changing the conversation: 
human rights and the power of words in tuberculosis care

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Objectives

At the end of this webinar, participants should be able to:
• Describe the human rights-based approach for patient-centered TB care;
• Assess one’s use of language and its implication during interactions with TB patients; and
• Share best practices for reducing stigmatizing language and empower patients to share their voices for TB
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Jigna Rao
TB Health Activist & Advocate

HUMAN RIGHTS AND THE ROAD TO ZERO TB

Mike Watson Frick
TB/HIV Project
WHO’s END TB Strategy

- 95% reduction in TB deaths by 2035
- 90% reduction in TB incidence by 2035
- Zero catastrophic spending due to TB

What are human rights?

- Universal, inalienable
- Defined by international law
- Primarily concerned with the relationship between individuals and their governments
- Governments are charged with the obligation to respect, protect and fulfill
- Rights can be civil and political (e.g., freedom of movement, religion etc.)
- Rights can be economic, social, or cultural (e.g., the right to health)
The right to health

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Human rights are interrelated

- Labor [article 7]
  - ...safe and healthy working conditions

- Health [article 12]
  - ...the highest attainable standard of health
  - ...the prevention, treatment and control of diseases

- Information [GC 14]
  - ...access to health-related education and information

- Scientific Progress [article 15]
  - ...to enjoy the benefits of scientific progress and its applications
Human Rights and Tuberculosis
An old story…?

“Detainees [in Russian prisons] are subjected to conditions in which they are guaranteed increased exposure to MDR-TB. In other words, increased TB risks should be seen as a violation of rights. TB as a form of punishment. This is due to overcrowding, ineffective infection control, tardy diagnosis and ineffective or interrupted treatment.”

“But we want treatment that can cure us.”

…that needs to be retold

“TB is a disease associated with poverty and social inequality that particularly affects vulnerable populations with poor access to basic services….TB has often been depicted as a disease driven by biomedical determinants, but increasingly efforts are focusing on addressing the social inequalities by putting affected people at the center of the health response.”

The Global Fund TB and Human Rights Information Note
What can human rights offer the response to TB?

- Human rights—and the right to health, in particular—must be used as **tools** to increase access to TB testing and treatment.

- In contrast to traditional public health (or strictly biomedical) approaches, a rights-based approach must:
  1) focus on underlying social & economic determinants of TB;
  2) articulate the rights of people living with and vulnerable to TB;
  3) encourage people to claim these rights.

- Rights-based approaches also establish the legal obligations of governments and other actors (e.g., drug manufacturers) to ensure good quality TB testing and treatment are available and accessible to all.

Adapted from Brian Citro et al, *Health and Human Rights* special issue on TB and the Right to Health

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How can human rights be put into Practice in TB Programs

What can someone working in a TB program do to integrate respect for human rights into individual patient care?

Here are a few—very much interrelated—starting points:

- Embrace patient-centered care
- Speak of rights alongside responsibilities
- Combat stigma and discrimination

…but first, a negative case example
Yellow car came to my house and ask the surname. She came out and put the gloves on and it was clear that this is bad. When she came inside the house, every thing was special and urgent…My child said, ‘We learned about this at school. It’s better when it’s MDR. When it’s X, it’s the last stage. That is when you are about to die’…I am sick of this vehicle because people knows about it…They were standing on the road, putting these things [i.e., masks] and writing names on the bottles…They don’t even come in the house. They ask while they are outside…[My son] just ran away. He doesn’t want to sleep there. It’s because they told me about XDR in his presence.


Embrace patient-centered care

Human rights principles are at the root of many of the activities that make up patient-centered care:

- Delivering care in culturally competent ways
- Supporting patient education (treatment literacy)
- De-centralizing care and limiting periods of institutionalization and isolation
- Reducing costs of treatment (where costs can be financial, psychological, social)
- Actively listening to patients and giving them a voice in decision-making
Speak of rights alongside responsibilities

“Few entitlements but plenty of duties…”

The TB Patient Charter lists rights and responsibilities …but never names who is in charge of upholding these rights (i.e., governments) …but never discusses what to do if rights and responsibilities conflict (i.e., deliberate, using tools like the Siracusa Principles)

The Siracusa Principles

When is it justified to limit human rights in the interest of public health or safety?

