TB Disease and End of Life Care

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I am not…an expert in hospice or palliative care

The Oregon TB program developed

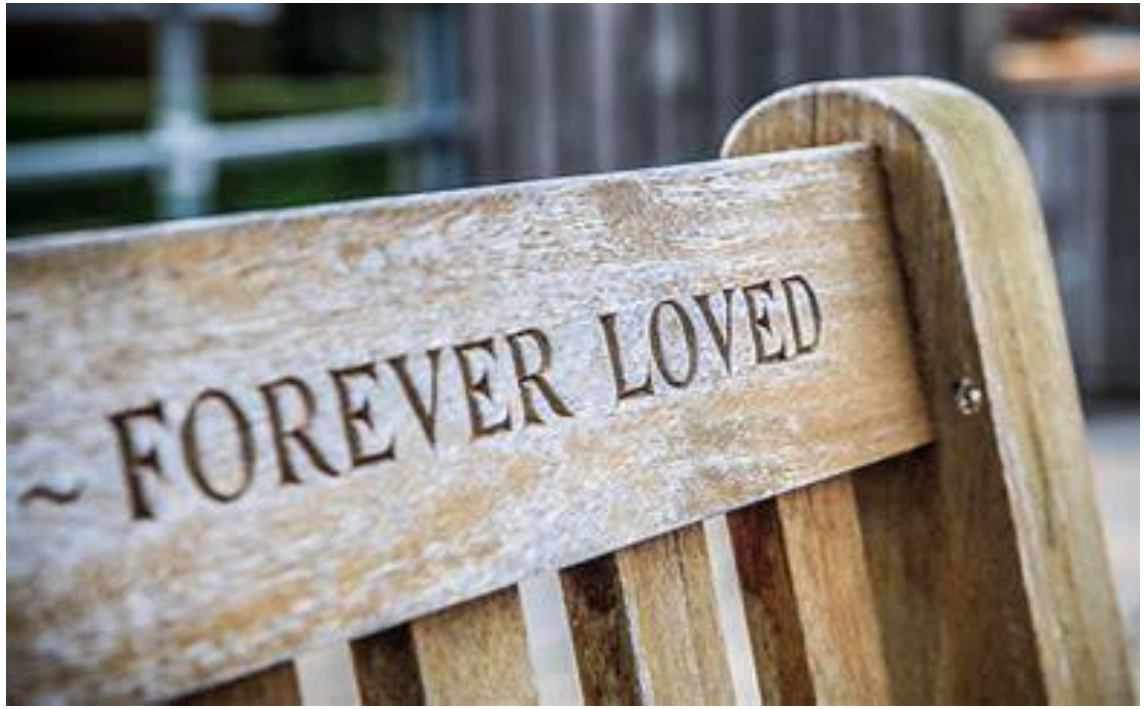
End of Life or Hospice Care and TB

out of necessity and with feedback from local public health partners.

This presentation is based upon this document.

TB disease at the end of life

- In U.S. most cases of TB disease, even XDR TB disease are treatable.
- Patients with TB disease may have multiple disease processes that are not always curable.
- Deciding if a person should continue TB treatment at end of life is a difficult ethical decision.



Aspects to consider…many dimensions

What the individual/patient wants.

Infectiousness if not on treatment: when, how to monitor.

Clinical follow-up required if on treatment.

People who might be exposed in the home.

What does the individual want

- **What are the person's goals of care?**
  - To not be in pain, to not take any medications?

- **What are their end of life goals?**
  - To be with family, to be home, to return to the country they were born in? To not have family see them suffering? Other?

- **What does the family want?** Consider culture. In some cultures, sick family member is protected by family from knowing seriousness of diagnosis.

- **What are burial or funeral rituals desired?** Consider culture. Islamic – trusted family or community members wash the body and shroud. Other religions – embalming

- **How can public health help the patient accomplish these goals in a way that avoids exposing people to TB.**

Considering infectiousness during hospice care

- How sick and likely infectious is the person with TB?
  - Sputum smear+? – Cavitary CXR? – How long on treatment?

- Is the TB drug-resistant?

- If pulmonary TB, how will infectiousness be monitored if treatment is discontinued and how long should this monitoring continue?

