



Sharing our Stories

Reaching Across Barriers, Listening Well

Ben Danielson

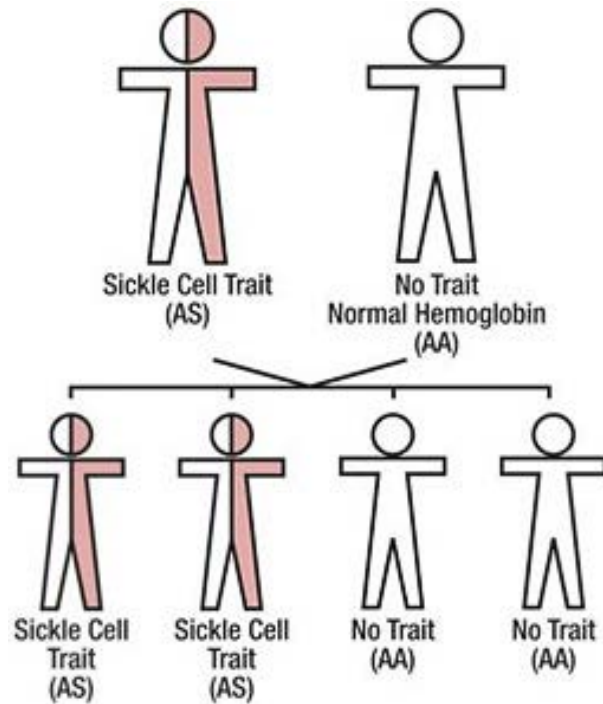
2015

NORMAL β -GLOBIN

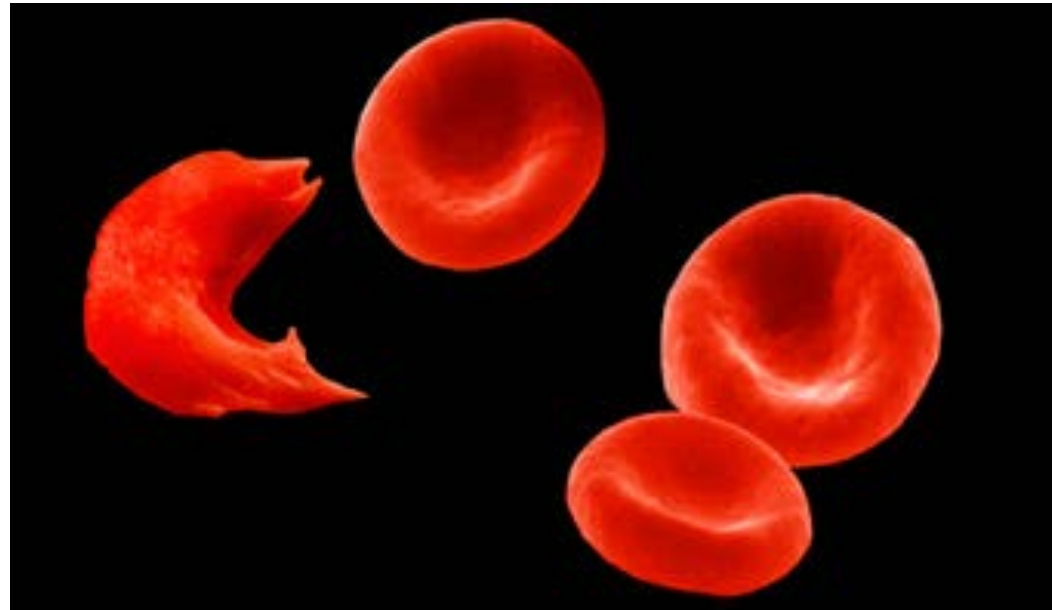
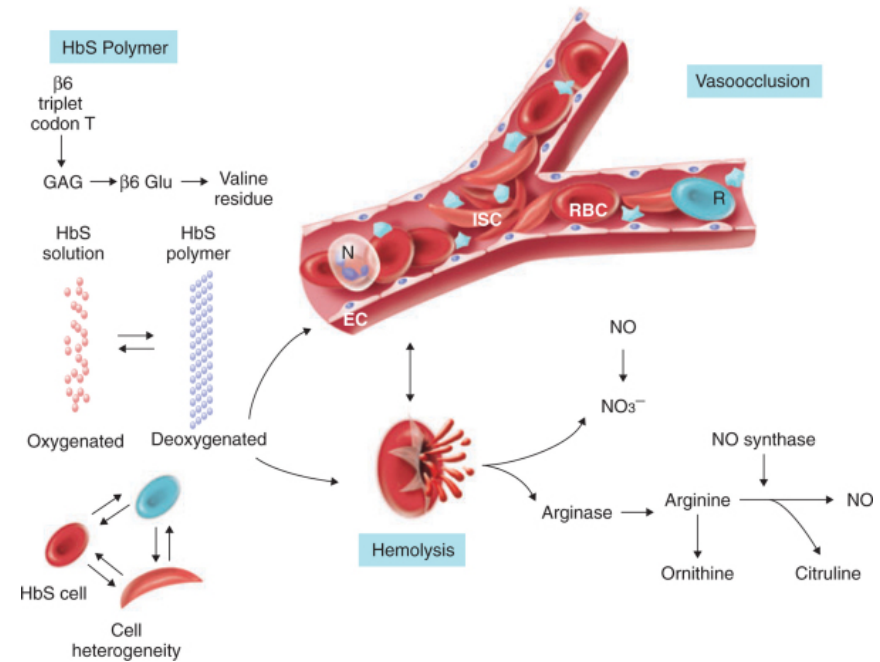
DNA.....TGA	GGA	CTC	CTC.....
mRNA.....ACU	CCU	GAG	GAG.....
Amino acid.....	thr	pro	glu

