

Manage TB
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Lecture - 68
Addressing Social Barriers in Tuberculosis Control-Session 01

Welcome to the session on Addressing Social Barriers in Tuberculosis Control. My name is Dr. Beena Thomas, I work as a social and behavioral scientist with the National Institute for Research and Tuberculosis at the Indian Council of Medical Research.

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Tuberculosis burden in India

- India accounts for one fourth of the global TB burden
- In 2015, an estimated 28 lakh cases occurred and 4.8 lakh people died due to TB

Estimates of TB burden (2015)	Global	India
Incidence TB cases	104 lakh	28 lakh
Mortality of TB	14 lakh	4.8 lakh
Incidence of HIV-TB	11.7 lakh	1.1 lakh
Mortality of HIV-TB	3.9 lakh	37,000
MDR-TB	4.8 lakh	1.3 lakh

Ref: TB India 2017, RNTCP Annual Status Report

Tuberculosis burden in India; it is alarmingly high despite all the strides that we have made to control tuberculosis. India still accounts for one-fourth of the global TB burden. As late as 2015 we had an estimated 28 lakh TB cases, 4.8 lakh people died due to TB. We have MDR TB which is on the rise with 1.3 lakhs.

So, what am I trying to say here?

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Where have we gone wrong?

- Disease control requires a multidisciplinary approach - one that looks beyond the biomedical and target driven model to manage any disease.

“Go to the people. Begin with what they know. Build on what they have...”

- We had always blamed the people for the failure to achieve TB control.



We have gone wrong somewhere disease control requires a multidisciplinary approach. One that looks beyond the biomedical and target driven model to manage any disease. So, we believe strongly very very popular Chinese proverb it says “Go to the people. Begin with what they know. Build on what they have”.

We had always blamed the people for the failure to achieve TB control. We had found the best regimens, we had decided that sanatorium care was not required and yet we found that TB continued to pose major public health challenges.

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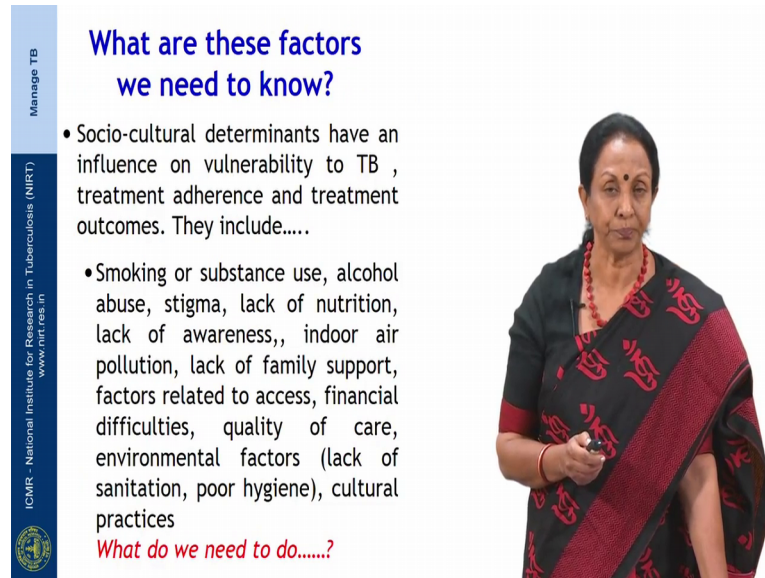
Why do we need to understand social factors?

- Control of any disease cannot be achieved so long as the disease is considered in isolation focusing only on the treatment without understanding the social and behavioral issues that influence it (*J.Ogden 1999*).



So, why do we really need to understand the social factors because control of any disease cannot be achieved, so long as the disease is considered in isolation only focusing on treatment without understanding the social and behavioral issues that influence it.

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What are these factors we need to know?

- Socio-cultural determinants have an influence on vulnerability to TB , treatment adherence and treatment outcomes. They include.....
- Smoking or substance use, alcohol abuse, stigma, lack of nutrition, lack of awareness,, indoor air pollution, lack of family support, factors related to access, financial difficulties, quality of care, environmental factors (lack of sanitation, poor hygiene), cultural practices

What do we need to do.....?



So, what are these factors that we need to know? There are many socio cultural determinants which I am going to be touching upon which not only have an influence on the vulnerability to TB, but also has an influence on treatment adherence and treatment outcomes.

