily because I did not have the monetary resources to pay for the treatment in a private-sector clinic. Treatment at a private clinic, though expensive, also means that you will get friendly care providers and services, and you will also have access to regular counselling during your treatment. But not having enough money became a barrier to accessing proper treatment.

The public sector offers the treatment for free but they do not care about the patients. Neither do they have a friendly attitude nor do they offer their full attention to a patient. Care providers in the public sector were often rude and used foul language to converse with me. The services themselves were often very slow. They are careless towards the affected. In such a situation, economic standing

becomes a huge issue. If the patient cannot afford to spend extra, they will not get proper treatment. Patients often have to give a lot of money at every stage, right from screening to diagnosis and treatment. All this can sometimes mean that you are on the treatment for a long time.

GCTA: You mention service providers using foul language to converse with you. Could you talk about other instances where you faced similar stigmatising behaviour?

Meas: When they used to come to check on me, the health service providers would often keep the duration of their visits very short. I also felt bad because I was kept away from the other patients who were seeking treatment for other diseases in the health facility. I think, for me, stigma took the form of self-stigma after this experience because I started hating myself. I was constantly angry with myself for having a disease like TB. This, in turn, made me deeply depressed. Even though my family members tried to be really supportive

and they did not show any signs of discrimination and stigmatisation against me, I began to notice that they would also keep the duration of their visits short. They did not stay with me for a long period of time. Most of them still believe that TB is a genetic disease.

My neighbours also started stigmatising me and my partner after they came to know about my diagnosis. My workmates did not particularly say anything to my face but they would also keep their distance from me. When I came back to work, I noted that many workmates did not talk to me as they used to when I was well. Some of them tried to stay far away until I was cured, and they acted normal when I was strong enough to work as usual.

GCTA: All this must have been very hard to go through. What do you think helped your recovery?

Meas: Counselling from a health service provider was really helpful in completing my treatment and recovering from the disease. Additionally, I also had support from my family. Another thing that helped was my self-commitment. I was

committed to getting better.

GCTA: As a TB survivor, what do you think needs to change in the global TB response?

Meas: I had some truly troublesome side effects because of the treatment. That was one of the biggest challenges in terms of going through the treatment. I could not eat properly. I would have trouble sleeping. I often had severe fever and would cough constantly. Coming from that experience, I would say, we need quicker treatment with shorter regimens. We also need to have drugs that cause lesser side effects. Additionally, we need to increase community outreach in order to identify people who are being missed, people who have symptoms but do not know where to seek treatment. This is crucial to reduce new infections.

“My neighbours also started stigmatising me and my partner after they came to know about my diagnosis.”



Rochmat is a DR-TB survivor from **Indonesia**. We met him during our Change-Agents Training Workshop in Jakarta, Indonesia. As a part of the training, we conducted a session called 'TB and Me'. This session gave space to people who have survived TB to openly share their journey, without instruction or direction. In the context of TB, where the human side of the disease is often unknown and unattended to, this space provided a unique and welcoming opportunity for people to talk about their extremely personal experiences without restrictions. Rochmat shared his story as a part of this session. Since his recovery, Rochmat has become an active TB advocate, working closely with affected communities and providing one-on-one peer support to many to commence and complete their treatment. He shares how TB can affect all aspects of a person's life.

Affected to Advocate: Bridges Built Through Peer Support

My name is Rochmat and I was diagnosed with TB seven years ago. My story might be short but my journey has been very long.

In 2012, I was working as a factory labourer and suddenly, over time, I started feeling really weak. A friend noticed that I was losing weight rapidly and asked me to check my weight. I had lost 10 kilograms in a matter of days. I did not suspect that I could have TB, because I had no knowledge about it. So, I kept going to work and my health kept on deteriorating. I had to keep working due to our economic situation. Finally, one day, I had to drag myself out of the bed. I had no energy left. I brought my motorbike to the door but I could not handle its weight and it fell to the ground. I told my mother that I could not go to work that day. Following this incident, I would try to get out of bed every day and would fail to do so. So, every day, I would call my shift officer and tell him that I could not come to work. Then, finally, after a couple of days, I called in to resign. My shift officer asked

me why I was leaving. All I could tell him was that I did not think my body could work anymore. I stayed in bed for a month. I resigned. I just could not work anymore.

After a month, a neighbour insisted that I go to the hospital immediately. I was taken to the Persahabatan hospital. I was hospitalised for 10 days before they started the TB medication. Gradually, I started feeling better and was ultimately discharged after 20 days. A particular doctor really wanted me to be happy. So, they would say things like, "Aren't you happy? You can go and visit the Jakarta Fair now. You are on the road to recovery. You need not be in the hospital anymore. You can get out." I felt really enthusiastic after that, but then, I found out that I still had to continue my treatment as an outpatient. [laughs] So, I started taking my medication and went back for a check-up after a month. At this point, I was told that I have DR-TB and will have to be on treatment for another 20 months.

