A Discussion of Ethics in TB Care

Erin Corriveau, MD, MPH

July 18, 2024

TB Intensive
July 16 – 18, 2024
San Antonio, Texas

Erin Corriveau, MD, MPH has the following disclosures to make:

- No conflict of interests
- No relevant financial relationships with any commercial companies pertaining to this educational activity

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Objectives:

- We will discuss ethical issues in caring for patients and families affected by tuberculosis, with special attention to the following:
  - Minimizing stigma
  - Caring for patients who have few resources
  - Prevention
  - Palliative care

My background…

- Training:
  - Family & Community Medicine
  - Preventive Medicine
  - TB training ‘on the ground’ and at Heartland
- Director, Division of Community Health
- Medical Director, local public health department

- Root Mentors:
  - Arthur Kaufman, MD, Helene Silverblatt, MD, and H. Jack Geiger, MD

“Ethics”

Ethics aim to figure out what the right thing to do or the best course of action may be. They can help guide our behavior as we interact with patients, plan programs, or determine policies. Ethics are ‘external’, socially constructed. They help us justify what is right and wrong. They are a structured system to guide appropriate conduct.

Bioethics is the interdisciplinary study of ethical issues arising in science policy, health care, and the life sciences.

The Hastings Center. https://www.thehastingscenter.org/what-is-bioethics/
Vermont Ethics Network: https://vtethicsnetwork.org/medical-ethics/overview

Where does morality come in?

- Morals may be driven by personal beliefs and values but also tend to be “group think” beliefs. It’s your group’s customs, values, and beliefs.

- WHEW!
  - Ethics are determined for you…a code of conduct.
  - You don’t have to be moral to be ethical.
  - But watch out – you could violate ethics because of a moral belief.

Core Principles of Medical Ethics:

- Beneficence
  - Duty to act in the patient's best interest and to help the patient advance their own good.
- Autonomy
  - Duty to honor patient decisions and self-determination regarding their care.
- Nonmaleficence
  - Duty to do no harm.
- Justice
  - Duty to be fair in how care is provided and how resources are allocated.

Vermont Ethics Network: https://vtethicsnetwork.org/medical-ethics/overview

Changing Medical Model

- 1977 ushered in the “biopsychosocial” model
  - Medical care no longer regarded the patient as a disease carrier, or just a disease
  - Health now conceived of as a combination of biological, psychological, and social factors

•George L. Engel, The Need for a New Medical Model: A Challenge for Biomedicine.*Science***196**,129-136(1977).DOI:10.1126/science.847460

How do we apply this new medical model?

“Patient” vs. “Person” Centered Care

- Differ in their connotation
- Overlap in some ways, but subtle differences

I’ll make a case for “Person Centeredness” in Tuberculosis Care….

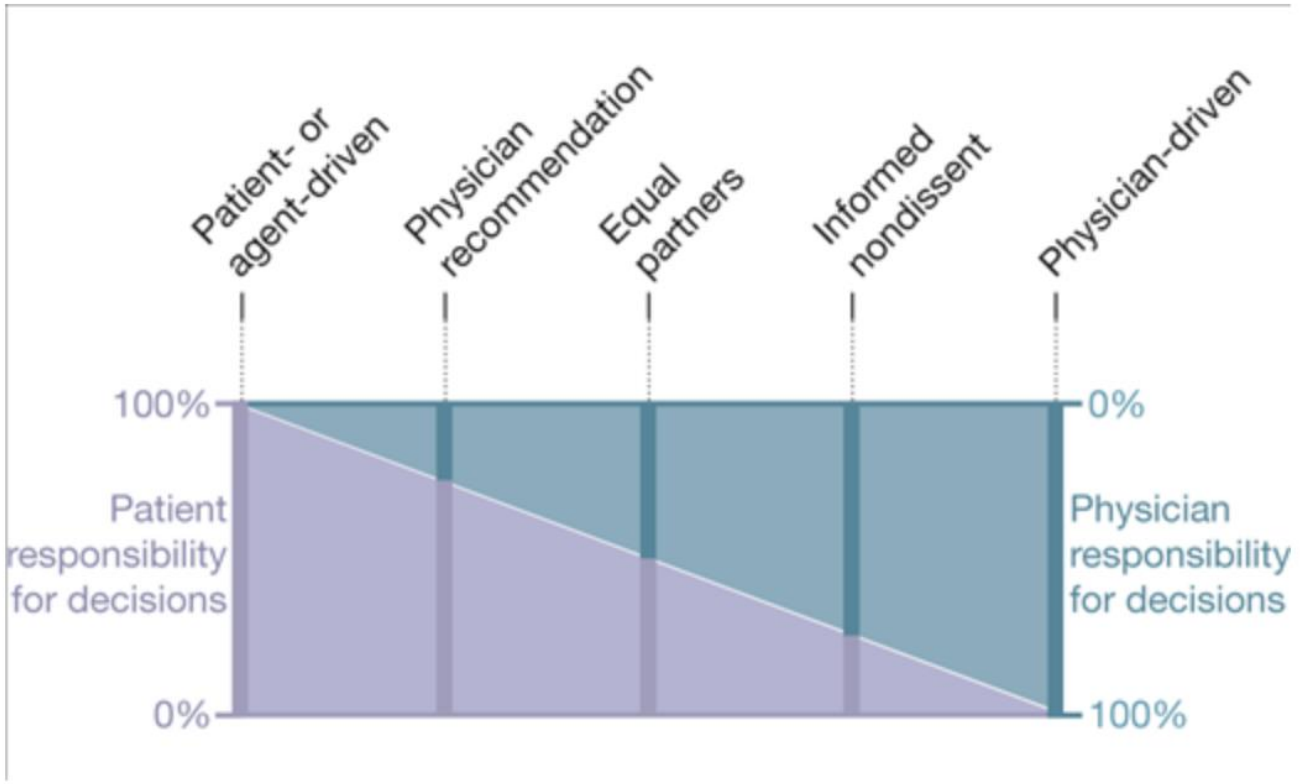
Patient Centered Care

- "….health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences. Moreover, patients have the education and support they need to make decisions and participate in their own care."

