Ethical Access To Care in TB

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Adriana Vasquez, MD - Disclosures:

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

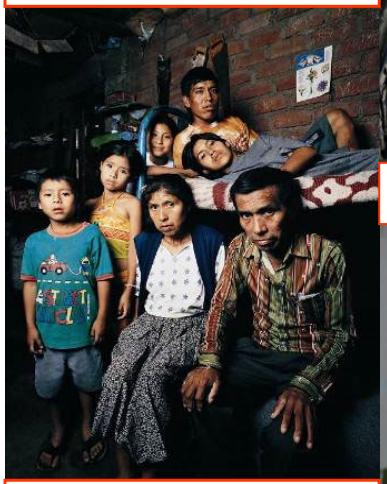
Objectives

- Discuss tuberculosis as a disease with global impact.
- Recognize the stigma associated with TB.
- Describe TB in those with mental illness and living with HIV.
- Discuss tuberculosis access to care and funding.
- Identify ethical issues in tuberculosis prevention, care and control.

Who carries the burden of tuberculosis? World Health Organization

...the most vulnerable

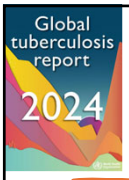
TB spreads in poor, crowded & poorly ventilated settings



TB linked to HIV infection, malnutrition, alcohol, drug and tobacco use, diabetes

1.25 million people died from TB in 2023

Migrants, prisoners, minorities, refugees face risks, discrimination & barriers to care

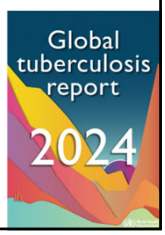


Global TB Burden, 2023

- Estimated **10.8 million** people fell ill with TB worldwide
- Estimated **1.25 million** people died from TB
- Around **87% of new TB cases** occurred in the **30 high TB burden countries**, with more than two-thirds of the global total in Bangladesh, China, Democratic Republic of the Congo, India, Indonesia, Nigeria, Pakistan and the Philippine

TB Burden and Response, 2023

- TB is the **leading cause of death** from a single infectious agent
- TB is the **leading killer** of people with HIV
- TB is a **major cause of deaths** related to antimicrobial resistance



Why TB carries Stigma

- **Association** with poverty
  - People link TB with poor-living conditions
- **Fear** of infection; TB is contagious
  - People often avoid those with TB
- **Association** with HIV/AIDS
  - In many countries TB is strongly linked with HIV, which carries its own stigma
- Historical **perceptions**
  - TB has long been seen as a shameful and dirty disease

Consequences of Stigma

- **Delayed diagnosis:** People may avoid testing because they don't want to be labeled as "having TB"
- **Treatment non-adherence:** Fear of being seen taking TB medication may cause patients to stop or hide treatment
- **Mental health burden:** Anxiety, depression and loss of self-worth are common
- **Economic impact:** Stigma may lead to loss of employment or educational opportunities

Types of Stigma

- **Social stigma:** Patient may be rejected or discriminated against
- **Self-stigma (internalized):** Patient may feel guilt, shame or self-blame leading to isolation and depression
- **Institutional stigma:** Discrimination can occur in healthcare settings, employment, or housing policies

TB Photo Voice Participant

Brenda, a TB Photo Voice participant: "We need to put an end to stigma, discrimination, negligence and indifference. We have the science, the medication and everything it takes to STOP TB. What is keeping us from doing this?"

"Stop the stigma, discrimination and negligence"

