



Healthcare Narratives
from Diverse Communities —
A Cultural Diversity
Self-Assessment Tool
for Healthcare Providers

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Healthcare Narratives from Diverse Communities – A Cultural Diversity Self-Assessment Tool for Healthcare Providers

by the Center for Practical Bioethics and Members of the Cultural Diversity Task Force

Research examining cultural diversity in the healthcare context has produced general themes about particular patient populations, and tools based on this research vary in their approach to improving cultural sensitivity and competency. Some tools pose questions that providers may ask patients to help them become better informed about their patients' cultures; others name areas of sensitivity that providers ought to be aware of in caring for culturally diverse patients. This tool is different. It focuses on the provider, and its goal is to raise the provider's consciousness through self-reflection and examination. It consists of three parts: stories from interviews with actual patients followed by thought-provoking questions; commentaries on four of the narratives to help the provider measure his or her assessment of the ethical issues contained in each one; and a decision-making analysis grid to help one use the tool more effectively. It concludes with a bibliography for additional reading.

Healthcare Narratives from Diverse Communities – A Cultural Diversity Self-Assessment Tool for Healthcare Providers recounts the experience of actual persons living in an urban area of Wyandotte County, Kansas. In all cases, the storyteller's healthcare needs were further complicated by his or her own, or another's, perceptions of culture, ethnicity, race, and class.

Four distinct groups are represented in the narratives. However, the tool makes no claim to represent fully any cultural or ethnic group or class, and no generalizations should be drawn concerning other individuals in these communities. Laotian, Hispanic, African American, and impoverished Caucasians shared their experiences during interviews or panel discussions in the presence of Center staff and members of the cultural diversity task force, including healthcare providers and ethics committee members. The collection and recording of the narratives was part of the cultural diversity project undertaken by the Center for Practical Bioethics (then the Midwest Bioethics Center) with funding from the W.K. Kellogg Foundation and the Wyandotte Health Foundation.

The narratives reprinted here are verbatim excerpts from these interviews with the exception of changes necessary to ensure confidentiality. Permission to use the narratives in this tool has been obtained. No other use shall be made of these stories without the express permission of each participant.

How to Use this Tool

There are no right answers to the questions posed in this tool. They will, however, facilitate your hearing of the stories and provide insights for self-reflection and discussion. They may also be used by groups, such as ethics committees, medical staffs, and clinical in-services to stimulate ethical discussion and self-education, or as a means to facilitate discussion in other areas of an organization.

Begin by reading each narrative thoughtfully. Take time to note any words or phrases that are particularly striking. If you are working in a group, do not be afraid to allow some silence as each participant becomes attuned to the narrative. You may be tempted to ask for more clinical

information or to dismiss the cultural and class issues on the assumption that healthcare needs are the same for patients from any culture. The emphasis here, however, is not on the medical facts or the person's clinical presentation. It is on the way that culture, ethnicity, race, and class can complicate our perception of healthcare and other needs.

In some cases, the questions for discussion will begin by asking you to share your first reaction to the story. Ask yourself that question about each of the narratives, and try to determine what if anything you would emulate or change if you were confronted by a similar case. Skip any questions that are not relevant or do not help you examine your thoughts, feelings, and attitudes to diversity.

Eight narratives are presented. Although individuals should eventually respond to each one, you may need to select among them if your meeting time is limited or you have a large number of participants.

Commentaries, written by ethicists at the Center, and a decision-making analysis grid complete this Cultural Diversity Self-Assessment Tool for Healthcare Providers. The commentaries, like the questions, are preliminary, not final, responses to four of the narratives. They do not represent complete analyses, but they can provide a measure for gauging your response to the narratives. If you are working in a committee, you may want to discuss the cases at one meeting and the commentaries at another.

You may want to use the decision-making analysis grid to determine a plan of action for addressing cultural diversity in your practice setting. The plan to address cultural diversity begins, as action plans typically do, with an assessment of the situation, then proceeds to diagnose the problem and plan for its resolution. The final plan is a combination of recommended actions, including the assignment of priorities and identification of the person or groups who will engage in the process. Whether or not you proceed to action at this time depends to some extent on the needs of your patients and their families, but

also on your readiness to listen actively to those who can help us trust our differences.

Finally, you may want to reexamine your response to this tool from time to time, or you may simply resolve to adopt a new orientation or policy for your practice. In both cases, the bibliography that concludes the tool can be used as a resource for more in-depth reflection.

Section I.—Narratives

A. African-American Voices

The Pastor's Wife. Reverend Smith, a community pastor for twenty-eight years, tells us a story about his wife, who died eight years ago after being diagnosed with ovarian cancer. She was diagnosed on a Friday and "was gone in four weeks." By the time her cancer was found, it was in the lining of her stomach, aorta, and liver. They operated on her ovaries but "didn't touch the aorta." She returned home, and after three weeks had to go back to the hospital because she was passing blood. He tells of developing a new respect for nurses in acute care, especially one of the nurses who was a member at his church and who visited his wife daily before and after her shift. After Mrs. Smith was rehospitalized, "a couple of days prior to her passing," the medical team found that she had cancer of the bone. Reverend Smith reported:

Now [the chief resident] has already told me that he's given her just a few days to live so I'm going to take her home. And so [the resident] says, "Well, I'm not talking about three weeks, Reverend, I'm talking about three days or so and she'll be gone," because her platelets were being eaten up. [But] he brought these doctors in there, and this is what really upset me and I did not appreciate it at all, they were going to drill in there to get this bone marrow, so he's going to let this student do this. My wife and I had been through a lot and she's in pain. I don't remember them giving her anything and they was going in there and she [the intern]

missed it and he says, "That's okay. That's all right. Let's try it again."

