

GLOBAL COALITION OF TB ACTIVISTS (GCTA)
PRESENTS

WOMEN
&
STIGMA

CONVERSATIONS OF RESILIENCE
IN THE WAR AGAINST TB

FOREWORD BY LUCICA DITIU



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, the 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 the voices of TB-affected communities influence the global TB and 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-centered 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 Dr. Lucica Ditiu

EXECUTIVE DIRECTOR, STOP TB PARTNERSHIP



There are a lot of conversations about Stigma and TB and the more this happens, the better it will be. Stigma affects the lives of people with TB, their relatives, children, wives, husbands, partners, friends and co-workers. Stigma is highly linked also to those working with and those affected by TB – volunteers, community workers, nurses, laboratory technicians, doctors – which makes it difficult to keep going, and difficult to bring young and new spirit to work in the TB response.

However, I want to say that as much empathy and love we have towards people that suffered because of TB, none of us will be able to fully understand and feel the huge impact that TB and associated stigma has on the lives of those affected by this disease.

Unless directly affected, it is difficult to express how it feels to face the rejection from colleagues, friends and families when they find out one has TB, the sudden “move back” at the hearing of the news, the loneliness in which people with TB remain most of the times.

Unless you feel it on your own skin, it is difficult to explain how you feel when you try to go back to

work and it is not possible, when you try to meet with friends and they avoid you, when your daughter or son is rejected as coming from a “TB family”, when you try to make new friends and partners and they run away from you.

This is why I am pleased to see the series of interviews with brave women by the Global Coalition of TB Activists (GCTA) – in which people share their own stories of stigma and TB, tears, anger, frustration and how they overcome them. And with this, I make a plea to everyone engaged in Stigma and TB efforts to always start and center their work on those that know the best what it means: the people affected by TB.

Message from Dr. Tereza Kasaeva

DIRECTOR, GLOBAL TB PROGRAMME, WHO



Stigma and discrimination is rife even today towards people affected with tuberculosis (TB), as powerfully expressed in this GCTA Community Chitter Chatter Book by survivors of TB and drug-resistant TB. While both men, women and children are stigmatised due to TB, this book focuses on the plight of women and girls, as they are more vulnerable in many ways. The stories in this book capture the essence of the suffering caused by TB, not just the physical but the emotional and social.

I was deeply struck by the heartbreaking personal experiences of Rhea, Naomi, Fabiola, Oxana, Prabha, Gulbahor, Phumeza, Mileni, Mona and Paran, who all hail from different parts of the world and have diverse economic, social and cultural backgrounds. They represent women from affected families who took care of their ill men and children, health workers, nurses, and women from all walks of life, demonstrating that TB itself doesn't discriminate and can affect us all. The battle against TB for these brave women was not just about taking medicines but grappling with stigmatising blame, guilt and societal pressures. For some of them, the disabilities caused due to side-effects of taking medicines for drug-resistant TB, caused double stigma.

These stories are representative of the over 3 million women and hundreds of thousands of girls around the world, who battle TB each year. Despite decades of awareness-raising efforts – negative, judgmental and fearful attitudes persist towards people living with TB – posing barriers to accessing health-care services or enrolling in care and adhering to treatment. The situation is even more acute for women and men in vulnerable situations.

As we look forward to accelerating efforts to end TB, as targeted in the Sustainable Development Goals and WHO End TB Strategy, we need to close the gaps that cause people with TB to be left behind. This requires a strong global effort to end TB-related stigma and discrimination, alongside broader efforts to address marginalisation and exclusion in access to care. This is among the commitments in the Moscow Declaration to End TB, which was adopted by 120 Ministers and other leaders, as well as over 800 partners including civil society, at the WHO Global Ministerial Conference on Ending TB in November 2017. As Heads-of-State come together in September 2018 for the first-ever UN high level meeting on TB, we look forward to a strong spotlight on this issue in the political declaration coming out of the meeting, as well as at the Interactive Society Hearing organised in advance by the President of the UN General Assembly in June. At the World Health Organization (WHO), our Director-General Dr. Tedros Adhanom Ghebreyesus is committed to promoting the rights of women to health, as part of

WHO's broader agenda for a healthier world, as well as within the organization itself. He is supportive of the TB community and is closely engaged with civil society on efforts to end TB, including to address stigma. All these high-level commitments will pave the way for strong action on the ground to step up access to TB services, free from stigma and discrimination.

I warmly welcome this book which is timely as we prepare for the UN High Level Meeting on TB. It is the stories of survivors – in this case of women and girls - struggling doubly against TB and the attached stigma, that will strike the deepest chord with Heads of State, Ministers, policy makers, and others in the global community. I strongly encourage everyone to read this book as it portrays the heart of the fight to end TB.

As we work collectively to accelerate the End TB response, I urge you to join me in committing to prioritise and confront the stigma and discrimination linked to this top infectious killer. This is a global shared responsibility as we move forward towards a TB-free world.

WOMEN & STIGMA: Conversations of Resilience in the War Against TB



Demanding change at The Union Lung Conference, 2015.



Desmond Tutu on World TB Day.

Photos credit: TB Proof

Message from Blessina Kumar

CEO, GLOBAL COALITION OF TB ACTIVISTS



In a conversation last year with a young college student being treated for MDR TB in Indonesia, she asked me what we can do to make sure we are protected 100% from TB. Without thinking, I blurted 'stop breathing' and both of us ended up laughing. That is the reality of TB, isn't it?