A social worker at the hospital told me that I will have to get educated about my treatment and offered to help. I was sceptical about continuing treatment because the hospital was far away and I could not afford the taxi fare. But the social worker said that I will have to come to the hospital and get my injections, and that I must complete my treatment. I told her that I will go back home and think about it. Once we were home, we ignored her advice. Also, we could not afford the travel, so I stopped coming in to get my treatment. But then, within a week, my condition deteriorated drastically and I was rushed back to the hospital. At this point, I was asked to sign a contract for the long-treatment regimen. I was told about the side effects and I was referred to a primary health centre close to my place.

I was planning to get married, but soon after my diagnosis, I decided that I wanted to complete my treatment before that. So, I told my partner that it would be great if she could wait for me to be cured, else, we would have to go our separate ways. Sadly, she chose the latter and that relationship came to an end. This was the same time when the side effects started to show. I felt weak and this emotional distress was difficult to cope with.

None of my family members had shown any symptoms of TB, but I

remember taking my girlfriend to the hospital to get a TB treatment. At that time, I had no clue what it meant to have TB or how it is transmitted. But now, when I think about that time, I think that I might have contracted TB from my girlfriend. I do not want to be prejudiced against her but it has been difficult to move on. But I am happy to share that I am happily married now.

I remember going to the primary health centre and trying to park my bike at the stand. I could not maintain the balance due to which my bike slipped and collided with the other bikes parked in the same area. All the bikes came crashing down, one after the other. Luckily, the doctor was nice and he did not say anything. Now I think of this as a funny instance but at that time, I was extremely weak and my body could not handle the weight. I started feeling better after approximately a year into the treatment. But then, my self-confidence was dwindling and I felt extremely hopeless. I started shutting myself off from everyone. The fasting month of Ramadan gave me some hope. I became a little more religious and started reading the Quran.

Another challenge was the duration of the treatment. I was fed-up, but then, I realised that if I stopped my treatment I would not only put myself at risk, I would also put my family at risk. I had learnt this through what they told me

at the hospital and so I continued to take my medication. Also, when I started my treatment at the primary health centre, there were six of us who started our treatment together. Within the first two weeks, one man from the group passed away. All of us were shocked. I mean, we had started the treatment together and we were hoping to finish together. And then, two weeks later, one more person passed away. Then, just the four of us left. But then, two weeks later, the news came in that one more person had passed away. This is the truth. This is what happened. Finally, it was only the three of us left. We managed to complete the treatment and survive. During the treatment, we would regularly call up each other and share what we were doing. We checked up on one another. We confided into one another. That was our way of trying to make it [TB] disappear.

Alhamdulillah, we always had the support of our families and they stood by us. I have always been a person who embraced his friends and kept them close. So, they stood by me when I needed them. I remember one of my friends said, "Rochmat, you must be strong. Because [a] person like you [is] still needed in the neighbourhood." His words and his enthusiasm kept me going, and finally, I was able to complete my treatment in 2014.

For my other friends out there who are still struggling to keep their spirits, I just want to say, TB is curable. The key is to take the treatment regularly and complete the treatment. Follow the doctor's recommendations. You will surely be cured.



Safar Naimov is an MDR-TB survivor from **Tajikistan**. He has also lost two brothers to MDR-TB. Today, he stands strong as a survivor and a TB activist, advocating for elimination of TB worldwide.

Burden of Stigma on Families

GCTA: Thank you for talking to us, Safar. How long did it take you to get the diagnosis and what were some of the challenges you faced?

Safar: My diagnosis happened in two stages. One was when I was already showing symptoms. It was the time when I had returned to Tajikistan from India with my brother. I got my X-ray report and sputum report on the day I was leaving from India. The doctor said the sputum tests were negative but there was some issue in the X-ray. He asked me to see a doctor in Tajikistan as soon as I landed. Before this, I had had two bouts of flu and the same doctor had said that it was nothing. But when the flu did not go away, and I started losing my voice and a lot of weight, he asked me to get an X-ray and a sputum test. So, as directed, I contacted the clinic near my house after I reached Tajikistan. The health providers at the clinic said that I might have been infected by a deadly disease in India and they put me in 10-day isolation and started the treatment. This treatment carried on for three to four months. Then, I contacted the nearest TB centre. They did a sputum test. That was the second stage.

