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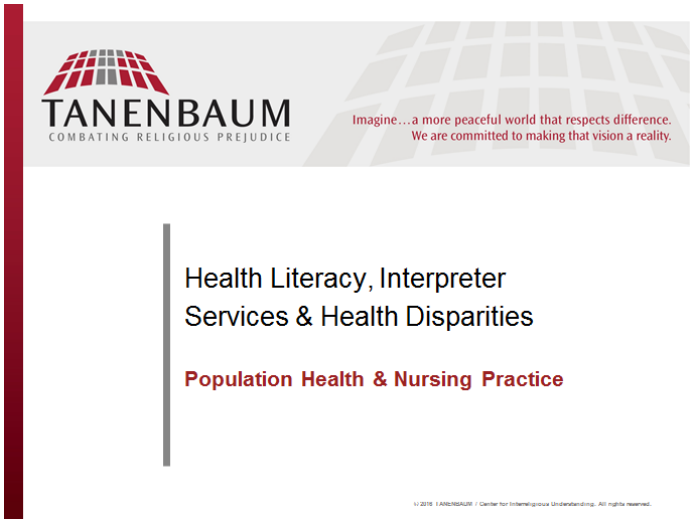
TANENBAUM
COMBATING RELIGIOUS PREJUDICE



Rationale: A wide variety of social, historical, socio-economic and cultural factors impact if and how patients access health care and access the knowledge and tools necessary to effectively receive treatment, prevent disease and promote their own health. This module outlines some of the important dimensions that impact health literacy and health disparities so that students are better equipped to identify and address communication and health care access barriers experienced by their patients.

Objectives:

- Define health literacy, both from a patient and provider perspective.
- Describe the skills necessary to appropriately access and work with interpreter services.
- Analyze how the care of a patient is impacted by the low health literacy of the patient and/or health care provider.

Time: 60 minutes

Materials: Projector, screen & laptop
Flip chart & markers
DVD player and speakers

Documentary: *Worlds Apart (*Purchased from http://www.fanlight.com/catalog/films/912_wa.php)

Process:

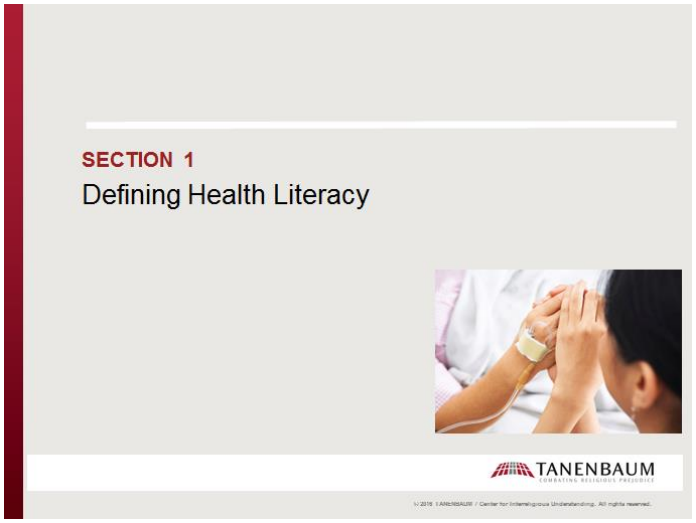
1) Tell participants that you will be reviewing a number of issues related to health disparities and health literacy including a discussion of a documentary clip.

Supplementary Learning**: Have students read the book *The Spirit Catches You and You Fall Down* by Anne Fadiman[1]and discuss the story in the context of the importance of health literacy and interpreter services. How did a lack of health literacy on the part of patient, family and provider impact the care of Lia Lee?**

While discussion topics and learning objectives vary, this book is also used as a discussion activity in learning module #1, Intersections of Identity, Diversity & Health Equity. **Refer to the teaching guide for the module referenced above if you wish to expand the discussion and student learning related to this book. However, be sure to coordinate with any instructors using this module to avoid duplicating course content.**

[1] Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures*. New York: Farrar, Straus, and Giroux.

Section 1 – Defining Health Literacy



1) Ask students to offer suggested definitions for health literacy. How would they define the term?

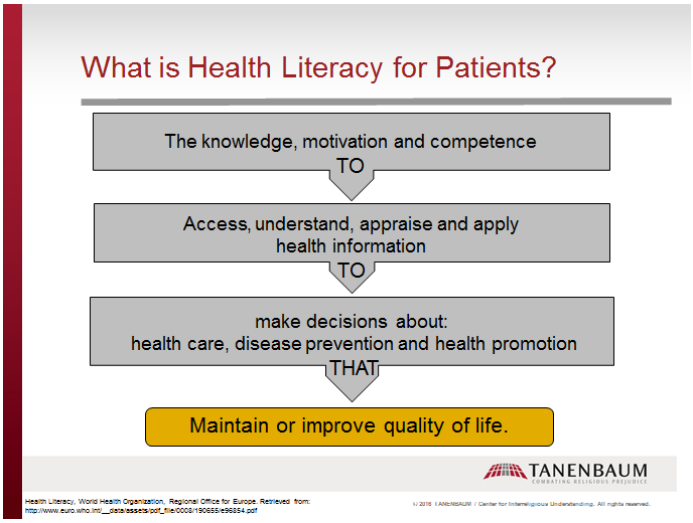
2) Ask students what skills or characteristics are associated with health literacy.

3) Be sure not to frame the question as being geared toward skills or characteristics of the patient or provider. Allow students to draw their own conclusions at this stage. Suggested definitions will likely reflect that most students see health literacy as defined by patient skills (or lack thereof) rather than health care provider skills sets (or lack thereof). The point can then later be made that health literacy can be defined from both perspectives.

4) Jot down responses from the audience on a flip chart.

5) Move to the next slide to review the World Health Organization's definition of health literacy.

Slide 3 – What is Health Literacy for Patients?



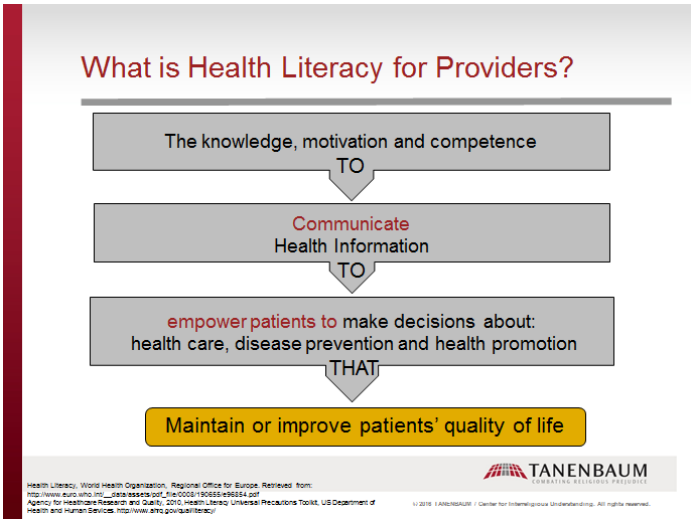
1) Review the definition on the slide and note that it comes from the World Health Organization. The full definition is as follows:

> "Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course."[2]

2) Note any similarities and/or differences between this definition and those offered by students.

[2] Health Literacy, World Health Organization, Regional Office for Europe. Retrieved from: http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf

Slide 4 – What is Health Literacy for Providers?



1) Review the definition on the slide. It reads as follows:

   The knowledge, motivation and competence to communicate health information in order to empower patients to make decisions about health care, disease prevention and health promotion that maintain or improve patients' quality of life.

2) Note that the only differences between this definition and the previous are the words highlighted in red.

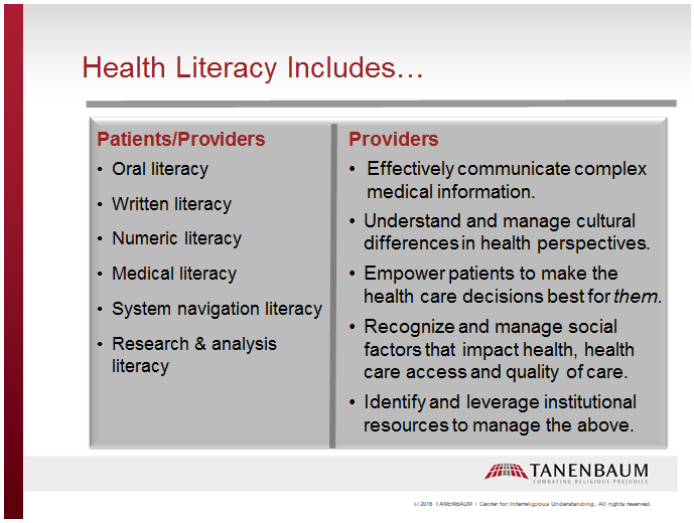
3) Make the point that, too often, health literacy is seen as a skill set, or deficit in skills sets, that relates only to the patient. In fact, health literacy can be seen as a competence required by both patient and provider. For example, health care professionals can have low health literacy skills in the form of insufficient ability to explain health issues in a way that patients understand or insufficient knowledge and skill sets in the use of tools such as interpreter services.[3]

4) Improving health care, disease prevention and health promotion requires effective communication skills on the part of both health care provider and patient. Ultimately the health care provider has the primary responsibility when it comes to enhancing

[3] Agency for Healthcare Research and Quality, 2010, Health Literacy Universal Precautions Toolkit, US Department of Health and Human Services. Retrieved http://www.ahrq.gov/qual/literacy/

his/her own health literacy skills and supporting patients in accessing and improving his/her own skill sets.

Slide 5 – Health Literacy Includes…



1) Compare the skills and tools suggested by students during the earlier discussion to the skills and tools listed on the slide.

2) Review each item briefly and offer the examples below to illustrate as needed.

3) Patients and families require facility with the following skills and tools in order to be fully health literate. Health care providers require skill sets in each other these areas as well in order to be effective at the skill sets listed on the right hand of the screen.

   a. Oral Literacy: This term generally refers to language skills as they relate to speaking and comprehension. Oral communication can be a challenge for patients who don't speak English or who speak it as a second language.

      Oral communication also refers to the ability to access and understand certain vocabulary linked to a particular situation. A patient may be fluent, or relatively fluent, in English in an every-day context but struggle to access or understand terminology specific to the hospital and medical setting. This can be a challenge for native and non-native speakers alike.

      Lastly, oral communication can also refer to the ability to accurately interpret words that can have different connotations in different contexts. This can be

challenging even for those individuals that have a high level of language ability and knowledge of vocabulary (see example below).

> EXAMPLE: In 2000, when former New York City Mayor Rudolph Giuliani was told he had a positive prostate biopsy, he thought it meant he was cancer-free. "I keep getting positive and negative mixed up," he said. "I kind of think of negative as bad and positive as good."[4]

b. Written Literacy: Written literacy refers to skill sets needed to fully comprehend written materials. As with oral literacy, written literacy can be a challenge for non-native speakers due to language barriers as well as native speakers that struggle with reading and writing. Native and non-native speakers may also struggle with reading comprehension due to unfamiliar terminology being used.