Contracting it is as easy as breathing. Yet the stigma around it is so huge and the blaming of those 'affected' is an everyday reality. Even those who have knowledge of TB and are health service providers continue to stigmatise. It is shocking.

Stigma is a huge barrier to accessing care and treatment. When the surrounding environment is stigmatising, it begins to push those with TB to start stigmatising themselves.

Stigma and very specially stigma in TB is a complex issue and addressing stigma means restoring the dignity of the individual and addressing the surrounding social causes.

Addressing stigma not only needs the understanding of what stigma is but also the courage to shake the societal structures that perpetuate stigmatising behaviour.

Therefore it is essential that the affected community drives the conversation on stigma and educates people on what living with the disease is really like.

This understanding led us at GCTA to embark on a mission to hear from those affected by TB, see and feel the stigma through their eyes, and seek their opinions on how to address it.

Over the past few months we started weekly conversations with women TB survivors. We spoke to one woman each week and this book is a compilation of those conversations called 'Community Chitter Chatter'.

Stigma seems to unite us in a strange way. Though from different countries across the globe, the experiences of stigma and suggestions on what needs to be done to address it are very similar.

I salute these brave women for sharing their painful yet powerful stories with us. It is my hope that these short conversations will help us to better understand stigma and why women end up with self-stigma.

Let us join hands to end TB Stigma.

#lightupalife2endTB

#lightupalife2endTB

This year we had an unprecedented response to light up for TB, a call initiated by the Stop TB Partnership and other colleagues to light up monuments around the globe. Over 40 historical monuments and buildings were lit up on World TB Day 2018.

That same day while running around to attend celebratory meetings, my colleagues and I were struggling to help a young woman get a proper diagnosis for TB and be put on treatment. It hit me so strongly again that our TB response is still far from being people centered.

TB response globally continues to be extremely medicalised and efforts to make it more about the people affected and a little less about the disease itself, have fallen short.

Let us make our TB response real again, bring the people affected, centre stage. Let us go a step further and **#lightupalife2endTB**.

My sincere request is that we use this hashtag in all our efforts this year and also practice it in real life.

In Conversation with TB Champions by Rhea Lobo

COMMUNICATIONS OFFICER,
GLOBAL COALITION OF TB ACTIVISTS

Before interviewing these strong women who overcame TB for Community Chitter Chatter on Stigma, I had only my own experience to go by on stigma. The biggest realisation was that stigma is a personal journey and affects people differently from different parts of the world based on a variety of socio-economic factors (including personality types), yet universally it is one of the biggest barriers to access. Many of the women we interviewed had a tough time coping with the physical aspects of the disease and going through treatment – the coughing, side effects of the medicines and the long duration of treatment. The mental trauma caused by stigma weighed in heavily as one of the main challenges after being diagnosed with TB.

Some internalise social stigma and that resulted in self-stigma. Others had no self-stigma whatsoever but they had to deal with the consequences of social stigma, like losing their jobs or finding suitable life partners.

For many of the women, stigma resulted in a worrying trend. Silence. This silence was sometimes self-induced, or the result of increased family pressure to remain silent for fear of being ostracised from society. And in some cases, care givers and doctors themselves told these strong women who were seeking care that

they would be better off not telling anyone about the fact that they had TB.

Silence kills

The biggest problem with this silence is that it kills. Just like TB silently kills thousands of people every day globally and 1.7 million people a year. Suffering and dealing with a disease like TB becomes something you just don't talk about, for many, even years after you are done with TB treatment and cured. As one of the resilient women I interviewed said, "I am still scared to tell people I was treated for TB, because in case someone gets TB any time in the future they may still blame me".

Learning from Community

Though the women are from different countries across the globe, the experiences are very similar. The infectious nature of pulmonary TB has usually been the root cause of facing stigma – whether it is self or social. Stigma has cost many survivors their livelihoods. Some survivors faced self-stigma exclusively ("Why me?" sort of questions), others didn't. A couple of them had extra-pulmonary TB, yet were told by their care providers that any TB is contagious and they shunned themselves from their families and friends.

The lack of treatment literacy was one of the many factors that has also contributed to stigma. One survivor pointed out that when she was taking the first line of TB treatment and when she found that her urine was red

(as a result of rifampicin), she thought she was bleeding and she was going to die – which contributed to her experiencing self-stigma hugely.

End the Stigma

One important revelation is that many survivors felt that if people understand that TB can affect ANYONE (not just poor people as many people believe) and that TB is completely curable, it will help deal with stigma to a large extent. Also sharing the right information – facts like pulmonary TB stops being infectious within 2 months of taking intensive 4-drug therapy (according to the WHO TB treatment guidelines) – can help combat stigma too. Not enough people are aware of these facts, and more needs to be done to increase awareness. In order to deal with self-stigma, however, counselling is a must, and a support group of people who have had TB before seems to be a top favourite among those interviewed.

The learning from the process of interviewing these bold, strong women was tremendous. Hear their voices, it is loud and clear. Because once we tackle the stigma, we are many steps closer to ending TB.

#lightupalife2endTB

WEEK 1

TB is NOT a poor man's disease



Rhea Lobo is GCTA's Communications Officer and an extra-pulmonary TB survivor herself. She had bone TB and went through 3 surgeries as a result of TB.

GCTA: How much self-stigma did you face after being diagnosed with TB?

