



# CASES IN BIOMEDICAL ETHICS

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# Dementia or depression

- ▶ The public guardian has just been granted healthcare decision making power for Ms. Long, a 78 year-old woman with severe dementia, diabetes with impaired vision, and poor kidney function, recent recurrent pneumonia, and prior strokes.
- ▶ You are seeing her for the first time in a skilled nursing facility.
- ▶ She was transferred there yesterday following a four-month hospitalization.

# Dementia or depression

- ▶ When you arrive at the skilled nursing facility to see Ms. Long, she looks very thin, and the nurse tells you that there is a large necrotic pressure sore on her sacrum.
- ▶ The aides are repositioning her so that the speech therapist can do her evaluation.
- ▶ Fluid is being administered via an IV in the patient's left arm, and her right arm lies limp on the bed.
- ▶ You notice that the patient grimaces when she's moved, and cries in apparent pain when she is rolled on her back.

# Dementia or depression

- ▶ Some of the time she seems to look at a face and track movements, but sometimes not.
- ▶ She does not give any answers to simple questions, either verbally or with nods or shaking her head, and does not consistently look at the person who is talking to her.
- ▶ She does not give any social smile in response to the speech therapist's attempts to engage her.

# Dementia or depression

- ▶ She opens her mouth when offered a straw but does not suck on the straw.
- ▶ She takes a small amount of ice cream that is offered by spoon, but after two more tries by the speech therapist she pushes it away and slaps using her left hand.

# Dementia or depression

- ▶ We know the patient has dementia.
- ▶ She has just spent 4 months in a hospital and has developed a sacral ulcer. That is usually indicative of poor nursing care.
- ▶ The patient only uses her left hand. Her strokes apparently involve the right half of her brain.
- ▶ The speech therapist evaluation is to learn how best to feed her to prevent aspiration and pneumonia?
- ▶ Is her intermittent lack of response to questioning because of stroke?
- ▶ Is she depressed?
- ▶ Is a DNR order appropriate?

# Dementia and futility of treatment

- ▶ Mrs. Doe is placed under guardianship because of her severe dementia.
- ▶ She has been a nursing home patient for more than five years.
- ▶ She has no family and left no written instructions about her health care wishes.
- ▶ She is on Medicaid.
- ▶ In the past two years, she has become unable to walk or to follow any simple commands.
- ▶ She has not spoken in months.



# Dementia and futility of treatment

- ▶ During the past year, she has required spoon-feeding, and she has been taking progressively longer to eat each meal.
- ▶ Because of episodes of coughing and possibly choking, her diet has been changed to puree with thick liquids.
- ▶ She still seems to prefer some foods, and the staff can tell you which foods she will usually spit out.
- ▶ She has been hospitalized twice for pneumonia in the past year but has recovered without needing ICU treatment.

# Dementia and futility of treatment

- ▶ One Saturday evening, Mrs. Doe is congested. She begins running a fever, and her breathing seems labored. The nursing home staff sends the patient to the hospital.
- ▶ The emergency room physician consults with the internist and the pulmonologist, and the patient goes to the intensive care unit.
- ▶ She is intubated and put on a ventilator.

# Dementia and futility of treatment

- ▶ After two days of antibiotics and vigorous suctioning, she seems to be breathing better, but she has required restraints to keep her from pulling out the breathing tube and sedatives so she does not try to hit the ICU staff.

# Dementia and futility of treatment

- ▶ The nursing home has just asked you to request the placement of feeding tube in Mrs. Doe tube placed while she is in the hospital. They point out that she has been losing weight and takes so long to eat a meal that it is impacting the staff's ability to get other jobs done. (I'm only thinking of her best interest)

# Dementia and futility of treatment

- ▶ When you arrive in the ICU, the patient is still on the ventilator, and each wrist has a binder that secures her to the bed frame. Although she is somewhat sedated, she seems uncomfortable, and there is still an aura of panic that penetrates her drug haze.
- ▶ The ICU physician is glad to see you because he has lots of questions about what happens next with the patient.

# Dementia and futility of treatment

- ▶ Should she be resuscitated if she suffers a cardiac arrest?
- ▶ Do you give permission for them to continue to restrain her arms so that she does not pull out the tubes?
- ▶ Will she be transferred back to the hospital again for her next bout of pneumonia?
- ▶ Can the nursing home do IV antibiotics?
- ▶ Will the nursing home accept her back if she overstays her seven-day bed hold?

# Right to refuse treatment



- ▶ Farhad Tabrizi, a 69-year-old immigrant from Iran, is brought to the emergency room at a private urban hospital after coughing up blood.
- ▶ He presents with severe coughing, fatigue, chest pain, shortness of breath, and headaches.
- ▶ After stabilizing Mr. Tabrizi, the emergency room team admits him to the hospital, where, over the course of a few days, he receives a thorough workup, including chest x-rays, CT scans, mediastinoscopy, and a PET scan.

# Right to refuse treatment

- ▶ At the start of the visit, the nurses attempt to gather a detailed health history; but this proves difficult, since Mr. Tabrizi speaks almost no English.
- ▶ He does speak fluent Farsi, but there are no Farsi-speaking medical personnel readily available.
- ▶ However, Mr. Tabrizi is accompanied on-and-off by his adult son, who is reasonably fluent in both English and Farsi.
- ▶ He is also accompanied intermittently by his wife, who speaks only Farsi.