- Restrictions must be judged:
  1) necessary and
  2) proportional to the potential harm

- Restrictions on rights must be non-discriminatory and non-arbitrary

- Restricting one right cannot be used as a justification for limiting all rights

*People with TB don't just have sick bodies, they have rights-bearing bodies*
**Fight stigma and discrimination**  
*by avoiding stigmatizing language*

<table>
<thead>
<tr>
<th>Treatment default</th>
<th>Treatment non-completion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuberculosis suspect</td>
<td>Person to be evaluated for TB</td>
</tr>
<tr>
<td>Tuberculosis control</td>
<td>Tuberculosis prevention and care</td>
</tr>
<tr>
<td>Compliance</td>
<td>Adherence</td>
</tr>
<tr>
<td>Research subjects</td>
<td>Research participants</td>
</tr>
</tbody>
</table>


Photo: CA Towries for Treatment Action Campaign

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**Fight stigma and discrimination**  
*by avoiding the politics of fear*

Informing the public should not involve terrifying the public and turning sick people into would be TB (or HIV or Ebola or MERS etc.) terrorists.

1. Do we need to announce every case of MDR/XDR-TB?

2. When are we “raising awareness” and when are we stoking fear?
THANK YOU!
Questions / Comments / Thoughts?
(or advocacy issues you want to bring to our attention)
mike.frick@treatmentactiongroup.org
@mwfrick

Stop the Stigma
Declaration:
Funding from TAG to support stigma reduction project
Barbara J Seaworth M.D.
Medical Director
Heartland National TB Center
TB is Associated with Significant Stigma

We all recognize the stigma our patients face - what I did not realize for too long is how I may have added to that with my words.

Responsibility for Successful Treatment

“...the prescribing physician, ..., is carrying out a public health function with responsibility not only for prescribing and appropriate regimen but also for successful completion of therapy.”

ORGANIZATION AND SUPERVISION OF TREATMENT

“... IT IS ESSENTIAL THAT TREATMENT BE TAILORED AND SUPERVISION BE BASED ON EACH PATIENT’S CLINICAL AND SOCIAL CIRCUMSTANCES ......(PATIENT CENTERED CARE).”

MMWR Treatment of Tuberculosis, June 20, 2003
We are Charged to Provide Medical Care that:

- Cures the individual and is non-toxic
- Respects the individual person
- Allows the patient to participate as a partner
  - It follows ... they should be free of stigma from their providers
    - That means all of us caring for the individual
    - That means in every facet of our care

I and others had recognized that no one should be identified as “illegal”. Persons were not illegal!
We also recognized that "non-compliant" was a word that placed blame.

We stopped using this word too.

A Call to Change

Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?

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SUMMARY

The words 'defaulter', 'suspect' and 'control' have been part of the language of tuberculosis (TB) services for many decades, and they continue to be used in international guidelines and in published literature. From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and crim-
It hurts me to see how stigma has affected friends and those that I have met on my journey.

I am lucky.
I have a support system.

I am not a "suspect". The doctor suspects I have TB.
Civil society calls for the retirement of stigmatizing and criminalizing language from the global TB discourse

March 10, 2015 open letter requests that The Union take steps to retire the use of stigmatizing and criminalizing terminology from the papers published in its journals and the abstracts submitted to its conferences.

Language is very powerful — it is important for all of us to change the way we speak and write about this disease. We hope that this letter and actions taken by the Union will open a dialogue between advocates, members of civil society, researchers, health professionals, and academics necessary to truly eliminate stigmatizing terminology in TB.

The Union’s response to the open letter by José Luis Castro (Executive Director of The Union), March 12, 2015:

Thank you for voicing your concerns ... The Union fully acknowledges that some of the terms that have been used for many years to describe TB activities can serve to stigmatize people affected by TB. Ultimately the responsibility for providing TB effective and high quality treatment and care falls on the healthcare system, not on individuals impacted by the disease. ...

The Union is committed to communicating in a manner that embodies respect for all people affected by TB. We will include guidance and a link to the Stop TB Partnership’s language guide in our abstract submission guidance for our conference participants. We have also shared your letter with the Editors in Chiefs of our journals, International Journal of Tuberculosis and Lung Disease and Public Health Action, and will pursue appropriate language guidance.

Thank you.
José
National Society of TB Clinicians supported the letter

Sent letters to each speaker at the national conference asking them to avoid stigmatizing language.