Rhea: Not so much self-stigma as opposed to dealing with the stigma around me in society as a whole. People reacted disproportionately to the actual matter in hand – close relatives said no one would marry me, for example, so it's best I hush about it. There were surprising reactions from those I least expected, including my doctor, who labelled TB as a poor man's disease (which itself is stigmatising, both for the poor and anyone who contracts the disease – we all know TB can affect anyone).

Being educated and confident, I didn't care what people think or felt as an endorsement of myself unless it was medically backed up. But to avoid any confrontation

and ill-reactions, I felt it was best not to talk about my journey with TB, because of people's reactions and misconceptions and just focus on getting better. People are not aware about TB. It took four years after being cured for me to publicly come out with the fact that I had TB and was cured. After I started talking about it, people around me came up to me and started admitting that they too had TB but never spoke about it, in that very familiar 'hushed tone'. With a problem that is so rampant, it baffles me how everything has been kept under wraps because of stigma.

GCTA: Are there particular instances when self-stigma would be more prevalent?

Rhea: I always wonder if my reaction may have been different if I had pulmonary TB (I had extra-pulmonary TB – in the bone) and the knowledge that I was infectious/contagious may have made me feel a bit more stigmatised, as the last thing I would want to do is infect other people with TB.

I feel nobody wants to feel bad about themselves and put themselves in that position without society playing a huge role in directing how we feel about ourselves and reinforcing stigma, which may cause self-stigma. When people around you constantly reinforce negative stereotypes, the person who is affected by TB needs to be that much braver to deal with it and come out stronger without getting inflicted with self-stigma. This is apart from actually getting cured from the disease. But what can solve the problem is increasing awareness.

For example, I didn't know that pulmonary TB is infectious only for the first 2 months after you start taking the intensive 4-drug therapy (according to the WHO TB treatment guidelines.) After 2 months you won't be considered infectious, though you will have to take the treatment for 6 months else you may become drug resistant. That knowledge itself can help reduce stigma.



*Labelling TB as a poor man's disease is itself stigmatising, both for the poor or anyone who contracts the disease.
TB can affect anyone.*



GCTA: Do you think addressing self-stigma alone would solve the problem of stigma?

Rhea: What we primarily need to do is address people's perception of TB and that can only be done if we raise awareness among the general public. While the stigma journey did not start with self-stigma, I think a lot of people who are affected by TB end up with self-stigma after the environment around them makes them behave a particular way, like not openly talking about TB because, 'what will people think'. If there is no societal stigma, I don't feel there would be much self-stigma.

To put things in perspective – If I have a cold, it’s so easy for me to talk about it. A cold is infectious too. But everyone knows that even if you catch it, it is easily curable. With TB, it is curable too, but will take many months to cure. It’s very easy for a person who has a cold to tell someone else, “Hey stay away from me, I have a cold”. But it’s very rare to hear someone say the same about TB. And that has everything to do with society’s perception of the disease. The truth is this – self-stigma is a reinforcement of society’s stigmatising attitude.

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WEEK 2

Community Stigma Led to Self-Stigma



Naomi Wanjiru from Kenya is a 41-year-old nurse and a MDR-TB survivor of Pott's disease (TB in the spine).

GCTA: When you were diagnosed with TB, what were your biggest challenges?

Naomi: I faced lots of stigma – mainly from my colleagues, friends and some family members. People did not want to visit or interact with me. They said that I will infect them and they will die. Only my immediate family stood by me. Other relatives did not want any association with me at all.

I faced so much stigma that for 4 months, I had to inject myself with TB drugs because nobody wanted to inject me for fear of getting TB.

Another challenge I faced were the side-effects of the medicines. I almost lost my memory completely and had peripheral neuropathy (lost sensation due to nerve

damage). Today I am taking medicines to try and recover my memory. Also, the duration of treatment was too long – I took medication for 3 years and it was very challenging.

GCTA: What are your thoughts on self-stigma?

Naomi: The moment people started stigmatising me, I started stigmatising myself. I started lying about the fact that I had TB. When friends would ask me if I had TB, I would say it was a back problem and would deny it completely.

I was even afraid to take the first step of finding out if I had TB. The back pain persisted. And after I found out I had TB, I could not believe it. Even though I worked in a TB clinic, I was in denial about it being TB. I used to think, 'How could it happen to me?'

GCTA: What do you think are the misconceptions people have about TB?

Naomi: People associate TB with HIV. They think that if you have TB, you have HIV too. People are scared and fear getting infected.

Another misconception is that many don't believe TB is a disease. They tell you someone has bewitched/ cursed you and believe that you have to take herbal medicines to cure it. I too took herbal medicines before I started taking TB drugs, my mother would travel far to get these herbal medicines.

GCTA: How do you think we can address stigma?

Naomi: To address stigma, people need to be aware that anyone can get TB – it doesn't matter if you are the poorest or richest person. Today it is me, tomorrow it can be you. People also need to understand that TB is a curable disease. If you get correctly diagnosed and treated, everything will go. Most people think that if you get TB you are definitely going to die.



I faced so much stigma that for 4 months, I had to inject myself with TB drugs because nobody wanted to inject me for fear of getting TB.



GCTA: You seem to have gone through a very challenging time with TB. How did you gather the courage to talk about your experience, despite the stigma?

Naomi: I was quiet about the fact that I had TB for a long time. But after a point, I stopped caring about how society would react and what people would say. I thought to myself, 'let everybody talk'. I will just use my voice to be a strong TB champion.