The sputum was to be tested and

reported in 72 days as the test went to Germany. Soon after, I got a message that there was some lab error, and I had to give sputum again. I had to wait for another 72 days. Then we had the same problem again. Finally, after the fourth time, I came to know that I had MDR-TB. Throughout this period, I was enrolled in the first line drugs for DS-TB, and I had already taken eight months of treatment. Finally, after that, my MDR-TB treatment was started. So, you can say, it took a year to get the correct diagnosis.

GCTA: And how long was your treatment for TB? What were some of the challenges that you faced during your treatment?

Safar: I was sure I had TB because I was caring for my brother and we were in the same room. But when I told this to the health care providers, they did not listen to me. I did not have my voice for four months and they kept sending me to different doctors thinking that I had some issues with my vocal cords. I felt that my voice was not being heard, both literally and metaphorically.

Then, finally, when I was put on DR-TB treatment, I regained my voice within three weeks. Unfortunately, my treatment was stopped midway

due to some complications. The doctors wanted to change my regimen a couple of times. So, I was on DR-TB treatment for a total of two years. The initial seven months of the treatment were harrowing because I had non-stop fever every day, and the heavy injections added to my plight. My TB doctor was also worried. Then, I got an X-ray that showed that my lungs were filled with fluid. I had to undergo surgery for that. Nearly three litres of fluid was removed from my lungs. My fever finally subsided, and I finally had a chance to think that I will survive.

All this was before starting the MDR-TB treatment, which went on for another two years. Within two to three weeks into the treatment, you start feeling the burden of the medication. It affects your soul, your morale. And the second burden is the side effects. I had intensive sensitivity to light and loss of memory. I remember feeling confused, lacking lucidity. I could not differentiate whether I was dreaming or not. And of course, you have bouts of vomiting and severe pain in the muscles.

GCTA: Did you get your treatment in the government sector?

Safar: In Tajikistan, the TB drugs are only provided under the NTP. Up until 2009, the second line drugs were only

available to the residents of the capital, i.e., Dushanbe. This was an issue for my brother who belonged to a remote district and it led to an interruption in his treatment. However, I, being a resident of Dushanbe, did not face this issue.

GCTA: Could you talk a little about your experience with stigma?

Safar: When I was admitted to the central sanatorium, the building was

“My wife had to drop her studies when I fell ill.”

getting renovated and there was a single tap in the corridor for drinking water. People were using the same sink to spit the sputum. This was the place where we were expected to take water from, for drinking and making tea. At the end of the same corridor, there was a better place to get water and this was allotted to the cleaners. We would want to get water from that place but the workers would stop us. There were multiple fights on this issue. They would say stuff like, “You are destroying everything. If you are given access to that tap, you are going to destroy that as well.” If the hospital does not provide a space for patients to go and spit sputum, where will they go? I asked them why they were treating us that way. They said, “If you want European treatment, go to Europe.” This was the view of the health service provider in a hospital for TB patients.

Outside the hospital, I was not afraid of stigma. Instead, I feared the pain my parents were going to go through after hearing the news of my diagnosis. We had lost a brother to TB, and I did not want them to feel that I was next. I had to hide it from my family. The initial two years of my treatment, I was completely lost to my parents. I did not meet them at all. I would make up excuses like I am travelling or pretend I was busy and avoided meeting them. At the same time, I also lost touch with my friends. I did not want to break the bad news to them. So, I went through all this alone. That was self-stigma for me.

GCTA: How did you break the news to your family? What was their response?

Safar: I told my wife immediately. She was not surprised because she knew I was with my late brother. She was in the third year of her college back then. She had to drop her studies because I was unwell and needed help. She is a good tailor, so she made money by taking up small tailoring assignments from home. She assisted me during my treatments, paid for other drugs that I

needed to combat the side effects caused by the TB medication. My sister also helped me financially. Till today, in Tajikistan the TB medicines are free, but people have to procure the drugs to control the side effects caused by the TB medication.

“My brother was not the same person after the treatment. The drugs caused multiple adverse reactions. He was completely disturbed. He used to hallucinate and have suicidal thoughts.”

I did not tell my parents. But I did tell one of my brothers and one of my sisters. When this brother of mine was still alive, he was admitted to the same sanatorium as I was. One of

his wardmates, who was also my wardmate earlier, mentioned my name in the passing. That is how he came to know. I did not want to tell him because he would have felt guilty. He was the first one to contract TB. Our second brother, who contracted TB from him, died two years after his diagnosis. So, I did not want to further his guilt.

Once he came to know, he called me and said, “I know. Please try and not interrupt your treatment like I did.” He felt guilty for interrupting his treatment. But he did not stop due to lack of knowledge or laziness. He stopped because of extreme side effects, which included psychosis

and suicidal tendencies. He was disturbed. He was never himself after the treatment started. At midnight we would have to bring him inside because he would rush out of the house. He would scream and shout because he was hallucinating. The family struggled to look after him. Those were the reasons why he had to stop his treatment. Cycloserine was the main cause of this.