And I said, "No! Whoever is the boss here and whoever is the most proficient at this [is going to do it], and if you are the head of the department, you'd better try it. And don't you miss it."

Because I'm upset because my wife is in all this pain and they've got these students. Now, I did not like that. They allow this training procedure to go on with my wife. Get the best person in here. Hit it. Get it. And not be experimenting. I think sometimes there's a lot of experimentation going on. I don't want to sound

What did you not want to sound like?

Like I am dealing with racism. I don't know that they wouldn't have done the same thing, but we're not a welfare recipient, we're paying. And I want the best medical, and I'm willing to pay for it and I don't want anybody experimenting at that time. . . . So, that was a problem for me.

Questions for Discussion

1. What is your gut reaction to the husband's perceptions of this event? What are your best guesses as to what might have influenced these perceptions?
2. What are your prejudices about this case or others like it?
3. When procedures such as this test are performed on African-American patients, should they receive special consideration because of the history of abuse experienced by African Americans in healthcare settings (e.g., the U.S. Public Health Service Syphilis Study)?
4. If you were part of the team involved in this procedure, would you be comfortable asking your instructors why such an invasive procedure is being done to a patient who is actively dying?

5. Do you think there is a difference between being fully "informed" and obtaining informed consent? How do you think the benefits and risks of this procedure were explained?

6. When informed consent is obtained for an invasive procedure, is there sufficient consent to repeat the procedure? If the person doing the procedure changes (e.g., intern, attending physician, or another), should you seek a new consent?

Death of a Paramedic. A 40-year-old African-American intensive care nurse tells of the unexpected death of her husband. Her husband was a paramedic who had been undergoing treatment for two years for a debilitating cardiac condition. The condition had grown so severe that he had been moved to a "desk" job. While attending a professional conference in a nearby city, he was found dead in his hotel room. His wife was called and she, with close family members, left immediately to claim the body of her husband.

[W]hen we got there to claim the body, we had to go all over [the town] . . . [before] we got to the morgue. It was closed. When it opened, I walked into the room, the way I was dressed, it was not like a nurse; it was like an everyday person. I don't even know if my top was matching my pants, y'know, I was just there. . . .

[The clerk] had told the family before I got there that they couldn't go back and see the body. We came [all the way here] to identify the body, and she tells me that we have to wait until we got back home to see the body.

And I thought, "Now come on." And you keep thinking all this time, this is not the right person. That it was a mistake. It was the wrong birthday, the wrong age. That's not my

husband. But she kept telling me I could not see the body. . . .

And I tried to push this way back into the back of my mind, but the only thing she had to identify who we were was all of us were black. So I kept thinking that they wouldn't do this to a white person from [the city]. Maybe if I had walked in there with my nursing license? And I hate saying that.

Questions for Discussion

1. What are your first reactions on hearing this story?
2. Do you think the person at the morgue desk was being racist or class-conscious?
3. This woman tried to repress her thoughts that she was being ill-treated because of her race and class or perceived class. What behaviors trigger our perception that class or race is being used against us? What triggers a tendency in us to stereotype a person?
4. This case raises important questions about how we handle sudden deaths in hospitals. Who in your hospital is first to greet a bereaved person after a sudden death? How do we train these people?
5. Are there institutional policies or barriers that prevent you from seeing someone's suffering?
6. Are people staffing morgues reflective of "our values?"
7. Does emphasis on efficiency and competency in healthcare sometimes excuse healthcare professionals from acting with compassion?

B. Hispanic Voices

What Happened to Anna? Mr. and Mrs. Lozoya, a Spanish speaking couple with a middle school education, tell us about the dying of their only daughter, Anna. She was a 15-year-old girl who

died of a cerebral hemorrhage in the intensive care unit (ICU). Two years prior to her death, she had a similar hemorrhage. After three months of being in the ICU and \$600,000 of care, she recuperated and was sent home. A social service agency worked closely with the family to get the hospital bills reduced and paid for. But Anna had a second hemorrhage that she did not survive. They tell us through a translator:

When they brought her in, they were going to put an IV in and the IV evidently wasn't placed in correctly and no medical professional had taken notice of that until a family member notified them. I can't help but wonder if the medication had gotten in there better if the situation would have turned out differently. The doctor never showed his face to us. He never, ever showed his face to us. Not one time. . . . He sent nurses, but he never came himself, so we never knew what was happening.