Institute Of Medicine, US. Crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press (US); 2001.

Institute Of Medicine, US. Envisioning the national health care quality report. Washington (DC): National Academies Press (US); 2001.

Figure. Shared Decision-Making Continuum



Kon AA. The Shared Decision-Making Continuum. *JAMA.* 2010;304(8):903–904. doi:10.1001/jama.2010.1208

Patient Centered Care continued -

- Disease-driven, and assumes a process of treatment
- Based in health-care encounters
- Pays close attention to the evolution of disease, and disease management

Zhao, Junqiang, et al. "Differentiation between two healthcare concepts: Person-centered and patient-centered care." *J Nurs* 2352.0132 (2016): 10-1016.

Starfield, B. MD, MPH. Is Patient-Centered Care the Same As Person-Focused Care? Special Report, The Permanente Journal. Vol 15, No. 2. June 1, 2011. https://doi.org/10.7812/TPP/10-148

Let's take the discussion further…

What is *Person* Centered Care?

- Views personhood in an integrated way
- More of a Health Promotion concept
- Disease episodes are part of the life-course
  - Diseases are interrelated
  - concerned with how persons experience health problems
- Does not rely only on the healthcare system
- Interdisciplinary
- Broad, integrated, and interrelated

Zhao, Junqiang, et al. "Differentiation between two healthcare concepts: Person-centered and patient-centered care." *J Nurs* 2352.0132 (2016): 10-1016.

Starfield, B. MD, MPH. Is Patient-Centered Care the Same As Person-Focused Care? Special Report, The Permanente Journal. Vol 15, No. 2. June 1, 2011. https://doi.org/10.7812/TPP/10-148

Patient-centered care	Person-focused care
Generally refers to interactions in visits	Refers to interrelationships over time
May be episode oriented	Considers episodes as part of life-course experiences with health
Generally centers around the management of diseases	Views diseases as interrelated phenomena
Generally views comorbidity as number of chronic diseases	Often considers morbidity as combinations of types of illnesses (multimorbidity)
Generally views body systems as distinct	Views body systems as interrelated
Uses coding systems that reflect professionally defined conditions	Uses coding systems that also allow for specification of people's health concerns
Is concerned primarily with the evolution of patients' diseases	Is concerned with the evolution of people's experienced health problems as well as with their diseases

Starfield, B. MD, MPH. Is Patient-Centered Care the Same As Person-Focused Care? Special Report, The Permanente Journal. Vol 15, No. 2. June 1, 2011. https://doi.org/10.7812/TPP/10-148

Can be complementary to Patient-Centered
Accessible
Comprehensive
Continuous relationships
Accrues over time
Not disease-oriented
Patient Priorities
Patient's viewpoint of issues
Not the sum of care for individual diseases

Person-Centered

Patient-Centered

Quality interaction between patient and clinician
Excellent communication enhancing

- **Trust**
- **Patient enablement, informed choices**
- **Understanding**

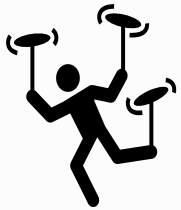
Person Centered TB Care?

"TB is a disease of poverty and inequality that particularly affects key vulnerable populations with little or no access to basic services. A human rights-based approach to TB prevention, treatment and care includes addressing the legal, structural and social barriers to quality TB prevention, diagnosis, treatment and care services"

The Global Fund to Fight AIDS, Tuberculosis and Malaria, Global Fund Information Note: TB and human rights (February 2013)
World Health Organization's Guidance on the ethics of tuberculosis prevention, care and control, published in 2010

There’s more to the story…

- Care for persons with TB is especially complex, because we must be guided not only by medical ethics, but also public health ethics!



Public Health ethics

Person-Centered

Patient-Centered

Parasidis E, Fairchild AL. Closing the Public Health Ethics Gap. N Engl J Med 2022; 387:961-963. DOI: 10.1056/NEJMp2207543

Within public health ethics and in caring for persons with tuberculosis, 2 important pillars:

- Social Justice
- Human Rights

Social Justice:

- In terms of Health:
  - concerned with inequalities and with the fair distribution of advantages and burdens among people

- Especially important in caring for persons with TB:
  - Social inequalities drive TB, and TB drives many people deeper into poverty. Ending TB and addressing social determinants of health are interdependent.

  - Social Justice captures "…the twin moral impulses that animate public health: to advance human well-being by improving health and to do so by focusing on the needs of the most disadvantaged"

Ethics guidance for the implementation of the End TB strategy. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO

Gostin LO, Powers M. What does social justice require for the public's health? Public Health Ethics and Policy Imperatives. Health Aff (Millwood) 2006; 25(4):1053–60.

Human Rights:

- Human rights are special rights that people have simply by virtue of being human. Human rights are legal guarantees that protect individuals and groups against actions that interfere with fundamental freedom and human dignity, while establishing entitlements requiring positive actions.