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WEEK 3

Battle 1: Getting Cured; Battle 2: Stigma



*This week we chat with **Fabiola Janet Rojas Coyca**, a 40-year-old MDR-TB survivor from Peru. She is a health promoter and works in the Villa El Salvador district municipality in Peru.*

GCTA: When you were diagnosed with TB, what were your biggest challenges?

Fabiola: I stopped working for a year because I had discomfort when I took my pills and it got worse when they started giving me injections. I did not want my colleagues to see me like this because they would ask me what happened to me.

I hid the fact that I had TB from colleagues at my workplace, some family members and friends in the community. I felt that people would criticise me for being sick with TB. Those who knew would mutter among themselves. They spoke not just about me but about my whole family.

It was tough to manage at my workplace too because I felt that people would not speak to me for fear that I would infect them or would end up getting fired from my job.

GCTA: As per your experience, how much of this stigma was self-stigma you think?

Fabiola: At the beginning, it was very difficult to accept that I had tuberculosis, even worse when I found out what type of tuberculosis I had – MDR-TB. As days passed, I cried a lot and preferred not to leave the house. I felt guilty because my family was at risk and I thought getting away from my family was the solution. I separated my cutlery and washed it with hot water. I did not want my son or husband to run the risk of getting infected.

Although I showed that I was strong in front of my family, deep in my soul I was broken, almost dead. I got to the point of blaming my older brother who had TB before me, shouting at him for putting me in this position and crying a lot (Fabiola gets emotional while saying this).

GCTA: Do you think addressing self-stigma alone would solve the problem of stigma?

Fabiola: No, we can face the stigma within ourselves but if society is not educated or prepared to tackle this social problem, we are faced with a second battle – not just dealing with TB but society as well.

GCTA: Are there particular instances when stigma is more prevalent?

Fabiola: Yes, in the social environment. With my immediate family, it was easier to get emotional support but not in the community. Our own fears add to the problem.

GCTA: What in your opinion needs to be done to end stigma?

Fabiola: Citizens need to be more prepared and aware of this social problem. The biggest problem is that society is misinformed or simply don't know anything and they judge people who have TB. There's ignorance about the disease, how contagious it is and how to prevent it.



We can face the stigma within ourselves but if society is not educated or prepared to tackle this social problem, we are faced with a second battle – not just dealing with TB but society as well.



The Government must show greater commitment and increase health and education budgets. Also, civil society needs to play an active role in this work of promoting health.

GCTA: How did you gather the courage to talk about your experience, despite the stigma?

Fabiola: My 14-year-old niece became ill with TB too and I could not let her be alone in this fight. I thought about her more than me – she was just a little girl in her third year of high school, I would constantly think what would become of her at school? I had to support her – this made me strong.

During my treatment I saw how the rights of the people affected were violated. I witnessed many problems of stigma, bureaucracy, economic need and indifference of some health professionals towards those affected by TB.

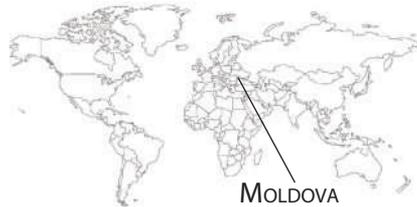
After facing so many difficulties I realised how important it was to counsel people affected by TB – it raises their morale and encourages them to complete the full treatment. I tell people that I am a TB survivor and it breaks the stigma.

I started working for TB as a board member of the association of affected people in the Health Center and then as a health promoter in the fight against tuberculosis for the municipality of Metropolitan Lima. I am currently the representative of people affected by tuberculosis at the national level too.

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WEEK 4

Human Approach to TB is Missing



*This week we chat with **Oxana Rucsineanu**, an MDR-TB survivor from Moldova. She completed three years of treatment in 2010 and is currently Program Director at ANB de TB din RM "SMIT".*

GCTA: When you were diagnosed with TB, what were your biggest challenges?

Oxana: I feel like not much has changed since I had TB. The human approach to TB is missing. Although I had access to medicines, there was so much stigma and discrimination. The attitude to TB is so wrong. No matter how educated someone is, people change their attitude towards you once you are diagnosed with TB because of personal fear of getting TB.

When people start keeping their distance from you, one can't help but feel guilty about contracting TB. You start thinking something is wrong with you, even when you stop being (medically) infectious because people just don't know or understand TB enough.

My own best friend stepped away from me when I met her. Even though I was not infectious anymore, her reaction to me made me feel so miserable.

People need to realise that anyone can get TB and certain circumstances can increase the chances of you catching the disease.

GCTA: As per your experience, how much of this stigma was self-stigma?

Oxana: No one wants to be troubled when they are ill. For a long time, I felt guilty. I started feeling responsible for what I had. When I saw people's reactions – how they avoided me or stayed away from me – it made me feel so bad. But sometimes I think if I was in the same situation (if someone had TB and I knew it was infectious), even I may have reacted the same way.



My own best friend stepped away from me when I met her. Even though I was not infectious anymore, her reaction to me made me feel so miserable.



We need to raise awareness about circumstances where you can get TB and talk about prevention of TB. Every word we say about TB affects peoples' lives.

GCTA: What are your thoughts on self-stigma?

Oxana: Not all people who have TB face self-stigma. Stigma is generated because of attitude of people and society. There needs to be a whole different approach to TB and people in TB. Self-stigma is a result of society's attitude to TB. If people had the right attitude and do not discriminate, things would be different.