MUTANT β -GLOBIN

DNA.....TGA	GGA	CAC	CTC.....
mRNA.....ACU	CCU	GUG	CTC.....
Amino acid.....	thr	pro	val



Pathophysiology of Sickle Cell Disease

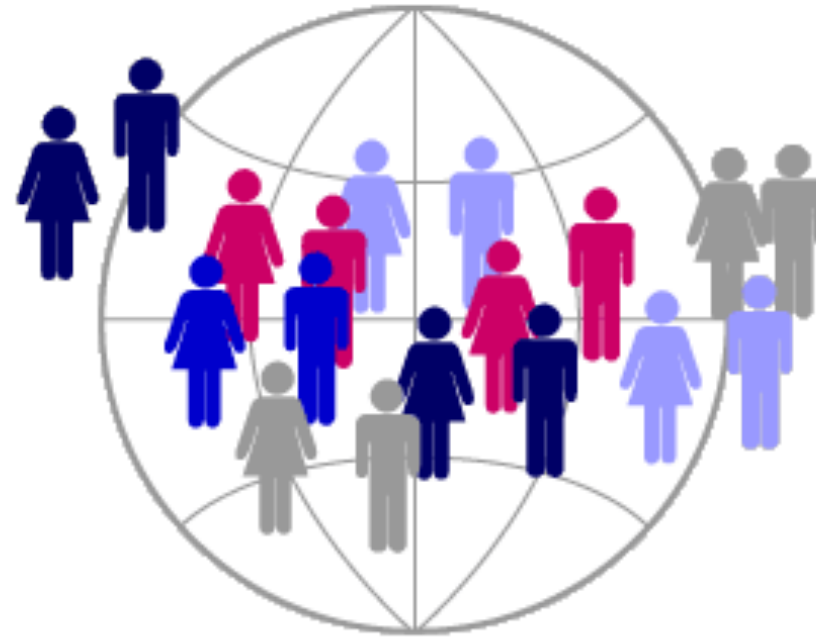






The further you are from me...

- *Shared culture* often leads to easier communication and understanding
- *Differing core beliefs* are more likely to lead to:
 - false assumptions,
 - broad generalizations,
 - misunderstanding and
 - poor communication



Unfortunate effects

- **Bias:** An inclination of temperament or outlook; especially a personal and sometimes unreasoned judgment.
- **Stereotypes:** Overall impressions based on the assumption that all members of a group possess similar attributes.
 - >the cognitive precursors of prejudice
 - > the unconscious beginnings of unintentional discrimination
- **Prejudice:** A negative feeling toward a group based on a faulty generalization

What is culture?

- “...knowledge, belief, art, morals, law, custom, and any other capabilities and habits...”
- Complex and dynamic
- Does not determine behavior
- informs potential ideas and actions
- Not a label, not a blueprint



What makes up personal culture?



- Ethnicity
- Race
- Socioeconomics
- Age
- Experiences
- Physical abilities
- Gender identity
- Lifestyle
- Spirituality
- Sexuality
- Political views
- Context : school, work, social set, community, organization, geography, emotional state