- They encompass civil, cultural, economic, political and social rights and are enshrined in international treaties, such as the International Covenant on Economic, Social and Cultural Rights

- Human rights are a concrete legal expression of a certain set of ethical values, including human dignity, equality, non-discrimination, participation, solidarity and accountability

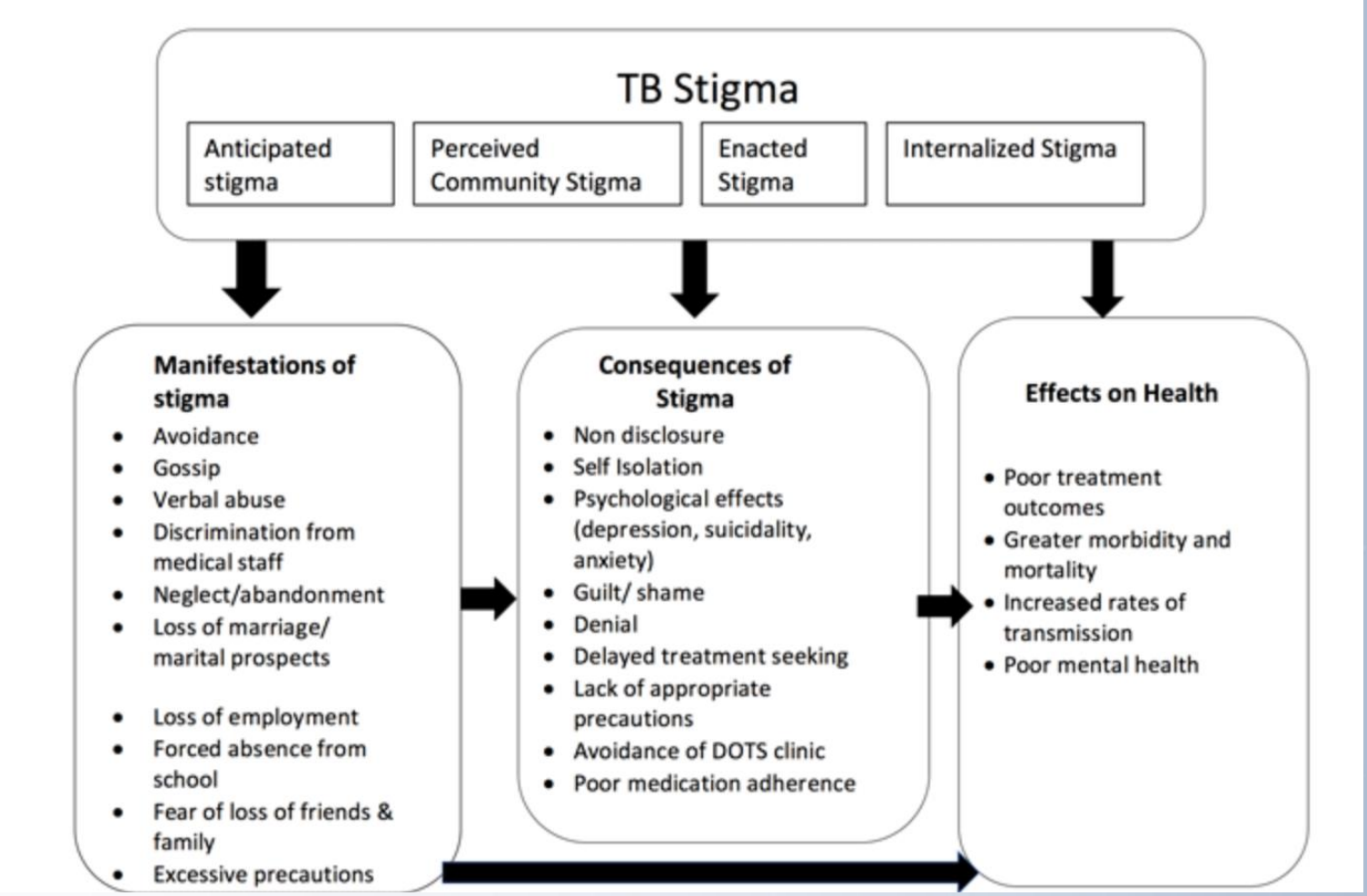
Ethics guidance for the implementation of the End TB strategy. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO
United Nations, International Covenant on Economic, Social and Cultural Rights. [website] (http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx, accessed 10 February 2017).
International Covenant on Economic, Social and Cultural Rights. 16 December 1966. Geneva: Office of the United Nations High Commissioner for Human Rights

...and several important TB care values

- Equity
- Common Good
- Solidarity
- Reciprocity
- Harm Principle
- Trust and Transparency
- Duty to Care
- Effectiveness
- Efficiency
- Proportionality
- Participation and community engagement
- Respect and Dignity
- Autonomy
- Privacy and Confidentiality

How do we apply person-centeredness along with public health ethics, values and goals to our everyday work with persons with TB disease, LTBI, and with those at risk?

Let's start with issues of ***stigma:*** defined as negative or discriminatory attitudes; negative and unfair beliefs



Mukerji, Rand J M Turan. "Exploring Manifestations of TB-Related Stigma Experienced by Women in Kolkata, India". *Annals of Global Health*, vol. 84, no. 4, 2018, p. 727-735.DOI: https://doi.org/10.29024/aogh.2383

Words matter

- The language used in TB-related communication has been implicated in the disenfranchisement and stigmatization of people affected by TB leading, in instances, to violations of their human rights
  - “case” no, you’re talking about a person!
  - “suspect” instead use “person with presumed TB”
  - “defaulter” instead use “person lost to follow-up”
  - “non-compliant” instead use “non-adherent”

- We in healthcare commonly framed issues as the responsibility of affected individuals rather than its bio, social, structural, etc. determinants or arduous treatment course

