

Thurston County Public Health and Social Services

Shining a Light on Tuberculosis at the End of Life: One Patient's Journey

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Patient History

▶ **Female in her early 80s**

- Second admission for septic left elbow
- Past medical history:
 - Idiopathic pulmonary fibrosis on 2L of oxygen at home
 - Coronary artery disease status post coronary artery bypass graft
 - Diabetes Miletus, Type 2
 - Polypharmacy

Patient History

► **Social history**

- Married to spouse for over 40+ years
- Religious
- Currently lives in a multigenerational eight-person household with 2-year-old, 2-month-old, and a post-partum person
- Immigrated from the Philippines in 2020
- Previous admission to a nursing facility in US
- No known TB exposures

Diagnosing Tuberculosis

► **Tuberculosis Evaluation**

- Fluid from left elbow joint found to be PCR positive for m. Tuberculosis
- Sputum specimen x3 obtained and were PCR positive for m. Tuberculosis
- Patient sputum samples were not AFB positive and remained culture negative

Treatment

► Initiating RIPE treatment

- Patient was initially started on Rifampin, Isoniazid, Pyrazinamide, Ethambutol, and Vitamin B6
- After 11 days of treatment, patient developed a generalized urticarial rash; treatment was halted
- Patient requested to stop treatment due to concern for symptom recurrence

Goals of Care

► **Goals of Care**

- The patient had experienced:
 - Episodes of fever
 - Waxing and waning mental status
- The patient requested:
 - Hospice care
 - An end to pursuit of clinical treatment
- Her last wish was to be buried in the Philippines

International Burial Considerations

► **Multiagency coordination was required**

- Agencies involved in post-mortem coordination for the patient included the Washington State Department of Health, the Centers for Disease Control and Prevention, and the Philippine Consulate General
- The family's burial request was communicated so that options which balanced public health and community safety with familial, religious, and cultural wishes could be discussed

International Burial Considerations

► **Multiagency coordination was required**

- TB bacteria can remain viable after embalming so it was necessary to determine what was needed for the remains to be safely transported to the patients final resting place.
- It was necessary to coordinate with the Philippines Embassy to ensure that criteria for the issuance of a certificate of no contagious disease and transport to the country were met.
- Transport of the remains to the Philippines was approved provided that the remains were properly embalmed and were enclosed in a hermetically sealed coffin.

Reassessing Goals of Care

► **Sharing information with the family**

- The patient wanted an open casket funeral so that family members in the Philippines could say their final farewells and spend time with the patient after passing
- Her clinical condition remained stable after several months
- TB treatment was resumed by patient decision so that her final wishes could be carried out

Restarting TB Medications

► **Coordination with Infectious Disease physician**

- Medications were restarted one by one starting with Rifampin followed by Isoniazid
- Patient developed a rash after starting Ethambutol, so Ethambutol was stopped and Moxifloxacin started
- The patient tolerated the new regimen well with few side effects which were effectively managed

Restarting TB Medications

▶ **Testing treatment effectiveness**

- Serial sputum collections were restarted and the patient remained smear negative
- Isolation was ended after two weeks of effective treatment with Rifampin, Isoniazid, Moxifloxacin, and Vitamin B6
- The patient was transferred to a skilled nursing facility for rehabilitation and eventual discharge to home

Coordinating with Long Term Care

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► **Fear of TB transmission was a key concern**

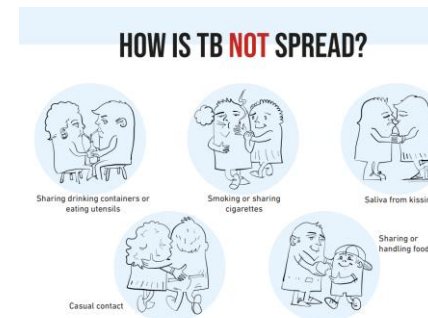
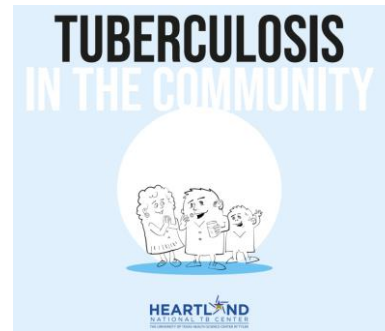
- Patient was transferred to a skilled nursing facility that had not provided care to tuberculosis patients in the past
- Staff was concerned that patient could transmit TB to them through ordinary care tasks such as feeding, pericare, and bathing
- Education and support to facility staff was critical to reduce fear and stigma

Coordinating with Long Term Care

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► Providing education to reduce fear

- Easy-to-read, “quick look” resources were used that could be posted at the nursing station, including pages from the “Tuberculosis in the Community” flipbook from Heartland National TB Center.