> EXAMPLE: "Archie Willard said he avoided going to the doctor for years before he learned to read at age 54. Even today Willard, now 80, said he struggles with reading - he is severely dyslexic - and identifies his medication by the shape and color of the pill, not by reading the label. Willard…said that before he learned to read he employed a strategy in medical settings common among those who cannot read or write. "I would say I couldn't fill out the paperwork because I forgot my glasses. And I didn't even wear glasses."[5]

> EXAMPLE: Compare the two passages for difficulty. One is written at an 11th grade level and the other at a 4th grade level.
>
> - 11th grade level: Fortunately, gastroenteritis usually has a limited life span. As long as fluid balance is maintained through adequate replacement, even complete lack of solid nourishment for a day or two won't harm your unborn baby.
> - 4th grade level: The stomach flu can last up to 3 days. Try to drink eight glasses of water or juice a day and your baby should be okay. This is true even if you can't keep food down.[6]

c. **Numeric Literacy** (also known as numeracy): Understanding and calculating numeric information in printed materials can be an additional challenge for patients, particularly those that are facing additional barriers around health literacy such as language skills.

> EXAMPLE: Tasks such as reading food labels, refilling prescriptions, measuring medications, interpreting blood sugars or other clinical data, and understanding health risks all rely on an ability to understand and calculate quantitative information.[7]

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[4] Holman, T. (2015). Common medical terms patients may not understand. *Dignity Health.* Retrieved from: http://www.dignityhealth.org/cm/content/pages/common-medical-terms-patients-may-not-understand.asp

[5] Boodman, S. (2011). Many Americans have poor health literacy. *The Washington Post.* Retrieved from: http://www.washingtonpost.com/wp-dyn/content/article/2011/02/28/AR2011022805957.html

[6] Mayer, G., & Rushton, N. (2002). Writing easy-to-read teaching aids. *Nursing* 2002, 32(3), 48 –50.

[7] Rothman, R., Montori, V., Cherrington, A., Pignone, M. (2009). Perspective: The role of numeracy in health care. *Journal of Health Communication.* 13(6). 583-595.

d. **Medical Literacy:** Medical knowledge refers to a patient's understanding of the body, the nature and causes of disease and the corresponding treatment options. Understanding of the inner workings of an illness or injury and its treatment can lead to greater patient acceptance of that illness and its treatment.

> EXAMPLE: A study of patients with hypertension found that "Participants intentionally adjusted their drug dose, took drugs sporadically, and stopped altogether, often without consulting their doctor. Reasons given for reducing treatment included a perception that blood pressure had improved because of a reduction in symptoms, that drugs were unnecessary when under less stress, a dislike of taking drugs, a fear of addiction or tolerance, and side effects…. The participants in the studies presented here did not simply have a knowledge deficit but held alternative explanations for their hypertension."[8]

e. **System Navigation Literacy:** "Navigation within the health care system involves interacting with the built environment and finding one's way between locations. In addition, it requires an ability to accomplish the myriad tasks needed to manage health within an increasingly complicated and fragmented medical system. It involves scheduling specialist appointments, enrolling for insurance services, understanding one's health care benefits, dealing with pharmacy benefits management companies, finding locations for diagnostic studies, and connecting with community agencies."[9]

> EXAMPLE: a clinical psychologist described the challenges of system navigation as follows: "Our coordinator of supportive oncology education has spent up to five hours helping just one patient apply for insurance through the Marketplace. She has needed to explain basics like premiums and deductibles, as well as how to compare insurance options. She has walked patients through checking to make sure their current doctors will be covered under new plans. Notably, despite having proficient health literacy and training, the coordinator has herself sought assistance to confirm the finer details."[10]

f. **Research and analysis literacy:** Research and analytical skills are necessary in order to be an informed health care consumer. Everything from selecting a health care insurance plan, a hospital, physician or other health care provider or service necessitates an ability to identify and then evaluate a wealth of information.

In addition, health care decision-making for oneself or a loved one requires research and analytical skills to identify the most appropriate treatment plan given the patient's needs, concerns and values. The increasing availability of

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[8] Marshall, I., Wolfe, C., McKevitt, C. (2012). Lay perspectives on hypertension and drug adherence: systematic review of qualitative research. *British Medical Journal.* 345, 1-16.

[9] Roundtable on Health Literacy, Board on Population Health and Public Health Practice, Institute of Medicine, How Can health Care Organizations Become More health Literate? Washington, DC: The National Academies Press.

[10] Garcia, S. (2014, January 30). Newly insured Americans don't understand basic healthcare terms: Why increasing health literacy should be a national priority. *The Atlantic.* Retrieved from www.theatlantic.com.

medical information in the form of books, the media and online sources leaves patients with a sometimes overwhelming wealth of information that must be analyzed for its usefulness and accuracy.

EXAMPLE: Women diagnosed with early-stage breast cancer can often choose either lumpectomy, followed by radiation therapy, or mastectomy. Either treatment offers similar long-term outcomes in terms of cancer recurrence and survival.[11] Women making decisions regarding treatment of early-stage breast cancer require a certain skill set in researching and analyzing treatment options in order to determine the best option for them.

4) Explain that the competencies just reviewed are also competencies that the provider must possess in order to be health literate themselves. Specifically, outline the following skill sets required and note the ways in which they are linked to the varying forms of health literacy listed on the left side of the screen.

   a. Effectively communicate complex medical information: Health care providers must be able to communicate often very complex medical information in order to help patients understand their illness and identify an appropriate treatment plan. This requires oral literacy (Ex: use of interpreter services), written literacy (Ex: writing discharge or prescription instructions), and numeric literacy (Ex: assisting patients in calculating dosages or reading food labels). Health care providers must also develop their skills in communicating complex medical processes in a way that patients and families can understand and retain the information.

   b. Understand and manage cultural differences in health perspectives: In order for health care providers to be able to assist patients and their families in making informed health care decisions that are in line with patient values, providers must be able to respectfully communicate with patients to understand any cultural differences in perspectives on an illness or treatment. This skill set could be labelled “cultural literacy” or “cultural competence.”

   c. Empower patients to make the health care decisions best for them: Once both a literal and cultural understanding of a patient’s illness and disease management exist, health care providers must be able to empower patients to identify a treatment plan or make medical decisions that are in line with the patient’s values and unique needs. This may require research and analysis literacy (Ex: directing patients to resources that outline treatment options), system navigation literacy (Ex: connecting a patient with the chaplaincy department to discuss religious concerns they might have around a treatment option) and cultural competence

[11] Stilwell, D. 2015). Health literacy and numeracy: The overlooked challenge for elders who want to tguide their own healthcare. *American Society on Aging.* Retrieved from http://www.asaging.org/blog/health-literacy-and-numeracy-overlooked-challenge-elders-who-want-guide-their-own-healthcare

(Ex: ensuring that the treatment options outlined are incorporating a patient's religious and cultural values).

d. Recognize and manage social factors that impact health, health care access and quality of care: A component of assisting patients in selecting appropriate treatment options is recognizing the various social factors at play and taking those into account in collaborating with the patient to develop a treatment plan.

> ****** NOTE TO FACILITATOR: This example is also suggested as a supplementary activity in learning module*** *#1, Intersections of Identity, Diversity & Health Equity.*
>
> EXAMPLE: Dr. Danielle Ofri: "Not so long ago, a middle-aged patient came to my office for a checkup. He cheerfully admitted that he hadn't been paying attention to his diabetes for the last few years. He'd stopped taking his medicine, stopped seeing his doctors, stopped thinking about the disease altogether. When I checked his blood sugar in the office, it wasn't just a little elevated — it was four times the normal level…. For my patient, his wide-angle lens took in the whole of his life, of which diabetes was one small part. For me, in the 20 minutes allotted, my lens was narrowly focused on the disease that posed the gravest and most immediate risk to his health. The challenge that lay ahead of us was to help each other adjust the angles of our respective lenses so that our visions could come into common focus. Otherwise, we'd slip into futile haranguing…. That required extended discussions over the next few months that touched upon matters both practical and philosophical. We had to figure out how a taxi driver who relied on street-vendor food and whose only exercise was pressing the gas pedal could adhere to the diet and exercise requirements to control diabetes. We had to talk about the diarrhea that his diabetes pills caused. We had to discuss how his religious background influenced his approach to the future. And we had to talk bluntly about his life expectancy and the legacy he would — or would not — leave to his children."[12]

e. Identify and leverage institutional resources to manage the above: Finally, remind students that navigating the health care system can be incredibly complex, confusing and challenging for even the most well-versed patient. Therefore, the responsibility of helping patients access appropriate institutional resources (Ex: interpreter services, discharge information in the appropriate language, chaplaincy services, health insurance assistance) fall to the health care team.

Slide 6 – Risks of Low Health Literacy

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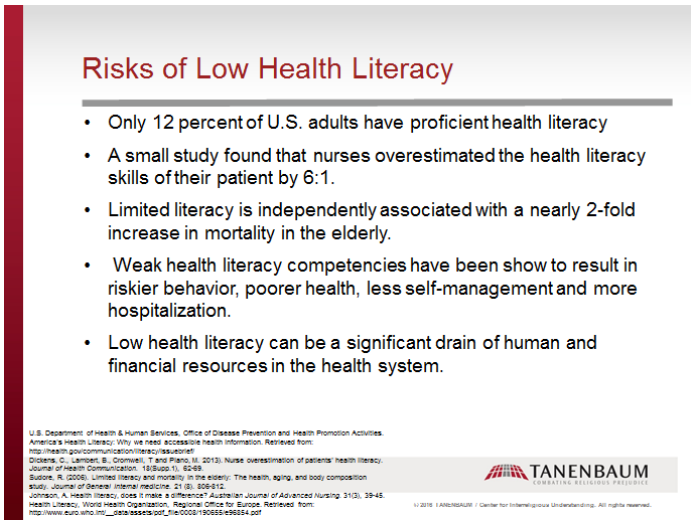
[12] Ofri, D. (2014, March 27). Doctor Priorities vs. Patient Priorities. *The New York Times.* Retrieved from: http://well.blogs.nytimes.com/2014/03/27/doctor-priorities-vs-patient-priorities/?_php=true&_type=blogs&_r=0



1) Note that only 12% of U.S adults have been identified as having proficient health literacy.[13] And point out that nurses have been found to overestimate the health literacy skills of their patient by as much as 6 to 1.[14]

2) Caution students that low health literacy can result in a 2-fold increase in mortality in the elderly[15] as well as result generally in riskier behavior, poorer health, less self-management and more hospitalization on the part of patients.[16]

3) Finally, point out that low health literacy can also result in a significant drain of human and financial resources for health systems.[17]

4) Note that, for all of the above reasons, health literacy is an essential skills set for health care providers that want to provide comprehensive, quality and patient-centered care.

[13] U.S. Department of Health & Human Services, Office of Disease Prevention and Health Promotion Activities. America's Health Literacy: Why we need accessible health information. Retrieved from: http://health.gov/communication/literacy/issuebrief/

[14] Dickens, C., Lambert, B., Cromwell, T and Piano, M. 2013). Nurse overestimation of patients' health literacy. *Journal of Health Communication.* 18(Supp.1), 62-69.

[15] Sudore, R. (2006). Limited literacy and mortality in the elderly: The health, aging, and body composition study. *Journal of General Internal medicine.* 21 (8). 806-812.

[16] Johnson, A. Health literacy, does it make a difference? *Australian Journal of Advanced Nursing.* 31(3), 39-45.