Citro B, Soltan V, Malar J, Katlholo T, Smyth C, Sari AH, et al. Building the Evidence for a Rights-Based, People-Centered, Gender-Transformative Tuberculosis Response: An Analysis of the Stop TB Partnership Community, Rights, and Gender Tuberculosis Assessment. *Health Hum Rights*. 2021;23(2):253–67. Epub 2021/12/31

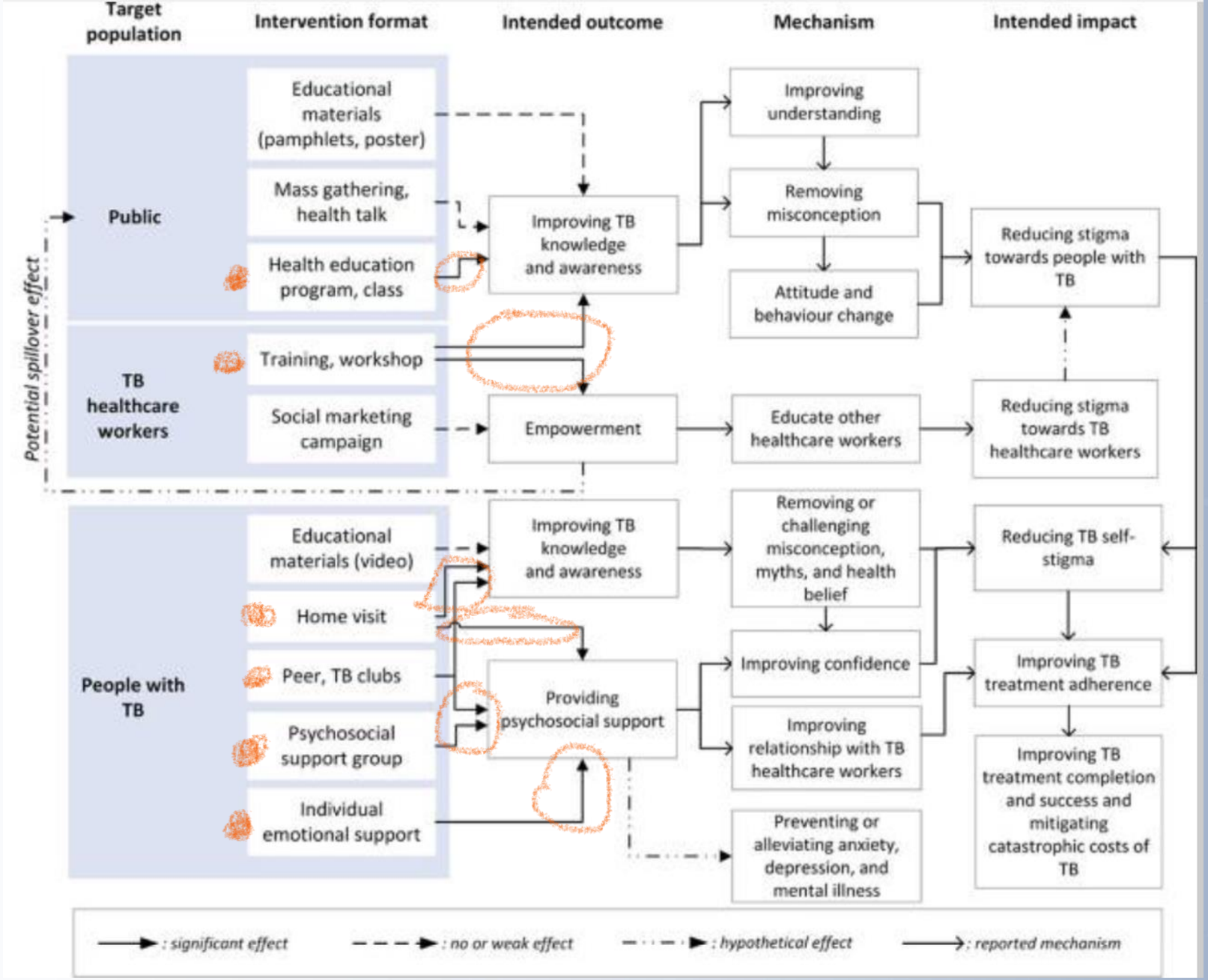
Words matter: Suggested language and usage for tuberculosis communications. Geneva: The Stop TB Partnership, 2022.

Umana B, Vorstermans J, Lewa R, Garcia D, Malar J, Daftary A. Transforming the language used in tuberculosis care. PLOS Glob Public Health. 2023 Mar 23;3(3):e0001657. doi: 10.1371/journal.pgph.0001657. PMID: 36963075; PMCID: PMC10035744.

Knowledge, Health Seeking Behavior and Perceived Stigma towards Tuberculosis among Tuberculosis Suspects in a Rural Community in Southwest Ethiopia

Gemeda Abebe, Amare Deribew, Ludwig Apers, Kifle Woldemichael, Jaffer Shiffa, Markos Tesfaye, Alemseged Abdissa, Fetene Deribie, Chali Jira, Mesele Bezabih, Abraham Aseffa, Luc Duchateau, Robert Colebunders

