



My life is now yours

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Received: 19-APR-2017

Accepted: 01-JUN-2017

Published Online: 30-JUN-2017

Mira

Seventeen year old Mira walked down the road, coughing and spluttering, just trying to breathe. Blood splattered on her hand and she wiped it off on her shirt. She was on her way to work. She had missed her medicines again today. The medicines slowed her down and she couldn't afford that. There were bills to be paid, hungry mouths to be fed back at home - cleaning houses and cooking food for others was the only way those needs could be fulfilled. Plus, it was just a cough and some fatigue. What harm could that do? Her mother would never let her rest anyway. She would force her, kick her out of the house if she had to, and send her to work. "It is okay for people who work like you do to be tired all the time," she told Mira.

As she swept the first house, Mira thought about what the doctor had told her. Tuberculosis. She had a lot of time to think because the occupants of the house were all out except an old woman

who cried softly and incessantly. Her granddaughter, Samaira, was sick and in hospital. She had been sick for a long time now. Mira had seen the girl coughing violently - as if trying to cough her lungs out. Just like Mira did herself. It was like looking into a mirror.

Samaira

Hadn't it been just a cough? How had it gotten so bad? How had it reached a point where I was throwing up scarlet red blood, enough to fill up a sink?

I lay limp as a rag doll in the hospital bed. I tried to open my eyes, but they seemed to be glued shut. When I finally did open them, I had to shut them right back again. It was too bright. The light seemed to pierce through my eyes, threatening to burn holes through them, leaving only the bony sockets behind. I tried again, more cautiously this time. Everything was white. The walls were white. The ceiling, the sink - everything. I didn't know what was going on.

Cite this article as: Singhi M. My life is now yours. RHiME. 2017;4:44-49.

A clock struck eleven somewhere and the tick tock echoed in my ears. I wondered for how long I had been lying like this. Towards the right, there were windows with white curtains partially drawn across them. A beam of sunlight was streaming into the room. I could see dust particles illuminated by the beam. They were floating in it - just floating about, aimlessly. I longed to reach out to the sun's rays and embrace them - to try and drive away the cold draft that seemed to envelop me. Towards the left, I saw a glass door with the letters ICU written in blood red.

The ICU? Why was I in the ICU? My brain couldn't figure it out even though it raced ahead trying to make sense of what was happening. I saw an IV stand next to my bed, and large black machines that beeped every now and then. I started to examine myself, trying to assess the damage.

My arms and legs felt heavy. There was a central line inserted into my neck, an arterial line into my left wrist, cannulas inserted elsewhere. I felt like a scarecrow with sticks for limbs and straw for a body. I tried to swallow but there was something pressing against my tongue and teeth. I tried to bite it. Tasted like plastic. A ventilator.

A machine was breathing for me. My heart sank as I realised the grave intensity of the situation I was in.

A tiny bird came and sat on my window sill and began to sing. It broke the monotony of the dreariness that hovered about me, bringing in a wave of faith and hope.

The next few days in the hospital passed by in a blur - in and out of sedation, some surgeries, bad food, fights with nurses, exhausting physiotherapy and

finally the road to recovery. Soon it was my last day in hospital.

It was time to leave. I was finally going to escape the morbid and dreary atmosphere of the hospital that I had been stuck in for more than twenty days now. Everything was ready. I had changed into a tracksuit, rid of the horrible striped gown that had made me feel more like a prisoner than a patient. I grasped at the crisp white bedsheet and took a long whiff to remember the smell. It smelled of sanitizer like the rest of the hospital.

My parents and my nurse stood in a corner of the room, waiting for one final meeting with the doctor.

I had hated my time here, but now that it was time to go, I began to feel conflicted. I was happy I was going home, but somewhere there was a tinge of melancholy. This place had given me life and alleviated my pain. The doctors had fought hard to keep me breathing even when I had given up. For some strange reason, the hospital felt like home and the doctors and nurses felt like family. I looked around, trying to memorize every inch of the place.

At the time, I could not have imagined how those twenty days in hospital would impact my life. I had no idea how much I would have to give up in exchange for a chance to live. With time, as the consequences would begin to unfold, I would be wishing it had all ended there, that day in the hospital. Consequences of my illness were going to kill me from within, ever so slowly, with each passing day.