[17] Health Literacy, World Health Organization, Regional Office for Europe. Retrieved from: http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf

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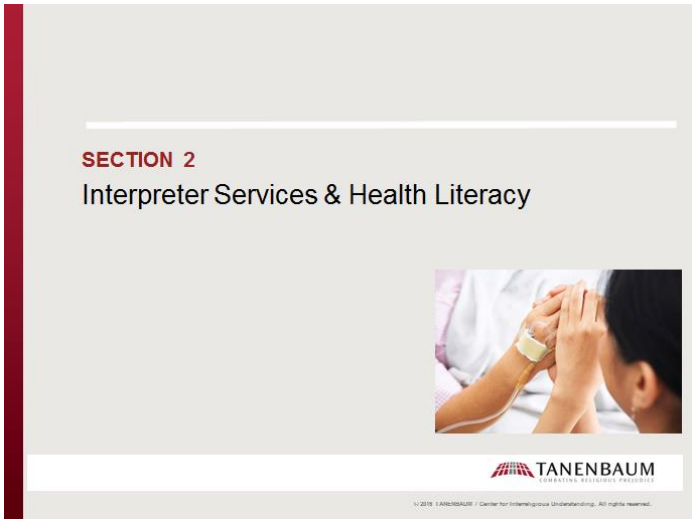
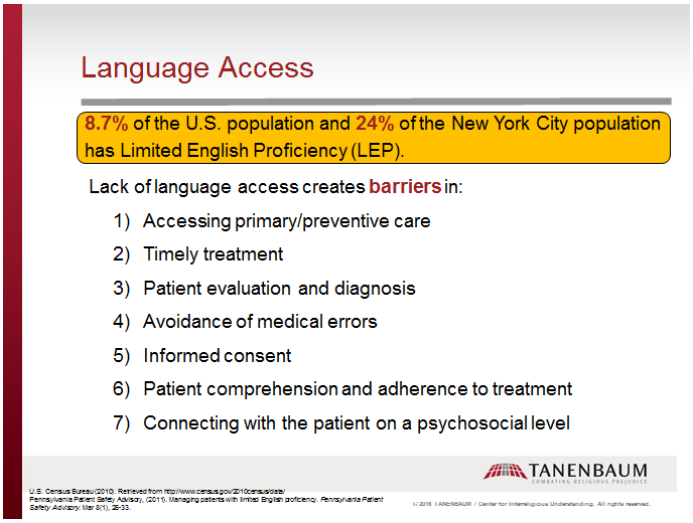
Section 2 – Interpreter Services & Health Literacy



1) Explain that the following section will review some of the knowledge and skills required to work with interpreter services, a key resource necessary for effective communication with patients with Limited English Proficiency.

Slide 8 – Language Access



******NOTE TO FACILITATOR: Find limited English proficiency statistics for your city and state using the following link and adapt the information on the slide accordingly. http://www.pewforum.org/religious-landscape-study/***

1) Point out that almost 10% of the U.S. Population and almost a quarter of the New York City population have Limited English Proficiency (LEP).[18]

2) Note that while there is no standard definition for LEP, it is generally understood to mean persons who have difficulty speaking or reading English because their primary language is not English and they have not developed fluency in the English language.

3) For patients who don't speak English, obtaining health care services can be frustrating and difficult and communication barriers may have potentially dangerous consequences. Explain that the items listed on the slide are some of the risks that studies have correlated to lack of or insufficient interpreter/translation services for LEP patients.

    a. **Accessing primary/preventive care:** The challenges that LEP individuals face in a health care setting lead to decreased access to primary and preventive care.

[18] U.S. Census Bureau (2010). Retrieved from http://www.census.gov/2010census/data/

Additionally, low patient satisfaction with past cross-language encounters can lead to future reluctance to access care, until conditions become acute.[19]

b. **Timely treatment:** Difficulty communicating with the patient and/or difficulty obtaining an interpreter to facilitate communication can lead to the delay of appropriate treatment.

c. **Patient evaluation and diagnosis:** Treating a patient who is unable to accurately and completely communicate his or her symptoms and ailments may result in delayed diagnosis or misdiagnosis.

> FOR EXAMPLE**:** Excerpt from *The Spirit Catches You and You Fall Down,* a book about a Hmong child diagnosed with severe epilepsy. "Foua and Nao Kao had no way of explaining what had happened, since Lia's seizures had stopped by the time they reached the hospital. Her only obvious symptoms were a cough and a congested chest. The resident ordered an X-ray, which led the radiologist to conclude that Lia had "early bronchiopneumonia or tracheobronchitis." As he had no way of knowing that the bronchia congestion was probably caused by aspiration of saliva or vomit during her seizure…, she was routinely dismissed with a prescription for ampicillin (Fadiman p. 26)."[20]

d. **Avoidance of medical errors:** Language barriers increase risks to patient safety.

> NOTE: In a study conducted by the Joint Commission, adverse event data on English-speaking patients and patients with limited English proficiency were collected and compared. About 49.1% of limited English proficient patient adverse events involved some physical harm, whereas only 29.5% of the adverse events for patients who speak English resulted in physical harm. These adverse events were also far more likely to result in moderate or temporary harm or death in the case of limited English proficient patients and to be the result of communication errors.[21]

e. **Informed consent:** Language barriers can lead to a failure in properly informing patients and obtaining consent. In some cases, language barriers can lead to misunderstandings as to whether or not consent has been given.

> FOR EXAMPLE: "Circumcision consent obtained without interpreter; the mother (Italian speaking) expressed in the delivery room that she didn't want her baby circumcised."[22]

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[19] Perkins, J. (1999). Overcoming language barriers to health care. *Popular Government*, Fall, 38-44

[20] Fadiman, A. (1997). *The spirit catches you and you fall down.* New York, NY: Farrar, Straus and Giroux.

[21] Divi, C., Koss, R., Schmaltz, S., & Loeb, J. Language proficiency and adverse events in U.S. Hospitals: A pilot study. *International Journal for Quality in Health Care, 19,* 60-67.

[22] Pennsylvania Patient Safety Advisory, (2011). Managing patients with limited English proficiency. *Pennsylvania Patient Safety Advisory*. Mar 8(1), 26-33.

FOR EXAMPLE: “The patient, who speaks Chinese only, was diagnosed with a brain lesion. The family and patient were not informed of the diagnosis. The morning of the procedure, the patient’s head was shaved and markings placed for a follow up…The surgeon's assistant admitted to shaving the head of the patient without informing the patient.” [23]

f. **Patient comprehension of medical forms/instructions:** Language barriers can also result in an inability to communicate vital instructions regarding treatment and medical prescriptions.

FOR EXAMPLE: “A previously healthy 10-month-old girl was taken to a pediatrician’s office by her monolingual Spanish-speaking parents when they noted that their daughter had generalized weakness. The infant was diagnosed with iron-deficiency anemia. At the time of the clinic visit, there were no Spanish-speaking staff or interpreters available. One of the nurses spoke broken Spanish and in general terms was able to explain the girl had “low blood” and needed to take a medication. The parents were thankful for the attention and nodded in understanding. The pediatrician wrote the following prescription in English: Fer-Gen-Sol iron, 15 mg per 0.6 ml, 1.2 ml daily (3.5 mg/kg). The parents took the prescription to the pharmacy. The local pharmacy did not have a Spanish-speaking pharmacist on staff, nor did they obtain an interpreter. The pharmacist attempted to demonstrate proper dosing and administration using the medication dropper and the parents nodded in understanding. The prescription label on the bottle was written in English. The parents administered the medication at home and, within 15 minutes, the 10-month-old vomited twice and appeared ill. They took her to the nearest emergency department, where the serum iron level 1 hour after ingestion was found to be 365 mcg/dL (therapeutic levels are 60-180 mcg/dL). She was admitted to the hospital for intravenous hydration and observation. Serial serum iron levels and electrolytes were monitored. Upon questioning, the parents stated that they had administered a household tablespoon of the medication, approximately 15 ml or 43 mg/kg (a 12.5-fold overdose). At the time of discharge from the hospital, the nurse counseled the parents on proper dosing through a hospital interpreter.”[24]

FOR EXAMPLE: Addition and omission errors of clinical consequence made by an ad hoc interpreter during a visit to a pediatric nurse practitioner by a 7-year-old-girl diagnosed with otitis media.
Nurse Practitioner: “And she’s going to have 1 teaspoon 3 times a day for 10 days.”
Interpreter: “Entonces para la amoxicilina – por los oídos…entonces le vas a dar una cucharadita tres veces al día.”
Translation of what Interpreter said: “So for the amoxicillin – in the ears…so you are going to give her 1 teaspoonful 3 times a day.”
Potential for confusion: Parent understands that the medication should go in the ear, as opposed to being taken orally.[25]

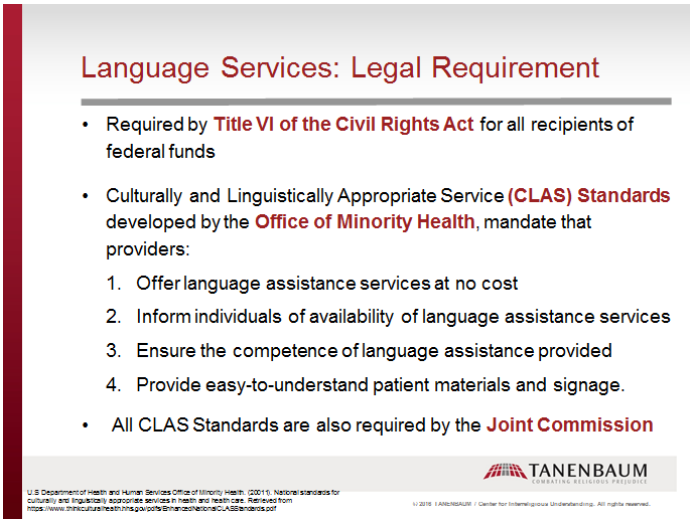
[23] Pennsylvania Patient Safety Advisory, (2011). Managing patients with limited English proficiency. *Pennsylvania Patient Safety Advisory*. Mar 8(1), 26-33.
[24] Flores, G. (2006). Language barrier. *Web M&M: morbidity & mortality rounds on the web.* Retrieved from: http://webmm.ahrq.gov/case.aspx?caseID=123
[25] Flores, G., Laws, M., Mayo, S., Zuckerman, B., Abreu, M., Medina, L, & Hardt, E. (2003). Errors in medical interpretation and their potential clinical consequences in pediatric encounters. *Pediatrics*, *111*(1), 7-14.

g. **Connecting with the patient on a psychosocial level:** An inability to fully communicate with the patient can severely impair the ability to connect with the patient on a personal level and develop a relationship of trust and understanding.

FOR EXAMPLE: A doctor saw a Muslim woman complaining of leg pains and stomach problems. The patient spoke no English and her husband translated for her. It became clear that the patient was very depressed, but the doctor was unable to openly ask standard questions about personal stressors that might have been affecting her health. She sensed that the patient's responses were guarded with her husband present. During her third appointment she was able to have a professional interpreter present and the husband remained in the waiting room. Her patient explained to her that the police had recently broken down the door of her family's apartment, thrown her to the floor, and arrested her son for financing terrorism because he owned a currency exchange, a common business practice in immigrant communities. This was when her symptoms had begun. She was also able explain why she hadn't gotten the hip x-ray that the doctor had ordered to assess for arthritis. The x-ray technician was a man, and he had wanted to lift up her hijab, so that he could properly position the equipment. The doctor provided a legal advocacy organization's telephone number and the patient thanked her with tears in her eyes. "For Mrs. Haddad, just as the legal advocacy organization's telephone number might have been more therapeutic than all the various antidepressants and pain medications we had tried, our professional interpreter was arguably a better diagnostic test than all the labs and x-rays I had ordered during the preceding months."[26]

[26] Chen, A. (2006). Doctoring across the language divide. *Health Affairs.* May/June, 808-813. Retrieved from http://content.healthaffairs.org/content/25/3/808.full

Slide 9 – Language Services: Legal Requirement



1) Emphasize to students that, not only are interpreter services necessary in order to effectively communicate with patients and provide a standard of care, providing adequate language services is also legally required by Title VI of the Civil Rights Act for all recipients of federal funds. Explain that Title VI guarantees that:

> "No person in the United States shall, on the ground of race, color or national origin, be excluded from participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."[27]

2) In addition, in August 2000, President Clinton signed Executive Order 13166 to "improve access to federally conducted and federally assisted programs and activities for persons, who, as a result of national origin, are limited in their English proficiency (LEP)."[28] The order was designed to better enforce and implement the existing obligation of Title VI of the Civil Rights Act.