# Right to refuse treatment

- ▶ The wife makes it a point of regularly offering prayers for her husband's health when she is visiting.
- ▶ The nurses attempt to gather a health history whenever the son is present, which is not always easy, since his visits are unpredictable.
- ▶ Even when his son is present to help translate, Mr. Tabrizi seems extremely uncomfortable offering up any detailed information about his own or his family's health history.
- ▶ This is causing high levels of frustration among the medical staff.

# Right to refuse treatment

- ▶ Additionally, Mr. Tabrizi appears extremely reluctant to eat whatever food is offered him in the hospital. This is most pronounced if neither his son nor his wife is present at a mealtime.
- ▶ On the second day of his stay, his son explains to the flustered nurses that Mr. Tabrizi is fearful that the hospital food may contain hidden pork by-products.
- ▶ Since he is a devout Muslim, he feels it is safest to refuse the food altogether unless he is absolutely certain.
- ▶ The son has explained to his father that he needs to eat.

# Right to refuse treatment



- ▶ Nurse Ratched curtly replies that, while religious belief is important, Mr. Tabrizi needs to keep his strength up if he hopes ever to go home; thus he will need to nourish himself by eating more.
- ▶ She says that she will "see what we can do" about ensuring that there is no pork used in the hospital's food preparation.
- ▶ The son thanks her for her help.
- ▶ From then on he and his mother attempt to bring outside food to Mr. Tabrizi whenever they visit.

# Right to refuse treatment

- ▶ After almost three days in the hospital, the attending physician, Dr. Looke, sits down with Mr. Tabrizi to discuss his situation. His son and wife are also present.
- ▶ Dr. Looke first offers a handshake to Mr. Tabrizi's son. He inquires explicitly about the extent of his English skills and asks if the son would be willing to translate what he is about to say to Mr. Tabrizi.
- ▶ He agrees, while Mr. Tabrizi and his wife sit by.
- ▶ The doctor then gazes directly into Mr. Tabrizi's eyes and tells him that he has extensive small cell lung cancer.

# Right to refuse treatment

- ▶ After a moment of stunned silence, the son turns to his father and tells him in Farsi that the doctor believes that he is very sick, with some "growths" in his body.
- ▶ Dr. Looke goes on to say that Mr. Tabrizi most likely does not have long to live.
- ▶ The doctor holds up two fingers (at which point the patient grows increasingly alarmed and agitated), describing that there are basically "two possible treatments" available for this cancer: chemotherapy and radiation; Dr. Looke strongly prefers beginning with the first (chemotherapy).

# Right to refuse treatment



- ▶ In spite of Mr. Tabrizi's alarm and confused expression, the doctor presses on that, given the apparently advanced stage of the disease, even chemotherapy would be very unlikely to provide a complete cure, but it could provide some relief and lengthen the remainder of his life.
- ▶ The son, again silent for several moments, then turns to his father and also holds up two fingers.

# Right to refuse treatment

- ▶ He tells him that the doctor says he must do two things to care for himself: eat well and get more rest.
- ▶ He also relays that his father could take some "strong medicines" which would most likely help him to get better.
- ▶ Mr. Tabrizi looks extremely uncomfortable but says nothing.

# Right to refuse treatment

- ▶ After a few more moments, Mr. Tabrizi, somewhat confused, asks (via his son) what the "strong medicines" would consist of.
- ▶ The doctor replies by describing (in some detail) what the course of chemotherapy would look like-how often it would be administered and that the treatments would last for several weeks.
- ▶ He also describes that it may produce severe side effects such as nausea, vomiting, increased fatigue, and elevated risk of infection.



# Right to refuse treatment

- ▶ In spite of his hesitations, the son attempts to translate the bare outlines of this information (leaving out the term "chemotherapy"), at which point Mr. Tabrizi declares flat-out that he doesn't want any such cumbersome treatments:
- ▶ They would compromise his relationships with his family and friends and place too heavy a burden on his wife.
- ▶ Further, he doesn't really know what might be in such a strong medication that could help him get better. Instead, he will simply do the two things the doctor had recommended-improve his diet and get more rest.

# Right to refuse treatment

- ▶ How should Nurse Ratched have replied once she was informed as to why the patient was not eating?
- ▶ Why did the hospital not search for a competent English-Farsi translator?
- ▶ What are the problems with using a family member as translator?
- ▶ Should Dr. Looke have greeted all the family and not just the patient's son?

# Right to refuse treatment



- ▶ Is it just the son who does not want his father (and mother) to know the detailed truth of the condition? Is that a problem for the family or the doctor?
- ▶ Is it rational to refuse therapy in these circumstances?

# Delivering bad news



- ▶ Leyla Ansari, 30, a recent immigrant from Afghanistan who is 22 weeks pregnant, presents with severe cramping abdominal pain, and is admitted to a large, suburban, non-teaching hospital.
- ▶ A preliminary ultrasound suggests brain abnormalities with her fetus.
- ▶ She is accompanied by her husband of eight years (also an immigrant) and her mother, who speaks no English and lives with the couple.

# Delivering bad news



- ▶ Mrs. Ansari (Leyla) also speaks very little English, though she does understand some; her husband speaks English better, though somewhat haltingly.
- ▶ Their primary language is Dari.