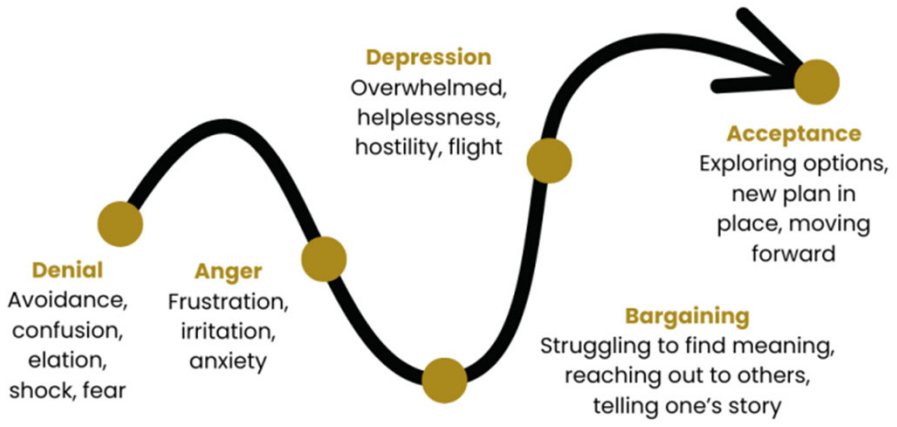
Source: *Border Health TB Photovoice Project* (link)

TB is a Unique and Painful Experience

- Patients believe that TB is always an **interruption** in life
  - Physically, psychologically, economically and socially
- People with TB are more likely to develop mental and psychological problems
- Following **initial shock** of diagnosis, a period of **denial** is followed by anger and depression

TB research and treatment;2013;Article ID 48986

Kubler Ross Stages of Grief



the LOSS foundation

Mental Illness and TB

- Shared **Risk Factors**:
  - Housing insecurity
  - Alcohol, tobacco, or substance use
  - Limited access to healthcare

- Patients with mental illness and TB:
  - **Higher risk** of TB acquisition and transmission
  - **Poor adherence to** TB treatment
  - After TB diagnosis risk of mental illness increases

TB research and treatment;2013;Article ID 489865

Depression is Common in TB Patients

- **Shared Symptoms**
  - Fatigue, weakness, low appetite, and low energy

- **TB Medications** can affect mental health
  - Drugs like **cycloserine** may cause confusion, mood changes, or even psychosis

- Impact of Depression:
  - Makes it harder to adhere and complete TB treatment
  - Can **worsen disability**

Untreated Depression in Patients with TB

- **Worsens TB outcome**
- **Leads to:**
  - Lower quality of life
  - More disability
  - Higher risk of treatment failure
  - Increased risk of death

Mental health screening and treatment should be part of TB treatment

Bull World Health Organ 2018,96:243-25

Isolation - One of the Most Difficult Aspects of the Disease

- **Feeling lonely**, confined, and abandoned
- **Shame** from wearing a mask
- **Feeling "dirty"** or stigmatized- like a leper
- **Social isolation:** Distanced from family/friends
- **Harmful myths:** Needing separate dishes, clothes, or laundry

Chang B. Quality of life in TB: A review of English literature

TB Photo Voice Participant:

"Burning this mask was very important to me. I wore it for several months and it was very painful. My peers didn't know what my face and smile looked like. When I burned the mask, it was like getting rid of the stigma (associated with Tuberculosis). I felt free."

Source: *Border Health TB Photovoice Project* (link)

If you think taking care of TB can wait, consider this…

The Spread of MDR-TB May Be More Significant than AIDS

- Unlike HIV, Tuberculosis is Airborne and Highly Contagious
- TB spreads through **casual, airborne contact**
- HIV spreads through **specific behaviors** (e.g., IV drug use, unprotected sex)
- TB poses a **greater risk** to the public

M.J. Selgelid IJTBLD 12(3);231-235 2008

TB in those with mental illness and living with HIV

Case Study 1:
38-year-old male with history of AIDS, substance use disorder, incarceration, and borderline personality disorder

Medical History

- **38 y/o** male with history of cirrhosis, AIDS, Substance use disorder
- Started at **10 y/o** as daily user of marijuana, speed, IV cocaine, tobacco
- **Legal**
  - 18 years in penitentiary
- **Post traumatic stress**
  - Physical and emotional abuse by mother and brothers
  - Sexual: "Mom gave me off to a gay drug dealer"
  - Worked as a prostitute in Las Vegas at 15 years of age
- Admitted to TCID for treatment of PTB under **court order**