3) The Executive Order required federal agencies to develop guidelines to clarify obligations for recipients (of federal funds) – The Office of Minority Health developed

[27] United States Department of Labor, Title VI, Civil Rights Act of 1964. Retrieved from: http://www.dol.gov/oasam/regs/statutes/titlevi.htm
[28] United States Department of Labor, Executive Order 13166. Retrieved from: http://www.dol.gov/oasam/regs/statutes/Eo13166.htm

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the Culturally and Linguistically Appropriate Service Standards CLAS Standards based on Title VI and the Executive Order.

4) The CLAS standards include 4 mandates that are current federal requirements for all recipients of federal funds. The 4 required mandates are.[29]

   a. Standard 5: Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.

   b. Standard 6: Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.

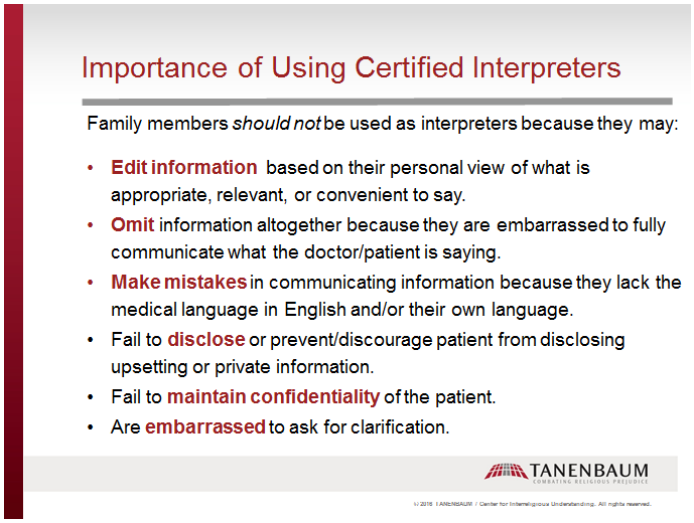
   c. Standard 7: Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.

   d. Standard 8: Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

5) Note that all CLAS Standards are also required by the **Joint Commission –** the accrediting body for the majority of hospitals in the United States.

[29] U.S Department of Health and Human Services Office of Minority Health. (20011). National standards for culturally and linguistically appropriate services in health and health care. Retrieved from https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedNationalCLASStandards.pdf

Slide 10 – Importance of Using Certified Interpreters



1) NOTE to facilitator and students: While the words “interpreter” and “translator” are often used interchangeably, the correct term is “interpreter.” The word “translator” is used for those who translate written text, while “interpreter” is used for oral translation.

2) Explain that family members should not be used as interpreters because they may:

   a. Edit information based on their personal view of what is appropriate, relevant, or convenient to say.

   b. Omit information altogether because they are embarrassed to fully communicate what the doctor/patient is saying.

   c. Make mistakes in communicating information because they lack the medical language in English and/or their own language.

   d. Fail to disclose or prevent/discourage patient from disclosing upsetting or private information.

   e. Fail to maintain confidentiality of the patient.

   f. Are embarrassed to ask for clarification.

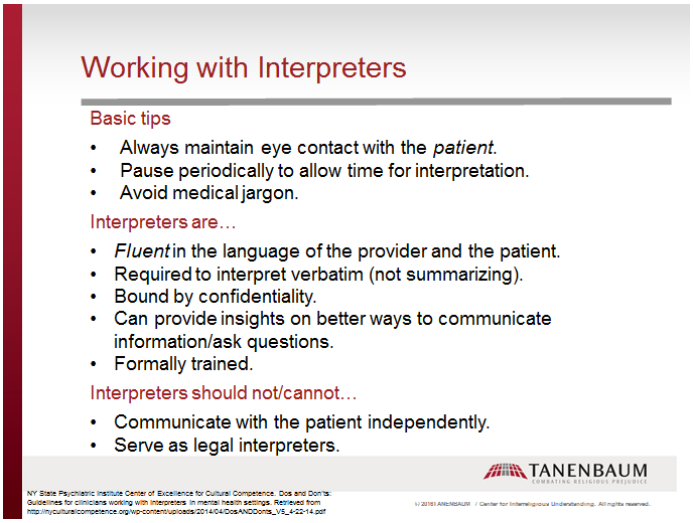
3) If a patient/family states that they do not wish to use an interpreter that request should be documented via a release form that states that the patient asked not to use an interpreter. In addition, the request to decline the use of interpreter services must come from the patient not the family member. Lastly, even if a form is signed, the provider has the right to bring in an interpreter at any point if they feel that not having one there is negatively impacting care.

> Ex: The manager of interpreter services was asked to manage a situation involving a Russian patient and her daughter. The daughter, who accompanied her mother, was adamant with the health care team that her mom didn't want to use an interpreter. The interpreter services manager said that she understood but explained that she had to confirm this with the patient. She contacted a Russian interpreter via phone services to confirm what the daughter was stating. The interpreter, after speaking briefly with the patient, stated to the mother said she absolutely did not want her daughter interpreting for her.[30]

4) Emphasize that under NO circumstances should a child ever be asked to serve as an interpreter even if the family or child say that that is their wish.

[30] Anecdote from Tanenbaum interview

Slide 11 – Working with Interpreters



1) Review the information on the slide to outline some very basic tips for working with interpreters and clarify what is and what is not within the role and responsibility of a medical interpreter.

2) Basic tips:

   a. Always maintain eye contact with the patient. Note that this may initially require some practice and feel odd. It is a natural reflex to direct attention to the person that is speaking in a language that is understood but it is important in terms of establishing and building trust, that eye contact remain with the patient when speaking.

   b. Pause periodically to allow time for interpretation. When time is limited, it can be tempting to speak quickly and continuously, however this makes it difficult for the interpreter to accurately communicate information to the patient.

   c. Avoid medical jargon. For example, instead of using the term electrocardiogram or EKG say "machine to monitor your heart." Medical terms can be difficult to interpret or may not have a direct translation in the patient's native language.[31]

[31] NY State Psychiatric Institute Center of Excellence for Cultural Competence. Dos and Don'ts: Guidelines for clinicians working with interpreters in mental health settings. Retrieved from http://nyculturalcompetence.org/wp-content/uploads/2014/04/DosANDDonts_V5_4-22-14.pdf

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3) Review the information listed outlining some of the characteristics of professional interpreters that are not always commonly known. Certified Interpreters are…

a. Fluent in the language of the provider and the patient: Note that health care providers who are not *fluent* in a language (speaking on the same level as a native speaker) should not attempt to communicate with the patient.

b. Required to interpret verbatim (not summarizing): Interpreters are trained to fully communicate everything the health care provider says to the patient without editing or summarizing information.

c. Bound by confidentiality as part of their professional/ethical standards. Encourage students to inform patients of this fact as some patients may be unaware and therefore reluctant or nervous about sharing sensitive information.

d. Can provide insights on better ways to communicate: Note, however, that the health care provider ultimately has authority over how information is communicated.

> FOR EXAMPLE: An interpreter was translating for a Haitian patient. The physician was taking a sexual history and asked the patient if they had sex with men. The interpreter cautioned that the way the question was framed would likely be seen as an extreme insult to the patient. She suggested reframing the question. The physician disregarded the interpreter's suggestion. The interpreter translated the question as requested and the Haitian patient became incredibly angry to the point of attempting to strike the physician.[32]

e. Formally trained: Interpretation is a professional skill set like any other. Therefore, it is not appropriate to use a staff person as an interpreter if they are not certified because neither their level of fluency nor their skill level in interpretation has been established or documented. For that same reason, it is not appropriate for a health care provider to try to communicate with a patient in a language in which they are not fluent.

4) Outline two key points related to roles that interpreters can *not* take on. Interpreter's should not/cannot…

a. Communicate with the patient independently. This means health care providers should not be asking the interpreter to ask or clarify a question without a health care team member present. In this instance, interpreters should be viewed as a

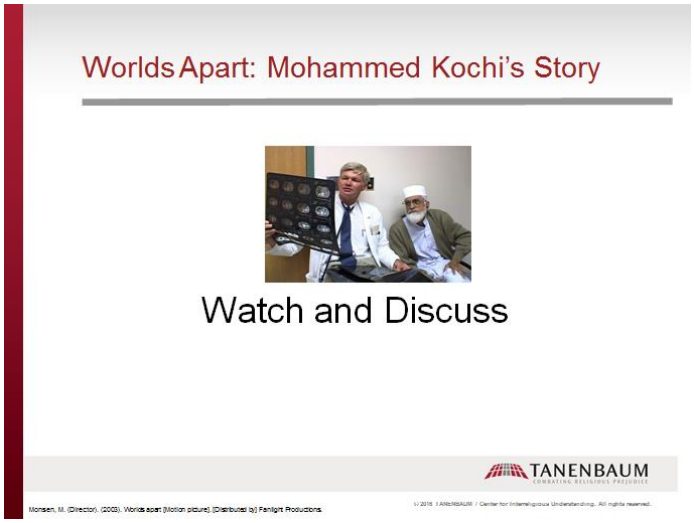
[32] Anecdote from Tanenbaum interview

tool for communication and, from that perspective, a valuable but not independent member of the team.

b. Serve as legal interpreters: Medical interpreters are not certified to be legal interpreters which means that if police need to speak with the patient in a legal capacity the medical interpreter is not certified to interpret those communications.

5) Acknowledge that effectively communicating with patients that have limited English proficiency can be time consuming. However, emphasize that this is necessary in order to maintain the standard of care. Point out that there are many standards of care that health care professionals must abide by that take extra time. These standards are there for a reason – to maintain a high standard of care for all patients.

Slide 12 – Hold Your Breath



******NOTE TO FACILITATOR: While discussion topics and learning objectives vary, film clips from Mohammed Kochi's story are also used as a discussion activity in learning module** #3a, History Taking & Physical Assessment: Taking a Spiritual History. **Reference the teaching guide for the module referenced above if you wish to expand the discussion and student learning from Mr. Kochi's story. However, be sure to coordinate with any instructors using this module to avoid duplicating course content.***

Rationale: This film will provide an illustration of how health literacy can come up in the context of a health care setting including issues around cultural competence and interpreter services. This film is NOT meant to blame the health care providers depicted, but rather to show the complex and difficult situations that can arise in a health care setting around the intersections of health literacy, culture and health care and learn from the challenges that the health care team and family depicted in the documentary faced. The film illustrates how a lack of effective communication and health literacy on the part of both patients and health can result in misunderstandings and ultimately impact the efficacy and quality of care.

Materials: Documentary: *Worlds Apart* - Purchase at http://www.fanlight.com/catalog/films/912_wa.php[33]

[33] Monsen, M. (Director). (2003). Worlds Apart [Motion picture]. [Distributed by] Fanlight Productions.

