What's New:
Stigmatizing Language and Substance Use Disorder Terminology in TB Care

World TB Day

What is Heartland Talking About

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Objectives

❖ Define Stigma

❖ Discuss Stop the Stigma in TB Care Movement

❖ Discuss the effect of Stigma on substance use disorder and preferred terminology

❖ Stigma defined

What is Stigma?

"Stigma is a mark of disgrace that sets a person apart from others. When a person is labelled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination."

Stigma-Free Society. https://stigmafreesociety.com/stigma/ Accessed June 16, 2020.

"A sign or a mark that designates the bearer as *spoiled* and therefore as valued less than *normal* people."-Goffman E. (1963)

How Can Stigma Affect Healthcare?

❖ Stigma is linked to poor health.

❖ Stigma is associated with greater social isolation.

❖ Social isolation increases risk for poor health outcomes.

❖ Stigma-health relationship is significantly strained after adjustment for social isolation.

Hatzenbuehler, M., Phelan, J., Link, B., Stigma as a Fundamental Cause of Public Health Inequalities, American Journal of Public Health, May 2013, Vol 103, No.5

How Can Stigma Affect TB Care?

❖ Contributes to a delay in diagnosis

❖ "At-risk individuals report that fear of TB stigma and the social and economic impact of stigma affects their willingness to undergo TB screening and to seek medical care after the onset of symptoms associated with TB."

❖ "Individuals with TB and their health-care providers also identify TB stigma as a cause of non-completion of treatment."

Courtwright, A., & Turner, A. N. (2010). Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports*, *125*(Suppl 4), 34–42.

The Stigma of Tuberculosis

❖ "Fear of infection is the most common cause of TB stigma"

❖ By using non-stigmatizing language we can begin to breakdown the stigma associated with TB.

Courtwright, Andrew, and Abigail Norris Turner. "Tuberculosis and Stigmatization: Pathways and Interventions." Public Health Reports 125.Suppl 4 (2010): 34–42. Print.

People First Language

For example:

When referring to a person with a disability, refer to the person first by using phrases such as:

- ✓ A person who …
- ✓ A person with …
- ✓ Person who has…

Communicating With and About People with Disabilities

About 50 million Americans report having a disability. Most Americans will experience a disability some time during the course of their lives. Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see.

People First Language

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: "a person who …", "a person with …" or, "person who has…"

Here are suggestions on how to communicate with and about people with disabilities.

People First Language	Language to Avoid
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with an intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defective or retarded, afflicted, special person
Person with an emotional or behavioral disability, person with a mental health or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Person who is hard of hearing	Hearing impaired, suffers a hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak, or uses a device to speak	Mute, dumb
Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
Person with a physical disability	Crippled, lame, deformed, invalid, spastic
Person with epilepsy or seizure disorder	Epileptic
Person with multiple sclerosis	Afflicted by MS
Person with cerebral palsy	CP victim
Accessible parking or bathrooms	Handicapped parking or bathroom
Person of short stature	Midget
Person with Down syndrome	Mongoloid
Person who is successful, productive	Has overcome his/her disability, is courageous

For more information about disability and health, visit www.cdc.gov/disabilities

National Center on Birth Defects and Developmental Disabilities
Office of the Director

CDC

CS214508-A

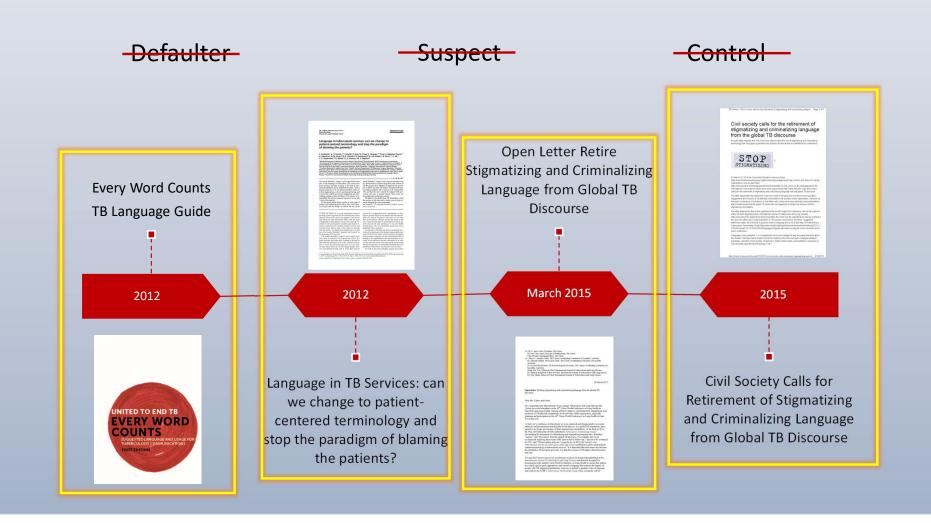http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter_photos.pdf