In the end, after 10 years of treatment, in 2012, TB claimed his life. His last five months were very painful. He was hardly conscious. We would have to rush him to the hospital where they would give him medications. But they could not also keep him for long so we were forced to bring him back home every time. His situation was so bad that he could not breathe without an oxygen machine. We had to buy a machine, on loan, just so that we could keep him around for a while longer. His demise left a deep impact on his wife. She was under psychological care for up to two years after his death. The month I completed my TB treatment and recovered was the same month when TB claimed my brother's life.

GCTA: Did you face stigma at your workplace? How did TB impact your work life?

Safar: In our culture, we think that men

should provide and women should not work. It is not that women are not allowed to work, but we feel that men need to be the head of the family, earn for the family. When you are disabled and cannot work, imagine the cultural burden you feel. We were a family of 10 that my brother was supporting in 2002 when he was diagnosed with TB. My brother could not even afford to leave his job and recuperate. He was working and taking medications simultaneously. This added to his plight.

I resigned from my job in 2008 to accompany my brother to go to India for his treatment and after I was diagnosed with TB, I did not have the strength to hold down a job. My wife had to support me.

GCTA: As a TB survivor, what do you think needs to change in the TB response?

Safar: You know, my late brother could not control his happiness when I first told him about the nine-month regimen. He said, "Someday, maybe TB will have a one-week treatment, like the flu." What we need is a shorter regimen with safer medicine so that people can continue their treatment. Some people work for TB, but this should be a fight against TB.



Thabo Pelesane describes himself as “a **South African**, father of three beautiful daughters, a TB survivor, a national TB ambassador and a community builder”, in that order. His struggle against TB spanned five stages and 19 years. It was during this time that he came close to permanently losing a part of his lung. Today, he has made it his mission to inform the affected communities about the importance of completing their treatment.

Growing up with Stigma

GCTA: Thank you for taking the time to talk to us. Could you tell us how long did it take for you to get diagnosed? What were some of the challenges that you faced?

Thabo: I had pulmonary drug-sensitive TB five times. The first time I was diagnosed, I was in primary school, in 1989. I started coughing really badly and my teacher realised that something was wrong. She took me to the nearest public health centre where I was diagnosed and immediately put on treatment. Then, it came back in 1993 when I was in high school, and then again in 1998. This was primarily because my entire family had TB, at different times, and at that time, no efforts were made to test other family members. An additional causal agent could be that I used to skip my medications for multiple reasons. I had TB for the fourth time in 2005 and the last bout was in 2008. My biggest challenge in getting a diagnosis was the stigma. I avoided going to the clinic to get myself tested because of what I had faced as a child

after starting my treatment

GCTA: For a person who has had multiple encounters with TB, the prolonged treatment must have also been a challenge. How long were your treatment cycles? Were there any delays in accessing treatment?

Thabo: All my treatment cycles were six months each. But due to relapsing for the third time, I was put on injectables for 40 days, and this regime carried on till my last TB treatment. Accessing the medication was a struggle because the medical centres were far away. The temperatures used to be really high and travelling till the medical centre would take a toll on me. Moreover, these clinics were not open 24 hours, and hence, we had a very small window of time to reach the clinic and get the injections.

I remember the psychological burden of having to take more than 10 pills every day when I was diagnosed for the first time. When you are that young [13 years old], you cannot make sense

of what is happening to you and I used to feel scared just by looking at the pills. After taking the pills, I would feel immensely nauseous and have itchy rashes all over my body. This made me very uncomfortable, and hence, I proceeded to skip the medication.

GCTA: With five different bouts of TB, did you seek care in both the private and the public sector? What was the difference between seeking treatment in the two sectors?

Thabo: I sought care in both the private and the public sector, but in my experience, the public sector was much better. In 2008, I was admitted to a private hospital where they found some cavities on my right lung and I was bleeding from the inside. They did a bronchoscopy and discharged me after giving me some medication. They did not tell me what it was. I was scared because I could feel blood in my mouth from time to time, and so, I sought care at another local hospital. There they told me that they will have to operate on me to remove the upper lobe of my right lung. Thankfully, they sought a second opinion and that is when I came in contact with a doctor who referred me to a government hospital. Finally, the

doctor there said that I did not need surgery, I could be cured with drugs, which, I was.

GCTA: You have gone through a gruesome journey with TB. What are some factors that helped in your treatment and recovery?