Published: October 11, 2010 • https://doi.org/10.1371/journal.pone.0013339

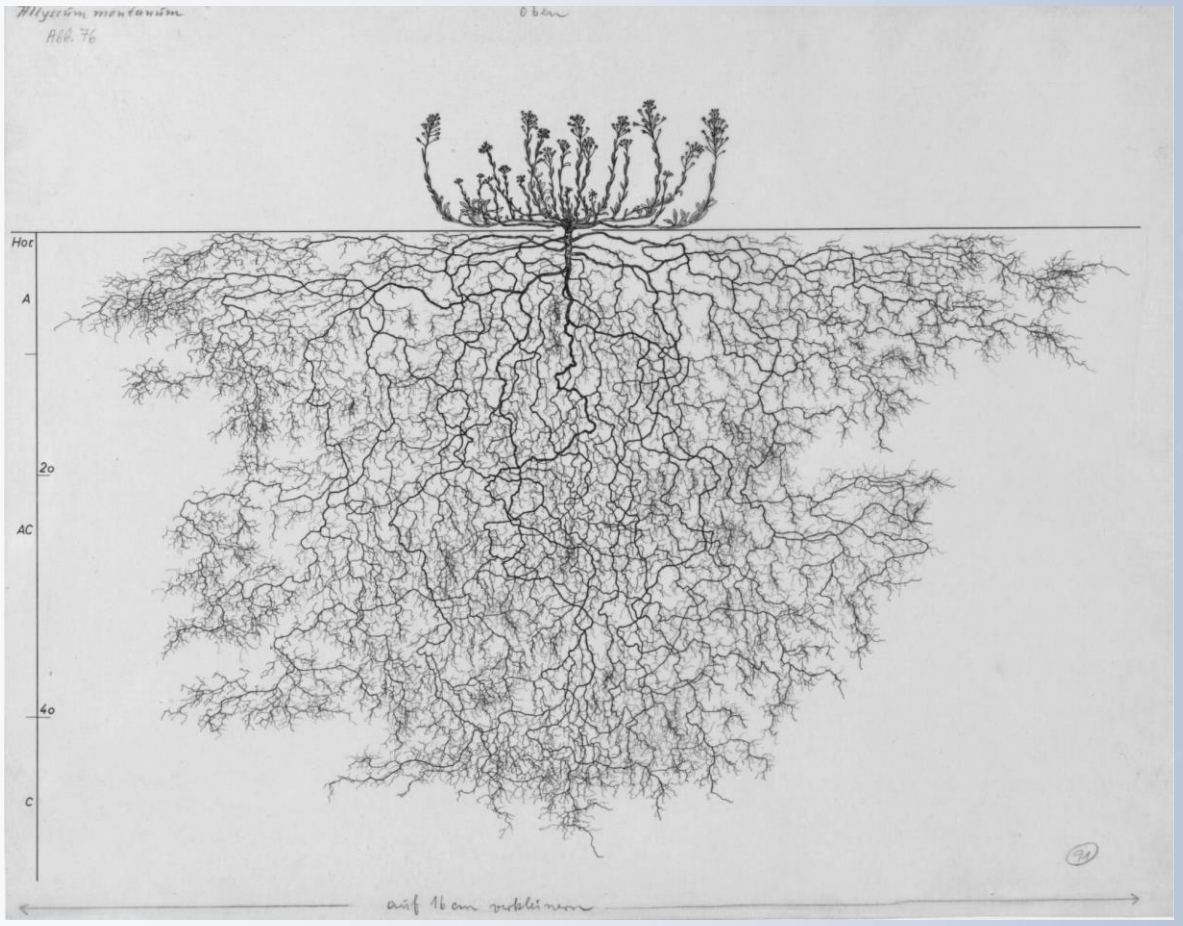


Nuttall C, Fuady A, Nuttall H, Dixit K, Mansyur M, Wingfield T. Interventions pathways to reduce tuberculosis-related stigma: a literature review and conceptual framework. Infect Dis Poverty. 2022 Sep 23;11(1):101. doi: 10.1186/s40249-022-01021-8. PMID: 36138434; PMCID: PMC9502609

Consider the ways you can either cool off or fan the flame of stigma

Caring for people who have few resources

…let's get back to the root of the issue



- Language barriers
  - Many patients do not speak English
  - Families not well integrated into U.S.
- Distrust of public health and different beliefs about disease
- Co-occurring mental health issues and substance misuse
- Variable employment statuses
- Struggle to pay rent, bills
  - Time off work during isolation and contact investigation
- School absence before and during isolation
- Lack of transportation for medical appointments
- Food insecurity
- Uninsured
- No primary care, medical home or routine care
  - Many other undiagnosed/untreated conditions (diabetes, OB/GYN concerns, etc.)

Example structural application of person centeredness:

- **Policy**
- **Continued Care, Post TB**

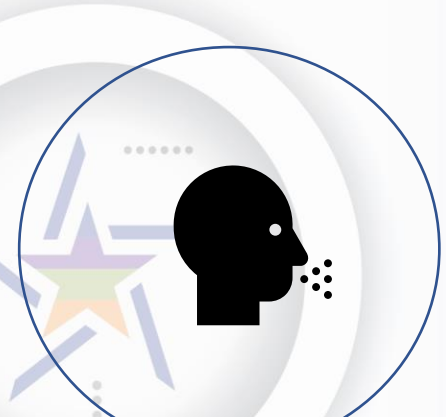
Intensive Coordination of Care
Close partnerships with interdisciplinary team

- Weekly internal team patient review
- Weekly patient review
- Monthly patient visits – hands on
- Master information spreadsheet
- Connections with other area Health Departments

Trust, Consistency, Caring for immediate needs

- Daily care and DOT visits, 2 teams
- Weekly Tx Incentives
- Responsiveness to social and other medical needs
- Attention to behavioral health and stigma
- Flexibility

Family, Community, Traditions, Beliefs, Understanding, Motivation, Language



Next issue: TB Disease Prevention

“An ounce of prevention is worth a pound of bandages and adhesive tape.”