# Delivering bad news

- ▶ Mrs. Ansari is stabilized, and additional scans are conducted on the fetus.
- ▶ The physicians soon discern that the fetus is afflicted with a relatively severe encephalocele; its size and location make survival outside the womb extremely unlikely.
- ▶ The attending physician, Dr. Fox, is not previously acquainted with the patient.

# Delivering bad news

- ▶ Dr. Fox enters Mrs. Ansari's hospital room, where she had been meeting with an Afghan female friend (who apparently also speaks English reasonably well) while waiting for news of the fetus with her husband and mother, all of whom appear agitated and anxious.
- ▶ Mrs. Ansari's other children (all girls, ages 2, 5, and 6) are in the outside waiting area, accompanied by an aunt.

# Delivering bad news

- ▶ Before Dr. Fox begins to speak, Mr. Ansari, noticing a look of deep concern on the doctor's face, asserts that his wife is sick with fear and anxiety and that she herself would prefer that her husband handle any news of the situation.
- ▶ Mr. Ansari requests that Dr. Fox meet separately with him first, outside of his wife's room.



# Delivering bad news

- ▶ Moreover, it is the traditional time for Muslims to offer prayers, and, since he and his family are devout Muslims, they would prefer to do so before any difficult conversations are had with the doctor.
- ▶ (This is also common with other religions)
- ▶ Mrs. Ansari, obviously upset but remaining silent, makes no visible objection to her husband's wishes. The friend also is silent. Mr. Ansari repeats his request that the doctor meet separately with him.

# Delivering bad news



- ▶ Dr. Fox, unsure of how to proceed but not wanting to stress Mrs. Ansari further, agrees to meet the husband separately across the hall, in an empty office.
- ▶ But he also informs Mr. Ansari that they must talk now, for he does not have time to wait for him to complete his prayers.
- ▶ Mr. Ansari silently follows the doctor to the empty office, where Dr. Fox discloses the most recent scan results to Mr. Ansari. Dr. Fox recommends termination of the pregnancy.
- ▶ Stunned, Mr. Ansari sits in silence for several minutes.

# Delivering bad news

- ▶ After several moments, there is a knock on the door from Mrs. Ansari's mother.
- ▶ She immediately discerns from the husband's face that something is terribly wrong, and asserts (in Dari) that her daughter must not be told anything of the situation until she is in a better frame of mind.
- ▶ She converses for some time with Mr. Ansari, becoming increasingly agitated through the course of the conversation.

# Delivering bad news

- ▶ Dr. Fox eventually interrupts and asks the husband to translate, which he does, relaying that Mrs. Ansari's mother insists that the medical information from the scans may be faulty, and it would be bad for her daughter to learn the scan results at this point.
- ▶ In fact, she asserts, her daughter may "lose the baby" from stress over the results.

# Delivering bad news

- ▶ She wishes for the hospital to keep her stable and let the fetus continue to grow inside her uterus in order to see "what God intends."
- ▶ She herself firmly believes (though there has been no information in this regard) that this baby is the long-anticipated boy that the entire family has been hoping for, and that God would not visit such an unhappy result on such a devout family.

# Delivering bad news



- ▶ Mr. Ansari then turns back to Dr. Fox and insists that the doctor refrain from telling Mrs. Ansari the scan results, assuring him that he will tell his wife himself once she is emotionally ready for the news.
- ▶ The doctor, increasingly frustrated with the direction of the conversation, informs the husband that such a choice is not his to make.
- ▶ He gets up and proceeds back across the hall, where he walks in on Mrs. Ansari awkwardly performing her prayers.

# Delivering bad news



- ▶ Dr. Fox interrupts her and asks the friend (who is still present) to help him translate his news for Mrs. Ansari.
- ▶ He then gently but firmly informs Mrs. Ansari of the scan results, as the friend awkwardly translates for her.
- ▶ Mr. Ansari has stayed across the hall, and Mrs. Ansari's mother retreats, wailing, to the waiting room. Mrs. Ansari struggles to keep her tears at bay as she listens to the doctor.

# Delivering bad news

- ▶ Is Dr. Fox's behavior defensible?
- ▶ Was it imperative to interrupt the family at prayer?
- ▶ Who should function as a translator?
- ▶ Was an undue burden placed on the friend?
- ▶ Why was no attempt made to reach into the Afghani community to gain some knowledge of family roles?
- ▶ Why was no religious figure consulted?
- ▶ Does the patient have a right not to be told of the diagnosis at the time and choosing of the physician?



# Poverty



- ▶ Gabriela Rivera is an 80-year-old New Yorker from Puerto Rico, who lives alone in her rent-controlled apartment. She has lived in New York for almost 40 years and speaks some English, albeit somewhat hesitantly.
- ▶ Gabriela is a devoted mother, calling her children as often as she can afford and even sending them homemade sweets. She raised her children through their teenage years in the same apartment in which she lives today. She is loath to leave it, although she now pays the rent only with great difficulty and substantial financial help from her children.

# Poverty



- ▶ Gabriela has long suffered from high blood pressure, which she controls with medication. She also has type-2 diabetes.
- ▶ When she was originally diagnosed with diabetes, she met once with a nurse who advised her on diet, exercise, and weight control, but Gabriela has found it difficult to adapt her traditional tastes in food and her lifestyle to the recommendations the nurse offered.
- ▶ Subsequently, Gabriela's doctor prescribed medication to help keep her diabetes under control.
- ▶ She tries to take her medication whenever she can remember and when she can afford it.