I asked myself - “What More Can Be Done to Make an Impact?”
...and with the help of the staff at Heartland National TB Center and patients at the Texas Center for Infectious Disease

Attitude and Passion can trump the stigma associated with TB.

#CommitToChange #StopTheStigma
We launched our campaign at the National TB Conference in Atlanta, June 9, 2015

Heartland Staff and Heartland’s Advisory Committee Started the Day by Wearing Our T-Shirts

We Asked Others to Pledge to Join Us
We Passed Out Calendars and Armbands

Testimonials of persons affected by TB Disease who participated in the “Stop the Stigma” Project were shown on large screens as attendees entered the meeting.

Their Stories Were Powerful!
“I am here to remind you that...”

“I am a person living with Tuberculosis and I need prevention and care.”
“I am not a TB suspect who needs TB control.”

#LANGUAGEMATTERS
#STOPTHESTIGMA #TB
Eliminating Stigmatizing Language

Members of the public health community understand the importance of using language that promotes the health and well-being of people with tuberculosis (TB). Stigmatizing language such as “defaulter,” “scofflaw,” or “scarecrow” is not only unhelpful but also judgmental, intimidating, and always biases on patients. Heartland has committed to join forces with patient advocates from the Global TB Community, the International Union Against TB and Lung Disease, and the American Thoracic Society to eliminate stigmatizing language. We are proud to introduce “Stop the Stigma”, a campaign to spread awareness and promote the elimination of the use of stigmatizing language to the public health workforce. We would like to invite you to join us and pledge yourself, your organization, and challenge others to pledge as well.

Supporting Documents
- TB Pulse Watcher
- MultiTB: Language in TB
- Open letter
- Stop Stigmatizing
- Brochure
- Pledge Form
- Pledge Sign

Health care professionals need to learn about TB disease.
I don’t want them to be scared of me.

I am a person. I am just like them. I am a nurse.
She was passionate about The Stigma Project. She served others her entire life. Her life made a difference.
HEARTLAND HAS ISSUED THE CHALLENGE

What is holding you back?

http://www.heartlandntbc.org/stopthestigma/index.php
San Antonio Metro Health Accepts the Challenge

National Level
What Can a Training Center Do?

Ask our speakers to eliminate stigmatizing language from their presentations.

Commit to eliminate stigmatizing language from our products.

Teach our participants about the negative effects that language can have on those affected by TB.

State Level
Local Level

Tommy Camden
Tuberculosis Health Program Manager
San Antonio City Chest Clinic

Mary Ann Rodriguez
Medical Director, Communicable Disease Unit
City of Austin Health and Human Services

Are you next?

Who can you challenge?

Thank you HNTC Staff and TCID Patients
You Have Truly Made a Difference!
Language Matters: The Power of Words

Jigna Rao
TB Activist & Advocate
TIME TO CHANGE THE LINGO

- TB bacteria is within a person’s body
- Diagnosis does not mean that the person is now defined by the bacteria he or she carries

TB Can Affect Anyone .. Even YOU

THEY

WE
STOP the “HUNTING”..

Definition | HUNT : To pursue and kill (a wild animal)

..and the Dehumanization
Language is not static
Modernize TB-related language

- Defaulter
- Suspect
- Non-compliant
- TB Control
- TB Patient (label)
- TB Suspect (label)
- Infected (associated with corrupt, dirty, tainted)

The BIG impact of little things

✓ Person affected by TB | TB Patient
✓ Persons affected by TB | People

✗ Acronyms= Loss of identity as human beings
✗ Limited use of the word “infection”
WHO is responsible for changing the language?

- Researchers and Scientists
- Medical Experts
- Clinicians, Healthcare providers
- Public Health Officials
- Media
- Health Advocates
- Community

WHAT do we do?

- **STOP**: Stigmatizing language and blame-game

- **RECOGNIZE**: People affected by TB are best suited to created this manifesto

- **BRING**: Multi-disciplinary scientists and experts together to find effective solutions
Sticks and stones may break my bones
But names will never hurt me!

• No one can control the air they breathe - but we can all control the words we use..

• Words are powerful - As Emily Dickinson writes, "I know nothing in the world that has as much power as a word...

• Change the words used to form the language around TB = End the stigmatization.

THANK YOU!
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