Where it All Began

Roots of the Language Change Movement in TB Care

Timeline

~~Defaulter~~   ~~Suspect~~   ~~Control~~

Every Word Counts
TB Language Guide

Open Letter Retire Stigmatizing and Criminalizing Language from Global TB Discourse

| 2012 | 2012 | March 2015 | 2015 |

Language in TB Services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?

Civil Society Calls for Retirement of Stigmatizing and Criminalizing Language from Global TB Discourse

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 criminalising, tending to place the blame of the disease or responsibility for adverse treatment outcomes on one side —that of the patients.

In this article, which brings together a wide range of authors and institutions from Africa, Asia, Latin America, Europe and the Pacific, we discuss the use of the words 'defaulter', 'suspect' and 'control' and argue why it is detrimental to continue using them in the context of TB. We propose that 'defaulter' be replaced with 'person lost to follow-up'; that 'TB suspect' be replaced by 'person with presumptive TB' or 'person to be evaluated for TB'; and that the term 'control' be replaced with 'prevention and care' or simply deleted. These terms are non-judgmental and patient-centred.

We appeal to the global Stop TB Partnership to lead discussions on this issue and to make concrete steps towards changing the current paradigm.

KEY WORDS: TB; language; defaulter; suspect; control; loss to follow-up

A Call to Change

Defaulter ✓ Person lost to follow-up

Suspect ✓ Person with presumptive TB

Control ✓ Prevention and care

Suspect

- Suspect (verb)
  - To believe or feel that (someone) is guilty of an illegal, dishonest or unpleasant act, without certain proof

- Suspect (noun)
  - Person thought to be guilty of a crime or offense

- Why did the TB community decide to transfer the 'suspicion' of the disease to the patient?

Default/a defaulter

- Oxford English dictionary
  - A person who fails to fulfill a duty, obligation or undertaking

- Banking context
  - To fail to repay a loan

- Legal context
  - Failure to appear in court when summoned by a judge

- Context of competition
  - Failure to take part in or complete a scheduled contest

- Common feature:
  - blame is designated by someone in a decision-making position upon another in the community

Control

- National TB 'Control' Programs

- Control
  - To limit, regulate or restrict an activity or a process
  - To maintain influence and authority over behavior
  - Synonymous terms:
    - power, to dominate, and be in charge of

"Control"

❖ What is being controlled here?
- TB? The patient? The affected community?

❖ 'control of tuberculosis' may inadvertently lead to programs trying to take control of tuberculosis patients by infringing on their rights and autonomy

❖ May be interpreted as something done to, rather than something done for, the patient

R. Zachariah. INT J TUBERC LUNG DIS 16(6):714–717

Substance Use Disorder (SUD) and Stigma

The National Institute on Drug Abuse produced a Words Matter publication, titled Terms to Use and Avoid When Talking About Addiction

Where does stigma come from?

For people with SUD, stigma may stem from antiquated and inaccurate beliefs that addiction is a moral failing.

How does stigma affect people with SUD?

- Feeling stigmatized can reduce the willingness to seek treatment.

- Stigmatizing views of other can lead them to feeling pity, fear, anger, and desire for social distancing

- Stigmatizing language can negatively influence health care provider perceptions, which can impact the care they provide.

Words Matter - Terms to Use and Avoid When Talking About Addiction | National Institute on Drug Abuse (NIDA)

Substance Use Disorder (SUD) and Stigma

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❖ These terms are discouraged when talking for the patients. There are alternative terms as who may wish be affected by substance use disorder.

When discussing test results, refer to TB patients who may well.