# Poverty

- ▶ Recently, tests have revealed that her kidney function has been declining.
- ▶ Gabriela's youngest son, Marcos, 49, lives near Gabriela.
- ▶ He speaks fluent Spanish and good (though heavily accented) English.
- ▶ He checks on his mother as frequently as he can.
- ▶ Marcos is a contract construction worker, married with three teenage children.
- ▶ His daughter, Cecilia, 15, spends a great deal of her time at her grandmother Gabriela's apartment, doing homework and helping out with daily chores.

# Poverty



- ▶ Marcos was also recently diagnosed with diabetes. He learned of his disease at a low-income medical clinic from a doctor who advised him to make major lifestyle changes in order to prevent the worsening of his disease.
- ▶ Marcos is a moderate-to-heavy drinker, but he refuses to cut back on his drinking, since he "can handle it," and it is an important part of his social life.
- ▶ He also has a great fear of needles, and he recoils at the idea of having regular blood tests. He reasons that he will just learn to live with his symptoms, which are still relatively mild.

# Poverty



- ▶ Lately, Gabriela has had an increasingly persistent cough and often suffers from headaches, shortness of breath, and generally feeling ill. She has been ignoring these symptoms and writing them off in part to her persistent insomnia.
- ▶ One afternoon, on her way home from work, Marcos' wife Maria receives a panicked phone call from their daughter, who has shown up after school at Gabriela's apartment only to find her grandmother feeling acutely dizzy and anxious, and having severe difficulty breathing.
- ▶ Maria hangs up and calls for an ambulance and calls her husband Marcos; then races to meet the ambulance at the hospital.

# Poverty



- ▶ Addressing all three of them equally, he informs them that, in addition to the advanced COPD and pneumonia, Gabriela also apparently is suffering from kidney failure, a complication of her diabetes.
- ▶ He would like to admit her to the hospital for observation and treatment of her pneumonia, and to call a nephrology consult regarding her declining kidney function. They agree.

# Poverty



- ▶ Gabriela's initial workup reveals a diagnosis of advanced Chronic Obstructive Pulmonary Disease (COPD) and bilateral pneumonia.
- ▶ In addition, blood tests show that her diabetes is out of control and that her kidneys are functioning at less than normal capacity.
- ▶ Once Gabriela has been stabilized with oxygen, the attending emergency department physician, Dr. Michael Johnson, speaks (in English) with Marcos, Maria, and Cecilia.

# Poverty



- ▶ Gabriela is admitted to the ICU, where she is begun on antibiotics for her pneumonia; bronchodilators, corticosteroids, and supplementary oxygen for her breathing are also begun.
- ▶ Upon admission to the ICU, Gabriela's attending physician there, Dr. Rachel Parker, also speaking English, attempts to discuss with Gabriela the option of a DNR (Do Not Resuscitate) order, but the doctor soon assesses that Gabriela does not have capacity at this time to make such a decision.



# Poverty



- ▶ Dr. Parker then approaches Marcos on the matter, explaining that in patients such as Gabriela, the chance that resuscitation will restore a patient to her previous quality of life is vanishingly small.
- ▶ Marcos, however, vehemently forbids the DNR and insists that it not be mentioned again, especially not in front of Gabriela.

# Poverty



- ▶ The following morning, the nephrologist consults with Dr. Parker and subsequently the two of them meet with Marcos and Maria.
- ▶ The nephrologist explains the extent of Gabriela's disease and that she is not a good candidate for a kidney transplant, given her other medical problems.
- ▶ Further, at Gabriela's age, long-term dialysis would put a tremendous strain on her body and her quality of life.

# Poverty



- ▶ After allowing this information to be internalized, Dr. Parker explains that, even if the pneumonia can be brought under control, Gabriela will need a high level of ongoing care; she will no longer be able to live independently, and it is unlikely that she will be able to manage her oxygen therapy on her own.
- ▶ In sum, Dr. Parker says, the decline in kidney function, along with the COPD, means that Gabriela's long-term situation is not favorable.

# Poverty



- ▶ Dr. Parker then gently raises the possibility of foregoing dialysis, accepting Gabriela's inevitable gradual decline, and instead providing hospice care at home.
- ▶ She attempts to convey to Maria and Marcos that hospice can provide excellent care and support of the patient, as well as a great measure of relief to families as patients approach the end of their lives.
- ▶ Hospice also can arrange for and manage Gabriela's necessary medications and other medical needs.

# Poverty



- ▶ During the conversation, Maria simply looks at the floor.
- ▶ Marcus, however, abruptly and angrily bursts out that his mother is not dying and that God will certainly protect such a saintly woman through this time of trial.
- ▶ He also insists that they are perfectly able to care for her needs as a family and that the doctors have no right to talk about matters such as "hospice" when they should be concerned only with his mother's recovery.
- ▶ He insists that dialysis be initiated immediately and that a kidney transplant be pursued.

# Poverty

- ▶ The patient lives in a rent controlled apartment.
- ▶ The son assists with financial support; however, he is a contract construction worker.
- ▶ It is likely Gabriela has Medicare and Medicaid insurance coverage.
- ▶ Long-term dialysis would be covered.
- ▶ Hemodialysis requires twice weekly visits; it is unlikely the patient could manage continuous ambulatory peritoneal dialysis.
- ▶ Should the physician speak with Gabriela directly once she assesses the patient is capable of comprehension?

