At a Crossroads: Culturally Competent Care vs. HIPAA

Chirag B. Patel, MSE HIPAA Summit 12/13/2007



Cultural Humility

- "Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patientphysician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations."*
- Bottom line: each individual has his/her own level of assimilation into the greater society and cannot be easily stereotyped or pigeonholed
- Make no assumptions

A Motivating Factor: Continued Diversification of the USA

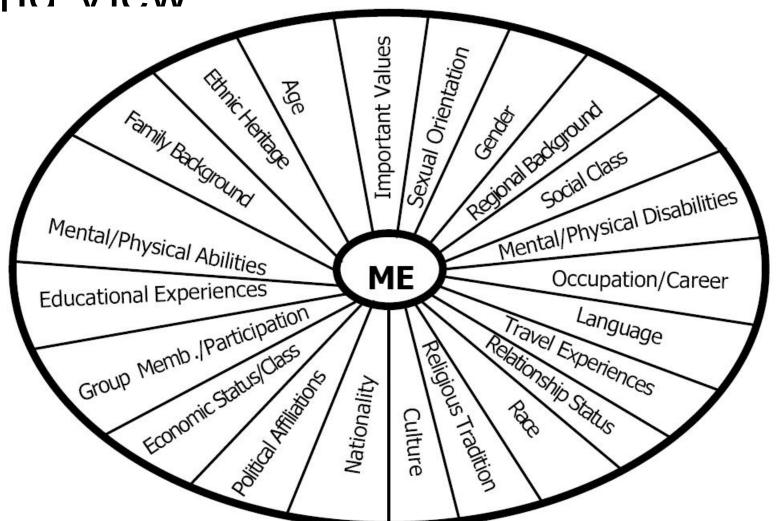
- USA population
 - □ 1915: 100 million
 - □ 1967: 200 million
 - □ 2006: 300 million
 - Most likely will be of European descent
 - □ 2050: 400 million
 - 50% will be of non-European descent

What is Culture? The Culture Iceberg Model



Patient-Focused Care:

Recognizing Key Components of World View



Source: Chaplain David F. Berg, MA, MDiv& Doretta E. Stark, MA, LICSW



Healthcare Disparities Exist

- IOM Report (2003): "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care"
- "Racial and ethnic minorities tend to receive lower-quality health care than whites do, even when insurance status, income, age, and severity of conditions are comparable"
 - ☐ Especially in CV disease, cancer, and HIV
- Includes recommendations for improving:
 - medical care financing
 - allocation of care
 - availability of language translation
 - □ community-based care

What does this have to do with HIPAA?



(Mis)Interpretations of HIPAA

- "Birthday parties in nursing homes in New York and Arizona have been canceled for fear that revealing a resident's date of birth could be a violation."
- "Patients were assigned code names in doctor's waiting rooms say, "Zebra" for a child in Newton, Mass., or "Elvis" for an adult in Kansas City, Mo. so they could be summoned without identification."
- "Nurses in an emergency room at St. Elizabeth Health Center in Youngstown, Ohio, refused to telephone parents of ailing students themselves, insisting a friend do it, for fear of passing out confidential information, the hospital's patient advocate said."
- "State health departments throughout the country have been slowed in their efforts to create immunization registries for children, according to Dr. James J. Gibson, the director of disease control in South Carolina, because information from doctors no longer flows freely."



- "Medical professionals can talk freely to family and friends, unless the patient objects. No signed authorization is necessary and the person receiving the information need not have the legal standing of, say, a health care proxy or power of attorney. As for public health authorities or those investigating crimes like child abuse, HIPAA defers to state laws, which often, though not always, require such disclosure. Medical workers may not reveal confidential information about a patient or case to reporters, but they can discuss general health issues."
- "There are "good faith nondisclosures," as when a floor nurse takes a phone call from someone claiming to be a family member but cannot verify that person's identity. Then there are "bad faith nondisclosures," like using Hipaa as an excuse for not taking the time to gather records that public health officials need to help child abuse investigators trying to build a case."