Challenges During Hospitalization

- Patient became **increasingly agitated** over time with inpatient treatment
  - **Refused** to talk to psychiatrist
  - **Refused** Seroquel, but took all TB medications
  - Became combative, violent, and disruptive with other patients and staff
- **Refused** to sleep for four days and discussed escape plans

Escalating Aggressive Behavior

- **Hit** walls, **destroyed** four glass monitors and six alcohol dispensers
- **Threatened** and **verbally abused** staff and patients
  - **Pushed** staff members and **slapped** patients
  - Everyone was horrified
- Kept insisting he was not “crazy”

Patient Attempted to Escape by Jumping from the 2nd Floor

- Patient **ran away**, but security caught him
- Minutes later, he **assaulted** a patient by removing his glasses and crushing them under his feet

Management and Diagnosis

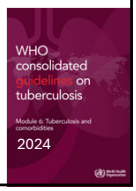
- **Contacted** security, police, and San Antonio State Hospital (SASH) director
- Placed on **1:1 supervision**
- Patient was sent on furlough to mental hospital for **2 weeks**
  - **Required** physical restraints at psych hospital, IM medications were given
  - **Diagnosed** with bipolar, antisocial and borderline personality disorders, uncontrolled

Returned to TCID after 2 Weeks at Psychiatric Hospital

- Wrote an apology letter
  - Was sorry for his bad behavior
- **Apologized** to patient for breaking his glasses and promised to replace them
- Behavior was appropriate and respectful
- **Took** his TB and psychotropic medication

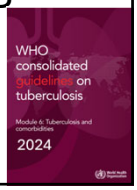
HIV and Tuberculosis Co-Infection

- People with HIV are **18x more likely** to develop active TB disease
- Progression from latent to active TB:. **10% lifetime** without HIV **10% per year** with HIV
- TB is the **most common presenting illness** and **leading cause of death** in people living with HIV



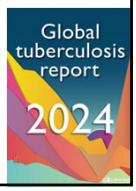
Joint TB/HIV Prevention and Care

- **HIV testing** should be offered to **all** patients with TB
- **Antiretroviral therapy (ART)** should be given to **all** TB patients living with HIV, irrespective of their CD4 counts.
  - ART reduces TB risk in people with HIV by up to **67%**
- Provide **Co-trimoxazole Preventive Therapy (CPT)** to TB patients with HIV to prevent opportunistic infections



Addressing the Co-Epidemics of TB and HIV

- **80%** global HIV testing among people with TB
- **56%** of people newly diagnosed with TB and HIV received ART (Antiretroviral Therapy)
- **13%** of all TB deaths were due to HIV co-infection
- In some high-burden countries, HIV prevalence among people with TB exceeds **40%**



Effects of HIV on TB

- **HIV and TB – AIDS-defining illness**
- HIV **accelerates** TB progression
- HIV **increases the risk** of extra pulmonary and disseminated TB
- TB is **more difficult to diagnose** in HIV infected patients
  - Sputum often AFB smear negative
  - CXR may be normal

Neil A. Martinson; Proc Am Thorac Soc Vol 8. pp 288–293, 2011

Effects of TB on HIV

- TB **increases** risk of death in HIV infected patients
- TB **increases** HIV viral load
- TB **worsens** HIV infection outcome

Badri M, Association between tuberculosis and HIV disease progression Int J Tuberc Lung Dis. 2001;5(3):225

Case Management

- **Consult** an expert in management HIV and TB
- **Ensure** adherence to ART and TB meds
- **Monitor** drug-drug interactions
- **Beware** of IRIS (Immune Reconstitution Inflammatory Syndrome)
- **Manage** side effects of medications
- **Prevent** TB treatment failure and relapse

https://www.cdc.gov/tb/publications/factsheets/treatment/treatmenthivpositive.htm