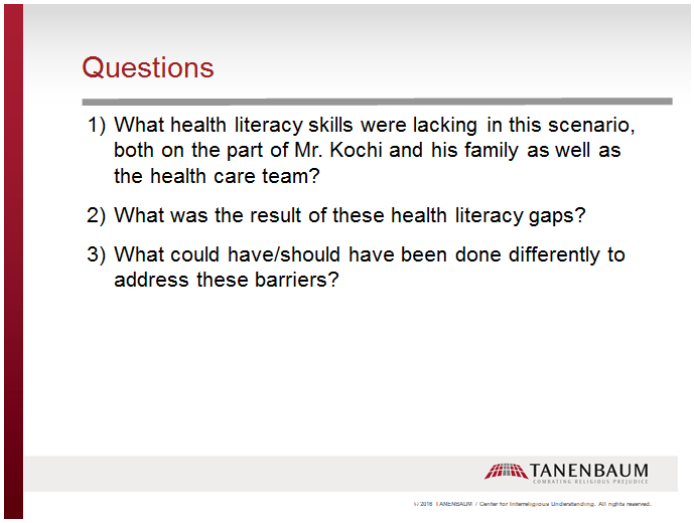
1) Provide a brief synopsis of the film as follows: Mohammad Kochi is a 63-year-old man from Kabul, Afghanistan who arrived in Fremont, California in 1988, escaping from a region torn by war after the Soviet invasion. The film captures a brief but intense period in the life of Mr. Kochi after he is diagnosed with gastric cancer. Mr. Kochi is a devout Muslim who prays five times a day, fasts during Ramadan, and has done the Haj (pilgrimage to Mecca), seven times in his life. He has nine daughters and one son.

2) Emphasize that this is a true story and is not a reenactment. The film captures events as they happened.

3) Go to the main menu and select the clip “Mohammad Kochi’s Story.” The clip will run for approximately 10 minutes.

4) Switch back to the PowerPoint presentation to review the discussion questions.

Slide 13 – Questions



1) Engage students in a discussion on the following questions and ultimately draw out the key points listed below.

   a. What health literacy skills were lacking in this scenario, both on the part of Mr. Kochi and his family as well as the health care team?

      - Oral literacy: Mr. Kochi was not fluent in English and a professional interpreter was not consistently used when communicating with Mr. Kochi.
      - Medical literacy: Mr. Kochi's illness, prognosis and treatment options were not communicated in a way that they were fully understood by Mr. Kochi and his family.
      - Research & analysis literacy: Mr. Kochi was unaware of the variety of treatment methods available to him, as it relates to chemotherapy.

   b. What was the result in these health literacy gaps?

      - Mr. Kochi's treatment was delayed.
      - Mr. Kochi's daughter was angry with herself for not realizing that her father was not receiving treatment.

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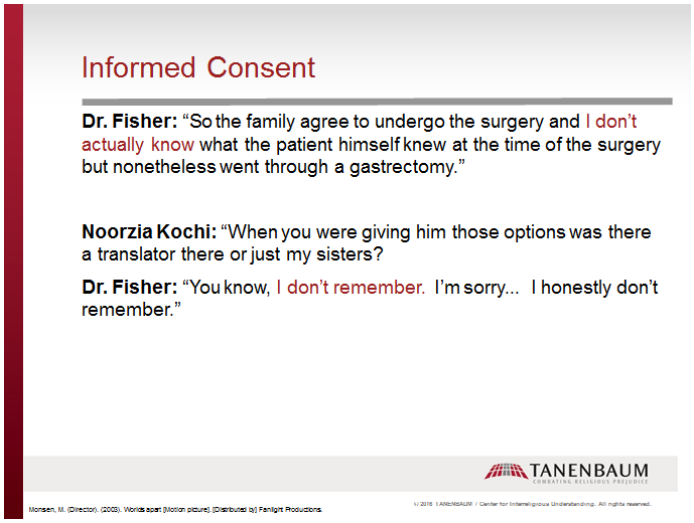
- Mr. Kochi's daughter was angry with the health care team for the role she felt they played in delaying her father's treatment.

c. What could have/should have been done differently to address these barriers?

- A consistent use of trained medical interpreters by Mr. Kochi's medical team.
- Health care providers respectfully asking Mr. Kochi why he did not want to undergo chemotherapy.
- With Mr. Kochi's permission, arranging a family meeting so that all members of Mr. Kochi's family had the same information in regards to his illness, prognosis and treatment options.

Slide 14 – Informed Consent



1) Highlight the quotes listed on the screen.

   Dr. Fisher: "So the family agree to undergo the surgery and I don't actually know what the patient himself knew at the time of the surgery but nonetheless went through a gastrectomy."

   Noorzia Kochi: "When you were giving him those options was there a translator there or just my sisters?

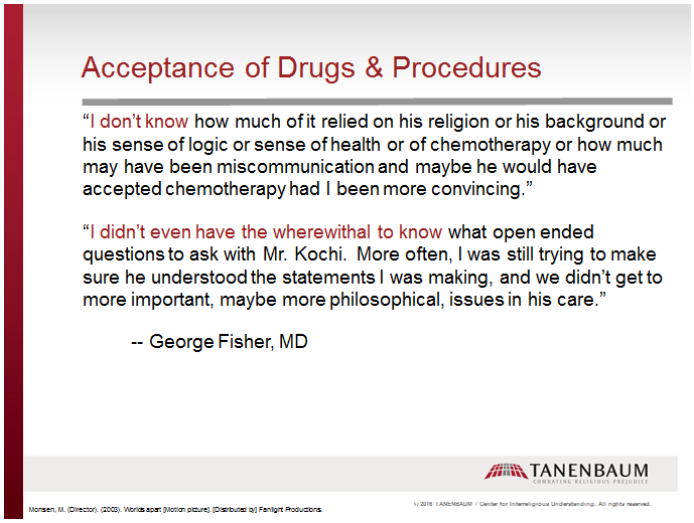
   Dr. Fisher: "You know, I don't remember. I'm sorry... I honestly don't remember."

2) Point out the concerns that these statements bring up related to informed consent. The first quote indicates a lack of clarity as to how fully Mr. Kochi understood his condition when he agreed to surgery.

3) In addition, the failure to consistently use and document the use of professional interpreters in communicating with Mr. Kochi left both Mr. Kochi's daughter and Dr. Fischer wondering if Mr. Kochi fully understood the treatment options available to him.

4) Reemphasize the importance of using and documenting the use of professional interpreters.

Slide 15 – Acceptance of Drugs & Procedures



1) Read the quotes on the screen:

> "I don't know how much of it relied on his religion or his background or his sense of logic or sense of health or of chemotherapy or how much may have been miscommunication and maybe he would have accepted chemotherapy had I been more convincing."
>
> "I didn't even have the wherewithal to know what open ended questions to ask with Mr. Kochi. More often, I was still trying to make sure he understood the statements I was making, and we didn't get to more important, maybe more philosophical, issues in his care." -- George Fisher, MD

2) Note that, in a more extended version of this documentary, one of Mr. Kochi's nurses says the following:

> "He has the idea that if he's meant to be cured that will happen because Allah says so. He also believes that Allah has given him this disease to a certain extent to have that experience on earth, as a life experience or a lesson. I don't know much about the Muslim beliefs but I certainly get that impression and I'm not sure if I'm interpreting his feelings correctly. -- Margreet Love, RN

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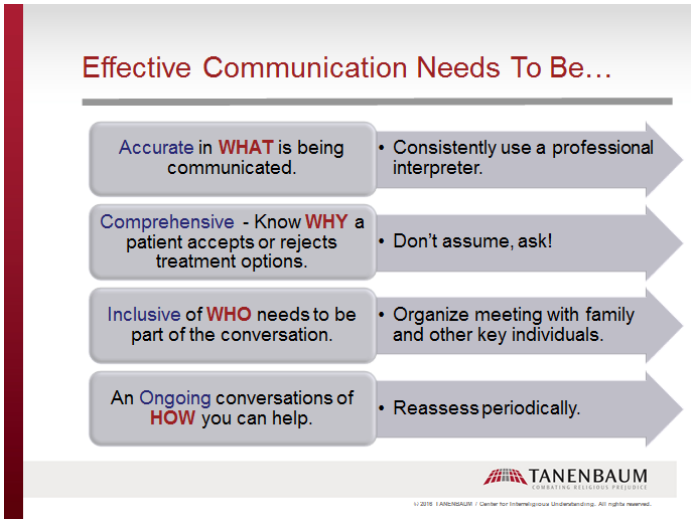
3) Point out the phrases highlighted in red on the slide. They illustrate that Dr. Fischer (and Mr. Kochi's nurse in the quote above) made certain assumptions about Mr. Kochi. Caution against making assumptions about a patient's religious beliefs. It is imperative to ask about rather than assume you know the intentions or reasoning behind a patient's decision regarding their care. "Why?" can be a very powerful question in avoiding misunderstandings.

4) Acknowledge that Dr. Fisher and the rest of the hospital staff are working under very difficult circumstances, given language barriers and the cultural divide. However, ask participants: What might have been the impact of Dr. Fisher or someone else on staff asking the question "Why?" in response to Mr. Kochi's refusal of chemotherapy?

5) End by briefly summarizing the conclusion of Mr. Kochi's story, which is as follows: Mr. Kochi ultimately underwent chemotherapy, but passed away a few months later. His family, especially his daughter, remained very upset with themselves and with Mr. Kochi's physicians, because a series of language and cultural barriers had led to a delay in Mr. Kochi's treatment.

Slide 16 – Effective Communication Needs To Be…



1) To conclude the discussion review the recommendations listed on the slide regarding better practices to consider when communicating with patients around different cultural and religious concerns related to diagnosis and treatment.

2) State that effective communication with patients and/or their families should meet the following guidelines:

   a. WHAT: Information must be accurately communicated to patients and/or their families. This requires, among other things, the use of a professional interpreter. Note that Mr. Kochi's story illustrates fairly clearly what can happen when a professional interpreter is *not* consistently used.

   b. WHY: All communications and conversations should be comprehensive in covering both *what* a patient and/or their family will or will not accept in terms of treatment but also *why* various treatment options are accepted or rejected. In the case of Mr. Kochi, his health care team made certain assumptions regarding *why* Mr. Kochi refused chemotherapy and, in doing so, missed some key concerns that Mr. Kochi had around the use of a continuous infusion pump.

   c. WHO: Conversations with the patient and/or his or her family should be inclusive of all individuals that are core to the decision-making process. This will include different individuals for different people. For example, in the case of Mr. Kochi it

would have been helpful to have a family meeting where all family members were included in the conversation. In addition, given Mr. Kochi's concerns around various religious beliefs and practices conflicting with suggested treatment, it might have been helpful to include Mr. Kochi's imam in the conversation.