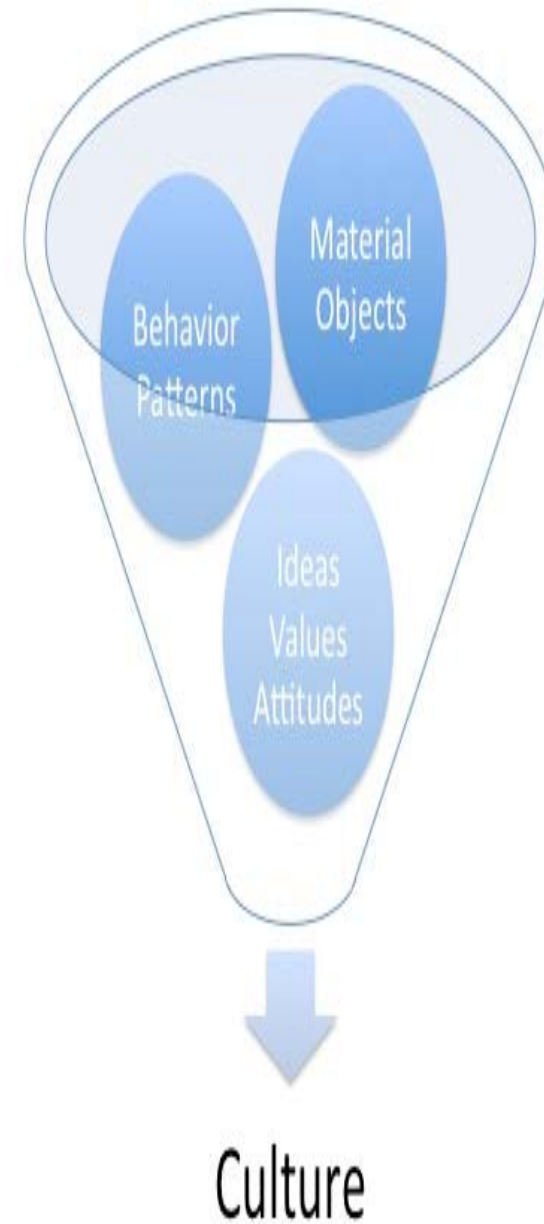
Cultural influences

- **History and social context of populations**
migration/resettlement
colonization
religious influences
territorial shifts
other social/political forces



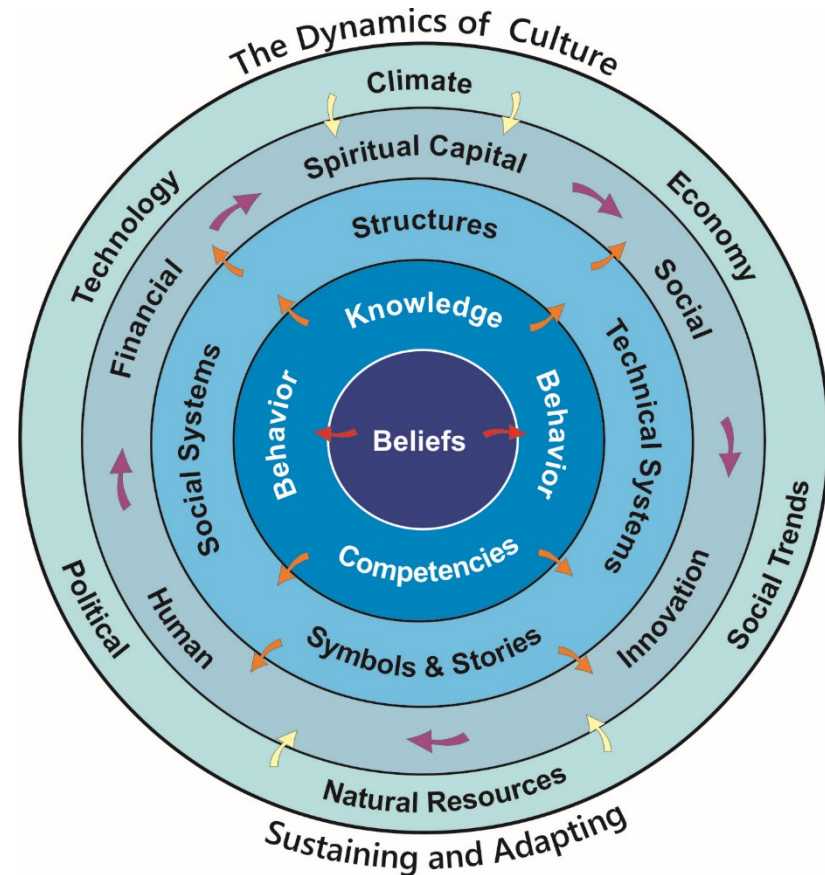
INDIVIDUAL CULTURAL DETERMINANTS

- Sense of self and space
- Communication and language
- Dress & appearance
- Food & eating habits
- Time and time consciousness



INDIVIDUAL CULTURAL DETERMINANTS

- Relationships
- **Values and norms**
 - group vs. individual independence vs. conformity
 - privacy respect
 - competition vs. cooperation
- **Beliefs and attitudes**
 - religion
 - position of women
 - social order/authority
- **Mental processes and learning**
- **Work habits and practices**



- **Culture is influenced by a Worldview:**
- A framework to interpret the world and interact in it.
- e.g., Western countries: technology will solve human disease and illnesses