~ Groucho Marx

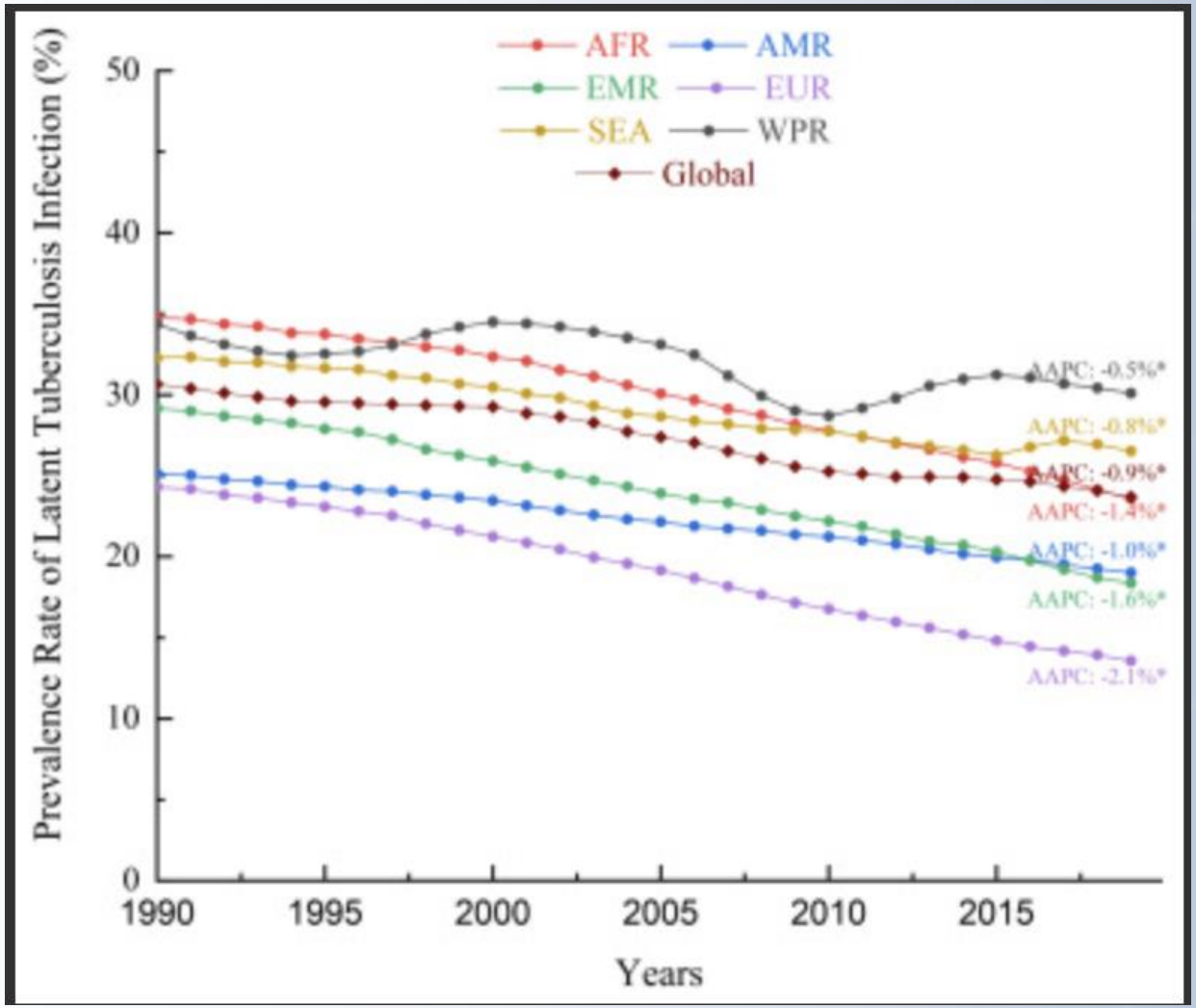


Figure 2 Prevalence trends of latent tuberculosis infection in six WHO regions, 1990–2019. AFR: African Region, AMR: Region of the Americas, EMR: Eastern Mediterranean Region, EUR: European Region, SEA: South East Asian Region, WPR: Western Pacific Region. AAPC: average annual percent change. *: P <0.05.

Ding C, et al. Prevalence trends of latent tuberculosis infection at the global, regional and country levels from 1990-2019. IntJourInfDisease. Vol 122, P 46-62. Sept.2022 https://doi.org/10.1016/j.ijid.2022.05.029