Dirty:
Not this

Use this

For toxicology screen results, use Testing positive

Addict / For non-toxicology purposes, use Person who uses drugs

Person with substance use disorder

Habit

Drug addiction

Clean

Abuse

Uses (for illicit drugs) and Misuse (for RX meds)

For toxicology screen results, use Testing negative

For non-toxicology purposes, use Abstinent from drugs

Addicted baby

Newborn exposed to substances

NIDAMED

Words Matter
Terms to Use and Avoid When Talking About Addiction

This handout offers background information and tips for providers to keep in mind while using person-first language, as well as terms to avoid to reduce stigma and negative bias when discussing addiction. Although some language that may be considered stigmatizing is commonly used within social communities of people who struggle with substance use disorder (SUD), clinicians can show leadership in how language can destigmatize the disease of addiction.

Stigma and Addiction

The TB Suspect

- Suspect (verb)
  - To believe or feel that (someone) is guilty of an illegal, dishonest or unpleasant act, without certain proof

- Suspect (noun)
  - Person thought to be guilty of a crime or offense

- Why did the TB community decide to transfer the 'suspicion' of the disease to the patient?

The Defaulter

- **What is default/a defaulter?**
  - Oxford English dictionary
    - A person who fails to fulfill a duty, obligation or undertaking
  - Banking context
    - To fail to repay a loan
  - Legal context
    - Failure to appear in court when summoned by a judge
  - Context of competition
    - Failure to take part in or complete a scheduled contest

- **Common feature:**
  - blame is designated by someone in a decision-making position upon another in the community

Common Causes of 'Default'

- Lack of regular, uninterrupted supply of drugs

- Patients having to pay for their drugs

- Lack of accessible ambulatory treatment centers in rural and urban settings (increased travel costs and time)

- Inconvenient clinic hours, long waiting times

- Lack of adequate numbers of motivated and friendly health workers

- Inappropriate patient education

- Lack of various alternative forms of treatment support (community, workplace or other)

- Lack of readily accessible joint HIV and TB services

Control

- National TB 'Control' Programs

- Control
  - To limit, regulate or restrict an activity or a process
  - To maintain influence and authority over behavior
  - Synonymous terms:
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Tackling TB stigma – a necessary step toward humanizing TB"

Blessina (Blessi) Kumar
Global Coalition of TB Activists
The Union, 2018

"I would like people who have been affected by stigma to be influencing decisions about how it should be addressed. There is no easy recipe for tackling stigma, it is about changing the behavior of society and that's not going to happen overnight. It needs to start with, not only addressing TB in a way that upholds the rights of the person"
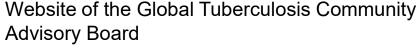
"I want the TB world to recognize that, as long as we only focus on the bio-medical, that alone is not going to end TB"

Who are our patients and what do we do for them?

❖ Are they defaulters?
- ✓ Or are they lost to follow up?

❖ Are they TB suspects?
- ✓ Or are they persons we suspect have TB disease?

❖ Do we 'control'?
- ✓ Or do we 'care and prevent'?

Let's Work Together to End TB!

Website of the Global Tuberculosis Community Advisory Board

[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.*

Stigma Product

Heartland offers educational material on preferred language to help eliminate TB stigma.

If you would like a copy, please visit Heartland's website for a downloadable copy.

Heartland National TB Center

https://heartlandntbc.org/

Eliminating Stigmatizing Language

Non-hurtful Replacement Language

Key Terms suggested by the Stop TB Partnership

Use this.....	Not that.....
Adherence / Non-adherence	Compliance / Non-compliance
Person lost to follow up	Defaulter
TB Prevention and Care	TB Control
Person to be evaluated for TB	TB Suspect
HIV-Positive	HIV-infected

HNTC Survey Results

Language suggested by participants

Use this.....	Not that.....
TB Infection	Latent TB
Lack of housing; Under-housed; People experiencing homelessness	Homeless/Homelessness
Immigrant	Alien
Undocumented	Illegal; Illegal alien
Person with TB disease	TB case
Treatment failed	Treatment failure
Missed doses/Non-adherent	Delinquent
Contact Analysis; Contact Elicitation; Contact Identification	Investigation; Investigate
Exposed to TB	TB contact
Tuberculosis	Consumption; White Plague

Stigmatizing language and suggested replacements was identified by an HNTC survey requesting pledgers to identify language that they personally experienced or witnessed.
**This list is non-inclusive.

Supported by Treatment Action Group (TAG)