- If a person with pulmonary TB cannot produce sputum, should airborne isolation be maintained? What are consequences of maintaining airborne isolation?

Clinical follow-up

- Can pills be swallowed? If not, will an invasive procedure be required to stay on treatment (NG or PEG tube, PICC)?
- What labs are needed if TB medications are continued and how to minimize or avoid discomfort from blood draws or sputum collection?
- Will the person living with TB need to go outside their home for care?

People who might be exposed in the home

- Will there be visitors who have not yet been exposed to TB?
- Are there immunocompromised individuals living with the person? Children?
- Will home health or hospice staff provide care if the person living with TB is not on treatment?
- Are home health or hospice staff equipped with fit-tested N95 masks or PAPRs? If not, can the LPHA help with PAPR loans or help with fit-testing?

Two strategies that can resolve some of these issues…

- A case conference.

- Continue on minimal TB treatment if possible.

Case conference

- A case conference between providers ensures joint decision making and messaging to the patient and family.

- Include the patient and family as appropriate.

Content of case conference

- ❑ What the individual/patient wants.
- ❑ Infectiousness if not on treatment: when, how to monitor.
- ❑ Clinical follow-up required if on treatment.
- ❑ People who might be exposed in the home.
  - Determine how visitors can be protected from TB while allowing the person living with TB to see their loved ones.
  - When possible, assist hospice and home health to obtain PPE (assist with N95 fit testing or provide a PAPR) and educate about TB so services can continue.

Continue minimal TB treatment

- People living with TB often report feeling better in the weeks following initiation of treatment.
- Initiating or continuing TB treatment at end of life might benefit the person and improve their quality of life.
- The person may start to feel better or improve while on treatment and infectiousness will be less of a concern.
- If the person has extrapulmonary TB, medications can be stopped without monitoring for infectiousness.
- Consult with TB expert. Consider INH and RIF.

Case study

- 77 y.o. male who arrived in U.S. from India 4 months ago.
- At hospital diagnosed with TB disease – CXR miliary pattern, sputum smear -, GeneXpert MTB+ no RIF resistance, culture pending. No cough noted. Discharged to home.
- Multiple comorbidities, decline in cognitive abilities, low body weight and very weak, family attempts to care for at home with great difficulty.
- Started on INH/RIF/PZA/EMB. Cannot tolerate. GI upset, LFT elevation. Has taken about 10 doses of treatment when it is stopped.
- Family decides to start hospice care in home. Patient unable to make own medical decisions due to cognitive decline. All medications except those for pain discontinued.
- Family is increasingly unable to care for patient at home and hospice staff are uncomfortable with possible exposure to TB.
- Admit to a facility is being considered.

Contemplate-

What are some of the ethical dilemmas in this situation?

Are there potential risks to the public and healthcare workers since TB treatment has stopped? What factors would you consider?

What level of engagement is appropriate for public health at this time?

What would you do if this was your TB patient as either the RN case manager or public health physician?

Discussion of case study

- Holding a case conference might help to create alignment and a plan of care. Could determine which care provider may be best to communicate plan to family.

- Benefits to restarting on a minimal TB regimen include decreasing infectiousness.

Other concerns related to TB and end of life care

- Infection control at home when patient not on treatment
- Infection control and move to a facility
- Long term public health follow-up
- After death
- Moral distress and taking care of yourself

Infection control at home when patient not on TB medication

- If a person with pulmonary TB stops medications, collect weekly sputum to monitor for changes in smear status.
- If unable to produce sputum or has no cough consider infectious at some point. When?
- Healthcare workers and new visitors should wear PPE. Consult with TB expert if an exception is warranted (e.g. pleural TB or miliary CXR).
- Open windows to allow in fresh air and sunlight.

Infection control and movement to a facility

- Most hospice, skilled nursing facilities, etc. do not have AII or negative pressure rooms.

- A patient who has stopped TB medications may be very difficult or nearly impossible to move from home or hospital to a facility because of this.

- These are “high risk settings”.