Thabo: This might seem counterintuitive, but because all my family members contracted TB at various times, we became each other's support. I had the best nurses who supported me a lot. In 2005, a nurse even came home and motivated me to continue my medication. But remember, it does not matter how

much support you get. The decision rests on you as an individual. I learnt this the hard way by coming very close to losing a part of my lung. This is also the time when I started thinking about

"I remember the psychological burden of having to take more than 10 pills every day when I was diagnosed for the first time."

my daughter growing up without a father. I had lost my father to TB. We were really close and he was my pillar of strength. I could not imagine my daughter having to go through the same pain as I did.

GCTA: What are some of the factors that were restrictive to your treatment and recovery?

Thabo: I used to take TB lightly. But once I started bleeding from the inside, the fifth time, I realised that this might be the end of me. I then decided to deal with it head-on. So, you can say that my stance was also restrictive. Another thing that posed a challenge was the distance between my residence and the clinic. It was a struggle to access medication due to that. I also suffered from depression when TB claimed my father's life. I lost my will to carry on my treatment. I gave up on life.

Apart from everything else, stigma was always a restrictive force. Strangers and friends talk behind your back and say stuff like, "He has to be HIV positive. That is why he keeps getting TB over and over again." This became the norm, especially when I started appearing on television shows and billboards and became a TB ambassador. That was also a struggle, but I was clear on what the truth is and that helped me persevere.

GCTA: Could you talk a little about your experience with stigma?

Thabo: My first big brush with stigma was when I was 13 years old. I was on

my first cycle of medication. During break time, some boys and I were in the boys' toilet and my urine was orange in colour. A lot of boys started laughing and the news spread like wildfire. That day onwards, the other children started pointing at me and calling out, "That is the boy with orange urine!" I felt ashamed and started skipping my treatment fearing that I might have the same experience again. When I finally did start taking the medication again, I waited for the toilets to be completely empty. If there were other boys in the toilet, I wouldn't use it.

As an adult, when I was working, people thought if they use the same cup as I do, they will get infected. People would not come up to me directly to ask about my ailment; instead, they talked behind my back and perpetrated

"I struggled with depression when TB claimed my father's life and I lost my will to carry on my treatment. I gave up on life."

myths and misconceptions to other colleagues.

GCTA: As a TB survivor what do you think needs to change in the TB response?

Thabo: After the UNHLM on TB, heads of state are dealing with TB as a priority. But it is equally important

to have dedicated funding for TB programmes. Also, we need to create awareness by investing in CBOs, especially in rural areas. Poverty makes it extremely hard for people to have access to proper nutrition, without which it is impossible to take medication. If heads of state could collectively plan to ensure the provision of nutritional aid to people on treatment, it would aid many in being able to complete their treatment. We also need more funding to create awareness and finding a cure.

A major component of the TB response has to be peer counselling. In peer counselling, people need to give statistics. We have been saying that TB is treatable but what we are failing to tell people is that if they do not take their TB medications, it will kill them. Tell people that TB is one of the highest killers in the world. It jolts people to understand that their children will be orphaned and their families will be left without any support. I have two friends who have only one lung each due to TB. I also lost my father to TB, so I tell people about that to motivate them to finish their treatment. We must tell them about the dangers of not taking TB seriously, especially men because they do not want to get tested at all. They will take over-the-counter drugs, self-diagnose themselves, and continue to avoid

seeking proper care. It is because of sayings like 'men don't cry' that they believe that men need to be strong and they cannot seek care. They will also go to traditional doctors who might give them some medication that will make them feel better for a while but will not cure them. So, we need to invest in making men aware of these perils.



Wilfrid Diamba from **Gabon** works as a librarian to support himself and his three kids. His journey reflects how stigma can chip away at a person until they no longer feel human.

Dehumanising Impact of Stigma[†]

GCTA: Thank you for taking the time to talk to us, Wilfrid. How long did it take for you to get your diagnosis? What were some of the challenges that you faced?

Wilfrid: I felt sick for two-and-a-half months. I coughed a lot, lost weight and had fever. I felt very uncomfortable. With time, it got worse and I became weaker. Noticing the significant weight loss, my parents insisted that we go to the hospital. I could hardly walk anymore. My bones could not give me the strength enough to stand. I assure you that it is something you cannot even wish for your enemy. I don't know how to explain the pain that I have been through.

I was diagnosed sometime in the 2000s. I don't remember the exact year. It is not always easy to cope with the diagnosis, especially when you are told something that can change your life all of a sudden. It is hard, especially with the accusing looks that a person gets. It is embarrassing; it is

hard to express; it is frustrating. It is not easy to live in those conditions. Getting a diagnosis was not easy. It took multiple tests and incurred a lot of expenses, both physical and financial. It takes a lot of money, and when you don't work or you don't have parents who can pay, it is quite difficult. When you can't afford it, it means death. It is extremely difficult to get all the tests done.