# Poverty



- ▶ Should the physician place Gabriela on a transplant list?
- ▶ Can the information regarding the need for dialysis be conveyed to Gabriela without precipitating a family conflict?
- ▶ Why not consult the priest?
- ▶ Is there really a need for a DNR?

# Poverty, mental health, and the criminal justice system

- ▶ At 15, Pablo Sanchez is already enmeshed in the juvenile justice system. Now he is also becoming immersed in the county mental health system.
- ▶ Pablo is a member of a large extended family in a medium-sized city in California's Central Valley. Crossing the Arizona/Mexico border on foot, Pablo's mother immigrated illegally to the United States from her small Mexican village, along with her four children, when Pablo was ten years old.



# Poverty, mental health, and the criminal justice system

- ▶ The trip itself was arduous, and Pablo and his siblings don't often talk about the physical exhaustion, thirst, and intense fear that characterized that journey.
- ▶ Pablo's father was in prison in Mexico. He was murdered a year later.

# Poverty, mental health, and the criminal justice system

- ▶ As the family does not have documentation and therefore lives illegally in the United States, neither Pablo nor his mother or siblings were able to travel back to Mexico for the father's funeral.
- ▶ Pablo's mother works as a maid in a local motel and struggles to put food on the table for her family.

# Poverty, mental health, and the criminal justice system

- ▶ Pablo has three siblings: an older sister, now 18, and twin younger brothers, age 8. Pablo's sister, who works sporadically in a fruit-packing plant, is studying at night for her high school GED.
- ▶ After coming to the U.S., Pablo and his siblings quickly became bilingual but speak with accents.
- ▶ Their mother, however, continues to speak only a few words in English and prefers to communicate in Spanish, something that embarrasses and often irritates Pablo.

# Poverty, mental health, and the criminal justice system

- ▶ At age 11, when Pablo entered middle school (and shortly after the death of his father in Mexico), his mother and older sister noticed a marked increase in his general anger level and emotional distancing from the rest of the family.
- ▶ He began having trouble sleeping and concentrating in school, and his class conduct grew increasingly disruptive.
- ▶ His grades dropped, and he began drifting away from his friends.

# Poverty, mental health, and the criminal justice system

- ▶ After speaking with several of her close friends and older relatives, Pablo's mother attributed his behavior to "nervios" (fear, anxiety, and anger brought on by stressful life circumstances).
- ▶ She hoped that the symptoms would ease with time and prayer. In addition, Pablo's mother sought help from a local Mexican herbalist who prescribes a variety of calming herbal remedies for Pablo's behavioral problems.

# Poverty, mental health, and the criminal justice system

- ▶ Shortly after Pablo turned 14, in the ninth grade, he became connected to a gang active at his large high school. He began to experiment with alcohol and marijuana, soon progressing to cocaine and methamphetamines.
- ▶ On several occasions he was suspended from school for days at a time.

# Poverty, mental health, and the criminal justice system

- ▶ The school counselor repeatedly tried to reach Pablo's mother to discuss his situation with her, but Pablo's mother was usually at work when the counselor called and had a great deal of difficulty navigating the school's phone tree and answering system in order to return the calls in the evening.

# Poverty, mental health, and the criminal justice system

- ▶ Pablo's mother grew increasingly worried about her son.
- ▶ At first she addressed the problem by insisting that he stay home in the afternoons and care for his younger brothers (while she was at work), since he was the closest thing to a "father" they had.
- ▶ But Pablo began instead to take his siblings with him to meet his friends, which upset his mother even further.



# Poverty, mental health, and the criminal justice system

- ▶ One day Pablo came home with a tattoo on his hand identifying him as a member of his gang. His mother, beside herself with worry and anger, insisted that he stop seeing his new friends altogether.

# Poverty, mental health, and the criminal justice system

- ▶ Pablo laughed at her, mocked her (in English), and even made a threatening gesture and offered to "show her" who was "the real leader" of the family.
- ▶ He spent that night at a friend's house; the next day when he returned home, his mother was relieved and gratified to have him back.
- ▶ These patterns continued for several months, at times escalating as Pablo spent more and more time with his new friends.

# Poverty, mental health, and the criminal justice system

- ▶ On several occasions he landed in juvenile hall for petty drug and other offenses.
- ▶ During Pablo's most recent encounter with the juvenile authorities, Pablo met a county social worker who took an interest in him.
- ▶ Suspecting that his history of poor concentration, irritability, and oppositional conduct might mask deeper issues, she referred Pablo to a county-supported therapy program for juvenile offenders.

# Poverty, mental health, and the criminal justice system

- ▶ As part of his probation agreement, Pablo was ordered to make weekly visits to a therapist at the county-affiliated mental health clinic.
- ▶ With some difficulty, Pablo's mother rearranged her work schedule so that she could accompany Pablo to his first meeting at the clinic.
- ▶ When they arrived at the reception area, the somewhat harried receptionist told them rather brusquely to "sit down and wait over there." Pablo, visibly irritated, slumped in the chair next to his nervous mother.