GCTA: Elaborate on one action that will help end self-stigma and one action that will help end social stigma.

Oxana: I feel that by ending community stigma, that in itself will end self-stigma. In order to end community stigma, we need to increase awareness. Stigma is a result of lack of awareness and information.

Everyone needs to understand that the needs of each country are different as far as stigma goes. Some countries are more tolerant inherently, others are not. Society must not be 'afraid' of people who are taking TB treatment.

GCTA: What made you open up and start talking about TB and your experiences with the disease?

Oxana: Somebody needs to talk about it, right? We need people to step up for TB and speak out. It is important for everyone to understand that TB is not a curse – it is completely curable and it is not the end of life. We need to move ahead.

#lightupalife2endTB

WEEK 5

Stigma, stigma... Everywhere!



*This week we chat with **Prabha Mahesh**, an extra-pulmonary (lymph node) TB survivor from India. TB, particularly the stigma, left such a big mark on Prabha that she even changed career paths to help the TB community since her recovery. She is part of Touched by TB, India's national coalition of people affected by TB, and is a healthcare professional who works for Alert India.*

GCTA: *When you were diagnosed with TB, what were your biggest challenges?*

Prabha: I had a lot of fear because of the physical aspect of the disease – although I had extra-pulmonary TB, my doctor still told me that it was contagious and I had to be careful not to spread it to others. I had so much guilt, because I feared I would spread it to my loved ones and I thought the solution was to distance myself from home.

At my workplace, I faced a lot of stigma. People no longer wanted to share my lunchbox, they would avoid me.

I wondered if I'll ever be alright, I thought that TB is a terminal disease. I had to undergo surgery to remove the huge lump on my neck. The side effects of the medicines too made it harder – acidity, pain, nausea. I didn't have any information about nutrition at that time.

GCTA: As per your experience, how much of this stigma was self-stigma?

Prabha: I induced myself to self-stigma because I was feeling very guilty – in my case, it was a physical problem, people were scared to come near me and that created more stigma. I lost complete interest in dressing up and looking good. I remember going for a wedding and I never went near any one.

If someone has HIV, you can't make out when you look at that person. But with TB, it is not like that – there's so much more physical representation like coughing, or in my case, the surgery.

GCTA: Are there particular instances where you felt stigma was more prevalent?

Prabha: Yes, in social situations where you have to go out and mingle with the outside world. Although no one said anything to me, I felt my employment was at risk. I was scared that people will say 'don't come to work'. In fact, my medical officer at work herself had

advised me not to tell anybody that I had TB so that there won't be any repercussions.

I think gender also plays a big role. If I was male, I don't think I would have reacted this way as far as stigma goes.

GCTA: Elaborate on one action that will help end self-stigma and one action that will help end social stigma.

Prabha: There is so much ignorance. Counselling needs to be thought through, like what are the components that need to be addressed? It's not just about educating a person but we need to look at self image. We need to remind people that TB is a normal, curable disease. I had no guidance whatsoever and couldn't diagnose what I was going through.



The trouble with stigma is that it does not put you at ease even when it is over.



One big influencing factor is the doctor who needs to explain the disease better, understand if people who are going through TB have other problems related to the disease. We need a checklist with indicators. It has to be a systematic process and counselling needs to

be done accordingly to address specific issues each individual faces.

GCTA: What made you open up and start talking about TB and your experience with the disease?

Prabha: It took me a long time to speak about it. I met a person who had TB who was not adhering to treatment. She told me that I had no idea what it was like to have TB and what those medicines did to her... in fact she spat out her medicines in front of me. That was the first time I opened up to someone that I had TB, and she couldn't believe it.

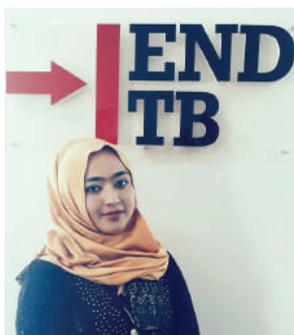
That day, word got around in office that I too had TB. Some colleagues had called me and said they had heard something and I had to clarify that I didn't have TB now and it was an old story.

The trouble with stigma is that it does not put you at ease even when it is over. That is stigma for you!

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WEEK 6

Women Face the Most Stigma



*This week we chat with **Gulbahor Mirzosharifova**, a 28-year-old MDR-TB survivor from Tajikistan. She considers herself fortunate to be one of the beneficiaries of the new, shorter regimen of MDR-TB treatment provided through Challenge TB, the project funded by USAID and implemented by KNCV in Tajikistan. Gulbahor has recently completed treatment in October 2017.*

GCTA: *When you were diagnosed with TB, what were your biggest challenges?*

Gulbahor: My main challenges were going through those nine months of treatment and dealing with the side effects of the medicines.

I didn't tell people I had TB, except my family and close friends. In Tajikistan, there's a lot of stigma, especially for women. Men don't want to marry women with TB. Even in my own neighbourhood, one man divorced his wife because she had TB. However in my case, my

family was always supportive and I didn't face much stigma – rather I overcame it.

My brother too had TB and because of his experience, I understood the disease well. From his example, I saw that by sticking to treatment and not giving up, you can get cured. This gave me the strength and courage to continue treatment.

GCTA: As per your experience, how much of this stigma was self-stigma?