Her medication was for inflammation of the brain, and it was going all over and her little arm was all swollen and red and nobody knew. And there was nobody [in the family] who spoke English so we didn't know how to tell them what was happening. She went into a coma and that may not have happened if she was able to get the medication. About six or eight hours later they said that there was no more brain activity, and there was nothing else that they could do.

No one in the Lozoya family spoke English and none of the hospital staff spoke Spanish in either the Emergency Department where Anna was taken first or in the ICU where she was later transferred. Additionally Mrs. Lozoya told us:

For me, my goal is to study English and know it well enough so that I can go to that doctor and say, "You can tell me what

happened to my daughter.” So I don’t need a translator . . . for me, it’s really important that the professionals take into account the pain of the family that’s experiencing this treatment. And they make sure that the family knows at all points what is going on, and that there’s no situation where the family would arrive and the organ donation papers [in Spanish] are already laid out.

I had been sitting with my daughter. I got up to go to the bathroom. While I was gone, the doctor came in and set out those papers. When I came out and I sat down and I sort of noticed those papers and so I realized that they were thinking that there was no hope. They were going to disconnect the machine. I hid the cards so my husband couldn’t see them until they could explain what was going on.

Questions for Discussion

1. What are the ethically and culturally salient issues in this case?
2. Are English-speaking patients and families treated in a different way than Spanish-speaking patients and families?
3. What obligations do institutions have to provide timely and appropriate translation services?
4. Although the healthcare providers in this case provided translated documents, did they adequately prepare the family for what was happening?
5. If you found organ donation papers already in the room of a loved one and no one had talked to you about his or her condition, how would you feel?
6. How did not seeing the physician in charge of Anna’s care impede the family’s ability to cope with Anna’s death?
7. Why would the physician not meet with

Anna’s family? What obligations do you believe healthcare professionals have to a patient’s family in situations such as these?

8. Do you believe the Lozoya family’s cultural background influenced how they wished information to be delivered and by whom?
9. How do the routines and processes of health care delivery cause healthcare professionals to look past this family’s needs and suffering?

Mother and Child. A twenty-nine year old Guatemalan woman, Monica, has been living in the United States for seven years. Monica has a sixth grade education and cleans businesses through a housekeeping service. She is a single mother of three children and speaks a small amount of English. She tells us stories of the births of her second and third children. Both were born at the same hospital, one year apart. Monica [told us what happened at the birth of her second son]:

They were telling me that I still owed money on the birth of my son [who is] five years old now. That I was making very small payments and that I needed to pay all of that first in order that they would give me good treatment now. They kept asking me, “Do you have insurance? If you had insurance, it would be better.”

They were telling me about how when they had to treat people without insurance they weren’t paid, and when they were treating people with insurance, the government could pay them. . . .

I was lying down when the doctor said to me, “Do you have insurance?” And I understood, more or less, what that meant. And I told him that I didn’t and so he brought the lady who spoke Spanish and she asked me.

They asked me if I was paying insurance at work, if I had insurance from my work. I only thought that there was car insurance. I didn’t realize there was insurance for people. And so

I told him “No, I don’t have insurance. I don’t even have a car. I don’t have anything.”

And she laughed.

Monica faced a much graver situation in the birth of her third child:

“I was learning a little bit of English and so when [the nurse] was saying c-section, I really didn’t understand at that point. [The nurse] couldn’t tell me in Spanish because she didn’t know how to say it in Spanish. So after about three days I woke up and I realized that I had had the operation. They told me that the baby had been born dead. I asked why, because I thought that the baby was ready to be born, I was full-term.

There was a doctor and he spoke Spanish and he said that the baby was born dead, and they had done an autopsy. . . . They showed me the baby and I noticed that the baby was cut from one ear to the other along the neck. I think that maybe something must have happened when they were doing the operation. I asked them if that was from the autopsy, because in my country when they do an autopsy the incision is from the chest to the abdomen. I kept asking why they did the cut in the way they did — why the baby died. . . . The baby was ready to be born.

After this happened, I was talking to a friend from Cuba and he was telling me, “No, they don’t do autopsies like that. You should talk about this with someone who knows more.” But you don’t have any money, so you don’t have the possibility of talking with anyone that would know. I called Sister two or three days later for help to get a casket. [Hospital staff] told me that if I didn’t sign a paper to release the baby to me, that they would throw the baby away.

Questions for Discussion

1. How does this case make you feel? What are the ethically and culturally salient issues?

2. What problems arise from the language barrier in Monica’s hospitalization? How do these problems influence the care she receives and her perception of her care?
3. How could Monica’s questions about her baby’s autopsy results have been better revealed and answered?
4. When significant cultural issues are apparent, should services other than translation be obtained? Patient advocacy? Outside agency involvement? Pastoral care? Others?
5. Do you know what your organization’s policy is when someone dies and there is no transportation, communication, or finances to provide for a burial?
6. Do you treat patients with insurance differently from patients without insurance?