Case Study 2: Patient with TB, HIV and Bipolar Disorder

Patient with TB, HIV and Bipolar Disorder

- **30 – year old** Hispanic male
- Referred to TCID for treatment of **pulmonary tuberculosis**
- **History** of HIV infection, bipolar disorder, hepatitis C, substance use disorder and housing insecurity.
  - Chest X-ray **normal**
  - Sputum AFB smear negative cultures **positive** for *MTB, pan-susceptible*

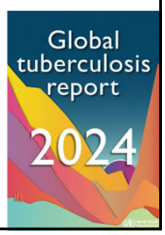
Hospital Course

- **Admitted to TCID**
  - Started on rifampin, isoniazid, pyrazinamide and ethambutol
  - Became manic and left against medical advice
- **One month later**
  - Readmitted under court order one month later
- **2 weeks after readmission**
  - Started on antiretrovirals
    - Truvada once a day and Dolutegravir twice a day
- **Developed** immune reconstitution inflammatory syndrome (IRIS), treated with prednisone

Funding and TB

Socio-Economic Factors

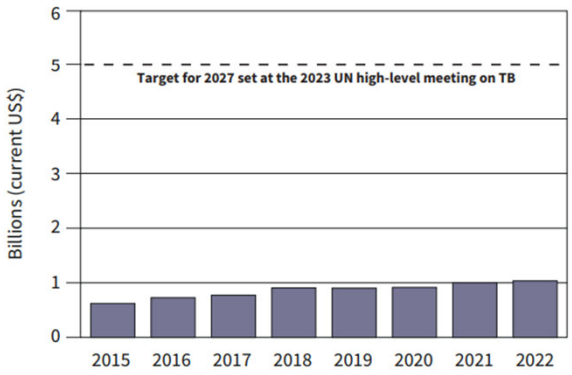
- Average total cost of treatment expenses: **$76 - $3,700**
- Up to **92%** of TB patients face financial hardship
- **50%** experience catastrophic costs (**>20%** of income)
- Delayed care **increases** severity and cost
- Many patients must **choose** between **treatment** and **work**



Funding TB Research & Development

FIG. 35

Funding for TB research, 2015–2022

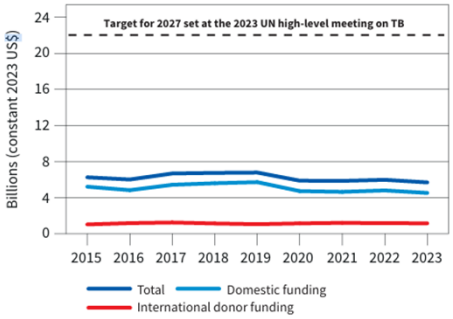


Global tuberculosis report 2024

Funding Gaps in TB Care, Prevention, Diagnosis & Treatment

FIG. 29

Funding available for TB prevention, diagnostic and treatment services in 132 low- and middle-income countries by source,[a,b,c] 2015–2023, compared with the global target of US$ 22 billion per year by 2027 that was set at the 2023 UN high-level meeting on TB



- Funding gap of **$16.3 billion (2023)**
  - Critical for patient services and program delivery

Global tuberculosis report 2024

Why Are TB Patients Missed

- **No Access**: Distance to care, poverty, stigma, limited facilities, financial barriers, conflict
- **No Diagnosis**: Lack of molecular testing, culture, susceptibility
- **No Documentation**: Weak reporting, lack of notification
- **No Treatment**: Lack of meds and poor links between services

Importance of Investing in Missed TB Patients

- TB is **curable** with six-month treatment course
- TB **respects no borders** – it spreads across communities and countries
- Every **$1 invested** in TB control yields a **$39 return** in economic benefits
- **1 person** with active TB can infect **up to 10-15 people per year**