Gulbahor: I personally didn't care much, but my mother and father insisted I hide the fact that I had TB. I just told people I have a problem, I didn't say it was TB. I didn't have any self-stigma.

GCTA: Are there particular instances where you felt stigma was more prevalent?

Gulbahor: The only instance where I think people will have self-stigma is when people don't think it's curable. I saw my brother was cured so I didn't think that way. My only real fear was that I may stop taking treatment because of the side effects of the medicines.

There are some factors that contribute to an increase in social stigma, particularly when people are misinformed and misled about TB. People think that TB is a family disease and believe it is not curable.

Many people go to traditional healers instead of taking proper treatment. They are prescribed roots, dog meat,

In Tajikistan, there's a lot of stigma, especially for women. Men don't want to marry women with TB. Even in my own neighbourhood, one man divorced his wife because she had TB.

bear or hedgehog fat and other such strange things to cure TB.

GCTA: Could you please elaborate on one action that will help end self-stigma and one action that will help end social stigma.

Gulbahor: The only way to address self-stigma is to raise awareness and give the correct information – we must particularly focus on the fact that it is curable and it is not a family disease because many people think that if you have TB your whole family must have it.

To end social stigma, we should encourage TB survivors to speak up about their experiences with the disease and stress on the fact that this disease is curable.

GCTA: What made you open up and start talking about TB and your experience with the disease?

Gulbahor: As someone who has the experience of going through TB treatment, I know that people who are affected by TB need social, psychological and moral

support. By telling people who are suffering from the disease that I too have had TB, they are encouraged to complete treatment.

Once I got connected to Stop TB Partnership Tajikistan's Patient Support Group, I realised that I'm not the only one who was suffering and who is trying to find ways to help others. I'm currently a volunteer there and I want to continue working with this strong group of people.

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WEEK 7

Stigma from Healthcare Providers



*This week we chat with **Phumeza Tisile**, a 27-year-old MDR/Pre-XDR TB survivor from South Africa who was on TB treatment for 3.8 years. TB left Phumeza deaf for 5 years, but with great grit and determination she has overcome all odds and has risen to be a true TB champion.*

GCTA: When you were diagnosed with TB, what were your biggest challenges?

Phumeza: I didn't know much about TB at all when I first found out I had it. I didn't even know that there was something called MDR and XDR-TB.

One of my biggest challenges was the way people look at you when you wear the mask. It makes you feel horrible. In the clinics particularly, healthcare providers had a weird way of talking to people with TB – so rudely and meanly. There were times I couldn't wear the mask – the N-95 mask is a hot mask and you can experience shortness of breath, and the healthcare providers

would just yell if you take it off for even a second.

In the TB hospital, there was not much stigma – maybe because everybody had TB – but when I went to other public (general) hospitals there was a lot of stigma. You can see the judgement on people’s faces and even the professionals behaved this way. I didn’t ask for TB, it just happened to me – people never understood that.



I started stigmatising myself because I was different from other people – because of the hearing loss due to TB medication. People constantly went on forgetting that I was deaf.



I was deaf for 5 years because of TB treatment. In the 2nd year after I turned deaf, I started forgetting how people sound. I had to learn how to lip-read people. When I tried to explain to those around me that I had gone deaf, many didn’t believe me because just the other day I could hear just fine. It was frustrating; I was lonely for the whole 5 years.

People who I did communicate with about TB, told me that I had the worst kind of TB and that I was going to die or that they knew somebody who had died, etc.

GCTA: As per your experience, how much of this stigma was self-stigma? And how much was social stigma?

Phumeza: I started stigmatising myself because I was different from other people – because of the hearing loss. People constantly went on forgetting that I was deaf. If I were to put a ratio to how much of the stigma was self-stigma and how much was social stigma, I would say it was 50:50. Since I couldn't hear/understand what people were saying, I found comfort in blogging about my story, rather than talking about it or sending text messages. It was easier for me.

GCTA: Are there particular instances where you felt stigma was more prevalent?

Phumeza: In the public hospital, I could really feel and see stigma. When I went out, to the mall for example, people would ask me why I was wearing a mask and just couldn't understand it. I thankfully had a very supportive family when I went through TB treatment, so I didn't feel any stigma from them.

GCTA: Could you please elaborate on one action that will help end self-stigma and one action that will help end social stigma.

Phumeza: We need to watch the language we use. People with TB are not cases or suspects. We are not criminals. We really need to mind our language in order to deal with self-stigma. People feel ashamed when you label TB as a poor man's disease. We need to start there.

With social stigma, there is a lack of awareness about TB – how you get it, etc. In South Africa, Nelson Mandela, Desmond Tutu all got TB. We need to stress on the point that anyone can get it.

GCTA: What made you open up and start talking about TB and your experience with the disease?

Phumeza: When I first shared that I had TB – I got strength from friends and people I didn't know who commented on my blog.

I also received a lot of tough love, from the nurses who were shouting at me to take my TB tablets – it was their way of encouraging me to pull through TB. Now I encourage others.

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WEEK 8

Doctors Face Stigma Too



*This week we chat with **Mileni Romero** from Venezuela, a 31-year-old dentist who had extra-pulmonary TB. Living in a country that does not do drug sensitivity tests for TB and little access to medicines, she lived through TB treatment in extreme uncertainty as to what the future holds. She went through adverse side effects of the first-line of TB drugs – from allergies to facial dermatitis and stomach problems. The severity of the side effects forced Mileni to stop treatment for several days before restarting again, but today she has come out stronger than ever.*

GCTA: *When you were diagnosed with TB, what were your biggest challenges?*

Mileni: The biggest challenge was that I had to stop working – I am a single mother of an 11-year-old girl. My mother died when I was just a child, my father is a pensioner and my brother earns minimum wage. I was financially independent, working as a dentist.