C. Laotian Voices

A Promise to Buddha. Mr. Leu is a forty-nine-year-old Laotian immigrant who came to the United States 4.5 years ago through a refugee resettlement program. He has a fourth grade education and speaks very little English. He tells us through an interpreter, who is his resettlement caseworker, about his current struggle of being on dialysis three times a week. Mr. Leu’s illness began when he came to the United States. He presented with acute back pain and after some time he was finally diagnosed with renal failure. The translator tells the story of his spiritual dilemma:

Before he came to refugee camp, he practiced Buddha[ism]. After he escaped from [the] communists [Laos], he said that one day he would come back to practice. He promised that to Buddha in the Temple, [which] he said [is a] very powerful Buddha. Before he came, he went to a safe place and [promised] Buddha.

So he’s been thinking that maybe he can’t rid himself of sickness because he didn’t have

a [chance] to go back to . . . show respect to Buddha. If he could go back and do what he said he would, maybe a doctor could cure him more quickly. He told [the] doctor, but the doctor said, “No, no spirit, nothing like that.” He tried to tell the doctor that [the reason it was taking so long] to treat him, maybe because he [had] promised that . . . when he come here, he go back to [the Buddha]. . . . But the doctor said, “Don’t believe in that nonsense. Let [it] go.”

Mr. Leu’s caseworker reported that through his insistence, she helped him, “fill out a travel document that let him go back, but he didn’t go because he has to go to dialysis three days a week. . . .

Everybody know[s] him at the hospital. They’re taking good care of him. But it’s just the one thing: that he thought he couldn’t get well because of the spirit. [Going to the Buddhist Temple here is not good enough], because he make promise. Not in Lao, [but] in Thailand [at the refugee camp] . . . that he would go back to be Baptized (a Holy order in the religion of Buddhism). But he didn’t have a chance [because he got sick]. Maybe that’s the thing that’s keeping him [from getting well].

Questions for Discussion

1. What is the problem here?
2. Was the patient ever asked what he perceived the problem to be?
3. What do you think of the physician’s response? What assumptions inform the physician’s response? Compare those assumptions with those that inform Mr. Leu’s perception of his illness.
4. Is there any way that Mr. Leu’s spiritual and medical needs could be accommodated simultaneously?

5. Mr. Leu’s case illustrates a conflict between two belief systems. What obligation does a health system have to meet the needs of patients whose world views are drastically different from Western medicine?

To Have or Not to Have Money? A fifty-five-year-old Laotian refugee, Mr. Hoang, tells of his struggles with health insurance. Upon his arrival in the United States in 1982, he was able to find work as a metal worker; his work provided health insurance and a retirement plan. Ten years later he had cardiovascular disease that required open-heart surgery. He was able to return to work after three months with frequent monitoring of his condition. However, in November 2000 he required an additional surgery, which was done at MD Anderson Medical Center. His 25-year-old son helped make all the arrangements.

Since then he has had considerable weakness and is now wheelchair bound. He was prescribed physical therapy twice a week, but claims that it was too painful for him, so he does his own at home. The refugee case manager completed her official work with him in 1987, but stays in contact with him and served as our translator. Mr. Hoang said:

Because I had health insurance, my family doctor referred me to the surgeon. He told me he’d take good care of me. Now [that I am disabled] I have to pay for health insurance because I worked and I had a 401K. [So,] now I have no insurance. So I went to Medicaid, but they said no because I had money [in the 401K]. Now [I’m supposed to] pay for health insurance. One hundred and something a month. I cannot withdraw [from the retirement money] without penalty.

He cannot withdraw the money until he’s 59.5 years old, but because he has that money he can’t get state assistance. Mr. Hoang made the decision

to deplete his 401K retirement fund so that he could qualify for Medicaid. Currently he is living with his son, daughter-in-law, and their two children, and maintains hope that he will return to work. He says:

Because the state didn't give to me, because I have money, I have to use my money up first because they only help poor people. So, it's good and bad having money.

Questions for Discussion

1. What are the ethically and culturally salient issues in this case?
2. What does Mr. Hoang believe the problem to be?
3. Do you think that Mr. Hoang believed that "spending down" is a policy that applies to all Americans who need access to Medicaid or did he think that this applies only to refugees?
4. Did he understand that physical therapy may make one hurt more in the beginning before he begins to feel better? Does your organization provide good translation in its ancillary departments?
5. Stoicism in the face of adversity is characteristic of Laotian culture. Do you think Mr. Hoang would act differently (perhaps demand services) were he able to speak English?
6. How ought continuity of care be assured when a non-English speaking patient is referred out of town for a surgery of this magnitude?

D. Impoverished Caucasian Voices

Too Poor for Privacy? Susan is a forty-nine-year-old single Caucasian woman who has obtained her GED and currently lives on \$900 per month of social security disability. She lives with her eighteen-year-old daughter and two-year-old granddaughter. She is confined to her split-level house because she is wheelchair bound. Her

medical story began twenty-five years ago when she developed necrotic hip joints after taking prescribed large doses of steroids for the treatment of asthma.

She subsequently had two hip replacements, which were revised fifteen years later with one hip requiring approximately thirty surgeries and a final amputation just three years ago. To further complicate things, Susan fell and broke her remaining leg while receiving physical therapy in her home. She told us stories from her multiple hospitalizations. One of her most recent experiences includes an incident two weeks into her hospital stay:

Somehow I got head lice and I felt like I was really discriminated against, because I told the nurse about it because my head started itching. And well, I had been there so long that I knew that I must have got it somewhere in the hospital. Well, "Oh no, there was no way!" they kept saying. There was no way I could've got this in the hospital.