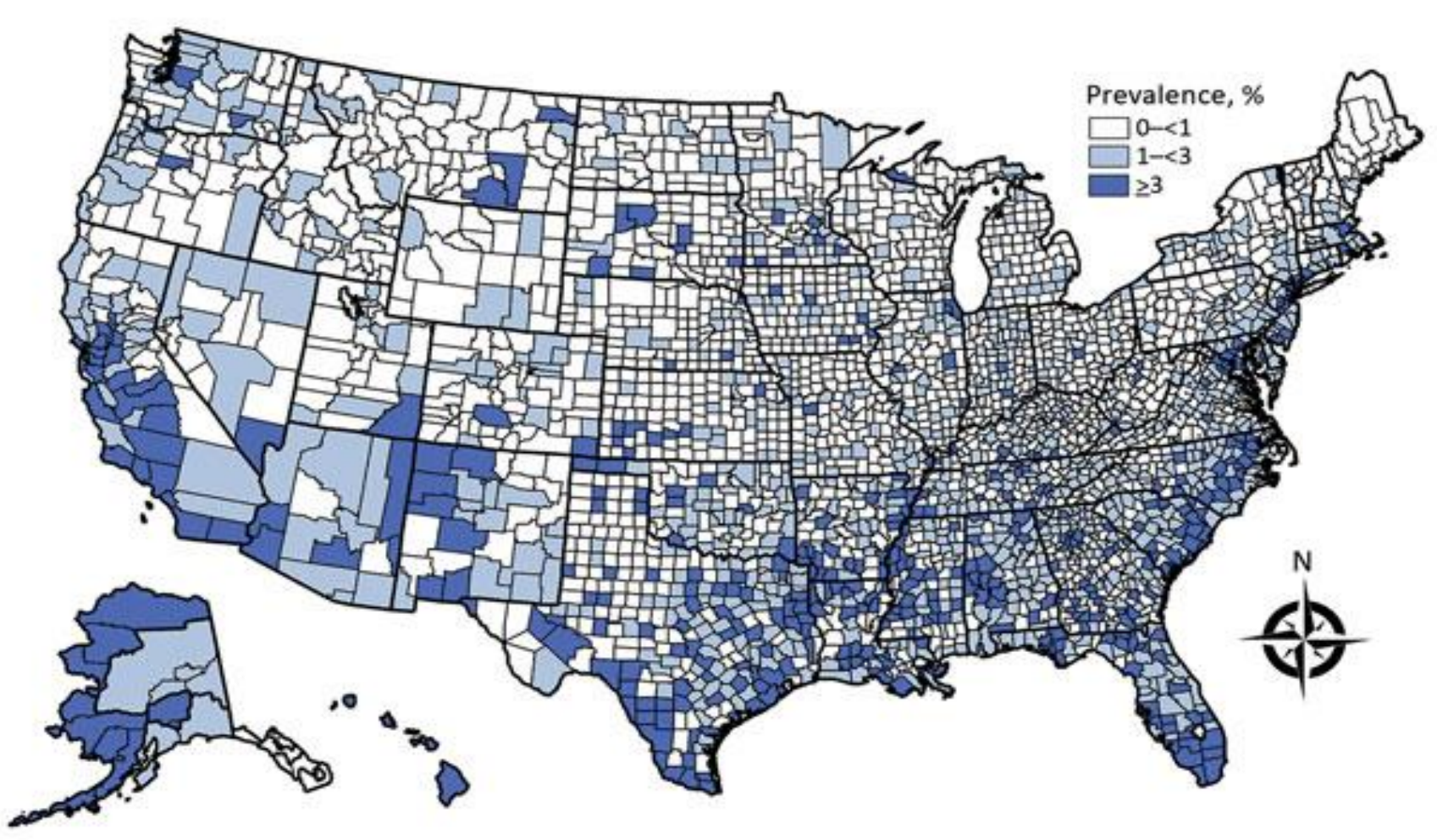
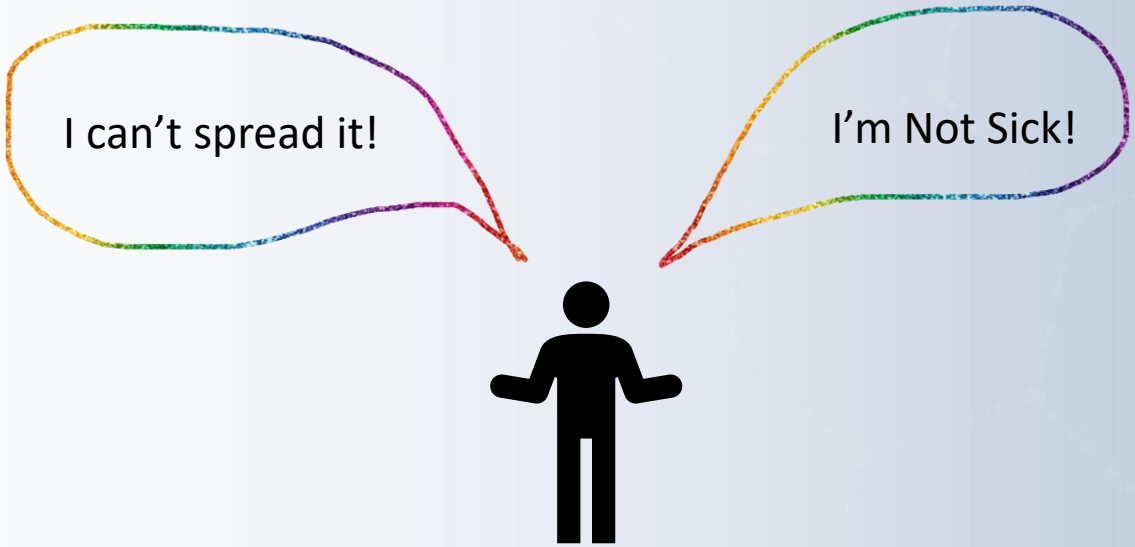


Figure. Estimated prevalence of latent tuberculosis infection, by county, United States, as derived from genotyped cases of tuberculosis reported to the US National Tuberculosis Surveillance System, 2011–2015. County equivalents (i.e., Alaska boroughs, District of Columbia, Louisiana parishes, and Virginia independent cities) are also shown. A modified method for analyzing data for Oklahoma is found in the text. Prevalence estimates for Alaska are aggregated by region.

Haddad MB, Raz KM, Lash TL, Hill AN, Kammerer J, Winston CA, et al. Simple Estimates for Local Prevalence of Latent Tuberculosis Infection, United States, 2011–2015. Emerg Infect Dis. 2018;24(10):1930-1933. https://doi.org/10.3201/eid2410.180716

LTBI: a state of persistent immune response to previously acquired Mycobacterium tuberculosis antigens without evidence of clinically manifested active tuberculosis (TB) disease.



Mack U, Migliori G, Sester M, et al. LTBI: latent tuberculosis infection or lasting immune responses to M. tuberculosis? A TBNET consensus statement. Eur Respir J 2009; 33: 956–973.

Ethically, must we treat all those with LTBI?