The click of the doctor's heels brought me out of my reverie.

"I would have liked to keep Samaira here

for a few more days, but she seems quite restless to go,” the doctor began, “Since she is out of danger, I think we can let her go. Of course, there will be a few things that need to be taken care of.”

The doctor went on to explain the precautions that needed to be taken, including foods to be avoided – spicy, sour and junk.

“You just need to focus on rebuilding your immunity. Avoid strenuous physical activity and take the medicines religiously. Do not miss them even for a single day or else you will suffer greatly,” she said. “Take it slow, Samaira. Bed rest for a month or two. DO NOT STRAIN YOURSELF. You will do more harm than good otherwise.”

I nodded, secretly determined to get off the bed in half a month. I couldn’t stand the sight of a bed after lying in one for so many days.

“So, Samaira, I guess this is goodbye. I hope we don’t meet under similar circumstances again. Best of luck and make the most of this life you have been given. You have a purpose, a destiny to fulfil,” the doctor said, patting my head.

At that moment, I wanted to hug her and cry. I had never felt gratitude so deep and so real for anyone before. I wondered if doctors remembered their patients. My eyes were filling up, but I fought back my tears and whispered, “Thank you, maam.” Never had a ‘thank you’ carried more meaning and intensity.

“It’s my job, Samaira. You don’t need to thank me. Take care,” she smiled and began to walk out of the room.

“Ma’am?” My mother called out.

“Yes?”

“Does Samaira need to be ... umm ... separated?”

“Separated?”

“You know, kept away from people she might spread this infection to?”

In that moment I felt my world come crashing down around me and all I wanted was to be buried deep under the debris and to never resurface. There I was - alive, after almost dying – and I had thought about so many things: the effect this would have on my body, the physical limitations it would impose, and so on; but I hadn’t thought about this.

“That will not be required. Samaira is fine now. She isn’t infectious at all. No need to keep her in isolation,” the doctor said, looking at me with empathy. I couldn’t meet her eyes. It was difficult for me now that I had heard the word ‘isolation’.

I guess my doctor understood the fight I was in for. It is the fight most patients with tuberculosis are fighting. A disease like tuberculosis has a certain social stigma attached to it in a country like ours. Quite a stigma. People usually avoid them, afraid they will contract the disease. The social isolation causes a great deal of mental agony and there is no way out of it - not until everyone is ready to shed their inhibitions and become aware about the real facts of the disease instead of holding on to the old concept of the disease.

A new fear gripped me. I did not need one more thing. I already had to worry about my studies, medications, restrictions, side effects and all the long term effects. And then there was the fear of drug resistant Tuberculosis. Now above all that, were people going to view me as dangerous?

How much more was this disease going to take away from me? How many people was I going to lose over something that I

couldn't control? Friends and relatives - would they avoid me if they knew?

My doctor knew I was not infectious. My parents knew. I knew. But how was I going to tell the rest of the world? Was I ready for the consequences? These were the thoughts that occupied my mind as I stared blankly out of the car window on my way home. What was I going to tell anyone who asked me what had happened – why I'd been missing for so many days?

I was still thinking about it all the next day when my mother called out for me. I opened the door and I heard a guest screaming to her daughter to not enter my room. I looked directly into the woman's eyes and saw fear. I quickly shut the door and retreated into a corner, just trying to breathe.

People at home began to change. They looked at me differently. I don't know if it was because I had almost died or if it was the look they'd give a person with tuberculosis. I don't know and I didn't ask. I began to view them differently, too. I looked at them with suspicion; misinterpreted their every action. When my mother asked my brother to study and leave me alone, was she actually trying to put some distance between us? The most important change of them all was that I began to view myself as "unsafe".

I remained holed up in my room in the days that followed. I completely refrained from meeting any guests. I stopped entering the common places in the house. In case anyone entered my room, I made sure I stayed as far away from them as possible. I lost interest in everything that used to make me happy before. I stopped talking and stared at the blank walls of my room for long hours imagining myself back in the ICU, reliving it all over again

- the pain, the desolation, the helplessness. I wanted to lean on my family for support but I was too wary. Everytime someone coughed in the house I felt like everyone looked at me with eyes that blamed me. I tried to find comfort in music and books but the word 'isolation' kept knocking on the back of my head like a constantly dripping faucet.