Menzies et al., PLOS Glob Public Health, 2023

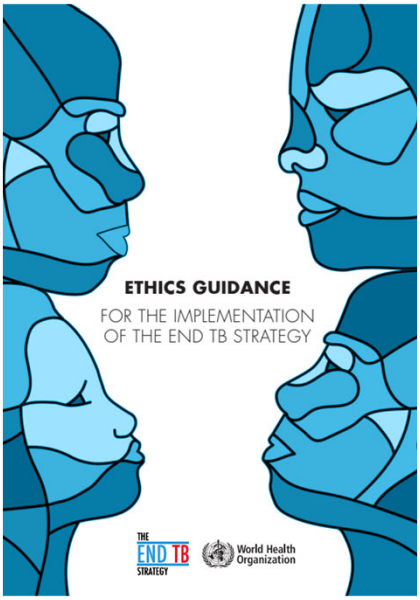
Distribution of Health Care Resources

- **TB is curable** with a short course of treatment; **HIV requires lifelong care**
- **TB medication cost:** ~$315-896 (six months treatment – medication cost only)
- **HIV medication cost per year:** ~$120-$286/year in low-resource settings
- **Clinical trials (2023):**
  - **TB: $**1.2 billion (24% of goal)
  - **HIV:** $7.91 billion
- **Global advocacy and funding for HIV/AIDS far exceeds TB**

Stop TB Partnership, TAG. TBRD Report. TAG; 2024
KFF, UNAIDS. Donor Government Funding for HIV in LMICs. KFF; 2024.

Ethics and TB

WHO Ethics Guidance

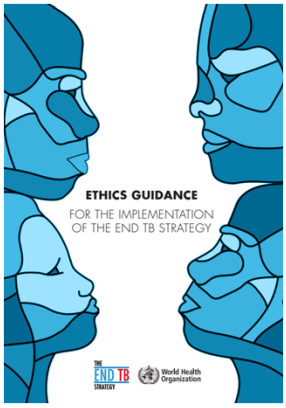


Ending TB as a Matter of Social Justice

- **Social inequalities** fuel the spread of TB globally
- TB drives many people deeper into poverty
- The **right to health** is a fundamental human right

Government's Role in Expanding TB Access to Care

- **Patient-centered** approach means treatment is
  - Accessible
  - Acceptable
  - Affordable
  - Appropriate

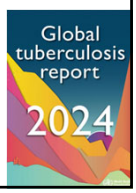


Government Obligation: Free and Universal TB Care

- Ensure **appropriate diagnosis and treatment of MDR/XDR-TB**
- Everyone with TB deserves **access to innovative tools and services**
- TB treatment benefits both individuals and communities by:
  - **Improving health outcomes**
  - **Stopping the spread** of highly infectious disease

Adopting New TB Diagnostics and Treatments

- Adoption of shorter, all-oral regimens for MDR-TB is expanding
  - e.g. BPaLM (Bedaquiline, Pretomanid, Linezolid and Moxifloxacin)
- New TB drugs are replacing older, toxic treatments
  - Bedaquiline, Pretomanid
- **62%** of pulmonary TB cases were bacteriologically confirmed in 2023
- **48%** received WHO-recommended rapid diagnostic tests
  - (goal: 100% by 2027)



Free Diagnostic Access for All TB Patients Drug Susceptible and Drug Resistant

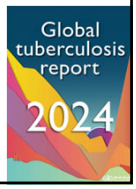
- Prevents patients from receiving ineffective treatment to which they are resistant
- Prevents additional spread of infection
- Prevents further development of drug-resistance
- Ensures patients are cured

TB and Social Determinants

- **Economic stability:** Poverty and overcrowding increase TB risk
- **Education:** Low literacy delays diagnosis
- **Social & community context:** Stigma and weak support delay care
- **Health care access:** Limited access delays treatment

How Social Determinants Impact Access to TB Care

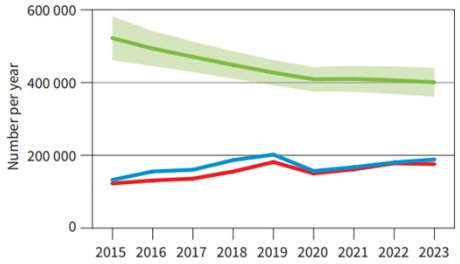
- **44%** of drug-resistant TB patients **do not** start treatment due to health system barriers
- Poverty, malnutrition & stigma limit TB care access
- Free TB treatment is common
- Income and food aid are uncommon



Drug Resistant TB

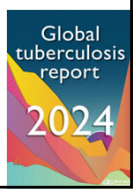
FIG. 26

Global number of people diagnosed with MDR/RR-TB (blue) and number enrolled on an MDR-TB treatment regimen (red), compared with estimates of the global number of incident cases of MDR/RR-TB (95% uncertainty interval shown in green), 2015–2023[a]



[a] The time period corresponds to the period for which estimates of the incidence of MDR/RR-TB are available.