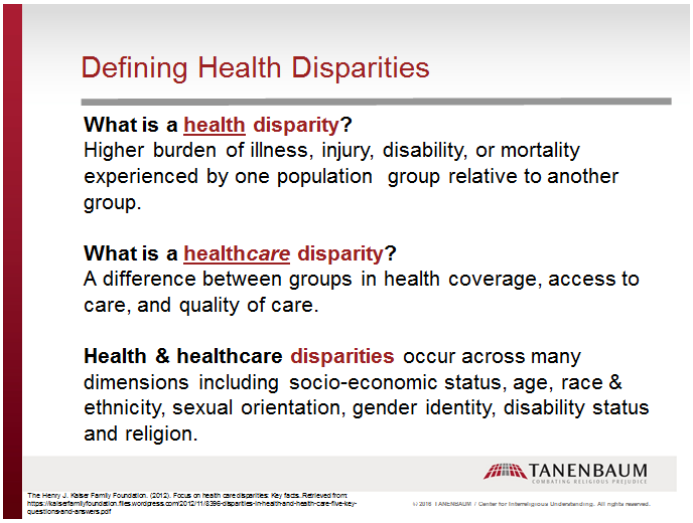
Meetings with key family members and others influential to the patient's decision making process may be time consuming to plan and implement but are essential in ensuring that all necessary parties are accurately informed as to the diagnosis and treatment options. Laying this groundwork can ultimately save time by avoiding confusion and identifying any questions or concerns the patient and/or their family may have.

d. HOW: Conversations regarding treatment options and long-term planning should be an ongoing conversation with the patient and/or their family. Reassessing the patient's perspectives periodically ensures that any changes in perspective around diagnosis and treatment are addressed and incorporated into the treatment plan. The case of Mr. Kochi illustrated that his position towards chemotherapy was not straight forward or static. Tracking this evolving thought process ensures that the treatment plan can be adapted, if necessary, to reflect changing attitudes.

Section 3 – Defining Health Disparities

1) Note that the previous two sections outlined barriers to health care that can emerge for patients related to language and health literacy. Explain that the following section will further explore some of the sources of health disparities related to overall health, health care access and quality of health care.

Slide 18 – Defining Health Disparities



******NOTE TO FACILITATOR: This slide is also used in learning module #1, Intersections of Identity, Diversity & Health Equity. Refer to the teaching guide for the module referenced above if you wish to expand the discussion and student learning related to health disparities. However, be sure to coordinate with any instructors using this module to avoid duplicating course content.***

1) Note that before having a more in-depth discussion regarding health disparities it is important to clarify *how* health and healthcare disparities are defined.

2) Ask for one person to share his/her understanding of the term "health disparity" and give an example. Then click to bring the definition onto the screen which reads as follows:

   Health disparity: Higher burden of illness, injury, disability, or mortality experienced by one population group relative to another group.[34]

[34] The Henry J. Kaiser Family Foundation. (2012). Focus on health care disparities: Key facts. Retrieved from: https://kaiserfamilyfoundation.files.wordpress.com/2012/11/8396-disparities-in-health-and-health-care-five-key-questions-and-answers.pdf

EXAMPLES:

- Race: People of color frequently report higher prevalence of health conditions, such as diabetes and obesity.
- Race: In 2004, the AIDS case rate for Black men was 104.1 per 100,000, compared to 13.7 for White men, and 8.0 for Asian men.
- Socio-economic status: Low-income people of all races report worse health status than higher income people and differences by race and ethnicity persist even within income groups.
- Race: Infant mortality rates are significantly higher for Black and American Indian and Alaska Native infants compared to other groups.[34]
- Sexual orientation/gender identity: Research has found that LGBT individuals are at elevated risk for some mental health and behavioral health conditions, with studies finding that they are two and a half times more likely to experience depression, anxiety, and substance misuse.[35]

3) Ask for one person to share his/her understanding of the term "health disparity" and to give an example. Then click to bring the definition onto the screen which reads as follows:

Healthcare disparity: A difference between groups in health coverage, access to care, and quality of care.[35]

EXAMPLES:

- Race: Research has shown racial and ethnic minorities often receive health care in hospitals and other facilities that offer lower-quality care than other institutions.[36]
- Race: A recent US government report showed that since 2007, inpatient care for people with heart failure has actually grown worse for Hispanics or Latinos, Native Americans, and Alaska Natives. These minorities with heart failure are younger than their white counterparts. They also encounter socioeconomic, language, and cultural barriers to care that lead to higher rates of readmission to hospitals and to poorer outcomes.[36]
- Sexual Orientation: 29% of LGB adults delay or choose not to seek health care, compared to 17% of heterosexual adults.[37]
- Gender Identity: 28% of transgender or gender nonconforming people postpone medical care when they are sick or injured due to concerns about discrimination.[38]

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[35] The Henry J. Kaiser Family Foundation. (2012). Health and access to care and coverage for lesbian, gay, bisexual, and transgender individuals in the U.S. Retrieved from: http://kff.org/report-section/health-and-access-to-care-and-coverage-for-lesbian-gay-bisexual-and-transgender-health-challenges/

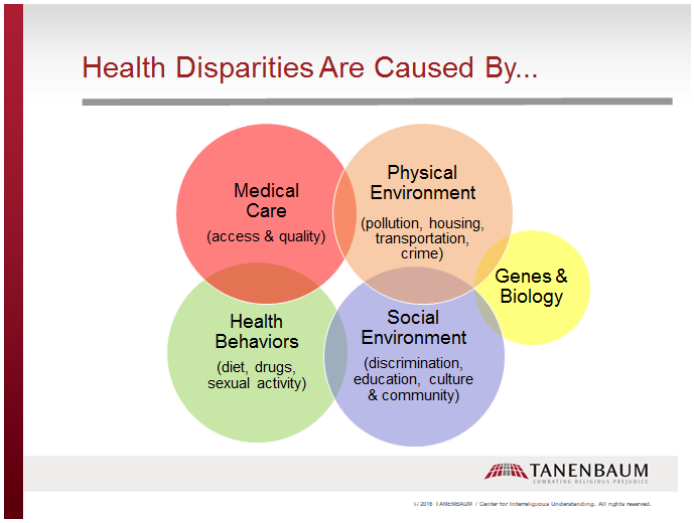
[36] Health Affairs. (2011, October 6). Achieving equity in health. Retrieved from: http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=53

[37] Krehely, J. (2009). How to close the LGBT health disparities gap. *Center for American Progress, 1-9.*

[38] Grant, J., Mottet, L., & Tanis, J. (2010). *National transgender discrimination survey: Report of health and health care*. The National Center for Transgender Equality and the Nation Gay and Lesbian Task Force.

4) Emphasize that both health and & healthcare disparities occur across many dimensions including socio-economic status, age, race & ethnicity, sexual orientation, gender identity, disability status and religion.

Slide 19 – Health Disparities Are Caused By…



******NOTE TO FACILITATOR: This slide is also used in learning module #1, Intersections of Identity, Diversity & Health Equity. Refer to the teaching guide for the module referenced above if you wish to expand the discussion and student learning related to health disparities. However, be sure to coordinate with any instructors using this module to avoid duplicating course content.***

1) Explain that the graphic on the slide illustrates the different factors that can result in health disparities.

2) Briefly review the 5 dimensions illustrated on the screen and discuss some of the examples that follow. Alternatively, if time is limited, move to the next slide and present the examples listed there.

3) Genes & Biology: Point out that genetic and biological determinants of health have proven to be a fairly small source of health and health disparities. In addition, it is important to understand that, given that race is a social construct rather than a biological one, when we speak of "genetic" factors relating to health disparities what is being referred to is genetic commonalities related to ancestry not race.[39]

[39] Silverstein, J. (2015, April 13). Genes don't cause racial-health disparities, society does. *The Atlantic.* Retrieved from: http://www.theatlantic.com

EXAMPLE: The TSD carrier rate in Jewish individuals of Eastern European descent (Ashkenazi) is approximately 1 in 30; the carrier rate for non-Jewish individuals is estimated to be 1 in 300. [40]

4) Physical Environment: Conditions related to a person's physical environment such as pollution, housing, transportation and crime can exacerbate health disparities. For example, compared to predominantly white neighborhoods, many predominantly black urban neighborhoods have more fast-food outlets, have fewer grocery stores and recreational facilities, and are in closer proximity to sources of industrial pollution, such as older factories and dump sites.

EXAMPLES:

- Pollution: In certain low-income neighborhoods of New York City, the prevalence of asthma approaches 25% and is the leading cause of childhood hospitalizations. The rates of asthma occurring in New York City's low-income neighborhoods such as East Harlem and Central Harlem are four times the national rate.[41] Children in East Harlem, for example, are almost thirteen times more likely than children living on the Upper East Side to visit the emergency room for asthma-related issues (81 per 1,000 vs. 6.4 per 1,000).[42]
- Transportation: Medicare rarely covers nonemergency transportation to a hospital or doctor's office. If a family has a loved one that, for instance, is unable to walk down a flight of stairs, it can be extremely difficult as well as costly to get them back and forth from doctors' appointments as needed.

5) Health Behaviors such as smoking, drug use, sexual behavior (having unprotected sex), alcohol abuse and choices/availability of food play a significant role in health. Emphasize that these dynamics do not operate in isolation of other causes of health disparities. Physical and social environment can increase the vulnerability and likelihood of someone exhibiting problematic or risky health behaviors.

6) Social Environment: The social dimensions of a person's environment – access to education, cultural norms, community dynamics and the impact of institutionalized racism – can also play a significant role in creating health disparities between different groups of people.

[40] The American College of Obstetricians and Gynecologists. (2005). Committee Opinion: Screening for Tay-Sachs Disease, 318. Retrieved from: http://www.acog.org/-/media/Committee-Opinions/Committee-on-Genetics/co318.pdf?dmc=1&ts=20150828T1032139794

[41] The Children's Health Fund. (2006). *Benefits of best practice: Asthma care for high-risk children.* Retrieved from http://www.childrenshealthfund.org/sites/default/files/AsthmaWP1206.pdf

[42] New York City Department of Health and Mental Hygience (2012). Preventing and treating childhood asthma in NYC. *NYC Vital Signs.* 11(4). Retrieved from: http://www.nyc.gov/html/doh/downloads/pdf/survey/survey-2012childasthma.pdf

EXAMPLES:

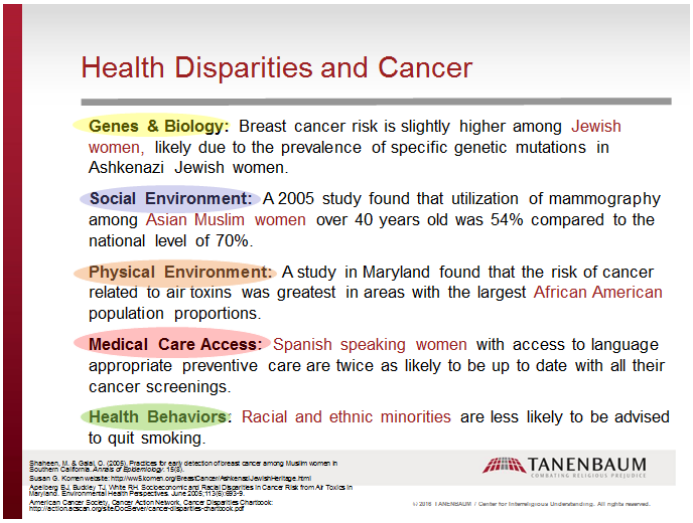
- Discrimination: Discrimination has been shown to increase the risk of stress. “There is growing evidence that some health disparities may result from the fact that specific social environments might ‘get under the skin’ to cause disease. Chronic stress related to poverty or hardship translates into high levels of the stress-related hormones cortisol and epinephrine, which may in turn influence other body processes such as inflammation or the performance of the immune system.”[43]
- Discrimination: “Stress leads to poorer mental and physical health. But this is not only because stress breaks the body down. It is also because stress pushes people to cope in unhealthy ways. When we feel stressed, we may want a drink and, if we want a drink, we may also want a cigarette. But discrimination is not just any form of stress. It is a type of stress that disproportionately affects minorities. Here we see how racism works in a cycle to damage health. People at a social disadvantage are more likely to experience discriminatory practices in areas such as policing, housing, hiring practices and health care which, understandably results in stress. These individuals are also less likely to have the resources to extinguish this stress, because they are at a social disadvantage.”[44]

7) Medical Care: Access to health care and the quality of care that an individual or groups of individuals have access to also play a significant role in health disparities. Lack of health insurance has been shown to be the most significant contributing factor to poor quality of care for some of the core measures captured by the Agency for Healthcare Research and Quality.[45] In terms of the quality of care, remind participants of the issues discussed earlier related to health literacy and interpreter services.