If the previous LTBI explanation is true, then risk for disease varies in different populations, reflecting underlying conditions that may impair the immune system

Why is LTBI ethically significant??

1. **Potentiality**
2. **Uncertainty**
3. **Vulnerability**

Potentiality:

- Two separate conditions vs. continuum of infection - disease??

- Importance is future potential for disease

Does not give any grounds for restrictions or quarantine

But we do have an obligation to appropriately manage LTBI, should a person opt for treatment, to prevent risk to the person, their family and to the community.

  - Beneficence, autonomy, nonmaleficence, justice
  - But, light on the “harm principle” in public health ethics

Denholm JT, Matteelli A, Reis A. Latent tuberculous infection: ethical considerations in formulating public health policy. INT J TUBERC LUNG DIS 19(2):137–140

Uncertainty:

90% of people with LTBI will never develop TB disease

How do we know LTBI treatment was a success??

These medications aren’t benign…

Nolan C, Goldberg S, Buskin S. Hepatotoxicity associated with isoniazid preventive therapy: a 7-year survey from a public health tuberculosis clinic. JAMA 1999; 281: 1014–1018.

Denholm JT, Matteelli A, Reis A. Latent tuberculous infection: ethical considerations in formulating public health policy. INT J TUBERC LUNG DIS 19(2):137–140

Vulnerability: (This is a significant!)

- Issues of equity and justice
- Most people living with LTBI are already frequently marginalized (living w/HIV, immigration status, impoverished, incarcerated, substance use)
  - Affected by power dynamics, stigma, discrimination, social barriers, physical harms

Denholm JT, Matteelli A, Reis A. Latent tuberculous infection: ethical considerations in formulating public health policy. INT J TUBERC LUNG DIS 19(2):137–140

When considering prevention, you'll never go wrong with a person-centered approach

- Steeped in humanism and trust
- Long term relationship
- Attention to social factor
- Beyond the health "system"
- Respectful of person's readiness and beliefs

Horter S. Person Centered Care in TB. The International Journal of Tuberculosis and Lung Disease, Volume 25, Number 10, 1 October 2021, pp. 784-787(4). https://doi.org/10.5588/ijtld.21.0327

Example of why ethical considerations in LTBI is of great importance:

US University screening – should we screen if no follow up available?

- IGRA required by the University upon arrival
- >500 students from abroad with LTBI
- No treatment offered

Last, but not least: Palliative Care

‘‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’’

World Health Organization. WHO Definition of Palliative Care. Geneva, Switzerland: WHO, 2013. http://www.who.int/ cancer/palliative/definition/en/.

Nelson JE, Puntillo KA, Pronovost PJ, Walker AS, McAdam JL, Ilaoa D, Penrod J. In their own words: patients and families define high-quality palliative care in the intensive care unit. Crit Care Med. 2010 Mar;38(3):808-18. doi: 10.1097/ccm.0b013e3181c5887c. PMID: 20198726; PMCID: PMC3267550.

- provides **relief from pain** and other distressing symptoms;
- affirms life and regards **dying as a normal process**;
- intends neither to hasten or postpone death;
- integrates the **psychological and spiritual aspects** of patient care;
- offers a **support system** to help patients live as actively as possible until death;
- offers a **support system to help the family cope** during the patients illness and in their own bereavement;
- uses a **team approach** to address the needs of patients and their families, including bereavement counselling, if indicated;
- will **enhance quality of life**, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and **manage distressing clinical complications**.

World Health Organization. WHO Definition of Palliative Care. Geneva, Switzerland: WHO, 2013. http://www.who.int/ cancer/palliative/definition/en/.

It is an ethical imperative to provide patient/person centered palliative care as part of comprehensive care for those with TB disease

- High burden of symptoms, both physical and psychological
- Uncertainty regarding survival
- Extreme form of social and family stress

- *A form of care that is fully concerned with relief of suffering. Respects the dignity and fundamental personhood of those persons with TB*

Harding R, Snyman L, Ostgathe C, Odell S, Gwyther L. The ethical imperative to relieve suffering for people with tuberculosis by ensuring access to palliative care. Int J Tuberc Lung Dis. 2020 May 1;24(5):3-8. doi: 10.5588/ijtld.18.0240. PMID: 32553036

World Health Organization . *no. November 2013, pp. 1–23.* 2015. Global strategy and targets for tuberculosis prevention , care and control after 2015.

When to involve Palliative Care?

- Not only in the time leading up to death, or for terminal diseases

- Can have a *profound* impact when integrated alongside serious conditions!!

Traue DC, Ross JR. Palliative care in non-malignant diseases. *J R Soc Med.* 2005;**98**(11):503–506. doi: 10.1177/014107680509801111.

Miss EP, 12 yo girl in Kansas City, KS

- Presented to the ER with severe diffuse body pain, night sweats, weight loss
- Found to have MDR TB
- Review of her hospital records after admission and D/C summary does not once address her pain
- The patient confided in our team she was frightened and in tremendous dicomfort

"What is the easiest pain to bear?

…somebody else's."

Mr. TT, 45yo man in Kansas City, KS

- Misdiagnosed x4 months
- Lost >100lbs
- Strong family support at home, but few resources
- Hospitalized initially for pneumonia, but sent home
- Late presented to University hospital – critically ill
- Expired after 1 day

Acknowledgements:

- Drs. Lisa Armitige and Barbara Seaworth
- Heartland National TB Center
- The Unified Government Public Health Department, Kansas City, KS
- Johnson County Department of Health and Environment
- The University of KS Medical Center

“My humanity is bound up in yours, for we can only be human together.”
~Desmond Tutu

Thank you for your attention!

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