Ref: "Keeping Patients' Details Private, Even From Kin," NY Times article by Jane Gross, 7/3/07



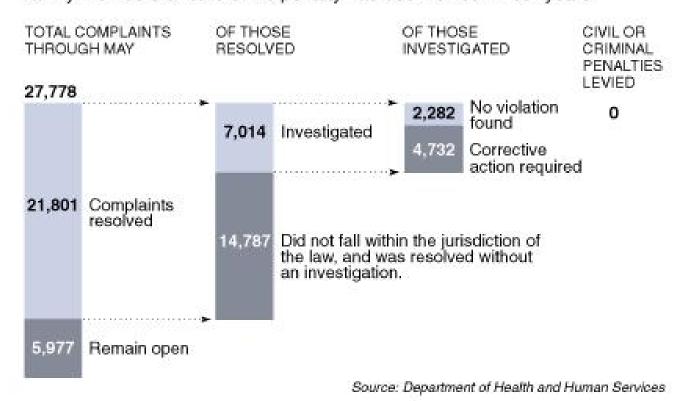
"Her 82-year-old mother had had a stroke. When Ms. Banks called her room she heard her mother "screaming and yelling and crying," but conversation was impossible. So Ms. Banks tried the nursing station. Whoever answered the phone was not helpful, so Ms. Banks hit the road. Twenty-two hours later, she arrived at the hospital. But more of the same awaited her. She said her mother's nurse told her that "because of the HIPAA laws I can get in trouble if I tell you anything. In the morning, she could speak to the doctor, she was told. The next day, Ms. Banks was finally informed that her mother had had heart failure and that her kidneys were shutting down. "I understand privacy laws, but this has gone too far," Ms. Banks said. "I'm her daughter. This isn't right.""

Ref: "Keeping Patients' Details Private, Even From Kin," NY Times article by Jane Gross, 7/3/07



A Misunderstood Law

A federal law known as Hipaa was meant to protect the privacy of health information. Since April 2003, more than 27,000 complaints have been filed, though it cannot be determined how many of these involved the withholding of information, versus illegal disclosure. Typically, complaints of nondisclosure are investigated only if they are made by a patient, not family members or others. No penalty has been levied in four years.



The New York Times

Ref: "Keeping Patients' Details Private, Even From Kin," NY Times article by Jane Gross, 7/3/07



The Interface

- Most of these cases were brought forth by English-speaking Americans of European descent
- But what about the (not necessarily) non-English speaking new Americans?
- What is this "crossroads" all about?
- One HIPAA issue: "health care providers may share information with others unless the patient objects, but does not require them to do so"1

Caution: Generalizing vs. Stereotyping/Pigeonholing

- Generalizing
 - using common trends and patterns as a starting point to better understand a subject
 - □ not absolute

- Stereotyping / Pigeonholing
 - ascribing rigid, inflexible rules / beliefs / attitudes to all people of a certain category

Asian (Latino, European, American, etc.) Family

- A 67-year old Asian male patient is terminally ill and the physician has just confirmed a diagnosis of pancreatic cancer.
- The patient's eldest son asks the physician to not reveal the diagnosis to the patient, asking that the patient be allowed to die in peace



Issues

- Why did the child find out before the patient?
- Can the physician withhold information from the patient, or provide modified information to pacify the family members?
- Medical directives, power-of-attorney, etc. may come into play



LGBT Couple

- A female patient arrives to the ER via ambulance, after suffering a motor vehicle accident
- Shortly thereafter, a woman claiming to be her partner insists on being by the patient's side

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Issues

- Legal status of domestic partnership varies from state to state
- Medical directives, power-of-attorney, etc. may come into play
- Who can receive PHI and make the decision if the patient becomes incapacitated (e.g. vegetative state) – her parents or her partner?



African-American Patient

- An African-American patient with recent diagnosis of type II diabetes is asked to enroll in a clinical trial of a new bloodglucose lowering agent
- Informed consent is obtained yet her husband objects due to a fear of human experimentation conducted under the guise of clinical trials¹



Issues

- Not enough minorities are enrolled into clinical trials – can skew results and recommendations
- HIPAA has been reported to make clinical trials more expensive and take longer to enroll sufficient patients
- More of a policy issue?

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Language Barriers

- So far we've discussed "cultural groups"
- Language barriers can prevent patients from knowing their rights
- Interpreters are essential to communicating vital health information to non-English speaking patients
- Healthcare providers should be trained in how to communicate with a patient using an interpreter

A Useful Equation

- Like most patient encounters in healthcare, F = E / R
- What are F, E, and R?
- Unless you're dealing with a technical aspect of HIPAA, use common sense
- This way, E ≈ R, and you'll experience a tolerable level of F

Thank You for your Attention

Any questions?

Contact e-mail: chirag3@gmail.com