When I had to stop working there was no money to pay for basic expenses at home. With the situation in Venezuela, nobody can afford to not work. But



On hearing that I had TB, my patients started getting scared and preferred not to visit me for dental consultations.



the most difficult part was being separated from my daughter, because the doctors told me that I could not be near her for at least the first 3 months of treatment. She has always lived with me since she was born and it was difficult to get away from her for three consecutive months for the first time in 11 years.

Also, at the beginning I felt rejected and kept myself away from everyone, including my family and friends because I did not want to infect anyone. That was hard to do.

GCTA: It is interesting that even though you had extra-pulmonary TB, your doctor advised you to stay away from your daughter. This seems to have led to self rejection as you say. Can you elaborate on this self-stigma you experienced?

Mileni: I put myself in a situation where I did not allow anyone to approach me. Little by little I started shutting myself out from the outside world. After many weeks,

I reconsidered what I was doing and decided to turn the situation around and with the help of my partner I went around trying to make people understand that I am a human being who deserves respect. I started respecting myself and gave myself the courage I needed to overcome the situation I was in.

GCTA: Did you also face social stigma? Are there particular instances where you felt it was more prevalent?

Mileni: Yes, as soon as people find out what you have, they look at you like you are some kind of disease waiting to be transmitted. People look at you suspiciously and start rejecting you.

In my case, I am a doctor and patients believe that doctors are immune to everything. On hearing that I had TB, my patients started getting scared and preferred to not visit me for any kind of dental consultations. I felt I was responsible for speaking the truth, because after I said that I had TB, nobody wanted to get treated by me.

GCTA: From your experience, can you think of one action that will help end self-stigma and one that will help address social stigma?

Mileni: With regard to self-stigma, I find that psychological help is very important and that makes us understand that, today, TB is not a deadly disease. You can live through it and have a normal life. To address social stigma, we must disseminate correct information to society. People need to understand what TB is: how it is transmitted, the different treatments that exist to

combat it and ways to prevent TB. By making society understand this, it will drive home the point that we are not less than anyone and we will be treated as equals.

GCTA: What made you open up and start talking about TB and your experience with the disease?

Mileni: I have always been a vocal person with an inclination to help others, and this time I realised that the world needs people who can speak freely about TB, particularly to end stigma.

I feel that my experience with TB will provide support to those people who feel that they have no way out and that they are going to die. I hope that they see themselves in me as a mirror, especially because I live in an over-crowded country where there is no food and medicines (not even the basic ones for headaches, let alone antibiotics).

But in spite of all these odds, I managed to survive TB and continue with my life in a normal way – I hope people who are suffering from TB realise that everyone can overcome tuberculosis. I hope these people who are affected by TB realise that they can live without fear and achieve all their goals in life.

Through my example, I hope people see that they can come out in the open without being rejected and learn to give themselves respect – they deserve that as human beings.

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WEEK 9

Losing all to TB



*Perhaps no one understands TB better than two-time TB survivor 42-year-old **Mona Balani** from India. Mona has lost her husband and two and a half year old baby to TB due to delayed diagnosis. Mona herself has experienced both pulmonary and extra-pulmonary TB and today is a strong TB champion.*

***GCTA:** What were your biggest challenges while seeking treatment for TB?*

Mona: I faced so many problems and so much stigma. I lost my job as a front desk manager – they told me that they didn't need me anymore and said I had become very thin (lost 30 kg) and I should rest at home. I lost my husband to TB just a year before I was diagnosed the second time around and my baby died from abdomen TB a few years before that – I was devastated.

There was a lot of gossip around me – about how weak I looked and even my in-laws reacted meanly. People

said that TB is a deadly disease and like my husband, I too will pass away. I had to cope with all this gossip and, most of the time, it used to upset me so much.

Apart from this, there was a lot of vomiting, diarrhoea and stomach pain. It took 1.5 years to diagnose that it was TB in my abdomen the second time around. Doctors were constantly giving me some gastric pills to get rid of the pain before I was diagnosed correctly.



I lost my job as a front desk manager – they told me that they didn't need me anymore and said I had become very thin and I should rest at home.



To top this off, to get an FNAC test done, I had to wait for 1.5 months. At the government hospital, due to bureaucracy, the staff delayed the procedure and it was very challenging. I then met a government hospital doctor in his private clinic and he asked me to do an ultrasound. One look at the ultrasound report, and he said that I had TB and asked me to get an FNAC immediately no matter what.

GCTA: As per your experience, how much of this stigma was self-stigma?

Mona: When I was diagnosed with TB in my abdomen,

I immediately remembered my baby who, before he died, became so skinny and weak from TB and I got scared since the same thing was happening to me.

I started hating myself – I didn't understand why I was falling ill like this. I was frustrated on the inside. When people heard that I had TB, they said that it was so dangerous and that my life couldn't be saved. People are always talking about problems and not the solution.

GCTA: What in your opinion needs to be done to end stigma – both self-stigma and community stigma?

