

Remarks by Jigna Rao on Patient-centered Approaches to Cure

Cascades: Improving TB Care
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Organized by: Department of Global Health and Social Medicine at the Harvard Medical School
Médecins Sans Frontières, Partners In Health, Stop TB Partnership Treatment Action Group

Jigna Rao: Good evening everyone. I want to start first by thanking Treatment Action Group and the Zeroes Campaign for inviting me to participate in this discussion on behalf of those affected by TB.

In 2006 I was one of the millions whose life changed because of Tuberculosis. After almost 2 years of misdiagnosis and invasive, painful infertility treatments playing constant havoc in my life - - I was finally diagnosed with Pelvic TB - forcing me to face the sad reality that motherhood was not my path. My life long dream of becoming a mother came to an abrupt end and the real ordeal had just begun.

The next many months instead of researching for baby names and decorating a nursery, my days were spent taking energy sapping TB drugs and coping with the stigma of having an infectious disease like TB and being infertile.

While I was surrounded by the unwavering love from my husband, I quickly found out that others would not be as generous. From being used to applauded and admired for my professional and personal accomplishments I soon detected an unspoken sense that some people around me looked at my illness as a moral failure.

As I began to tell family, and friends of my diagnosis, I saw that many of them shared this unspoken belief that only people with moral failures succumb to TB. Their facial expressions and body language changed, sometimes very subtly and some times in ways that were impossible to ignore.

Some people abruptly ended a conversation with me when I spoke of the diagnosis. With others, just the look in their eye let me know that as a person with TB, I had become less valued in their eyes.

Worried about how people I knew in the US where I live and back in India where most of my family lives would react, some well-meaning family members counseled me not to speak so openly about my diagnosis. I knew that my talking about TB affected their social standing – I soon understood that the stigma of TB affects not only the patient but also their entire family and to the very people you love and to the community in which you - live you are now seen as a threat.

The feeling that I had something to hide, that TB was not something I could talk openly about, was painful and left me feeling emotionally isolated. I understood why people go to great lengths to hide the disease, even to the point of avoiding clinics or public health officials associated with TB.

The weight of this stigma and the grief of losing the most important desire of becoming a mother were soon becoming too much for me to bear. I started experiencing daily stress, anxiety and depression and was beginning to lose my motivation to fight this disease. My illness had changed me from being a rational, confident and independent woman to someone who was more secure behind closed doors. TB's adverse effects had now surpassed my physical body and had invaded every aspect of my life.

Yes there is no doubt that patients need drugs to rid their body of TB but psychosocial support is equally important to help them successfully make their difficult journey back to good health. However most current TB treatments focus purely on medical care missing the social implication of being diagnosed with this disease.

TB affects more than just the physical self. It also scars the psychological, social and spiritual self – so it becomes imperative that TB treatment be more holistic and there be a more inclusive care that extends beyond TB medications.

I was fortunate that I had access to the psychosocial support that I so badly needed in order to cope with my fears and anxieties and that allowed me to stay on track to successfully complete my TB treatment. However this is not always the case for other TB patients around the world, especially those who have limited financial resources or where TB programs are poorly funded.

I was fortunate that I had the love and support from my husband and family to cope with the stigma of TB and infertility. My husband ensured that I was getting the care that I needed both medically and emotionally and I know how lucky I was— because there are thousands of women around the world whose families and loved ones abandon them forcing them to lose their children, their livelihood, their home and their dignity because of their TB.

But while I was fortunate in some ways – it was my great misfortune that there was such a long delay in my diagnosis – because who knows had I been diagnosed early on today I may have realized my dream of being a mother.

In 2012, 8.6 million people fell ill with TB and 1.3 million died from it – But yet I hear experts speak enthusiastically about how they are seeing success in reducing TB deaths –but how can 1.3 million lives lost be a success in any way? Success can only be proclaimed if we can achieve Zero deaths. Even a single person dying from this curable disease is a huge failure and in my eyes it is a crime against humanity.

To achieve real success we must thinking outside the box. TB treatments must extend beyond the physical body and include social and psychological support as an important aspect of care. Unless we do so millions will continue to die due to insurmountable social or psychological obstacles they face from diagnosis to treatment completion.

The journey of TB patients from diagnosis to treatment completion is dotted with challenges and hurdles. From the stigma that keeps people out of treatments or diagnostics that are either unreliable and delay diagnosis or the physical, social and emotional isolation that patients must suffer silently without any psychosocial support. And when patients do enter TB treatment they must then endure the absurdly lengthy and difficult treatment laced with toxic medications.

It is no secret that these toxic medications can have horrific side effects. But there are also other kinds of side effects that bear huge costs on individuals, especially women – in my case it cost me my fertility and took from me what I feel it means to be a woman – TB robbed me of my sense of femininity and my sense of purpose – My husband and I lost our dream of having a family - now

years later I still wake up each morning trying to figure of what my role is in this world now – this too is a side effect of TB.

Including psychosocial support regularly as a part of TB treatment will allow individuals to cope these other kinds of side effects. It will help them overcome individual challenges, empowering them to deal with the social, psychological and emotional impediments and recover from all effects of TB. Counseling and social support can help TB patients and their families cope with the stigma and fear and enhance the quality of their life.

The consequence of a TB diagnosis can lead to loss of socio-economic status. Often people lose their jobs, their income their home and the chance for a fulfilling productive life. For individuals and those around them, psychosocial support can be a critical factor in positive treatment outcome.

Such support should be an important part of care at not only at the institutional level but also at the community level. Creating patient support groups within communities would give those affected by TB an opportunity to tell their story. Support from peers can help empower all TB patients and help alleviate loneliness, anxiety, stress, confusion and depression all of which can disrupt treatment.

Because I live in the US, I was able to get the highest standard of complete care to heal from the scars TB left on my mind and my body– but that’s not the case in most parts of the world.

Success from diagnosis to treatment completion cannot rely on just a single intervention but rather has to be comprehensive and integrated – this should not be the privilege of only those that live in rich countries – but the same high level care is the right of every TB patient irrespective of their geographical location or their race, class or gender.

The key to achieving zero TB deaths is to ensure that we have newer efficient diagnostics that can quickly and accurate diagnose TB with no cost to the patient. Patients need shorter treatments that are less toxic TB treatments so that there is minimal impact on their life and their body.

Access to psychosocial support will allow all TB patients and those around them to overcome barriers such as stigma and discrimination clearing the path for them to stay in treatment. Patient support groups will help build a network of people with similar problems, drawing strength from each other, empowering each other so that they are able to fully recover from TB and go on to live productive and fulfilling lives.

The words of Sir William Osler have never been more true than today that - “Tuberculosis is a social disease with a medical aspect” and so looking for keys beyond medicine will bring real solutions and help deliver a patient centered approach to cure.

In an instant TB robbed me of my lifelong dream – which was to hear someone call me a mom someday. It robbed me of what I thought would be my greatest legacy. TB boldly invaded my life and my body robbing me of my sense of womanhood.

When TB and its social and psychological consequences tried to push me into darkness – because of the care I received I was able to not only move out of its shadow but am now doing everything in my power to cast light on the disease and those affected by it.

Because only in the light of day can TB be understood, its transmission rates thwarted and its sufferers supported. I am just one face among many, but my voice speaks for all those that are affected by TB.

I would like to end by thanking my friends at TAG for making sure that TB patients always have a seat at the table and I want to thank you all for including me here today and for your time and attention.