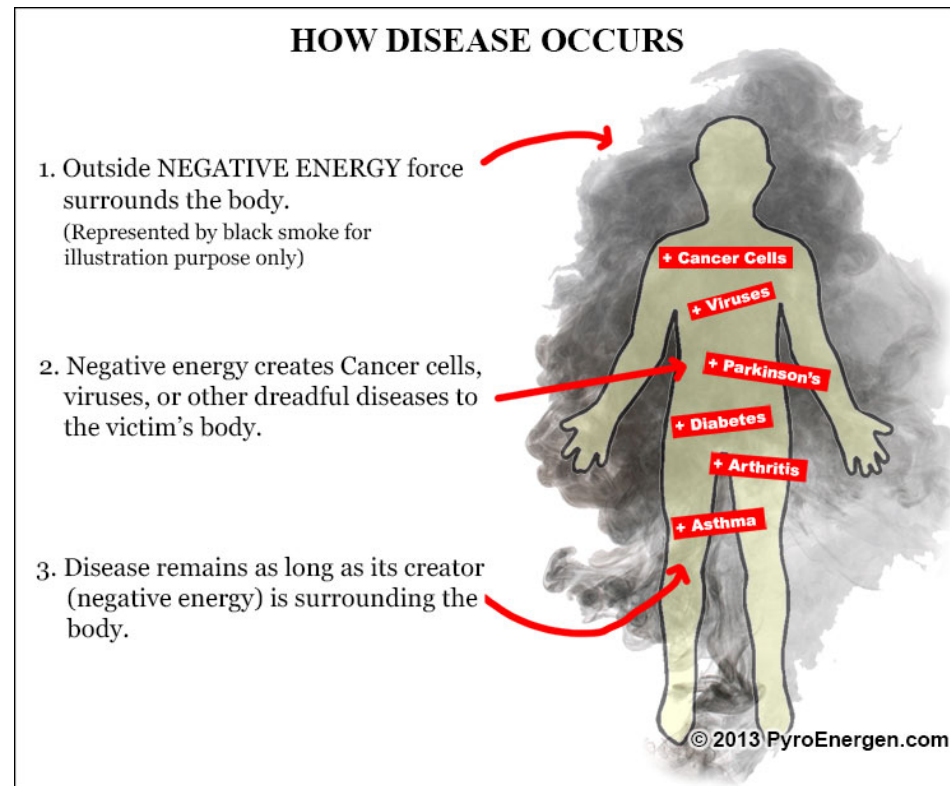


Theories of disease causation

Individual etiologies

Behavioral risk factors for disease (e.g., lifestyle, diet, habits, and sexual behaviors)

The individual is responsible for the illness.

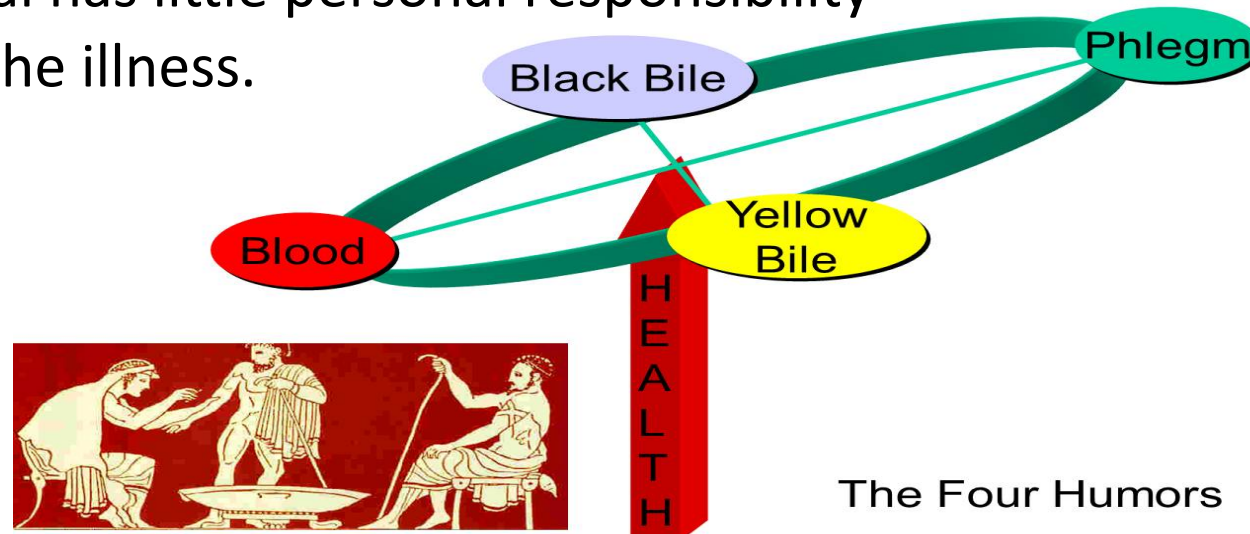


Theories of disease causation

Natural etiologies

germs, environmental factors, humoral factors (hot/cold elements), and the heavenly bodies (moon, planets, constellations).

All are beyond human control,
the individual has little personal responsibility
for causing the illness.



Theories of disease causation

3. **Social etiologies** arise from social interactions or conflicts
conflict between friends or family members;
jealousy, envy, or hatred;
giving someone the “evil eye”

4. **Supernatural etiologies**
Angry God may punish sinful thoughts
kharmā forces from previous lives will influence events in this life;
lack of respect for ancestral spirits can cause sickness.
Prevention or cure is provided by religious prescriptions.



CULTURE OF BIO-MEDICINE:

- Influenced by: historical, social, economic, political, religious, and scientific events.
- Has its own language, vocabulary, and concepts.
- Has its own values
- A sub-culture of Western society, has values of the larger society.