- **79%** tested for rifampicin resistance
- **44%** of MDR/RR-TB patients started treatment
- **68%** of MDR/RR-TB are treated successful
- **58** countries use 6-month BPaLM regimen



Risks and Benefits in Promoting Diagnosis in the Absence of Treatment

- **Risks:**
  - Stigma
  - Discrimination
  - Anxiety
  - Isolation
- **Benefits:**
  - Knowledge of condition
  - Make life plans
  - Prevent transmission
  - Seek treatment

Goal: Maximize benefits, minimize risks

TB Diagnosis in the Absence of Treatment

- Gap between **diagnosis** and **access** to treatment
- Should patients be diagnosed when treatment is **unavailable**?
- Patients should receive **true** informed consent before testing

Healthcare Workers: Duty to Treat and Right to Protection

- Healthcare workers have a duty to care for patients

- Governments and institutions must ensure a safe working environment
  - Access to protective equipment, training, infection control and TB prevention measures

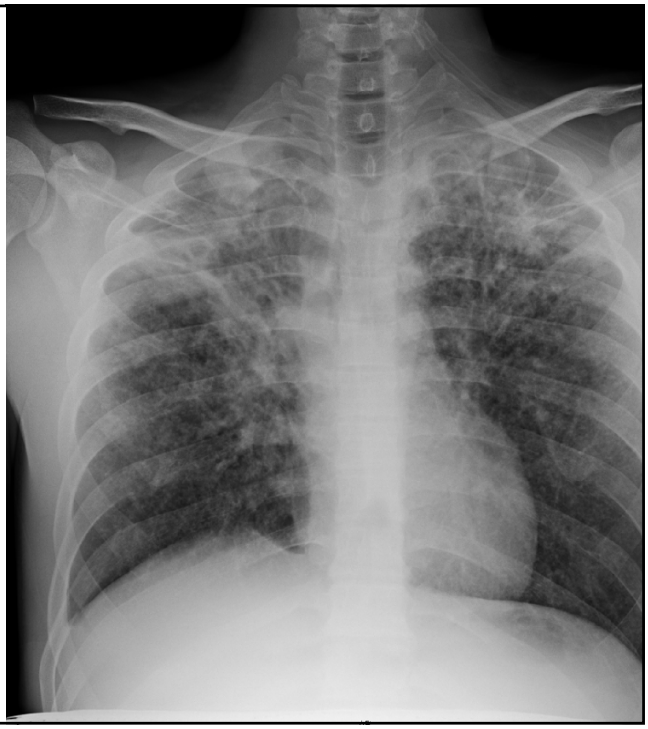
Case Study 3:
Patient declined treatment for TB infection 8 years later.....

Latent TB Infection in a 17-Year-Old Male

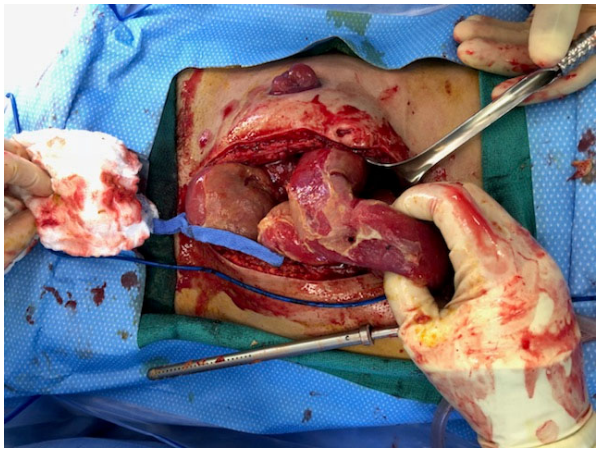
- **TST performed** following a TB outbreak at school
- **History** of substance use disorder
- **Declined treatment** for latent TB infection with rifampin