EXAMPLE: Uninsured people are less likely to get recommended care for disease prevention, such as cancer screening, and for disease management, such as diabetes care management.[45]

8) Present students with a common illness such as diabetes or heart disease and ask them to give examples of the varying ways in which the dimension just reviewed can result in health disparities for a person with that disease.

[43] Health Affairs. (2011, October 6). Achieving equity in health. Retrieved from: http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=53
[44] Silverstein, J. (2013, March 12). How racism is bad for our bodies. *The Atlantic.* Retrieved from: http://www.theatlantic.com
[45] Health Affairs. (2011, October 6). Achieving equity in health. Retrieved from: http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=53



1) Review the examples for each category discussed on the previous slide:

   a. Genes & Biology: Breast cancer risk is slightly higher among Jewish women, likely due to the prevalence of specific genetic mutations in Ashkenazi Jewish women.[46]

   b. Social Environment: A 2005 study found that utilization of mammography among Asian Muslim women over 40 years old was 54% compared to the national level of 70%.[47]

   c. Physical Environment: A study in Maryland found that the risk of cancer related to air toxins was greatest in areas with the largest African American population proportions.[48]

   d. Medical Care Access: Spanish speaking women with access to language appropriate preventive care are twice as likely to be up to date with all their cancer screenings.[49]

[46] Susan G. Komen website: http://ww5.komen.org/BreastCancer/AshkenaziJewishHeritage.html

[47] Shaheen, M. & Galal, O. (2005). Practices for early detection of breast cancer among Muslim women in Southern California. *Annals of Epidemiology.* 15(8).

[48] Apelberg BJ, Buckley TJ, White RH. Socioeconomic and Racial Disparities in Cancer Risk from Air Toxics in Maryland. Environmental Health Perspectives. June 2005;113(6):693-9.

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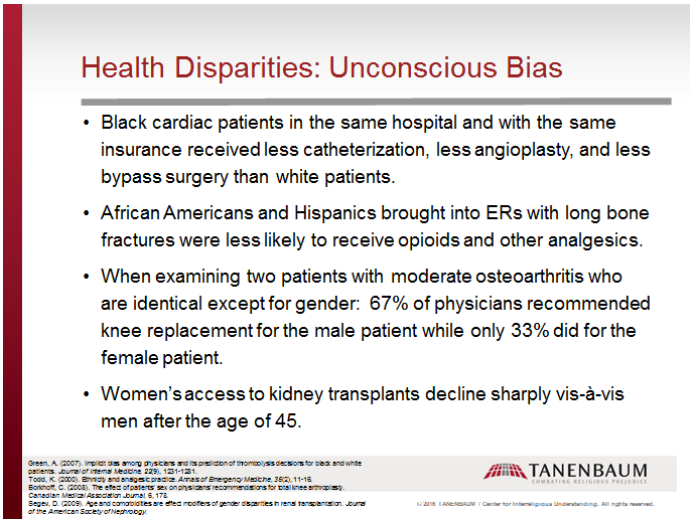
e. Health Behaviors: Racial and ethnic minorities are less likely to be advised to quit smoking.[49]

[49] American Cancer Society, Cancer Action Network, Cancer Disparities Chartbook: http://action.acscan.org/site/DocServer/cancer-disparities-chartbook.pdf

Slide 21 – Health Disparities: Unconscious Bias



******NOTE TO FACILITATOR: This slide is used in learning module #1, Intersections of Identity, Diversity & Health Equity. Be sure to coordinate with any instructors using this module to avoid duplicating course content.***

1) Explain that unconscious bias is another influencing factor on health disparities, particularly as it relates to medical care. Unconscious bias is a stereotype that has become so ingrained that it operates automatically – and therefore unconsciously. It forms out of the natural categorization process that our brains use to process information. Our mind indiscriminately picks up information and cultural attitudes displayed in society, the media and advertising. Unfortunately, the attitudes picked up are not always accurate and are so ingrained in our thought process that we are often completely unaware of them.

2) Emphasize that internal, unconscious biases are often attitudes that you would *never* consciously endorse. It is also essential to remember that unconscious biases are associations that we ALL carry with us.

3) Use the following examples to demonstrate that unconscious bias also plays a role in interactions with patients.

    a. Black cardiac patients in the same hospital and with the same insurance received less catheterization, less angioplasty, and less bypass surgery than white

patients. One hypothesis for this phenomenon is that physicians unconsciously believe that black patients are less likely to adhere to treatment recommendations than white patients, and therefore offer treatment less often.[50]

b. African Americans and Hispanics brought into ERs with long bone fractures were less likely to receive opioids and other analgesics. In the United States some doctors may have the ingrained bias that African Americans or Hispanics do not experience pain as intensely, or may be coming to the ER specifically to seek drugs. As a result of this unconscious bias, providers are less likely to prescribe pain medication such as opioids to African American and Hispanic patients.[51]

c. When examining two patients with moderate osteoarthritis who were identical except for gender, 67% of physicians recommended knee replacement for the male patient while only 33% did for the female patient. This may be based on unconscious stereotypes that women's complaints of pain are emotional or psychosomatic rather than physical, or because physicians are better able to understand the way men generally present complaints of pain (in a more factual and reserved manner) compared to the way women present complaints of pain (as more of a narrative and personal style).[52]

d. Women's access to kidney transplants declined sharply vis-à-vis men after the age of 45. In this instance, unconscious bias might make providers think that women are frailer than men of the same age, even though there is no medical evidence supporting this.[53]

Supplementary Learning**: To expand learning on the topic of unconscious bias, see learning module** #1, Intersections of Identity, Diversity & Health Equity. **However, be sure to coordinate with any instructors using this module to avoid duplicating course content.**

[50] Green, A. (2007). Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. *Journal of Internal Medicine, 22*(9), 1231-1281.

[51] Todd, K. (2000). Ethnicity and analgesic practice. *Annals of Emergency Medicine, 35*(2), 11-16.

[52] Borkhoff, C. (2008). The effect of patients' sex on physicians' recommendations for total knee arthroplasty. *Canadian Medical Association Journal,* 6, 178.

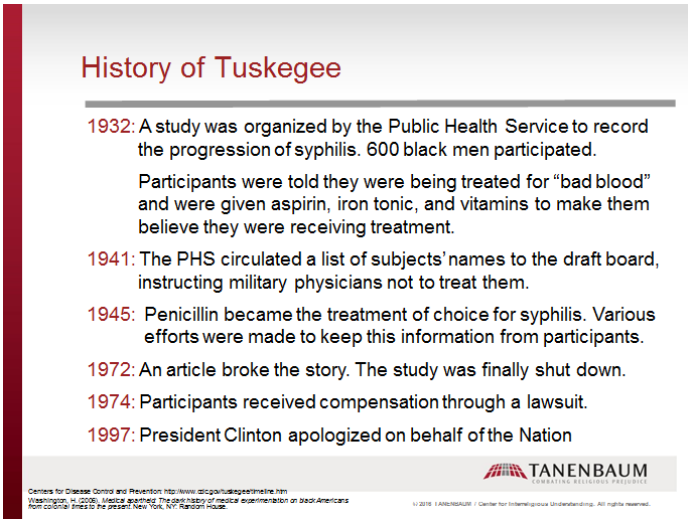
[53] Segev, D. (2009). Age and comorbidities are effect modifiers of gender disparities in renal transplantation. *Journal of the American Society of Nephrology*.

Section 4 – Minority Communities & Medicine: A History of Discrimination and Exploitation

1) Note that a dimension related to health and health care disparities that merits further exploration is the impact of a history of discrimination and exploitation of minority communities by the U.S. government and health care entities. This history has resulted in an understandable lack of trust, on the part of minority communities, regarding the motivations and intentions of health care professionals and health care institutions.

2) The long history of discrimination and exploitation of minority communities in the U.S., and the evolution of the ways in which this discrimination manifests within the health care field, is just one illustration among many of the challenges the United States still has to overcome related to institutionalized racism.

Slide 23 – History of Tuskegee



1) Ask students to raise their hand if they're familiar with the name Tuskegee and the story/history that it represents to most people.

2) Review the case as follows for those that are not familiar with the case or unsure of the specifics.

   a. 1932: A study was organized by the Public Health Service to record the progression of syphilis. 600 black men participated – 399 with syphilis and 201 who did not have the disease (although a number of participants in the "control group" became infected with syphilis over the course of the study). The study was called the "Tuskegee Study of Untreated Syphilis in the Negro Male." The *initial* objective of the study was to record the impact of syphilis on black men in order to justify treatment programs for the disease. At the time some members of the medical community believed that syphilis manifested itself differently in black men. [54]

   b. Participants were told they were being treated for "bad blood" and were given aspirin, iron tonic, and vitamins to make them believe they were receiving treatment. In exchange for participating in the program, participants received free meals, burial insurance and medical exams.[54]

[54] Centers for Disease Control and Prevention, U.S. Public Health Service Syphilis study at Tuskegee: The Tuskegee Timeline. Retrieved from: http://www.cdc.gov/tuskegee/timeline.htm

c. 1941: The PHS circulated a list of subjects' names to the draft board, instructing military physicians not to treat them. Local physicians were also asked to "assist" with the study by not treating the participants.[54]

d. 1945: Penicillin became the treatment of choice for syphilis. Various efforts were made to keep this information from participants. 7.5% of the infected study participants managed to obtain treatment despite the efforts of the government.[55]

e. 1972: An article broke the story. The study was finally shut down and an investigation was launched into the program. By this time, 28 participants had died of syphilis, 100 were dead of related complications, at least 40 wives of the participants had been infected and 19 children had contracted the disease at birth.[56]

f. 1974: Participants received compensation through a lawsuit. In 1974, a $10 million out-of-court settlement was reached. As part of the settlement, the U.S. government promised to give lifetime medical benefits and burial services to all living participants. The Tuskegee Health Benefit Program (THBP) was established to provide these services.

g. 1997: President Clinton apologized on behalf of the Nation.[57,58]

> Excerpt, President Clinton's Statement: "The United States government did something that was wrong -- deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens. To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry…To our African American citizens, I am sorry that your federal government orchestrated a study so clearly racist. That can never be allowed to happen again.
>
> The legacy of the study at Tuskegee has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no

[55] Washington, H. (2006). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. New York, NY: Random House.

[56] Kinsey, P. & Louden, D. Eds. (2013). *Health, ethnicity and well-being: An African American perspective*. Xlibris.