I said, "Well, maybe one of the aides' children had it or something like that." Right away it was just the gossip that spread like wildfire. "She's got head lice. She's got head lice." And they wanted to know where I had been and run into the rooms so they could go clean up again and everybody had to dress in masks and gowns when they came in.

And I was like, "[Lord]! If I had known this I would've had my daughter just bring in some Kwell." . . . I was bedfast then [so] I couldn't even sit up too well for them to get my head really good. The nurse washed, gave me a treatment of Nix . . . and she kept talking about how her kids had it and stuff like this, and I really didn't want to talk about it. I just wanted to get rid of it. Y'know?

And then since I was in rehab, I had physical therapy and occupational therapy. Well, they canceled all of my therapy since I wasn't

able to go out among the group. I couldn't go to any meetings. I had to stay in my room because of the head lice, and I couldn't eat with other people. I had to eat in my room. And, an occupational therapist . . . , we worked really close together, and she came in with a mask and gown on. And what she said to me was, "I'm pregnant and I'm afraid it might give my baby something." . . . And I'm thinking, after all they should be apologizing to me since I got it in the hospital. . . .

I felt like I was being punished, and I felt like I had a real bad contagious disease, like tuberculosis, or something like that, because the people just didn't want to come around me. . . . I was educated enough to know that it had to come from someone who had kids at home with it or something. The nurse who checked my head for it was the school nurse at my church. I could've died. Not only were we involved with the people in the hospital, now the church is getting involved. I felt like everybody at church knew that I had head lice.

Questions for Discussion

1. Were the healthcare professionals in this case "classist" in their treatment of Susan? Were assumptions being made about the cleanliness of her home or her own personal hygiene because of her economic and educational status?
2. What facts about Susan gave the healthcare staff permission to spread the news of her head lice? Are you familiar with regulations regarding privacy and confidentiality in your organization?
3. Should Susan have been assigned a patient advocate or a case manager?
4. Are we partially responsible for Susan's current condition?

5. What about "us" blinds us to Susan's suffering? What about Susan causes us not to see her, enabling us to talk about her in front of her?

6. Do we value Susan? Do we count Susan as one of us?

Ralph's Financially Troubled Heart. Ralph, a fifty-seven-year-old Caucasian, is disabled from chronic heart disease. His source of income is Medicare, approximately \$14,000 per year. He lives with his wife, daughter, and two grandchildren. His chronic disability is further complicated by financial burdens.

I went on vacation, two weeks' vacation, to work in the field, and when I come back that Sunday night, I couldn't breathe. I went to the doctor Monday. I was supposed to be back at work Monday night. And I couldn't breathe so I went to the doctor. He took some samples of blood and all this. I went home and he gave me a prescription and I was taking them. I went to work. I went to work late and I called the supervisor and I told him [that] if I wasn't feeling better, I'd go home at midnight. I was supposed to work 6 P.M. to 6 A.M. And he told me if I wanted to go home, I could.

So, I went on home, and the doctor called the house the next morning and told my daughter to get my butt up to Hospital B as soon as possible, that he had a room waiting for me. I checked in, and that's when they told me that I had congestive heart failure.

My oxygen level in my blood was only about 70 percent. When [the doctor] did come around and talk to me, because he's really busy, I was half asleep and he was talking about how I had such an irregular heart beat, that if it didn't go back on its own, that they were going to stop it and restart it. [The healthcare team was] talking about a transplant and I didn't know about that either.

Eventually Ralph was stabilized and returned home with a diagnosis of cardiac myopathy with approximately 50 percent cardiac function. He would no longer be able to work. He said:

All the talk about [a transplant] just quit when the insurance and everything got screwed up. Well, when I had to retire at work, they canceled my insurance immediately and I had to pick up COBRA. Well, COBRA I could keep only for eighteen months, but for me and my wife it was about \$480 a month. And I had no income so I had to pick [my insurance] up on myself, which was about \$180 a month.

You've got to be disabled for two years to get Social Security and the first time they denied me. They deny everybody. I guess if you want it you have to fight for it. I had a lawyer help me. Other than that, they'd probably tell me no the second time. I don't think the system that makes all them rules knows what the hell's goin' on. Like I said, if it hadn't been for the 401K and my wife working, I don't know how the hell we would of lived.

You gotta be disabled six months before you can start drawing. And I was off ten months, and see that's what I didn't know. I was off ten months and then when I did get it they said you had to be disabled six months. And so I got four months back payment to help make up all the difference with all that 401K money I blew keeping the house and the bills caught up. And then you have to be off 24 months before you can get insurance.

When asked if the 401K was meant to be his retirement, he said, yes. When prodded and asked if he had to use part of it, he said,

I had to use it all.