So, what are they? They include smoking or substance use, alcohol abuse, stigma, lack of nutrition, lack of awareness, indoor air pollution, lack of family support, factors related to access, financial difficulties, quality of care, environmental factors which are manifold and cultural practices many more.

So, what do we need to do?

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Smoking or substance use

- Active smoking
- Role of passive smoking
- Second hand smoke
- Environmental Tobacco Smoke exposure (ETS)
- Active smoking increases risk of active TB 2-3 times
- Associated with chest symptoms

A study in India reported a relative risk of 2.68 (95% CI: 1.524.71) for M.TB infection in children less than five years of age who lived in a household with an index case of PTB and were exposed to ETS compared with children not exposed to ETS (Singh M, et.al Arch Dis Child 2005)



I would like to stress on smoking. Sometimes as doctors we kind of underestimate the influence that smoking has on vulnerability to TB. If you look at smoking it is not only in terms of active smoking but passive smoking.

Studies have shown the children below 5 years are 2.68 times more at risk to get TB as compared to those who are not exposed to TB. So, one always does not realize the dangers of smoking within the household especially with children whose mainstay is within the house as compared to children over 5 years.

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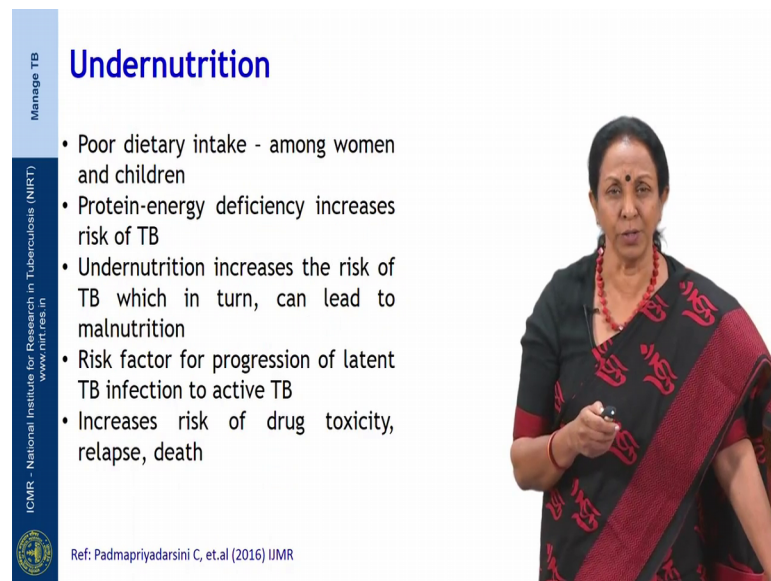
Indoor air pollution

- Cooking inside in open fire, biomass fuel
- Poor ventilation, rooms with no natural light
- Children under 5 years spend much time with their mother and thus receive higher exposures than older children, who may spend much time away from the household.



Indoor air pollution; there again we have smoke not only the smoke of tobacco, we have the smoke from fuel and this is especially in terms of biomass we find this not only in our urban slums and our rural but very very prevalent in private tribal areas. This coupled with poor ventilation with absolutely no natural light again exposes children not only children below 5, but also women most often.

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The slide features a vertical blue bar on the left with the text 'Manage TB' at the top, 'ICMR - National Institute for Research in Tuberculosis (NIRT)' in the middle, and 'www.nirt.res.in' at the bottom. The main title 'Undernutrition' is in blue. The bullet points are as follows:

- Poor dietary intake - among women and children
- Protein-energy deficiency increases risk of TB
- Undernutrition increases the risk of TB which in turn, can lead to malnutrition
- Risk factor for progression of latent TB infection to active TB
- Increases risk of drug toxicity, relapse, death

At the bottom left of the slide, there is a small circular logo and the reference text: 'Ref: Padmapriyadarsini C, et.al (2016) IJMR'. On the right side of the slide, there is a photograph of a woman with dark hair, wearing a black and red sari, holding a small object in her hand.

Under nutrition who are dietary intake among women and children. We always find that as caregivers women are more interested in providing nutrition, the limited nutrition that they have to their families. But they do not consume the nutrition that is required for them and you find that this translates very often into children being malnourished.