Healthcare's contribution to health injustice

- Health injustice spans the lifespan
- Poor pregnancy outcomes, chronic disease, life expectancy
- Cancer treatment outcomes
- Likelihood of getting a transplant
- Adequate treatment for pain
- Instilling a sense of privilege

Cultural Context in research is important



- Lead studies in Baltimore
- International studies
- Tuskegee
- Not enrolling and feeling left out

Difficult Experiences happen daily

- Younger mom with a baby with heart disease
- Inadequate and stigmatizing social services
- Somali and autism
- Kids in a homeless family daycare program on display
- Sickle Cell Disease and school systems

[The Opinion Pages](#) | Op-Ed Columnist | NYT Now

Is Everyone a Little Bit Racist?

AUG. 27, 2014

[‘School administrators suspend](#) black students at more than three times the rate of white students.

Police arrest blacks at 3.7 times the rate of whites [for marijuana possession](#), even though surveys find that both use marijuana at roughly similar rates.’

‘Two scholars sent out nearly 5,000 résumés in response to help-wanted ads, randomly alternating between stereotypically white-sounding names and black-sounding names. They found that it took 50 percent more mailings to get a callback for a black name.’

‘...the challenge is ... subtle and complex: People who believe in equality but who act in ways that perpetuate bias and inequality.’

Traditional Healthcare is a hard place to get care

- Paying for a previous transgression
- Expecting the right kind of grief
- Expecting the right schedule
- The buffet of choices
- Everyone is struggling
- Many people, many perspectives



Cultural competence

- Traditional concept
- Focuses on vulnerable populations
- Designed to make health systems more functional for underserved groups
- The idea of 'competence' is elusive and untenable
- Can also be stereotyping; a laundry list
- Can emphasize esoteric traits



Cultural humility

- Aspires to subtly integrate culture and clinical agenda
- Rather than examine cultural 'traits' it starts with considering one's own assumptions and beliefs
- Lifelong process of self reflection, self critique
- Utilizes self awareness to help inquire respectfully about points of view



Cultural humility attributes

- Acknowledge power imbalance
- Be willing to say when you don't know
- Align your accumulation of knowledge with broadening behavior and attitude
- Give up the role of expert; embrace role of student of patient
- Build trust as you develop a care plan



Conveying our connectedness, showing our support



Improving our listening skills

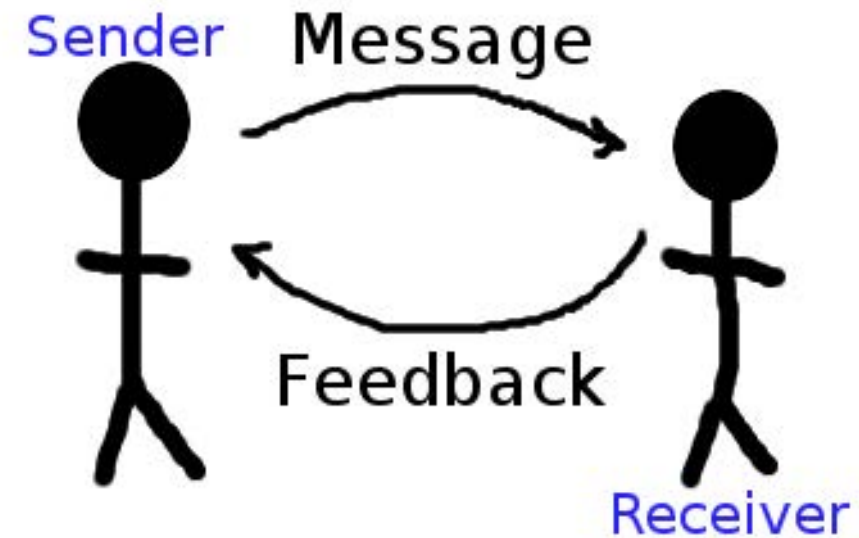
- Put yourself in a position to be attentive
- Start with, and keep, an open mind
- Remove distractions, inside and out
- Watch for nonverbal cues
- Don't interrupt
- Ask questions and clarify
- Convey empathy but don't get lost in emotive talk