# Poverty, mental health, and the criminal justice system

- ▶ Thirty minutes later, a middle-aged counselor emerged and instructed Pablo and his mother to follow her into a small, dark meeting room down the hallway. There she informed them (in English) of her name and that she had reviewed Pablo's case file from the county. She asked Pablo directly whether he was currently using any drugs, to which Pablo muttered a simple "no."

# Poverty, mental health, and the criminal justice system

- ▶ She went on to ask him what drugs he had used in the past, and for how many years. When Pablo's mother offered that she frequently gives Pablo doses of herbal tinctures, the counselor wrote it down furiously, with a hard expression on her face.

# Poverty, mental health, and the criminal justice system

- ▶ After about ten minutes, the counselor switched into passable (if imperfect) Spanish, telling Pablo's mother that this was purely a short intake interview, but that she would be able to offer Pablo one hour per week of talk therapy, paid for by the county, and potentially referring Pablo to a psychiatrist if a need for medication arose.

# Poverty, mental health, and the criminal justice system

- ▶ Pablo did in fact return to the counselor the following week and for several weeks thereafter, in spite of the fact that he resented his probation officer's insistence on it. But he did not develop a sense of rapport or trust with the counselor, and his participation in the sessions was grudging.



# Poverty, mental health, and the criminal justice system

- ▶ After two months of meeting with Pablo, the counselor does not feel that they were making significant progress. She agrees with the juvenile social worker that Pablo's anger and concentration issues may be related to deeper, unaddressed issues. The counselor has failed to achieve the level of trust with Pablo that would have allowed her to explore the matter further.

# Poverty, mental health, and the criminal justice system

- ▶ Additionally, Pablo's counselor is irritated with the frequent (three to four times per week) phone calls she now receives from Pablo's mother, inquiring about the content of the sessions and about her son's overall progress.
- ▶ The counselor believes that Pablo's mother is inappropriately "enmeshed" with her son, thus fueling his desire to differentiate from his family by connecting with his peers in the gang.

# Poverty, mental health, and the criminal justice system

- ▶ She believes that Pablo needs to take responsibility for his own health and well-being.
- ▶ Pablo's mother, supportive of the counseling at first, is growing increasingly opposed to it as the weeks pass by with little improvement in her son's behavior and attitude.
- ▶ She fundamentally does not trust the counselor and wonders if Pablo's growing talk of becoming more "independent" from his family is in fact driven by the counseling sessions themselves.

# Poverty, mental health, and the criminal justice system

- ▶ Why did it take encounters with the police before teachers or other professionals noted a mental health problem and acting out behavior?
- ▶ Why no Spanish speaking counselors?

# When one does not speak the language

- ▶ Ana Lopez is 17 years old and works in the U.S. as a farm laborer.
- ▶ Ana speaks no English and very little Spanish; she is an immigrant from Oaxaca, Mexico, and her primary language is Mixteco. She is illiterate.
- ▶ Roughly estimated to be 36 weeks pregnant, she is admitted through the emergency room to suburban non-teaching hospital with cramping and vaginal bleeding.

# When one does not speak the language

- ▶ Upon examination, placental abruption is diagnosed, and the medical team recommends a Cesarean section.
- ▶ Although the medical team considers Ana's C-section to be an emergency measure the hospital staff nevertheless do attempt to obtain Ana's consent before the surgery; she replies "yes" to all questions and appears to acquiesce to everything the medical team suggests.
- ▶ However, no one on staff speaks Mixteco.

# When one does not speak the language

- ▶ After the C-section, the baby boy's APGAR scores are low. He is immediately transferred to the neonatal intensive care unit (NICU) with diagnoses of neonatal encephalopathy and small for gestational age (SGA).

# When one does not speak the language

- ▶ Ana had arrived at the hospital early in the morning with her mother and sister, neither of whom speaks English or Spanish.
- ▶ She does have a husband, Hugo, but he was not present at the admission or the time of the birth since he feared losing his job if he missed work for the day.
- ▶ Hugo eventually arrives at the hospital later in the afternoon. He speaks no English but is haltingly conversant in Spanish.



# When one does not speak the language

- ▶ A social worker, fluent in Spanish but not Mixteco, meets with Ana and Hugo and discovers (to the best of her abilities) that Ana has no health insurance and had not been able to obtain any regular prenatal care.
- ▶ The social worker guesses that Ana had worked in the fields right up until the previous day. She wonders privately about Ana's exposure to harmful pesticides during her pregnancy. She is fairly certain that Ana has no legal immigration papers.

# When one does not speak the language

- ▶ Once Ana is stabilized after the birth she is allowed to go to the NICU to see her baby.
- ▶ Her husband Hugo remains with her in the NICU, along with a Spanish-language translator called for by the social worker. Through this translator, Hugo is able to communicate imperfectly on and off with the medical team.
- ▶ Throughout this process, Ana shows very little emotion, at least publicly, and the nurses present are bothered by her flat, unemotional affect.

# When one does not speak the language

- ▶ Nurse Ratched, manager of the NICU, in particular wonders (aloud, to her co-workers) why Ana "doesn't seem really to care about" her sick baby.
- ▶ Ana's mother and sister, meanwhile, speak quietly but urgently with Hugo whenever they get the chance.
- ▶ Late that evening, Hugo tentatively interrupts a nurse and asks her (via the translator) whether the baby might be visited by a "curandero," a traditional healer from their community.