Protein energy deficiency has been widely reported as being one of the indicators for risk for TB. And again you find that under nutrition increases the risk of TB which again increases the risk of developing malnutrition. So, it is a kind of a vicious cycle.

Risk factor from a progression from latent TB infection to active TB one of the major ones as under nutrition. It also increases the risk of drug toxicity, relapse and death, how often does one ever view treatment of TB with this factor.

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Religious or cultural beliefs

- Culture influences health and healing practices
- Deep rooted belief in traditional healing
- Faith or spirit healing
- Superstitious beliefs



And then you find religious and cultural beliefs which again influences the kind of health seeking behavior patterns of patients. Most often they come to you after completely you know reaching saturation point trying to go to traditional healers or going through their superstitious beliefs or faith healing and we realize that so much of delay in seeking care.



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Lack of awareness

- Illiteracy
- Lack of knowledge on TB, ignorance
- Misconceptions on TB - symptoms, spread
- Poor awareness on healthcare facilities
- Delay in seeking care **TB ?**
- Catastrophic costs due to
- TB



All this compared with lack of awareness you find literacy; poor literacy has had a major role in just influencing care seeking behavior. Not only care seeking behavior which results in delays to diagnosis, but also when there is illiteracy they need to be more time

given to these patients to explain the whole prognosis, the need for adherence for better treatment outcomes. Again you find a lot of misconceptions on TB, you we realize through many of our studies that we always try to associate misconceptions with HIV, but the misconceptions on TB are manifold.

Again the fact that they have so little knowledge on the link between being symptom free and continuation of treatment, 2 months down the line they feel fine they stopped a treatment, look what is happening to us with MDR on the rise, how often as doctors do we take time to explain this to our patients. Again very few patients are even aware of the health care facilities that are available and this again results in delays in seeking care. Another profound truth is the way patients shop around for care and this results in unnecessary catastrophic cost you to TB.

One does not realize that by the time the diagnosis is made the patient has hopped through so many private and public doctors that they come you know sometimes even mortgaging their own house.

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Stigma and discrimination

- Marital prospects (Gender differences)
- Guilt and sense of shame
- Suicidal
- Threats
- Lack of social support
 - Rejection and loneliness
 - Social seclusion
 - Family/community shame of the infected person
- Hard to maintain social networks due to the symptoms
- Loss of job

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Ref: Ganapathy S, et.al (2008); Thomas B, et.al (2005), Somma D, et.al (2008).

The slide features a photograph of a woman in a black and red saree, standing and speaking. The background is a light blue gradient.

There are also factors which are related to stigma and discrimination. These are factors that most often doctors do not really you know think about. When you talk about a diagnosis of TB of a female patient in front of her husband we do not realize the kind of relationship that they have whether this disclosure is at the right time, how this disclosure

needs to be done, what needs to be disclosed and how important it is to maintain privacy and confidentiality.

The diagnosis is just made with whoever it is not realizing that this can have a lot of repercussions, how often are we sensitive to the needs of these patients. We also find that in many of our studies women go through this stigma more than men. Even bringing out sputum it is one never realizes the kind of shame that a woman goes through given a sputum cup or asked to just go and give sputum you know where she has nothing called privacy even to bring out the sputum.

These are issues which so often are overlooked and this affects the quality of the sputum it affects even the whole reaction that she has to the diagnosis of TB. We find not only an HIV, the TB also has reactions such as being suicidal, the threats of family breakups, lack of social support, rejection, loneliness, we find this more and more happening especially now with MDR TB which has come to stay. Women themselves exclude themselves you find very often they would say we do not even want to go for a function; we do not want to go coughing because people would look up at us and question us, men would say we are scared to even go to work.

So, these kind of issues cough is just taken you know so lightly you find that many of them have even been asked to shift house because of coughing. So, it is something that has resulted in sleepless nights, again how often do we address this issue of just not being able to sleep because of this coughing or the kind of fear that accompanies all these the actions that they go through. They find it very difficult to maintain their networks because they themselves it is a kind of cell stigmatization which we do not deal with.

Why I am stressing on the importance of knowing all these things as this is how the time that we take to even counsel the patients or we talk to them saying TB is a curable disease there is no need for all these reactions. The problem of cough and how it will slowly obey these kind of things, but the need to continue adherence we do not take time we just prescribe tell them to go and we do not realize the repercussions thereafter.

With this we conclude our first session.

Thank you for your attention.