Long term follow-up

- Sometimes people recover and live longer than anticipated while on hospice.
- When TB medication is stopped, public health should remain in contact with the person living with TB or their family during the remainder of the person's life.
- If condition improves, consider asking patient to try TB treatment again.
- Those living with an infectious family member should be tested 8-10 weeks after their last exposure

Considerations after death and handling body

- Advise mortuary staff or other people moving body to wear N95 masks or PAPR if person was not on TB medication at death.
- Minimize handling of body if possible.
- Cultural considerations: shrouding of body and washing or embalming or sitting with body.

Taking care of yourself

- This presentation outlined steps that may be helpful to you when caring for someone with TB disease who is nearing the end of life.

- The reality is in public health we may not be able to access services the patient needs such as hospice care due to lack of insurance, legal status in country, etc.

- This can be **very** distressing for public health workers.

Moral distress

Moral distress describes the anguish felt when the right action for the patient is known but you cannot take it because of constraints outside of your control.

Frequent occurrence in health care and can be especially difficult in public health when there may be conflict between patient needs and public health protection.

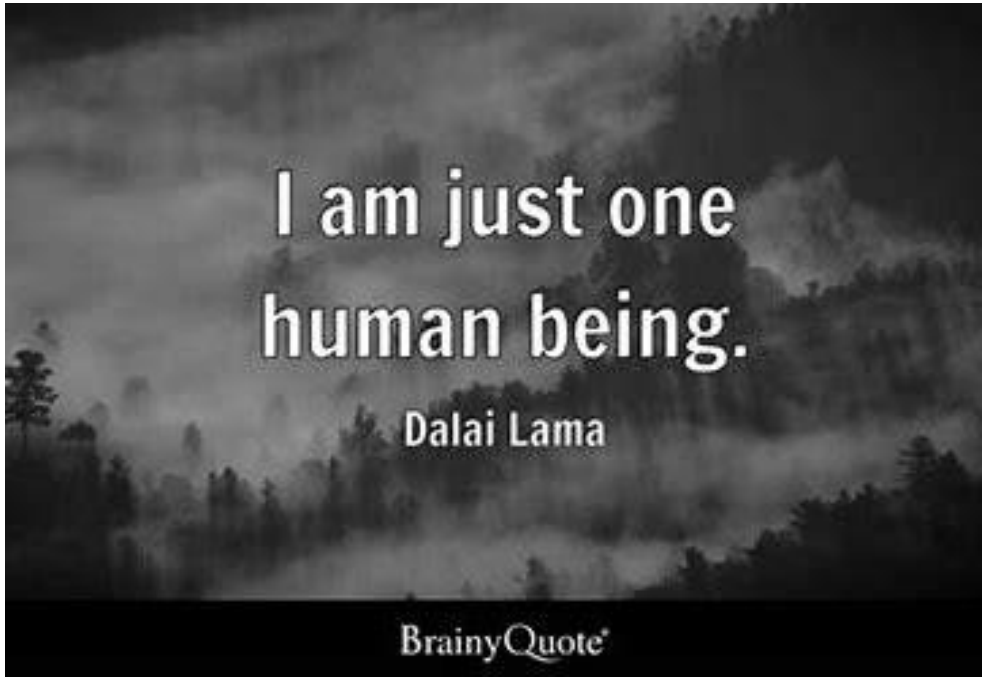
As a public health worker, what strategies did have you utilized, or could you use to help **yourself** cope with the stress of this type of situation?

Some of my strategies

- Request supervisor to switch public health workers to give a respite. Also, others might have new ideas.

- Engage all and any outside assistance to decrease stress and feeling of sole responsibility for situation. Adult protective services, behavioral health, do home visits with a co-worker, encourage family and patient to return to hospital if no other safe options, consult with others, seek counseling for yourself.

- I remind myself I did not create the situation. I am just one human being doing the very best I can in a hard situation.



Resources and References

- End of Life or Hospice Care and TB, TB Program, Oregon Health Authority
- Clinical Practice Guidelines for Providing Palliative Care to Patient with Tuberculosis. Kyrgyzstan Republic Ministry of Health.
- Occupational Safety for the Death Care Agency. Oregon OSHA.
- Providing Care and Comfort at the End of Life. National Institute on Aging.

Thank you

You can get this document in other languages, large print, braille or a format you prefer free of charge. Contact Heidi Behm at heidi.behm@oha.Oregon.gov or 503-358-8516. We accept all relay calls.

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