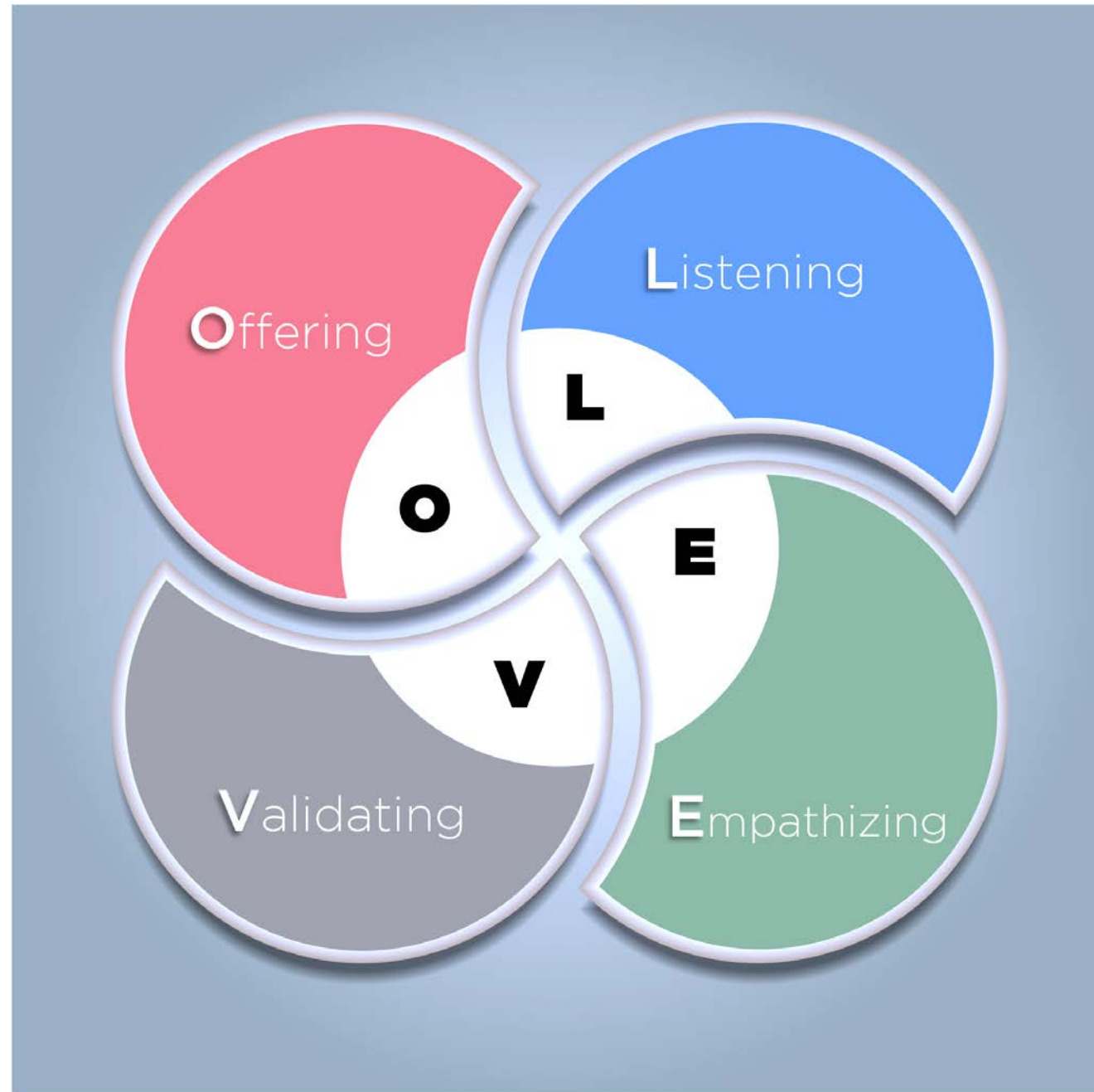




Reflective Listening Skills

- Paraphrasing: show you've heard the content
- Reflective feeling: show you've appreciated the feelings
- Summarizing: show you've understood the main ideas or themes
- Questioning: Open ended, to draw out their story





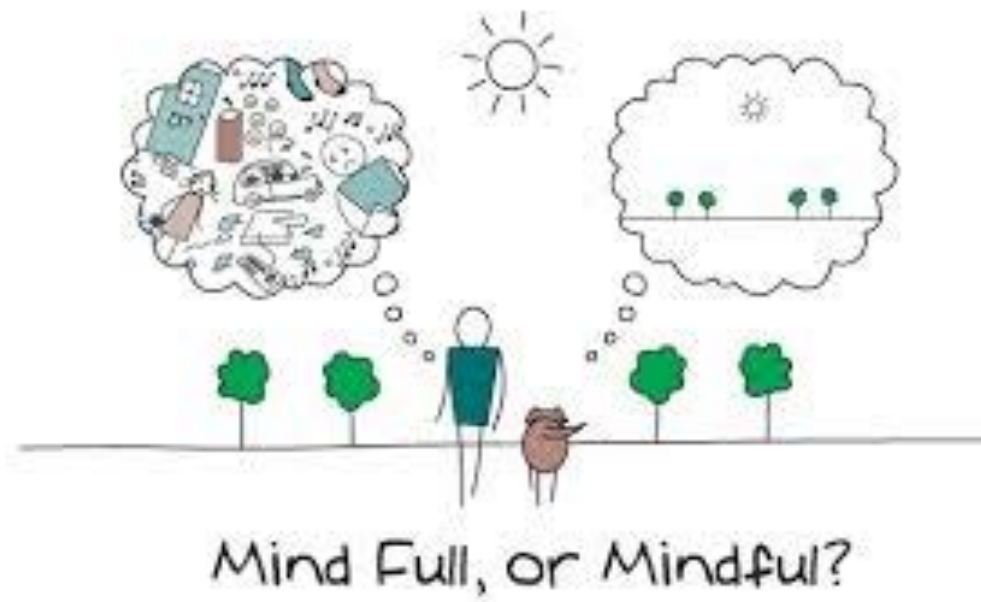
mind·ful·ness

/ˈmɪndfəlˌnəs/

noun

1. the quality or state of being conscious or aware of something.
"their mindfulness of the wider cinematic tradition"
2. a mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique.