HOW ELSE IS TB NOT SPREAD?

- You cannot get TB germs from:
 - ~ Touching or sharing bed linens
 - ~ Sharing towels and clothes
 - ~ Shaking someone's hand
 - ~ Toilet seats
 - ~ Sharing toothbrushes
- Remember, since TB is spread through the air, if you are in close contact with someone with TB disease in the lungs, you **can** breathe in the TB bacteria
 - ~ Close contact means someone you spend a lot of time with, like family members, classmates, co-workers, etc.

Images from the flipbook “Tuberculosis in the Community,” by Heartland National TB Center.

Available at https://www.heartlandntbc.org/wp-content/uploads/2021/12/Tuberculosis_in_the_Community_flipbook_ENGLISH.pdf

Coordinating with Long Term Care

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► **Providing education to reduce fear**

- Providing education helped to alleviate staff fear and stigma fueled by misconceptions:
 - Knowledge empowered the healthcare providers to understand TB and dispel common misconceptions
 - Providers were able to communicate effectively with patients and improve the quality of care they provided
 - Education created provider awareness, creating a more supportive and successful rehabilitation environment

Coordination with Health Care Partners

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► **Process varies by jurisdiction**

- Thurston County manages pulmonary TB cases, and we coordinate with infectious disease physicians to manage complex cases and cases with extrapulmonary TB
- Connecting with the entire clinical care team ensures that:
 - All team members caring for patients with TB are kept up to date on isolation status and treatment plans
 - There are clear pathways for communication when an adverse event occurs or when there is a change in goals of care

Supporting the Family

- ▶ **Case management includes supporting the family**
 - Family support includes:
 - Ensuring that household contacts are tested and, if positive, referred for follow-up care and treatment
 - Serving as an intermediary to relay concerns to care team, and information/results from the care team
 - Connecting families to resources as needed
 - Advocating for patient wishes when possible

Supporting the Family

- ▶ **Case management includes supporting the family**

- Family support also includes:

- Answering family questions about TB disease, treatment, disease process, infectiousness, transmission, etc.
- Providing fact-based information about TB to reduce stigma and fear of the unknown
- Serving as a “listening ear” for concerns and family stressors surrounding diagnosis, treatment, and the daily reality of living with TB

Current Outlook

- ▶ **Currently the patient is at home with her family... and is thriving**
 - She is no longer on hospice
 - She is able to perform video direct observed therapy, most days on her own
 - The swelling in her elbow is significantly improved and her pain is resolving
 - She is receiving TB nurse visits every other week
 - She has strong family support

The Balancing Act: Individual, Family & Community Needs

► **Honoring patient needs while keeping the community safe**

- In public health, we are responsible both for the care of the patient and ensuring that the tuberculosis does not spread within our community
- Sometimes the wishes of a patient and their family may clash with the need to keep the community safe
- Patience, compassion, understanding, problem-solving, and education are needed skills during these times

The Balancing Act:

Individual, Family & Community Needs

► **Balancing patient needs with community safety**

- Providing education to families of patients with TB who are in isolation is critical to ensure that:
 - People who have contact with the patient are aware of the patient's diagnosis
 - PPE is appropriately worn to reduce risk of exposure
 - People at high risk for severe disease are not put at risk
- In congregate settings, such as long-term care facilities, preventing the spread of TB is particularly important

Lessons Learned & Takeaways

► **Taking care of patients with TB and their families**

- Treatment for TB can significantly increase quality of life and allow people to spend more meaningful time with loved ones
- It is important to reassess goals of care frequently since situations can change rapidly
- TB is a team effort: we work to support both patients and their families for better treatment outcomes

Lessons Learned & Takeaways

► **Working with partners and providers**

- Collaboration with other providers and partners is key to provide support for patient goals of care
- Education for staff who have not cared for patients with TB is critical for reducing stigma and fear so that patients can receive compassionate, high-quality care
- The National TB Centers of Excellence have many excellent educational resources available for a variety of different audiences

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Questions / Comments

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