When asked what he did for healthcare when he didn't have insurance, he answered,

Nothing. What the hell could I do? The insurance was too high. . . . I didn't have no pills. I was about four or five months without no pills at all. Because the last time I had any prescription was from the doctor in St. Louis, and they called once and had it refilled . . . and after that I didn't have the money, so I didn't even go. Because it cost you a \$100 or \$150 just to go to the doctor, just for him to see you. Because you go in and they automatically charge you about 30 bucks for the office call.

And by the time you go and talk to him and they draw blood and all this and you go around the circle and come back out the front, you owe a 100 to a 150 bucks. And you don't get nothing done. Maybe a few prescriptions wrote. And if you don't have the money for the office call, you ain't going to have the money for the prescriptions. And besides that, every time I go, they always tell me I've got something else wrong with me, so I quit going. He laughed.

When asked if it had been his experience that he or others in his family were treated differently because of their financial status, he replied:

Well, I know they are. Like waiting in waiting rooms and stuff like that. You sit up there in the waiting room and you can see the difference. If somebody comes in and they've got Blue Cross/Blue Shield, they sign in, and then they go around the corner. This guy comes in but he don't have no insurance but he's going to pay his bill anyway or make a deal with them, and he'll go around the corner later. Blue Cross and Blue Shield will go right on in, but this guy will sit maybe an hour. Then they'll finally come call him and he'll go in. Or if you have a Medicare card, you'll go in before the guy with nothing.

When asked about the last time he was hospitalized, he replied:

I slept on my knees at the foot of the bed, using the foot of the bed as a pillow and slept on my knees all night.

The parish nurse asked him if he thought that going to the hospital was a last resort?

Yep! That and my wife. . . . [She] told me to go somewhere and die or go to the hospital.

Questions for Discussion

1. Do you and your colleagues treat “financially fragile” patients differently than those with “good insurance”?
2. What is our responsibility to patients who cannot pay for the care they need?
3. What do healthcare institutions owe the community of which they are a part, especially institutions that get a tax break to be in the community? What portion of a healthcare system’s revenues should be directed to indigent care?
4. How could you have advocated on Ralph’s behalf to ameliorate the punitive/detrimental impact of these policies? Do you think the reimbursement/disability policies are punitive?
5. Would you have requested a case manager or patient advocate?
6. Did care providers avoid this patient because his situation felt “too close”? Could you see yourself or someone you love being in a similar situation?
7. Would your view of this case be different if Ralph had been African-American? Hispanic? Or another minority?

Section II.—Ethical Commentaries

The Pastor’s Wife

This is a story about the emotional response to suffering and pain: the patient’s pain and the husband’s suffering. I want to distinguish between pain and suffering. Pain is the physiological response to stimulation of specific nerve endings that are interpreted as pain by the brain. Suffering is the response of the whole person to whatever threatens the integrity of the person.

The patient’s perspective is suggested, but not fully developed in the narrative. “My wife and I have been through a lot and she’s in pain.” No doubt the patient has suffered that which threatens the integrity of her person, but her pain is not the theme of the story. The husband also suffers in response to seeing his wife in pain, but his suffering is also not the main theme of the story. Rather, the story is about the husband’s angry response to those who increased his wife’s pain and his suffering.

Suffering, as the result of threat to the integrity of the husband’s person, is the disintegration he feels because he cannot control the cruel clinical situation in which his beloved wife is rapidly dying. He cannot protect her from pain. He can only yield to the situation and suffer through it. That kind of acceptance and suffering he could endure with patience and grace. But not all suffering is endurable.

Suffering with another person is made more acute when other people do not share in that suffering. Suffering is an individual response that is validated by others’ sympathetic participation. The medical team is represented as not showing any sympathy for the patient. Instead, they create more pain in the patient apparently for their own interest in procedural instruction. Their insensitivity is magnified by their failure to use analgesia to block the patient’s pain.

Suffering causes additional responses, for example, anger at those who cause pain. This story is about anger. Those who trigger the anger are powerful, white, young agents of a medical establishment who were unable to help the vulnerable patient but who used her to help themselves. Would the anger have been as intense if any of the contributing factors — powerful, white, young, self-interested — had been eliminated? If the medical team had been African American, would the anger have been as intense? If the medical team had been more caring, used analgesia, apologized for their intrusion, or been less self-absorbed and more sympathetic, would the anger have been less intense? If the bone marrow procedure were curative, would it have aroused anger?

The husband believes that because she is not on welfare his wife ought to get the best treatment from the most capable physician — from “the best — I don’t want anybody experimenting.” What had the medical team told the husband and the patient about doing a bone marrow aspiration? Had a convincing reason for doing the bone marrow been given to them? Who was expected to benefit from the procedure, the patient or the student? Were the risks, including the degree of pain, discussed? Was it made clear to the couple that a student would perform the procedure? Did the patient or her husband give informed consent? Would a well-done, informed consent conversation have blocked the anger? Would the patient and husband have given consent if they knew the balance of risks and benefits gave all the benefit to the students? What is the obligation of a student, or the student’s supervisors, to advise a patient that a student will perform a procedure?