*Mindfulness is paying attention
in a way that is*

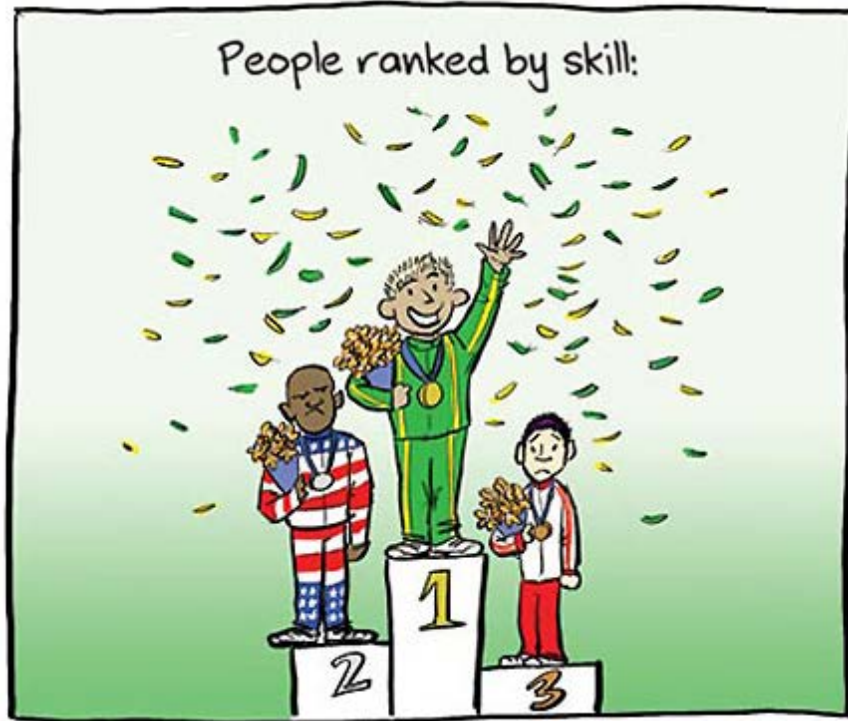


from Jon Kabat-Zinn
by Himalayan Connections



**KEEP
CALM
AND
GO
SLOW**

dignity+respect
= Inclusion



Important elements of cultural humility

- Negotiation between two perspectives
- Openness and flexibility to recognize and address differences between orientations
- Engaging and willing to explore acceptable compromise
- Not about cultural minutiae mastery
- Not about becoming a culturally traditional healer
- Not about achieving a bar of 'competency'