Mona: There needs to be treatment literacy to address any kind of stigma, particularly self-stigma – there really should be a platform to share the challenges of stigma, treatment literacy and treatment access. I didn't know what kind of medicines I was taking and what the side effects were. I didn't understand why I was getting red urine and red stools. I first thought it was blood and was about to stop taking the TB medicines (that caused it). Treatment literacy will increase the confidence of the community to respond to stigma.

As for community stigma, the right information needs to be circulated. People should know how TB spreads and how to prevent it. For example if there is no proper ventilation in the house, TB can spread. If we give out the right information and educate society, stigma will reduce automatically.

We also need TB counsellors to address questions people who are suffering from TB have. I was told just to take the four tablets and nothing else about TB itself. There was no literature to read and no counselling about nutrition either – no one told me what I should eat and that I'll be better off if I eat a protein diet.

GCTA: TB has affected your life in so many heartbreaking ways, how did you gather the courage to talk about your experience?

Mona: After 3-4 months, I started gaining some weight and looked better. This gave me the confidence to speak up and talk about it.

I also met another woman who told me she got TB because of a spinal surgery. That didn't make sense to me, and I thought to myself how can there be so many misconceptions about TB and we need to do something about it. That's why I started speaking about it.

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WEEK 10

Self-stigma and its Wrath



*Meet two-time TB survivor from Indonesia, **Paran Sarimita Winarni**, who works as a Peer Educator in a DR-TB Organization. This 35-year-old has had both drug sensitive and MDR-TB and had a hard time coping through treatment and getting cured.*

GCTA: What were your biggest challenges while seeking treatment for TB?

Paran: The first time I was diagnosed with TB, I felt normal. I had very little information about TB and little to worry about. My biggest challenge was when I was diagnosed with DR- TB the second time around. The long duration of treatment and side effects I had to face was hard on me.

I feared losing my job and I ultimately had to quit working. I didn't have a choice -- I just could not handle the side effects of the medicines.

I faced stigma, starting from the health worker I met

initially. I felt maybe that was because I was the first person who had MDR-TB in my environment.

I was also asked to shift houses because I lived next to a small kindergarten and people feared I would infect the children there. In fact when the kindergarten had classes going on, I would never go out of my house till they were done and I made sure I didn't have any interaction with anyone. However, I am grateful to a couple of people, including my public health officer and my subsequent health worker, who made sure the treatment was convenient for me.

GCTA: It must not have been easy to be forced to shut yourself from the world like this. What were your feelings and did you ever blame yourself or stigmatise yourself?

Paran: I always said, why is this happening to me? Why is God being so cruel? And I started staying away from everyone around me. I even closed myself from my best friends and neighbours. My world turned upside down and I started living like a frog in a well.

It wasn't people who made me feel like that. I made myself feel that way. My family, particularly my mother, was very supportive and so were people around me. Till today, I still have self-stigma. I always feel so scared that if anyone close to me gets TB one day, they would blame me.

I was also very worried about whether I'll be able to go back to work or if I had to search for a new job. I would

also worry if I would ever find a partner to grow old with after I got TB.

GCTA: What in your opinion needs to be done to end this sort of stigma – both self and in the community?

Paran: For self-stigma, I feel after a patient completes treatment, there needs to be consultation sessions with TB survivors to help build their confidence again and face the community.



I was very worried about whether I'll be able to go back to work. I would also worry if I would ever find a partner to grow old with after I got TB.



For social stigma, we need to give proper information and education about TB, especially in public areas (like buses, trains, schools, airports, hospitals) so that everyone knows what TB is and how it is transmitted. We can adopt prevention measures this way too.

GCTA: TB has affected your life in so many heartbreaking ways, like it does to so many women, how did you gather the courage to talk about your experience?

Paran: After I got involved in PETA (an organisation where fellow MDR-TB survivors give support to those

affected by MDR-TB), I met a lot of people who had the same problems as me or even worse. But they don't speak about it.

After seeing this, I realised that only if we speak, will everyone know and pay attention to us. It was then that I decided to be brave and speak about TB. I felt comfortable to do so since I had a community that supports and understands me. But what about the other patients who don't have that?

I started sharing my story to all my friends who are still on treatment. I don't want people to be scared when they go through treatment. And most important of all, I don't want to leave anyone behind in TB. So I decided to speak up about this now.

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"The Community Chitter Chatter on Stigma series by GCTA importantly gives people affected by TB the all-too-rare opportunity to voice their experiences, and in turn, gives us the opportunity to learn how we can and must do better in addressing TB and ending the stigma that can so unjustly accompany it."

- Erica Lessem, Deputy Executive Director,
TB Project, Treatment Action Group

"Community Chitter Chatter is a really important publication. It shares the first-hand experience of stigma from those who know best - those who know what it is to have TB. Their collection of stories needs to be read by policy makers, programmers and researchers as we continue to do more and do better around TB-related stigma at all levels – self-stigma, social stigma and discrimination. An excellent publication and well done GCTA."

- Nadine Ferris France, Director,
The Work for Change

"People usually understand the stigma around HIV but when it comes to TB, it is largely misunderstood. The Community Chitter Chatter initiative by GCTA is an excellent way to increase people's understanding of stigma against those living with and affected by TB. I really love and appreciate these series highlighting women living with and affected by TB sharing their stories of how to cope with the disease and to fight against stigma. I eagerly look forward to the next series"

- Choub Sok Chamreun, Executive Director of KHANA
and Co-Chair of ACT!AP



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