GCTA: How long was your treatment? Were there any delays?

Wilfrid: The treatment was not within my reach. One needs money to go and buy the medication as the treatment is not free. It is only getting more complicated and more expensive. I have a friend who faced the same situation. Empathising with his condition, I supported him morally. He too was cured but with much difficulty because the treatment had become much more expensive by that time. The authorities and various bodies must find mechanisms to mitigate this phenomenon and

facilitate access to treatment.

TB treatment is not free. My friend told me that now you pay per box. Each box costs about 24,000 or 25,000 francs', and it lasts two weeks. It is tough for those who cannot afford to pay. Our authorities do not have a strategy to facilitate access to treatment, even for those who cannot afford it. There is a need for the TB campaign to raise awareness. There is a lack of strategies to put patients on treatment immediately. Everyone should have easy access to treatment.

GCTA: Where did you seek treatment, in the private sector or the public sector?

Wilfrid: I sought treatment in the public hospital, and even until now, it is the only hospital in Gabon where tuberculosis and pulmonary infections are treated. During my treatment, I had a notebook for them to see how I was following my treatment. There are no private centres in the town. Till today, when we think about tuberculosis or any other pulmonary infections we immediately seek help at that public

centre, in Libreville.

GCTA: Could you talk a little about your experience with stigma?

Wilfrid: Stigma starts in the family. They look at you like you are the microbe itself. It is as if you as a person need to be eliminated. You are a person who is embarrassing the family. You are isolated, your utensils are put aside, and you feel rejected by everyone. You feel like a person

"Today, I am able to understand people who are affected by TB, who are being led to death because of accusations, rejections and contemptuous looks. They are not supported; they do not feel loved."

whom others should not approach. They don't know how to accept you, and deep inside, you feel bruised. I got stigmatising looks from my family members. I felt like I was no longer a part of the family and they wanted to isolate me right away. A feeling of loneliness descends on you in such situations, especially when your parents can't even properly prepare food for you. You are treated as if you want to kill or contaminate everyone.

Today, I am able to understand people who are affected by TB, who are being led to death because of accusations, rejections and contemptuous looks. They are not supported; they do not

feel loved. They no longer feel the love of their family, and hence, they say that life is not worth living. They say that it's certainly better to die, and they let themselves go. We get to know of many such instances. It is hard. It is complicated. I do not have the words to explain how we feel about our own family and the outside world. Even friends think you don't deserve their attention and affection anymore.

GCTA: So, as a TB survivor and an activist working to end stigma, what do you think needs to change in the TB response?

Wilfrid: First and foremost, we need to help people affected by TB, so that they don't feel depressed and are encouraged to fight. We also need to put other mechanisms in place so that others don't give people affected with TB a hard time, so that they do not subject them to trivialising stares, forcing them to stay cloistered. Survivors need to play the role of advisors for patients undergoing treatment and the community at large to stop more people from being infected. The role of an advisor is the role of a community leader. It is extremely important.

Ask our authorities to find a strategy that makes treatment easier. Everyone is experiencing this crisis in their countries, so our leaders need to find ways to fix it. This is a wake-up call. I am trying to raise awareness at the international and national levels. Earlier, there was a kind of flame at the national level, but I don't see that anymore. The will is there, but if we do not have the financial means to carry out this fight, at some point, we are bound to fall back.

[†]This interview was conducted in French.

¹CFA Francs



Ahmad is a 17-year-old student from **Kabul**. Before he was diagnosed with TB, his days were spent going to school and working part-time as a tailor to support his family. He is the fourth person in his family to contract TB. Before him, his mother and two sister suffered from TB. They completed their treatment and are now TB-free. Ahmad started his treatment in July 2019.

Facing Stigma at a Young Age

GCTA: Thank you, Ahmad, for taking the time to talk to us. How long did it take you to get the diagnosis? Could you talk a little about your journey so far?

Ahmad: It took a month to get my diagnosis. First, I sought care at a private-sector establishment, but they were unable to diagnose my disease. They did not even ask me about TB. There was a delay in getting the results of the sputum test. It took four days! Then, when I sought care in the public sector, they were able to diagnose my disease quickly. I started my treatment in July [2019]. In the private sector, you have to pay OPD charges for every visit. The public sector, however, offers the treatment for free. Now, I can easily get my medications from the DOTS nurse and the clinic happens to be close to my place. But poverty is a constant challenge. We do not have enough resources for me to have access to nutritious food. This has become an obstacle in the path of my treatment and recovery.

GCTA: This must be really hard for you to go through. What are some of the factors that you feel are helping you in your treatment and

your journey to recovery?

