As I began to tell family and friends of my diagnosis, I saw their facial expressions and body language changed, sometimes very subtly and sometimes in ways that were impossible to ignore. Some people abruptly ended a conversation with me when I spoke of the diagnosis. With others, just the look in their eye let me know that as a person with TB, I had become less valued in their eyes.

Some well-meaning family members counseled me not to speak about my diagnosis. I knew that my talking about TB affected their social standing – in our culture as well as others, the stigma of TB affects not only the patient but the entire family.

The feeling that I had something to hide, that TB was not something I could talk openly about, was hurtful and left me feeling emotionally isolated. I understood why people go to great lengths to hide the disease, even to the point of avoiding clinics or public health officials associated with TB.

Jigna Rao
TB and Cultural Competency Newsletter
globaltb.njms.rutgers.edu/products/culturalcompetency/TB%20&%20Cultural%20Competency-Spring2012.html

WHAT IS PATIENT-CENTERED CARE?

Nisha Ahamed, MPH

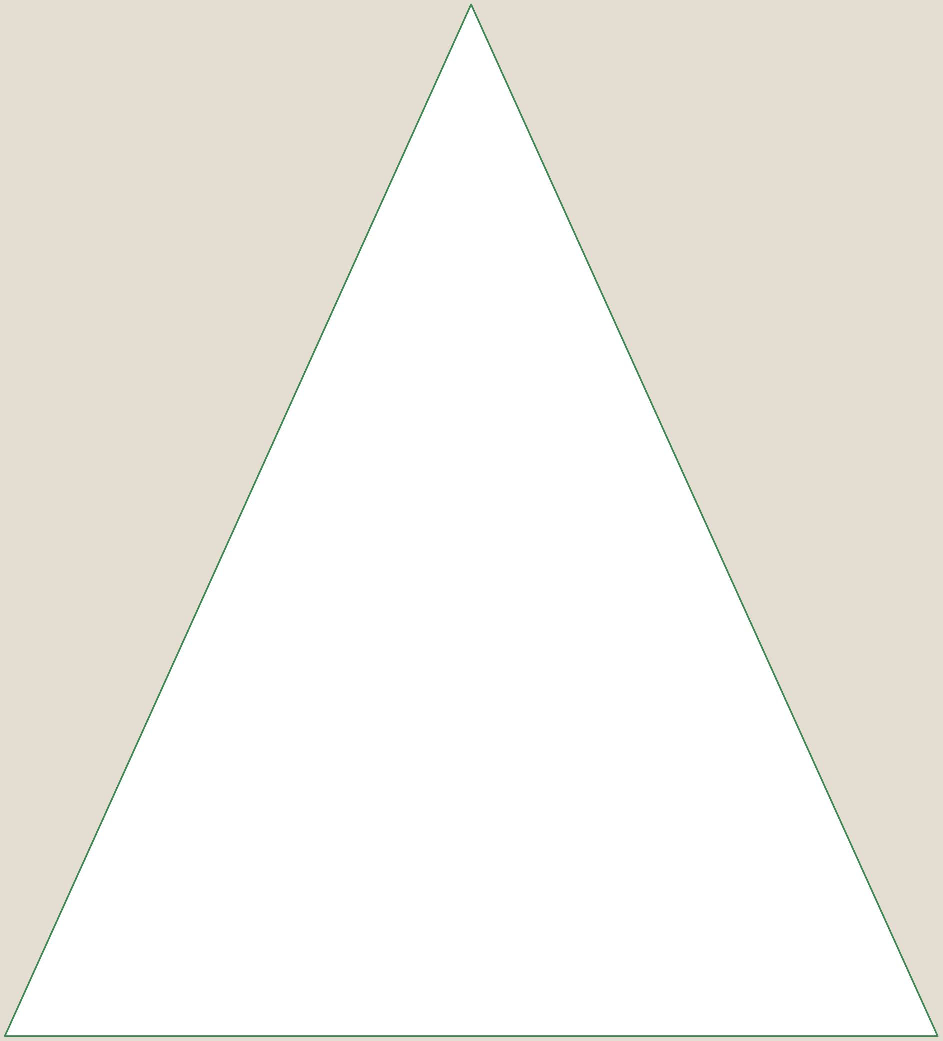
Patient-Centered Care

- “Care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decision”
  - Institute of Medicine, 2001
- Overarching goal is to improve the quality of health care by integrating the patient’s perspective
- But what does this mean?

And Why Should We Do It?