I watched the outside world only when I parted my curtains in the morning to let the sunshine in to warm the cold being that I was becoming.

At some point, going out became unavoidable. I had to get back to my daily routine and attend classes. Once there, I limited interactions. I stopped breathing when anyone passed by. I had terrible mood swings and shunned whoever tried to talk to me. It was easier for me to isolate myself than to let people do it to me.

Worst of all was the fear – it was a bottomless pit in my stomach. It manifested as nausea. As palpitations. A feeling that never went away. A feeling that was later termed as anxiety. Anxiety that crippled me completely and yet was never taken seriously by anyone.

I froze every time someone asked me what had happened. Every time, I came up with an answer that revealed everything but the truth. I had to spin up an entire web of lies to cover up the fact that I was suffering from tuberculosis. I constantly feared my secret getting out and did everything to prevent that from happening.

Once the six months of treatment were over, I still could never muster up the courage to tell anyone about it because I knew it would have lifelong effects. I had read the application forms for admission

to the Armed Forces Medical College and to the army. A person with history of pulmonary tuberculosis could not apply. I knew that this was just the beginning.

A bigger tragedy was that a few months later, when I entered a hospital ward as a medical student to take the history of a patient with pulmonary tuberculosis, I hesitated. I stood at the door and looked at my patient, afraid to go any further. I was not as afraid of contracting the disease as of the isolation it would cause. I wouldn't be able to bear it. Not again.

Mira

"Mom, what happened to Mira? Did she get married?" I asked my mother when I saw the sixth maid in six months.

"She passed away."

"Passed away? How did that happen? She was my age!"

My mother looked into my eyes and I could tell she was trying to figure out how much to tell me.

"Tuberculosis. Don't you remember she coughed all the time? She passed away when you were in the hospital. You probably contracted it from her," my mother said in a low tone.

My heart pounded against my chest wall. I went to my room and did not know what to feel. Should I be angry that the maid hadn't informed us? Should I be sad that she had passed away because of a disease that is curable? What if I had not contracted it from her? What if it had been the other way round and Mira had contracted it from me? The thoughts were killing me.

The next day, I called Mira's mother to my house and asked her everything.

"She kept saying she wanted to rest but I wouldn't let her," her mother wailed.

She appeared devastated by her daughter's death and apparently felt the ghost of her absence torturing her. I wondered if somewhere deep down she was slightly relieved too. It was one less mouth to feed. One less child she would condemn to a life of slaving for others. The thought shocked and saddened me.

Mira had known she had tuberculosis, yet no one in her house ensured that proper treatment was taken. This was despite the fact that free treatment was available. Was it simply because they didn't understand the seriousness of it, or because they didn't think it necessary to continue with medication once the cough subsided - even though the doctor had advised otherwise?

I did not know whom to blame. I felt slightly guilty myself. Suddenly, I felt like this huge burden had been placed on my shoulders. The timing of it all was so uncanny. I could not help but feel that a deal had been struck - life in exchange for death. Life for me. Death for Mira. As if the life had been sucked right out of Mira and given to me.

And why? Because I happened to have parents who could provide money and the right education? Despite being the same age, suffering from the same disease, in the same city, with availability of the same medications, Samaira was alive. And Mira?

Mira got the rest she had been craving. Permanently.

After six months of complaining about the ill effects of my illness, and suffering the isolation of it, I realised that I had completely missed the bigger picture.

People are dying. And it isn't because of absence of health services. It is because of lack of awareness. Low immunity due

to malnourishment makes people more susceptible to these diseases. The government is providing free treatment for tuberculosis but there is lack of proper utilization due to lack of knowledge, contempt for modern medicine, and superstitions buried deep in people's minds.

I am coming out of hiding. I have work to do. I have found my calling. I recall the words my doctor uttered - "You have a purpose, a destiny to fulfil".

I feel like I now have to live for two people. For Mira and for myself.

[Acknowledgement](#)

I would like to thank my mentor, Dr Richa Ghay Thaman, my family, and my friend, Deepali, for helping me put together this article.