The medical team assumed permission to act in this way toward the patient. Would the medical team behave the same way with any patient, in any condition, in any situation, and with any racial group? There likely would be some variation in behavior with different situations, but can one assume this behavior to be the standard of practice in teaching hospitals? The medical team’s behavior

changed only when they were challenged by an angry protesting family member. This circumstance suggests that they were indeed accustomed to behaving in this way unless confronted. What is happening in the moral formation of developing professionals that they only change their behavior if they are confronted by this kind of anger?

My answer is that medical professionals are being formed to a standard that promotes the unjustifiable use of dominating power that is modified only by anger. The internal mind set of the developing medical professional hears this guiding formula: “To achieve your educational aim, push the patient as far as you can until somebody screams stop.”

Is it morally justifiable for the patient’s husband to demand that the procedure be stopped? Yes. Is it morally justifiable that he had to resort to anger to stop the procedure? No. Therefore the husband’s behavior was morally right and the medical team’s behavior was morally wrong. Neither a patient’s pain nor a husband’s suffering could raise a sympathetic emotion that could change behavior. Only the emotion of anger was sufficient to change behavior. Sensitivity to negative emotion caused the medical team to change its behavior; sensitivity to anger, not sensitivity to suffering. I conclude that the first step in the moral formation of developing professionals is not increasing cultural sensitivity, but rehabilitating a sympathetic response to suffering. □

What Happened to Anna?

This case demonstrates a remarkable dearth of face-to-face communication. It also raises an important question: How is it possible to provide care — especially for patients with life-threatening conditions — without serious communication? Ethical issues are also in play: autonomy and justice as well as respect.

Autonomy is expressed within relationships, and often through an awareness of one’s own sense of power and control. Relatively uneducated,

non-English speaking, middle-aged parents from Latin America may well experience and express autonomy within a context of family and assuming the reliability of those who are in power. A system of beneficent patriarchy may be familiar and acceptable, but must be based on trust. They won't, unlike many in our culture, including me, begin with questions and expectations of shared decision-making with the provider. They are much more likely to put themselves, and Anna, trustingly into the hands of the professionals. They not only want to trust the system – they feel powerless to do anything else.

Anna has previously suffered a very serious cerebral hemorrhage – one requiring three months of ICU care, at a cost of \$600,000. A local social service agency has helped resolve that hospital bill. I suspect that this family doesn't want to cause trouble, doesn't want to be a problem, doesn't want to disrupt the relationship they have with the doctor and hospital.

Putting the best face on it, the providers may be culturally sensitive and aware of the trusting expectations of the family. They may believe that the situation is under control, and that real communication can wait for a "better time," when a translator who is known and trusted by the family may be available. That will be much simpler, less time-consuming, and less expensive than arranging for a translation service. Just by bringing their daughter to the hospital in an emergency condition may constitute consent for treatment. Further, the family and providers have had a successful – though difficult – treatment of the same condition in the past.

But when it becomes clear that death is imminent, there is no excuse for not being present and available with this family. Nonverbal expressions of care, sympathy, and grief, and sharing time and space with the family are vital no matter what language barriers exist. Death is above all a relationship event, and to rely on forms and documentation in the face of death demeans the value of our shared humanity.

What should the institution do? What is the obligation to communicate and how? This family will find communication more helpful if it is oral, and if they can see the face of the person speaking. In their experience, communication is a face-to-face encounter and occurs after some time spent building and acknowledging the relationship of trust and care between the providers and the patient and her family. Communication will be more effective if it comes directly from a trusted, knowledgeable healthcare provider.

Emergency rooms and trauma services need to have a provider available who speaks Spanish (or any other language that is relatively common in their community). This service is not only an issue of respectful care; it is an issue of justice. It violates this patient's basic access to care if no one can speak with the family. Telephone translation services are very useful as supplemental ways to share information, but ought never be the only or primary way that patients and families have access to communication.

An alternative that may be helpful and congruent with a Latino communication style is to have a video that provides basic information and orientation to emergency procedures and information about translation services. The video should be narrated by Spanish-speaking healthcare providers who begin by establishing who they are and what their role is in relationship to this patient and her family.

A healthcare provider should be present while the video is being played to provide a sense of connection and confirmation between the video and the viewers – to reinforce the message that the patient and family can trust that the video is "speaking for" the hands-on providers. Finally, the local Spanish-speaking social service agency could take a more proactive role in helping their clients understand their need for information, reassure them that asking for information won't alienate the powerful healthcare system, and provide assistance with translation in an emergency.

This family in this situation needs the provider's live presence. Written words and documents aren't congruent with the way they communicate, and would be inadequate for any of us. To provide such forms instead of opportunities for verbal, face-to-face, relational conversation is to disrespect the values and expectations of this family, this patient, and everyone who represents or relies on the caring values of healthcare. □

A Promise to Buddha

It continues to amaze me what slow learners we have among us. In this twenty-first century where healthcare providers have initials after their names that stretch for a yard, we are still so slow to consider factors outside our narrow, highly sophisticated ways of knowing. "Disease" is not simply a physiological occurrence because human beings are not simple physical organisms. Everyone in healthcare would answer "No" to the abstract question: Is disease adequately defined as a physiological malfunctioning? Then why, in a face-to-face encounter with Mr. Leu, did they fail so miserably?