# When one does not speak the language

- ▶ He suggests (apparently at the insistence of his mother-in-law) that the baby should be "cleaned with an egg."  
(An egg is passed over the patient to remove any malady or demon).

# When one does not speak the language

- ▶ Nurse Ratched is clearly uncomfortable with his request (and a treatment unfamiliar to her) and responds that the baby may be too unstable to be subjected to any "alternative" treatments. She reminds Hugo, somewhat sharply, that his baby is very sick but under the care of the best medical experts.
- ▶ Ana's relatives appear chagrined at this response.
- ▶ Hugo looks to the ground. He never again makes the request.

# When one does not speak the language

- ▶ After three days, Ana herself is discharged from the hospital, though the baby remains in the NICU. Over the course of the next few weeks, the baby stabilizes. The extent of brain impairment is unclear and, according to the medical team, will only make itself known over time.
- ▶ During these few weeks, Hugo is unable to be present at the hospital much during the day, but Ana is regularly accompanied by her mother and other family members, who bring food and sit with her as much as possible.

# When one does not speak the language

- ▶ The social worker pays special attention to Ana and Hugo's situation, particularly making an effort to get them signed up with a Medicaid-sponsored program. While ultimately successful, this move proves challenging, since they initially fear discovery of their undocumented status.
- ▶ Ana and Hugo eventually are able to take their baby boy home, unsure of what long-term complications he may encounter.

# When one does not speak the language

- ▶ How can informed consent be obtained when no common language is spoken?
- ▶ If consent were not required because abruption is an emergency, why did the staff go through the motions?
- ▶ Was any attempt made to reach someone who spoke Spanish?
- ▶ It is unusual for immigrants to move to an area in which there are not others from the same home area, language and customs. Why did no one seek them out?



# When one does not speak the language

- ▶ If the hospital would not allow a “curandero” access to the NICU, is there a more acceptable manner of explaining why this not possible rather than the approach of Nurse Ratched?
- ▶ How are Ana and Hugo supposed to understand the consequences of caring for their baby if there is no information in their language?
- ▶ Should pesticide levels have been measured or would that be too great a threat to the financial interests of the community?

# Low back pain

- ▶ After suffering a back injury at work, Lowell Baxter has completed three weeks of physical therapy.
- ▶ While unable to work, Lowell has been going three times per week to see therapist Eve Nye.
- ▶ After Mr. Baxter's ninth treatment, his physician, Dr. Felton Craz, explained that he had made good progress.
- ▶ Lowell no longer needed PT but was unable to return to his physically demanding job. He continued the home exercise regimen that Ms. Nye had given him.

# Low back pain

- ▶ Dr. Cranz, who was not adverse to ordering additional physical therapy if necessary, told Lowell to call him if he had any further problems.
- ▶ One month later, Mr. Baxter called Dr. Cranz's office and told the nurse that there had been "a flare up" in his lower back. After talking with the doctor, the nurse called Lowell and told him that Dr. Cranz ordered another round of PT - 3 times per week for 3 weeks - that he should begin right away.

# Low back pain

- ▶ During his third session, while telling Eve about his recent activities, Lowell mentioned that he slipped and fell on a rainy night while coaching his daughter's soccer team. He said that this happened "a couple of days" before the "flare up".
- ▶ Eve asked if he told his doctor about this latest fall. Surprised at the question, Lowell replied, "Well, no. Why would I? Anyway, I was having some painful twinges in my back before I slipped. Besides I fell on the soft grass. I'm sure I didn't hurt myself when I slipped.
- ▶ Dr. Cranz is always so busy and I don't need to waste his time."

# Low back pain

- ▶ When Ms. Nye saw Mr. Baxter on his fifth visit, he complained of increased pain with radiation down his left leg.
- ▶ During her evaluation, Eve concluded that his pain was different from the pain he experienced after the first fall and was almost certainly related to the second fall.
- ▶ She explained this to Lowell and suggested to him that he talk to his doctor to ensure that he received the appropriate treatment.
- ▶ Lowell insisted that he did not need to do so. It was none of her business.

# Low back pain

- ▶ The patient was injured at work and placed in a less physically demanding job.
- ▶ He reinjures his back while coaching his daughter's soccer team.
- ▶ He had earlier told the physician he had a recurrence and did not inform him of the circumstances. He does not want to inform his physician of the injury as it would raise questions as to the mechanism of injury and likely jeopardize any workmen's compensation or civil claim that may be pending.
- ▶ Should you tell the treating physician?

# Alternative therapy



- ▶ Mr. Chen, a 40 year-old patient originally from China, has had lumbar problems for one year. The condition includes dull pain in his right leg and the inability to sit still for long periods. X-ray examination reveals a prolapsed lumbar disc. He has been treated with conventional pain medication with minimal effect.

# Alternative therapy



- ▶ His physician, Dr. Robert Olson, recommends back surgery, but Mr. Chen is reluctant to take this option. Instead, he asks the doctor to refer him to an acupuncturist because his insurance coverage requires physician's approval for "alternative" therapy. He mentions to the physician that he has tried acupuncture before, and it has helped him.



# Alternative therapy



- ▶ But Dr. Olson is skeptical about any kind of alternative therapy.
- ▶ This derives his belief that allopathic medicine is the most efficacious because it has been scientifically proven through clinical trials.
- ▶ He has also had extensive positive experience with surgical treatment for Mr. Chen's condition (and for which he is compensated).