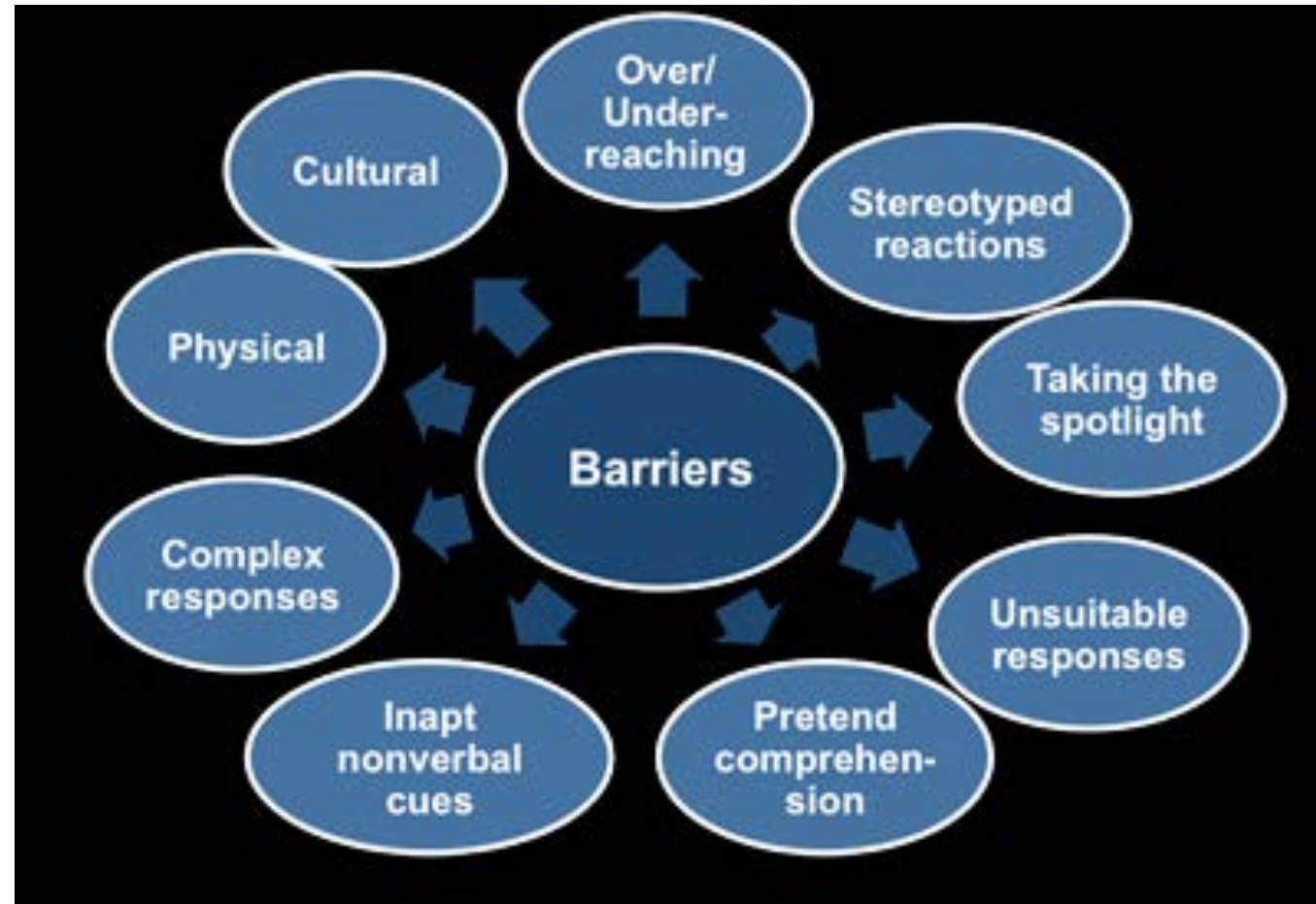
**CHANGING THE WAY YOU
SEE THE WORLD**

Listening Skills and Cultural Humility are hard to incorporate into the Healthcare System

- Conflicts with traditional learning methods and quantitative approach
- Measurement
- Power Sharing
- But I'm a good person
- Institutional self reflection
- The Business Construct



We can all fall victim to listening barriers



Traps that Promote Disengagement



- The Assessment Trap
- The Expert Trap
- The Premature Focus Trap
- The Labeling Trap
- The Blaming Trap
- The Chat Trap

Eliciting the Patient's and Family's Story and Models

1. Would you please tell me more about yourself?
2. How does this illness fit into or change your story?

Illness/Problem

3. What health problems or illnesses do you have, what do you think caused them, and what kind of care have you sought?

Impact of the Illness on the Individual

4. How is this illness affecting your daily functioning and the things that are most important to you?
5. What do you miss most from before you were ill?
6. What do you think will happen in the future?

Impact of Illness on the Family

7. What changes have occurred in the family since the illness began? (daily routines, care, finances, etc.)
8. How well do you feel the family is coping? Is there anything the family wishes they could do differently?

Cultural Humility (HUMBLE) Model

H: Humble about the assumptions you make

U: Understand your own background and culture

M: Motivate yourself to learn more about the patient's background

B: Begin to incorporate this knowledge into your care

L: Life-long learning

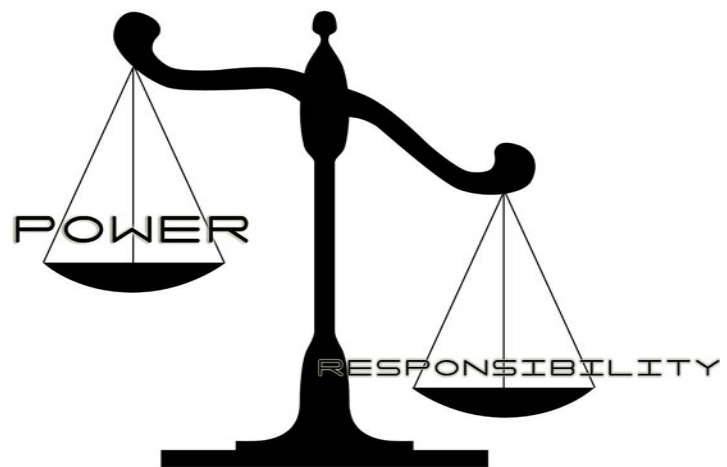
E: Emphasize respect and negotiate treatment plans



Privilege, Responsibility, Transforming, Gift, Better World

- It is a profound privilege to experience someone sharing their story
- It is a personal responsibility that we must hold ourselves accountable to being effective listeners
- It is a transforming experience to help someone slow down
- It is a great gift to not carry the full weight of traditional healthcare
- It would be a better world if the least empowered consistently got the best of health support





Equality



Equity



Maybe it's more about the first 20,000 days...

Her Wellbeing



Her Wellbeing



Cultural Humility and Effective Listening

- A caring stance can overcome almost anything
- A continuous process based on intentional listening
- Begins with self
- Selected Searchable References:
 - Cultural Humility resource: Melanie Tervalon MD MPH, Children's Hospital of Oakland
 - Lane, Lara Lynn (2005). "Reflective listening". Gale Encyclopedia of Psychology
 - <http://cultureofempathy.com>
 - <http://greatergood.berkeley.edu/topic/mindfulness>