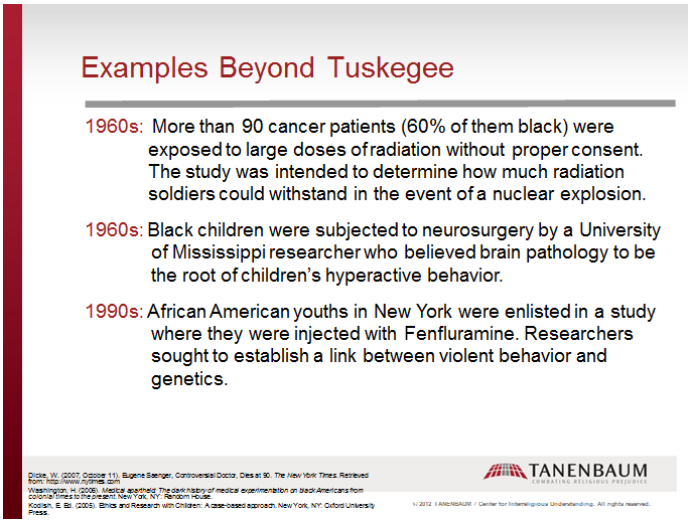
[57] Centers for Disease Control and Prevention, U.S. Public Health Service Syphilis study at Tuskegee: The Tuskegee Timeline. Retrieved from: http://www.cdc.gov/tuskegee/timeline.htm

[58] Washington, H. (2006). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. New York, NY: Random House.

trust in America. An apology is the first step, and we take it with a commitment to rebuild that broken trust."[59]

[59] Centers for Disease Control and Prevention. U.S. Public Health Service Syphilis Study at Tuskegee: Presidential Apology. Retrieved from: http://www.cdc.gov/tuskegee/clintonp.htm

Slide 24 – Examples Beyond Tuskegee



1) Emphasize that while the Tuskegee Syphilis Study may be one of the better-known cases of abuse and discrimination that minority groups in the United States have been subjected to, it is by no means the only case. Unfortunately, the Tuskegee case is only one example of a larger pattern of experimental abuse and ethical violations inflicted on African Americans and other people of color that span well over a century of the history of the United States.

2) Provide an overview of the additional case examples outlined on the screen.

   a. From 1960 to 1971 more than 90 cancer patients (60% of them black) were exposed to large doses of radiation without proper consent. The study was intended to determine how much radiation soldiers could withstand in the event of a nuclear explosion. The study was conducted at the University of Cincinnati by Dr. Eugene Saenger and was a Pentagon-sponsored radiation study. 21 of the patients died within a month of exposure. [60] On October 3, 1995, President Clinton apologized on behalf of the nation.

[60] Dicke, W. (2007, October 11). Eugene Saenger, Controversial Doctor, Dies at 90. *The New York Times.* Retrieved from: http://www.nytimes.com

Excerpt, President Clinton's Statement: "Thousands of government-sponsored experiments did take place at hospitals, universities, and military bases around our nation. The goal was to understand the effects of radiation exposure on the human body. While most of the tests were ethical by any standards, some were unethical, not only by today's standards, but by the standards of the time in which they were conducted. They failed both the test of our national values and the test of humanity. In one experiment, scientists injected plutonium into 18 patients without their knowledge. In another, doctors exposed indigent cancer patients to excessive doses of radiation, a treatment from which it is virtually impossible that they could ever benefit. The report also demonstrates that these and other experiments were carried out on precisely those citizens who count most on the government for its help, the destitute and the gravely ill. Informed consent means your doctor tells you the risk of the treatment you are about to undergo. In too many cases, informed consent was withheld…. So today, on behalf of another generation of American leaders and another generation of American citizens, the United States of America offers a sincere apology to those of our citizens who were subjected to these experiments, to their families, and to their communities."[61]

b. 1960s: Black children were subjected to neurosurgery by a University of Mississippi researcher who believed brain pathology to be the root of children's hyperactive behavior. On one particular patient, neurosurgeon Dr. Orlando Andy, performed a series of five surgeries removing six areas of the patient's brain in order to address what was informally diagnosed as a "behavior disorder." [62] Ask students to consider how unconscious bias could have impact this physician's perspective of informally diagnosing young black children with a "behavior disorder."

c. 1990s: African American youths in New York were enlisted in a study where they were injected with Fenfluramine. Researchers sought to establish a link between violent behavior and genetics. The research was conducted at the New York State Psychiatric Institute, affiliated with Columbia University. Researchers felt that a relationship might exist among serotonin levels, aggressive behavior and "a childhood history of socially adverse-rearing conditions." All of the 34 participants, between 8 and 10 years old were children of color, 44% identifying as African American and 56% as Hispanic. Participants were selected because they had an incarcerated sibling and were therefore seen as "at risk" for aggressive behavior. Names of potential subjects were obtained from sealed court records and given to researchers so that siblings of juvenile offenders could be contacted. At the time of the study, Fenfluramine, had been withdrawn from

[61] U.S. Department of Energy. Building Public Trust: Actions to respond to the report of the advisory committee on human radiation experiments. Retrieved from: https://ehss.energy.gov/ohre/roadmap/whitehouse/appa.html

[62] Washington, H. (2006). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. New York, NY: Random House.

marketplace because of evidence that it led to heart damage in patients taking it as a component of the anti-obesity drug "Fen-Phen."[63]

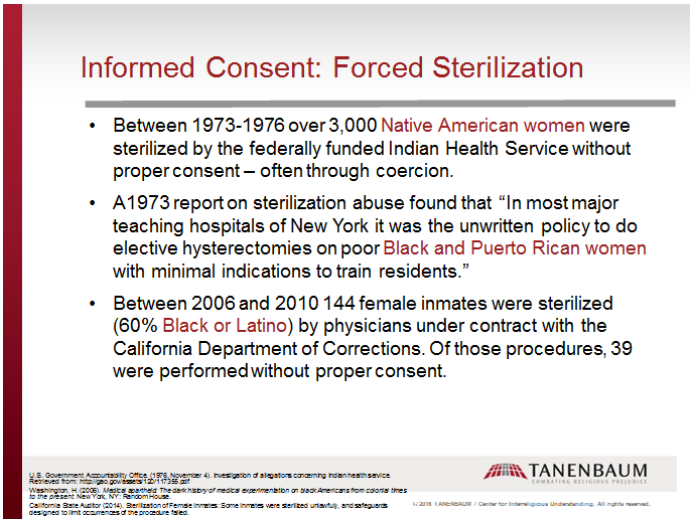
Ultimately, the OPRR determined that the New York State Psychiatric IRB had been properly reviewed and approved the study for their compliance with federal regulations. However, patient advocates and other critics complained that the evaluation of the study was inadequate.[64] One critic outlined concerns with the study as follows:

> CRITIQUE BY ETHICIST AND PHYSICIAN ERIC KODISH: "The investigators who conduct this study are serious behavioral and biomedical people with worthy research goals. They followed procedures specified by the research oversight authorities of their institution and did not cause known or measurable harm to any identifiable people. They did, however, gain access to data that should have remained confidential, offered substantial inducements to elicit participation by impoverished children, took advantage of power and social position to recruit participants, and put healthy child participants at some medical and psychosocial risk with no chance of direct benefit. They did all this to conduct a study with trivial statistical power, inadequate control participants, and highly questionable generalizability but significant potential to perpetuate social stereotypes. Nonetheless, the study survived peer review and attained publication. The reader is left to determine the ethical propriety of the fenfluramine challenge study."[65]

3) Because of the wide prevalence of these forms of abuse over the course of American history, many African Americans and individuals that identify with other minority groups may have a justifiable explicit and/or implicit mistrust of the American health care system and clinical studies in particular.

[63] Kodish, E. Ed. (2005). Ethics and Research with Children: A case-based approach. New York, NY: Oxford University Press.
[64] Shamoo, A. & Tauer, C. (2002). Ethically questionable research with children: the fenfluramine study. *Accountability in research: policies and quality assurance*,9:3-4, 143-166.
[65] Kodish, E. Ed. (2005). Ethics and Research with Children: A case-based approach. New York, NY: Oxford University Press.

Slide 25 – Informed Consent: Forced Sterilization



1) An additional dimension to discriminatory and exploitative practices faced by minority and socio-economically disadvantaged groups is that of the history of coercive sterilization practices.

2) Provide an overview of the additional case examples outlined on the screen.

   a. Between 1973-1976 over 3,000 Native American women were sterilized by the federally funded Indian Health Service without proper consent – often through coercion. The U.S. Government Accountability Office conducted an investigation and found that the Indian Health Service performed 3,406 sterilizations where consent forms were not in compliance with IHS regulations.[66] One example reported of consent being withheld or coerced and included the story of young women undergoing appendectomies and then receiving tubal ligations without their knowledge.[67]

   b. A1973 report on sterilization abuse (drafted by Health Research Group, a division of consumer rights advocacy group Public Citizen) found that "In most major teaching hospitals of New York it was the unwritten policy to do elective

[66] U.S. Government Accountability Office. (1976, November 4). Investigation of allegations concerning Indian health service. Retrieved from: http://gao.gov/assets/120/117355.pdf

[67] Lawrence, J. (2000). The Indian health service and the sterilization of Native American women. *American Indian Quarterly* 24(3), 400-419.

hysterectomies on poor Black and Puerto Rican women with minimal indications to train residents." [68,69] The primary author of the report, Dr. Bernhard Rosenfeld, was instrumental in stopping the practice of sterilization without consent. As an intern at Los Angeles County-USC medical Center, he came to his supervisor with accounts of minority women being sterilized without their consent and through coercion when they checked into the hospital to give birth.[70] A class action lawsuit was ultimately filed on behalf of a group of Hispanic women (Madrigal v. Quilligan) and while the judge ultimately ruled in favor of the physicians, the case led to the implementation of better practices around informed consent for patients.

c. Between 2006 and 2010 144 female inmates were sterilized (60% black or Latino) by physicians under contract with the California Department of Corrections. Of those procedures, 39 were performed without proper consent. These findings were published by the California State Auditor in a 2014 report.[71]

4) Ask participants to consider how these various cases could frame interactions with women of minority groups as it relates to conversations around reproductive health and family planning choices.

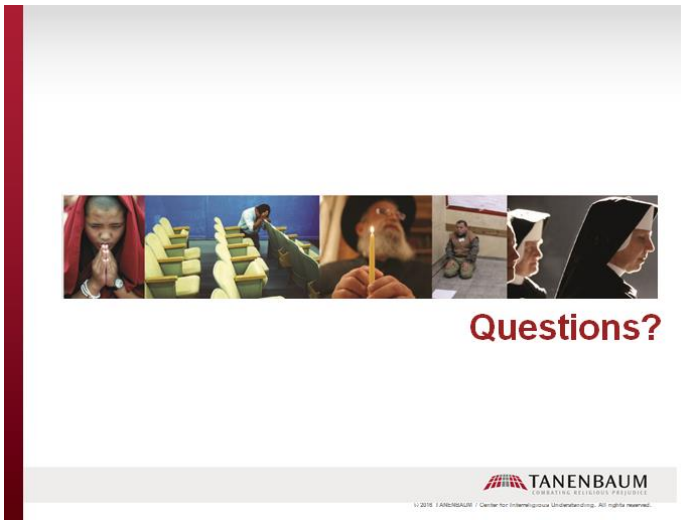
[68] Washington, H. (2006). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. New York, NY: Random House.

[69] Hansen, R. & King, Desmond. (2013). Sterilized by the State: Eugenics, race, and the population scare in Twentieth-century North America. New York, NY: Cambridge University Press.

[70] Dr. Bernard Rosenfeld is recognized for his work to stop sterilization without consent – Madrigal v. Quilligan (2014). Retrieved January 8, 2016, from http://rosenfeldmd.com/stop-sterilization/

[71] California State Auditor (2014). Sterilization of Female inmates: Some inmates were sterilized unlawfuly, and safeguards designed to limit occurrences of the procedure failed. Retrieved from: https://www.auditor.ca.gov/pdfs/reports/2013-120.pdf

Slide 26 – Questions?



1) Ask students if there are any questions and thank them for their participation in the discussion.