Mr. Leu thinks he is not getting well because he has not fulfilled his promise to return to the Buddha. The caseworker must have put some credence into his assertion because she brought travel documents and helped him fill them out. But that was only half her job. The physician failed even more miserably when he called Mr. Leu's statement, "Nonsense" and bade him to "let it go."

Each of us is a complex of body-mind-spirit. Each facet affects the others: mental stress can cause a stomach ache; spiritual desolation can suppress appetite and make it impossible for us to focus on anything else; bodily pain can result in emotional distress. Action follows being, according to any metaphysician that I ever respected, and when one is as complex an entity as we humans are, then our actions are that much more intricately convoluted in cause/effect relationships.

Why isn't Mr. Leu recovering from his renal failure, or if not recovering, why is he so sick? What

is the truth here? And again we must be willing to ask, "...from what perspective?" I don't know if returning to the Buddha in his native Laos will affect his sickness. But I believe Norman Cousins and Richard Bloch when both of them attribute their cancer remission to the healing effects of laughter. Is Mr. Leu any different?

What might be done here? The caseworker could complete her task: she not only brings the travel documents and begins to help him write them, but she also begins discussion with Mr. Leu about locations where he can secure dialysis. And the physician? He or she could suppress the throw-away retort and explore with Mr. Leu the convictions that underlie his promise to the Buddha.

Or, consider the case this way: perhaps Mr. Leu is suffering moral distress, namely, a situation in which his conscience tells him the right thing to do but circumstances make it impossible for him to carry out his conscientious decision. This places Mr. Leu in a moral conflict, and there is no reason why healthcare providers ought to be instruments of the distress. Why are they not enablers preventing the distress instead of throwing up roadblocks to create the distress? What effrontery! □

Too Poor for Privacy?

Over thirty million Americans were counted as officially poor in 2001. Like Susan, these people count for little else. Poor and near poor Americans are routinely overlooked, disregarded, and disrespected. This sad fact is especially true in the health and healthcare arena. A number of health-related factors are linked to low socioeconomic status (SES), including health status, healthcare access, healthcare utilization, and quality of care when it is used. Less advantaged people — whether gauged by income, education, social class, race, or ethnicity — suffer worse health and shorter lives than their more advantaged counterparts.

Over forty million Americans have no health insurance. And, when persons of lower SES do use healthcare, their treatment is of lower quality. It

should sadden but not surprise us that Susan was treated disrespectfully by her care providers. The discrimination she experienced can be interpreted as classism, an “ism” we talk very little about in this country compared to racism and sexism.

The discrimination Susan experienced took at least two forms: (1) the assumption and insistence by staff that her head lice came from somewhere other than the hospital, and (2) the liberty with which staff shared the information with other hospital staff. The assumption that Susan was exposed to head lice somewhere other than the hospital may reflect some unarticulated, unconscious assumption about her personal hygiene.

People living in poverty or at its edge are commonly portrayed figuratively or literally as “dirty.” They live in “squalor” or are “unclean” in their habits of mind and behavior. The ugly epithet “white trash” is searingly clear in its meaning: unworthy of keeping or caring about. Would the staff have dared to suggest to a prosperous woman — well-dressed and well-spoken — that she had gotten head lice in her own home instead of at the hospital? It is unlikely, not only because of the staff’s preconception about the home of such a woman but also because they would be unlikely to speak to her in that manner.

The staff’s nonchalant attitude about Susan’s privacy may also be connected to her lack of status. As someone who does not count for much, staff most likely did not think much about Susan’s privacy, much less the need to protect it. Had they actually considered the consequences of breaching her privacy, calculating the cost-benefit ratio of doing so, Susan would have come out on the losing side of the equation. It is unlikely that Susan would or could seek recourse in an effective or persuasive way.

Susan’s dignity as a person was assaulted and her rights as a patient breached. Respect for persons is not reserved only for those we believe merit it. The value of respect for persons is grounded in our humanity, in the fact that each of us is capable of making meaning in the world, of discovering

and pursuing the good as best we can. Our duty to respect and protect a person’s privacy rests on the back of this value and this understanding of persons. In the context of healthcare, the value of privacy is utmost. It powers the therapeutic relationship between patient and provider by enabling trust to form. Without trust, information and treatment are unlikely to flow freely.

In this case, Susan had no control and was given no choice about intimate health information: she was being treated for another health matter and in the process became infected with head lice. The healthcare professionals shared information about Susan’s condition not on the basis of a need to know but on their desire to tell. □

Section III. — Applying the Tool

Decision-Making Analysis

1. Assessment

- Identify cultural, social, and economic issues relevant to the situation.
- What professional and organizational factors act as facilitators or barriers to resolving the problem?
- What other information needs to be collected about the situation?
- Describe your own personal reaction to the situation.

2 Diagnosis

- Define the problem.
- Who needs to be involved, and what is needed to resolve the problem?
- Can the problem be resolved?

3. Plan of action

- What is your recommended action (at the individual, family, community level)?

- What plan for change within the system should be instituted (professional, agency, society)?
- How do you prioritize these actions?
- Identify the person(s) or groups who will deal with this problem.

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