# Alternative therapy



- ▶ In his view, other forms of medicine are at best placebos, and he does not see it as his duty to recommend them. He refuses to order the acupuncture.
- ▶ Is Dr. Olson correct?
- ▶ Is his judgment clouded by the means by which he is compensated?
- ▶ Should Mr. Chen seek another physician?

# Refusing treatment

- ▶ At 80, Robert Lewis lives with his wife in a retirement community.
- ▶ He has always valued his independence, but recently he has been having trouble caring for himself. He is having difficulty walking and managing his medications for diabetes, heart disease, and kidney problems.
- ▶ His doctor diagnoses depression after noting that Mr. Lewis has lost interest in the things he used to enjoy.
- ▶ Lethargic and sleepless, he has difficulty maintaining his weight and talks about killing himself while holding a loaded handgun.

# Refusing treatment

- ▶ He is placed on medication for his depression.
- ▶ Two weeks later Mr. Lewis is hospitalized for a heart attack. The heart is damaged so severely that he suffers prolonged hypotension and develops acute renal failure.
- ▶ Hemodialysis is needed three times a week to maintain life.
- ▶ After the second week he asks to stop the hemodialysis and be allowed to die.
- ▶ His physician, Dr. Rose, consults with a psychiatrist and continues the antidepressant and maintains hemodialysis.

# Refusing treatment



- ▶ His wife was asked to give consent for a feeding tube.
- ▶ After conferring with the rest of the family, Mrs. Lewis denied the doctor's request. Her husband's repeated refusal of dialysis had convinced the family he really did want to die. Further, he had resisted entering a nursing home.

# Refusing treatment

- ▶ Ultimately, the physician accepted the family's assessment that Mr. Lewis' consistent refusals indicated an authentic wish to halt treatment. He was taken off dialysis and put on comfort measures. Six days later, he died.
- ▶ Was Dr. Rose correct in insisting on continuing antidepressant therapy and hemodialysis in the face of little improvement?
- ▶ Was Dr. Rose convinced that a depressed patient cannot think clearly and is therefore not competent to decide what care he would find acceptable?
- ▶ Is that why she went to his wife?

# Inadequate insurance coverage

- ▶ Alan and Monica Sinclair have been your friends for many years. Though they live in another state, you are able to get together with them every now and then, and a Sunday night doesn't seem complete without your weekly phone conversation.
- ▶ These phone calls became even more important when Alan contracted cancer at the age of 40.
- ▶ You've followed his illness carefully ever since he began treatment for non-Hodgkins lymphoma at University Hospital.

# Inadequate insurance coverage

- ▶ Alan and Monica found University more than deserving of its reputation as a center of excellence for cancer care.
- ▶ When his early treatment was successful, Alan could only be grateful for the expertise of his doctor and the entire medical staff.
- ▶ Monica also found the hospital's location an additional, but real, benefit. Close to her home and work, the hospital was convenient for her frequent visits as well as those of their son.



# Inadequate insurance coverage

- ▶ Proximity became even more important when the hospital began the long process of harvesting stem cells from Alan's blood for returned to him after high dose chemotherapy treatments (autologous stem cell transplant).
- ▶ In this Sunday's phone call, Monica, still trying to be brave and matter-of-fact, tells you Alan needs a bone-marrow transplant.
- ▶ You reassure her that she just needs to trust the doctors at University, as she has in the past, and everything will turn out well.

# Inadequate insurance coverage

- ▶ "But," she tells you, " Alan's HMO wants to send him to a different hospital -- Fair Oaks -- a couple of hours away. I mean, Fair Oaks is a very good hospital, and they tell me it has a renowned oncology center, but so does University. I don't understand how the HMO can pull Alan away from his home, especially now when he's so sick.
- ▶ I'll probably have to quit my job to be with him, and our other friends and family will never get there. And they'll probably have to start the stem cell harvest all over again at the new hospital!"

# Inadequate insurance coverage

- ▶ When you ask why the HMO is doing this, she tells you the company saves money at Fair Oaks. The transplant costs from \$100,000 to \$150,000, and the HMO gets a discount because it has a contract with Fair Oaks. Some other companies have a contact with University, but not Alan's.
- ▶ "We didn't know this would happen to us," she whines. "We knew we might have fewer choices about doctors and hospitals, but who reads all the fine print in those contracts?"

# Inadequate insurance coverage

- ▶ She tells you that Alan Jr. is very upset. As a lawyer, he's been pushing the HMO, but they insist that they are upholding their end of the bargain - providing care at a good hospital and, at the same time, making sure the transplant is done in the most cost-effective way.
- ▶ "Alan Jr.," she tells you, "got pretty upset when the HMO said they weren't concerned that we would be inconvenienced. They say they are passing all the savings on to their customers, but I don't believe it. This is a for-profit company. I just don't trust them."

# Inadequate insurance coverage

- ▶ A contract is entered into freely.
- ▶ One is not excused for not having read the contract. The son, a lawyer, is aware of this.
- ▶ The HMO is correct.
- ▶ Did the son approach University Hospital to learn whether they would accept the payment the HMO would offer before he began “pressuring the HMO”?
- ▶ Not even a Gold plan with the Affordable Care Act would provide what the HMO is providing.
- ▶ Should health outcomes be determined by what type of insurance or lack thereof the patient possesses?