Ahmad: My mother and sisters have had TB in the past, and they have completed their treatment. So, my parents already know about TB and they insist that I complete my treatment. That is a big support.

GCTA: Could you talk a little about your experience with stigma?

Ahmad: Once my friends came to know about my diagnosis, they started asking me to wear a mask. So, I started wearing a mask. I have separated my dishes from others', and I no longer share my food with anyone. I also had to stop going to school due to my diagnosis.

GCTA: As a person who is undergoing treatment, what do you think needs to change in the TB response?

Ahmad: We need to diagnose patients early and private-sector establishments should diagnose people free-of-cost. We also need to provide support to the patients undergoing treatment, especially for nutrition.



Ezio Tavora Dos Santos Filho

*was a TB activist even before he was diagnosed with TB. He contracted TB while working for the national TB programme in **Brazil**. Ezio believes that empowered communities need to be the focal point of the global TB response to not only further access to treatment and care for all but also to work towards the alleviation of poverty.*

Self-Stigma and Stigma: Concurrent Barriers

GCTA: Thank you for talking to us, **Ezio.** Could you tell us what were your biggest challenges related to diagnosis?

Ezio: In 2002, I was struggling with my health as I was coping with advanced HIV. I had started transitioning out of the AIDS movement, and at this time a friend of mine approached me to help her in social mobilisation for the Rio de Janeiro State TB programme, in Brazil. I agreed to help. The same year I also hired a transgender woman who was being released from prison. She had advanced HIV and glandular TB. However, she was unaware that she also had pulmonary TB. While working with her, I contracted TB. I got my diagnosis when I was in Uruguay for a TB conference. My friend, who was the TB programme manager in Rio, noticed the symptoms and asked me to get tested. But since I had advanced HIV, it took me three months to get my diagnosis. I could not produce sputum. All this while my health deteriorated. Soon, I did not have the energy to leave the bed. Finally, I went in for a scan and

I remember the doctor telling me that my lungs looked like stars in the sky, and only then I was put on the treatment for TB.

GCTA: How long did your treatment for TB last? What were some of the challenges that you faced during your treatment?

Ezio: I was in treatment failure for advanced HIV when I started the treatment for drug-sensitive TB. The issue was that I was still taking my medications for advanced HIV because my doctors were worried that my health would deteriorate further if I were to stop. This, in turn, was an issue because both the treatments combined led to multiple adverse drug reactions. I had to continuously stop one drug or the other to try and figure out which drug was causing which reaction.

Hence, even though I had drug-sensitive TB, I had to shift my treatment to MDR TB to find a combination that would work for me. It was a nightmare taking the

injectables. On the 11th day of taking Streptomycin, I had a Stevens-Johnson allergic reaction. I could hardly breathe, got all swollen, literally could have died. To date, I do not know how someone can even stand the injectables. Taking an injectable is indescribable. At the same time, I was prescribed Terizidone, which is a highly neurotoxic drug. It caused my limbs to twitch and turn and flex without control. I would have uncontrollable seizures because of this drug. Reactions like these caused me to be hospitalised multiple times during my treatment.

It was a nightmare. Things got so bad that I had to try each drug one by one to ascertain which drug was causing which reaction. This harrowing treatment took 20 months because even though I was sputum positive within 18 months, my doctors were worried that I could relapse. But then, soon, I changed my ART regime and that turned out to be a lifesaver. However, it also triggered IRIS (immune reconstitution inflammatory syndrome), causing the TB to resurface.

TB makes you weak; it knocks you down. I did not have the energy to do

anything before the treatment started working. I could not even get up from the bed until then.

GCTA: Could you talk a little about your experience with stigma?

Ezio: I remember, my father was in shock because he had already lost a brother to TB. My grandmother was also diagnosed with TB and had to be admitted to a sanatorium. He did not want to believe that now his son was also diagnosed with TB.

People would ask if they should even be in the same room with me. But I had resolved to not hide my diagnosis from anyone. I am a middle-class educated person who had the means to understand what stigma is. Also, I have been openly living with HIV, and hence, I was no stranger to stigma. But, for me, it was crucial to talk about TB and tell people that after 15 days of my treatment, I was not going to infect anyone.

If one feels that they have been victimised and think that god is punishing them for something wrong that they have done in their life, that is to say, if people overstate their issue, it will make the treatment and recovery

“We need to stop victimising ourselves. People will always look for ways to stigmatise. It is crucial that we do not look at ourselves from the same lens.”

tougher. That is self-stigma. And I fear self-stigma because it potentially can cause a setback to the treatment and recovery. Till we combat stigma and provide access to stigma-free care and treatment to one and all, irrespective of their economic background, we will never be able to end TB. Living with discrimination was and is a part of my life because I am gay, living with HIV, and later, because I had TB. But, one cannot fall victim to discrimination.