- Can lead to improved:
  - Quality of care
  - Patient and staff satisfaction
  - Cost effectiveness
- And it is the right thing to do…
  - Multiple international documents supporting this approach
  - Incorporated into national TB guidelines

Principles of Patient-Centered Care



Respect for patient preferences

Coordination and integration of care

Information and education

Physical comfort

Emotional support

Involvement of family and friends

Continuity and transition

Access to care

Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- Patients are individuals with unique values and preferences
  - Involve in decision-making
  - Treat patients with dignity, respect, and sensitivity to cultural values and autonomy

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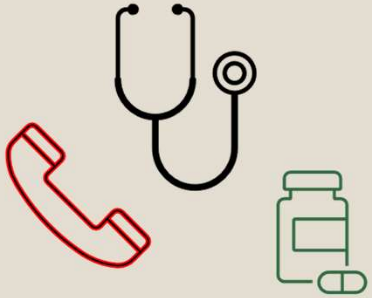
Principles of Patient-Centered Care

- Fragmentation of services vs. coordination and integration
  - Patients can feel vulnerable, anxious, and powerless
  - Coordination and integration can alleviate these feelings



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Principles of Patient-Centered Care

"After they told me, I was like, am I going to die? Because I had no knowledge of tuberculosis. I just knew it WAS tuberculosis…

I could read it on a piece of paper, but I was so sick I couldn't even read it but I might not fully understand it. I might have questions or whatever. Even though they did answer my questions when I asked, I would have kind of prefer to be told a little bit more about it than I was,"
Thomas

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Principles of Patient-Centered Care

- Feel they are not completely informed of condition or prognosis
- Information can facilitate autonomy, self-care, and health promotion
- Can share information:
  - Clinical status, progress and prognosis
  - Processes of care

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Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- Very important to patients
  - Pain management
  - Assistance with activities and daily living needs
  - Surroundings environment

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Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

"Was I going to be able to get rid of it? Was this something I was going to have to deal with for the rest of my life, how it was going to affect my body."

Thomas

"I had lots of questions. It was more than just going through the physical TB treatment. It was a mental process. You know how do you cope with having this condition, Feeling like this, not being able to leave your house."

Mildred

- Respect for patient preferences
- Coordination and integration of care
- Information and education
- Physical comfort
- Emotional support
- Involvement of family and friends
- Continuity and transition
- Access to care

Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- Fear and anxiety can be as debilitating as physical impacts:
  - Physical status, treatment, and prognosis
  - Impact on self and family
  - Financial impact

Respect for patient preferences

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Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- Important role of family/friends in care
  - Decision making
  - Supporting them as caregivers
  - Recognizing needs

Respect for patient preferences

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Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- Concern about ability to care for themselves
  - Clear detailed information about meds, limitations, dietary needs etc.
  - Plan for ongoing treatment
  - Information on how to access clinical, social, physical, and financial support

Respect for patient preferences

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Physical comfort

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Continuity and transition

Access to care

Picker Institute and Harvard Medical School

Principles of Patient-Centered Care

- How to get care when needed
  - Where facilities are
  - Ability to get appointments/ be seen
  - Access to specialty care and clear instruction on how to get referrals if needed

Respect for patient preferences

Coordination and integration of care

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How Do We Provide Patient-Centered Care?

- Start by viewing care from the patient's perspective – what is important to THEM
  - Ask
  - Educate
  - Respect
  - Collaborate
- Build trust and rapport
- Get patient buy-in
- Develop patient-centered case management plans….
  - Consider 8 elements

Patient-Centered TB Care

- Focus on individual care and personal relationships
- Engage patient as active participant in care
- Consider the patient's perspective and plan TB care based on each patient's circumstances
- Adapt care to meet the physical and emotional needs and expectations of the patient
- Understand the patient's beliefs, attitudes and interpretations of illness and wellness
- Strive for solidarity, empathy, and collaboration with the patient – partnership…

Culture & Patient-Centered TB Care

- The learned and shared values, beliefs, and meanings that form the lens or perspective through which an individual understands and interprets their experience*
- Can impact:
  - How we communicate and respond to information
  - Beliefs about health and illness, generally, and specifically about TB
  - When, where, and from whom we seek care

* Helman, CG: Culture, health and illness, 4th ed, 2001

Fitzgerald MH, et. al: Cultural issues from practice, 1997

Culture & Patient-Centered TB Care

- Strive to provide culturally responsive care
  - Aim is to provide the best possible care in a way that is most acceptable to the patient within their cultural context
- The best source of cultural information is from the patient, do not make assumptions as each person is an individual

Some things to consider

- Cultural beliefs and relationships to care
- Stigma and stigmatizing language
- Impact of stigma on patients, care, and treatment

Breakout Session 1

- Watch brief video together as a large group - think about these questions as you watch!
    1. What might the patient be feeling?
    2. What elements of patient-centered care did you see?
    3. What would *you* have done differently, in terms of a patient-centered approach?
- Go into breakout rooms and discuss the questions in your small group for 10 minutes
- Come back to main room – one group will report back, and we'll discuss!

BREAKOUT SESSION 1 – DEBRIEF

1. What might the patient be feeling?
2. What elements of patient-centered care did you see?
3. What would *you* have done differently, in terms of a patient-centered approach?

Resources

We are TB

https://www.wearetb.com/

Personal Stories, CDC

cdc.gov/tb/topic/basics/personalstories.htm

TB and Cultural Competency Newsletter & TB and Cultural Competency: A guide for self- assessment

http://globaltb.njms.rutgers.edu/educationalmaterials/productlist_cultural.php