

# Let's Talk TB

A Series on Tuberculosis, A Disease That Affects Over 2 Million Indians Every Year

## What Counselling and Support Do Patients With Tuberculosis Need?

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### Abstract

*Persons affected by tuberculosis and their family members should be counselled at every opportunity, to address information gaps and to enable informed decision-making. Counselling should also address issues such as healthcare, physical, financial, psycho-social and nutritional needs. The objective of counselling is to meet the needs and ensure the rights of the patient. The objective is also to support the patient where possible to overcome barriers to successful treatment. During counselling, patients need to be informed about TB, how the disease spreads, signs and symptoms, consequences of not following treatment guidelines, why treatment is long and why completion of treatment is critical, likely adverse events during therapy, and cost involved in treatment and what free/public services are available to patients. Patients need to be told that TB is a fully curable and treatable disease. We must use patient centred approaches, and recognize that all TB patients deserve a minimum package of holistic TB care services that are not restricted to diagnosis and pharmacological treatment, but include counselling and support services as well.*

Key words: tuberculosis, counselling, patient support, patient-centric care

### WHY IS COUNSELLING IMPORTANT?

Have you ever walked into your GP's clinic, waited in line for 30 minutes, spent about 5 minutes with your doctor and left with a prescription in hand? Unfortunately, due to the extremely busy schedules of our GPs, the average consultation time lasts barely a few minutes and during this time, very few questions are asked of the patient.<sup>1,2</sup> A crucial step missing in this process is that of 'patient counselling'. In India, the patient-provider relationship is often one where there is unparalleled re-

spect for the physician; the patient often has blind faith in their diagnosis and subsequent treatment guidelines. Due to this asymmetric relationship and rushed consultation, patients do not always receive the adequate education and counselling they deserve.

Patient education is defined as follows: Education to help patients and their families understand the disease and treatment, cooperate with healthcare providers, live healthily, and maintain or improve their quality of life.<sup>3</sup> In the case of a disease such as tuberculosis (TB), patient education along with appropriate counselling i.e., enabling them to cope with the stress and take personal decisions related to the disease, is the need of the hour. TB in India is plagued by a number of challenges; some of these are related to the patient's inaccurate or incomplete knowledge, incorrect behaviour beliefs and stigma-generating attitudes. Patient counselling can therefore play a crucial to counter these problems.

The Revised National Tuberculosis Programme (RNTCP) of the Ministry of Health and Family Welfare (MoHFW) also recognizes the urgent need to scale up counselling and psychosocial support services for patients.<sup>4</sup> India's ambitious National Strategic Plan (NSP) for TB prevention and control (2012–2017) highlights that patient counselling through a professional counsellor is a missing link in the programme. It attributes counselling to be a critical intervention that can enhance treat-

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## Standards for TB Care in India<sup>6</sup> (STCI) states:

*Standard 26: Addressing counselling and other needs*

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ment adherence and improve treatment outcomes.<sup>5</sup>

## CHALLENGES FACED BY TB PATIENTS

The journey of a TB patient from the time of the onset of symptoms to treatment completion is not an easy one. Many of the factors that increase a person's vulnerability to TB or reduce their access to services to prevent, diagnose and treat TB are associated with their ability to realize their human rights.

A former TB patient herself, Deepti Chavan Musale highlights that, 'a TB patient has to deal with a lot of things including the side effects of the medicines, stigma, discrimination etc. Additionally the duration of treatment is very long and fighting TB is not only a physical battle but one that requires you to be very strong mentally too.'

In the case of TB, adherence to treatment is vital. Inability to comply can lead to advanced stages of TB, such as multi drug resistant (MDR) TB. TB drugs come with a host of side-effects and counselling helps patients become aware of the effects that they might face and the importance of compliance. Some of the side effects to commonly used TB drugs may include feeling sick or dizzy, skin rashes, pins and nee-

dles and flu like symptoms which become worse (e.g., jaundice) in the case of second line TB drugs used to cure MDR TB.<sup>7</sup>

Along with the potential of infecting families and communities, there is a deep-rooted stigma attached to a TB patient, which often prevents them from accessing services. Any gap in timely and accurate diagnosis and treatment perpetuates TB transmission, despite the widespread availability of effective and inexpensive treatment. The principal effects of stigma in developing countries are social isolation of patients, both outside the family, where the person may be avoided by former friends and acquaintances and inside the family where the patient may be forced to eat and sleep separately.<sup>8</sup>

Patient and family counselling plays an important role in addressing the above issues and also plays a role in helping patients deal with the financial burden and nutritional barriers to cure TB successfully.

## PATIENT COUNSELLING AND SUPPORT: WHEN AND HOW

Psychological distress such as depression and other mental co-morbidities have often been associated with TB,<sup>9</sup> with rates of mental illness reaching as high as 70% among TB patients.<sup>10</sup> Resulting chronic stress can impact a TB patient, firstly by impairing his or her immune system,<sup>11</sup> and secondly (and more specifically) affect his or her ability to adhere to treatment.<sup>12</sup> With challenges related to adherence to TB treatment resulting in a number of undesirable consequences, it is important to understand the contributing factors and the role for counselling. A critical review by Sabaté describes these as five interacting factors, i.e., socio-economic, health system, condition related, therapy related, and patient related.<sup>13</sup> Counselling, which can take on the form of simple infor-

mation sharing or more specialized services directed toward improving outcome expectations for the illness and encouraging patient self-efficacy and motivation to achieve a complete cure, can be used to address some of these contributing factors.