Consequences 8 Years Later

- Initial Presentation & Diagnosis
- **Admitted** with night sweats, cough, and hemoptysis
- **Diagnosed** with pulmonary tuberculosis (pan-sensitive)
- **Initiated** on RIPE therapy (Rifampin, Isoniazid, Pyrazinamide, Ethambutol)



6 Weeks after TB Therapy was Initiated



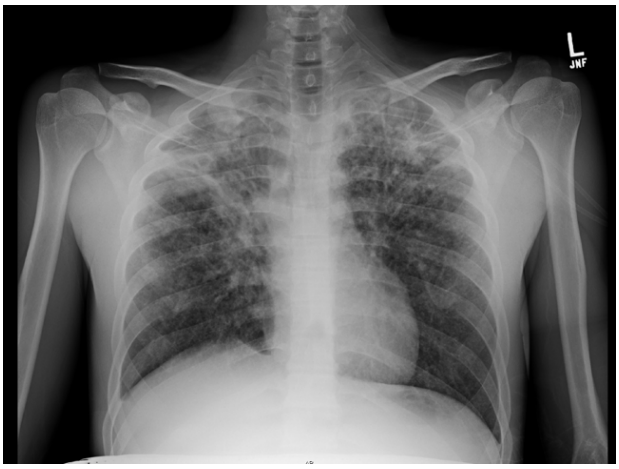
- Presented with **severe** abdominal pain
- Underwent **laparotomy** revealing small bowel perforation
- **19 cm** of small bowel resected
- **Ileostomy** placed during the procedure

Pathology

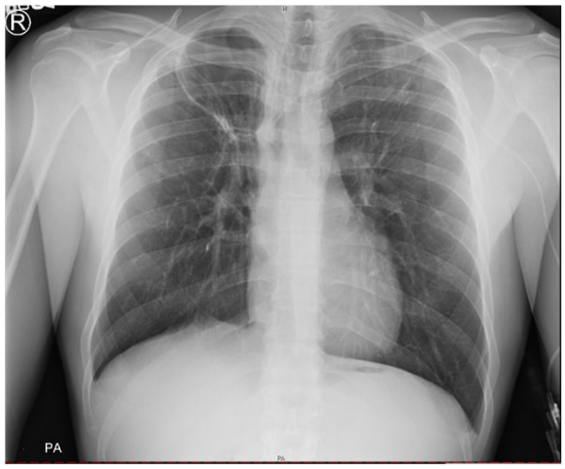
- Small bowel full-thickness inflammation with perforation
- Multiple intra-abdominal adhesions
- **Histopathology:** 11 lymph nodes with caseating granulomatous inflammation (suggestive of TB)
- Two episodes of small bowel obstruction postoperatively
  - Both required exploratory laparotomies

X-Ray Results

Baseline



End of therapy



Values that Need to Be Embraced as Core Aspects of TB Programs in the New Millennium

- TB services **are not** just about science of treatment; they are about something more fundamental:
  - **Dignity**
  - **Social fairness**
  - **Social justice**
  - **A willingness to serve**

R. Zachariah IJTBLD 16(6):714-717 2012

Conclusions

- TB causes major **human and economic suffering**
- TB treatment must be delivered **with dignity and compassion**
- **Wealthy nations** have an **ethical duty** to support care in low-resource countries
- **Infectious diseases fail to respect borders**
  - Inadequate health care systems in poor countries threatens global public health
- **MDR/XDR-TB** is a serious global threat
- Urgent need for **universal access** to diagnosis and patient-centered treatment

Recommended Films for TB Awareness and Education

PBS Frontline TB Silent Killer

Any Questions?

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