GCTA: Do you think that men experience stigma differently?

Ezio: TB affects more men than women. Women might be the largest labour force, yet they are still seen as weak and vulnerable. So if a woman falls ill, that is not seen as dramatic, as if the economy will not suffer because of women falling ill. But for a man, who has to be the provider, it is more shameful for him to fall ill and look for health services because he will no longer be able to provide for his family. This, in turn, leads to stark realities like lesser men seeking care and more of them going undiagnosed each year.

GCTA: What were some aspects that were conducive to your recovery?

Ezio: I feel I had more tools at my disposal when I was diagnosed with TB as opposed to when I was diagnosed with advanced HIV. I was an AIDS advocate, working in community mobilisation for TB, and suddenly I was a person affected with TB. This empowered me to understand my treatment and deal with it. That, in turn, inspired me to become a TB research advocate. Now I know that knowing the treatment and research not only empowers you to deal with your problems and the social issues that surround TB, but also helps you in aiding others around you, and change policies.

GCTA: What was your biggest challenge while undergoing treatment?

Ezio: What made my life miserable while undergoing the TB treatment was its combination with the AIDS treatment. To combine two treatments, was, and still is, a nightmare. Having AIDS and TB together is the worst possible combination.

“Our cultures view men as the providers for the family, and hence, when they fall ill, the added burden of not being able to work can be a huge source of shame.”

GCTA: What needs to change in the global TB response?

Ezio: There needs to be multisectoral accountability. Till the time all aspects of the TB problem do not get equal importance we cannot begin to imagine a TB-free world. We need to invest in communities, curb poverty, pave roads for better housing conditions for all, and at the same time, invest in research to look for more innovative diagnostics and treatment avenues for TB.

What helped my treatment, my journey? I knew I had my family backing me. I knew I had shelter. I lived in good conditions. I never had to struggle to eat. But half of the population of the world has nothing. It was my obligation to react positively to my diagnosis because of the standing that I came from, because we cannot victimise ourselves.

Glossary

AIDS *Acquired Immune Deficiency Syndrome*

ART *antiretroviral therapy*

ARV *antiretroviral*

CBO *community based organizations*

CD4 *cluster of differentiation 4*

DOTS *directly observed treatment*

GeneXpert *The Xpert MTB/RIF is a cartridge-based nucleic acid amplification test for simultaneous rapid tuberculosis diagnosis and rapid antibiotic sensitivity test.*

HIV *human immunodeficiency virus*

IPT *isoniazid preventive therapy*

IRIS *immune reconstitution inflammatory syndrome*

MDR TB *multidrug-resistant tuberculosis*

NGO *nongovernmental organization*

NTP *National Tuberculosis Programme*

PLHIV *people living with HIV*

Sputum *a mixture of saliva and mucus coughed up from the respiratory tract, typically as a result of infection or other disease and often examined microscopically to aid medical diagnosis.*

Steven Johnson Allergic Reaction *stevens-johnson syndrome is a rare, serious disorder of your skin and mucous membranes. It's usually a reaction to a medication or an infection. Often, it begins with flu-like symptoms, followed by a painful red or purplish rash that spreads and blisters.*

TB *tuberculosis*

UNHLM *UN High-Level Meeting*

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"We recognize that TB and the stigma associated with the disease have gendered dimensions. We also know that men who are affected by TB suffer both economic and social consequences and the entire household is impacted. Stigma can lead to loss of employment and damage relationships, pushing people further into the vicious cycle of poverty and disease. I congratulate GCTA on this timely publication which will strengthen our collective understanding of how TB stigma affects the lives of men with TB. We cannot end TB if we do not address stigma in a comprehensive and cross-cutting manner."

- Dr. Nalini Krishnan,
REACH India

"Statistically, more men are affected with TB and yet the overall treatment rates continue to be low. These are alarming numbers and makes one stop in their tracks and wonder why this happens. The answer, to a large extent, is stigma. Society often forces men to be the stronger gender, consequentially inhibiting many from accessing treatment and care. GCTA is turning a poignant leaf by putting the voices of men who have faced stigma front and centre and breaking the glass ceiling. We need more voices to be heard to take stigma head-on."

- Wim Vandeveld,
Global Network of People Living with HIV (GNP+)

"I have often attended meetings where colleagues and partners question the evidence of stigma in the TB response. With this book and related testimonials, we have more evidence today that stigma is there and is positioning itself as a fundamental challenge in TB response as well as a drift for human rights. It is interesting to listen to the reality of men who are often perceived as the strongest person in any community."

- Bertrand Kamper,
Board Member - Global Coalition of TB Activists