There are a number of tool-kits<sup>14,15,16,17</sup> that have been created to train counsellors for patient counselling. It is however important for the physician to also understand and value this component of TB care. Broadly summarizing the wealth of information cited, it is important to remember:

- The objectives behind counselling
- The type of counselling setting suitable to the patient
- The stage of the patient's care pathway

**The Objective.** As per the 'Patient's Charter for Tuberculosis Care', patients have the right to Care, Dignity, Information, Choice and Confidence.<sup>18</sup> The objective of counselling is to meet the needs and ensure the rights of the patient. The objective is also to support the patient where possible to overcome barriers to successful treatment.

**The Type.** Counselling can take place through providers adequately trained to identify the needs of the patient, through community engagements, support groups, and individual counselling.<sup>16</sup>

**The Stage.** *Before diagnosis* is confirmed, the patient must be informed of and understand all relevant information about the disease, its symptoms, the tests, the need for follow-up and treatment, and that it is treatable and curable.

*Once diagnosis* is confirmed and treatment is to be initiated, the patient must understand the regimen and its duration, the details of adverse drug reactions and what action to take if they encounter them, the importance of adherence and nutrition, the importance of infection

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control. It is equally important to enlist family support (if consented to) for the patient to successfully complete treatment. Once TB is diagnosed, it is important for the patient to also undergo HIV testing, and testing for other comorbid conditions such as diabetes. These tests also require counselling and education.

*After treatment* is underway, along with monitoring physical and biological parameters, in order to ensure adherence, motivation and psychological well-being, it is important that the physician understands the health needs of the patients including if necessary the need to be referred to trained counsellors, community level support groups or mental health services if needed.<sup>15</sup>

It is important therefore to acknowledge the need for a patient centred approach to TB care and understand its benefits.

## TAKING THE PATIENT CENTRED APPROACH

The 'Patients Charter for TB Care', states that each patient has a "right to receive timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives."<sup>18</sup> It is this information, which is often overwhelming for the patient, where counsellors can ensure the patient has a foundation in understanding the illness and the critical importance of treatment adherence. Patient programmes integrating counselling services can also significantly improve treatment adherence and the use of a multimodal approach is more effective in improving adherence than stand-alone programmes.<sup>19</sup>

An integral measure therefore in ensuring these patients receive the care they need and continue with their treatment regimen is providing counselling ser-

vices to strengthen the support system throughout their treatment timeframe. The model of implementing counselling as a supplement to treatment is not a novel technique, and has been successfully implemented for diseases such as HIV/AIDS.

Recognizing the importance of providing patient support services that include counselling, the RNTCP has also undertaken a project for providing integrated counselling services to TB patients. In May of 2014, in partnership with Population Services International, Project Axshaya was implemented to provide facility and home based counselling for DR-TB patients across 28 districts with the help of 30 DR-TB trained counsellors. Project Axshaya is implementing strategies that will increase capacity for healthcare providers and ensure patients are equipped with the knowledge to maintain treatment.<sup>20</sup>

Another example of a point-of-care and community-based counselling is the Saksham project. Saksham, is implemented by the Tata Institute for Social Sciences (TISS) and was developed to strengthen human and institutional capacities of the national health system in the field of HIV/AIDS counselling. Mumbai which is implementing counselling services for. Counselling services for HIV/AIDS patients have ensured patients understand the disease as well as limit risky behaviours which can increase the spread of the disease. Owing to the success of Project Saksham, TISS is leading the way in integrating counselling services for TB patients and families, building capacity through training healthcare providers and ensuring patients receive supportive supervised care while being treated for TB.<sup>21</sup>

It is evident that scaling successful models such as the ones implemented by Project Saksham and Project Axshaya are essential in ensuring TB patients are able and empowered to adhere to treatment guidelines. Implementing this approach will enable the patient to access the best possible care. Creating an environment which is supportive of TB patients is integral in addressing the societal problems faced by patients, and will strengthen the patients resolve while going through the treatment process.

TB patients continue to experience difficulties in navigating the path from diagnosis to cure and find it personally distressing. With the help of a dedicated counsellor, the journey to a TB free life would be much easier and is something which is not too difficult to provide. Rather than focusing on just the disease, it is imperative to treat the patient as a whole. We must use patient centred approaches, and recognize that all TB patients deserve a minimum package of holistic TB care services that are not restricted to diagnosis and pharma-

### Notes from a MDR-TB Patient Advocate

- Patients constantly need someone to motivate them and help them sail through this phase of life
- A counsellor can guide the patients and advise them on how to deal with their day-to-day problems
- Patients need a good listener who will hear them out and guide them appropriately
- A patient needs hope, hope that she/he will come out of all this and hope that there will be a better future. Who better than a counsellor can give her/him that?

Watch "Deepti's Story : From Survivor to a Champion" on YouTube - <https://youtu.be/hvaormVqOvE>

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## Key take away messages for healthcare providers

ALL TB PATIENTS DESERVE A MINIMUM PACKAGE OF COUNSELLING AND TB SERVICES

- **Use good communication principles when counselling all patients**
- **Explain the details of TB:**
  - What TB is?
  - How the disease spreads?
  - Signs and symptoms
  - Consequences of not following treatment guidelines
  - Why treatment is long and why completion of treatment is critical?
  - Likely adverse events during therapy
  - Cost involved in treatment and what free/public services are available to patients
- **Identify TB diagnosis and treatment services available to the patient at all government health facilities free of cost**
- **Explain that TB is a fully curable and treatable disease**
- **Listen to the patient and assure them the services they need are available**
- **Refer to mental health services for further psycho-social support where required**

ological treatment, but include counselling and support services as well. ■

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**Make TB the enemy and  
TB patients your friends**

• Complete cure is possible  
• TB does not spread through touch or by shaking hands  
• Befriend patients, don't discriminate

**TB HAREGA, DESH JEETEGA.**

For more information, consult your doctor.