

Worlds Apart

FACILITATOR'S GUIDE



A Four-Part Series on Cross-Cultural Healthcare

VIDEO MODULES

by Maren Grainger-Monsen, MD, and Julia Haslett,
Stanford University Center for Biomedical Ethics

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by Alexander Green, MD, Joseph Betancourt, MD, MPH,
and J. Emilio Carrillo, MD, MPH

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Worlds Apart

Facilitator's Guide

Background

In 1999, award-winning physician/filmmaker Maren Grainger-Monsen and filmmaker Julia Haslett embarked on a project to develop a documentary film and teaching vignettes that explore culturally diverse patients' and families' experiences with the American health care system. The project, called *Worlds Apart*, was carried out over the next three years with funding from several foundations, and was developed in collaboration with physician experts in the field of cross-cultural medicine. *Worlds Apart* captures many of the conflicts that arise when patients and health care professionals come together with different perspectives on health, illness, and medicine. Similar to the well-known Anne Fadiman book, *The Spirit Catches You and You Fall Down*, these videos aim to shed light on how cross-cultural conflicts arise and how they can affect health decisions and outcomes.

The people and the situations shown here are real. The documentary style of the videos captures live clinical interactions as they happened, as well as interviews with patients, family, and medical staff. They highlight a variety of important and challenging cross-cultural issues in medicine that health care professionals should be aware of and should be competent to manage in a respectful, open-minded manner. The goal of these videos and accompanying facilitator's guide is to give health care professionals an engaging experience

through which to explore ideas about cross-cultural issues in health care and to learn from the actual experiences of both patients and clinicians.

Overview

Worlds Apart tells the stories of four individuals and their families: Mohammad Kochi, Justine Chitsena, Robert Phillips, and Alicia Mercado. Mr. Kochi is a 63-year-old man from Afghanistan who is diagnosed with stomach cancer. He agrees to have surgery, but later refuses his oncologist's recommendation for chemotherapy due to religious beliefs, language barriers, and family conflict. Justine Chitsena, a 4-year-old from Laos, has an atrial septal defect (a hole in the muscle wall of her heart) which her doctors feel should be repaired by surgery. Her mother is considering the operation but her grandmother is opposed. They are part of an ethnic minority in Southeast Asia called the Khmu, and have strong cultural beliefs and traditional healing practices as well as mistrust of Western medicine that give rise to this conflict. Robert Phillips is an African-American man in his mid-thirties who has been on hemodialysis for end-stage renal disease and is hoping for a renal transplant, which will greatly improve his life. He speaks very eloquently and candidly about his experiences with medicine as a bureaucracy and about the racial disparities that he has witnessed and experienced. Alicia Mercado is a 60-year-old Puerto Rican woman living in New York's "Hell's Kitchen" neigh-

borhood, who has struggled with diabetes, hypertension, and asthma for years. The many social problems she faces as a Spanish-speaking woman living alone, and her fears about reliance on medication, put her chronic illness management into a different perspective.

Format

The *Worlds Apart* videos and facilitator's guide are designed to be used as a major component of a teaching curriculum on cross-cultural medicine, racial/ethnic disparities in health care, and diversity. They do not represent a comprehensive curriculum on cross-cultural health care, which might include other components such as cross-cultural communication skills, patient care experiences, simulated patients, cultural awareness exercises, and textbooks or other reading materials. However, the videos do provide a fascinating presentation of the types of issues that are most important in cross-cultural medicine in a moving and powerful format. As such, they are well suited for interactive discussions.

The four videos can serve as powerful educational tools in a variety of settings. They range from 10 to 14 minutes in length and are versatile enough to be used either separately or together. Many educators will opt to use them in specific workshops or courses on cross-cultural health care. Others may integrate them into courses on the physician and patient, ethics, or social and behavioral sciences. One useful approach would be to present the videos in courses or problem-based learning modules on specific organ systems such as the kidney and urinary tract, the heart, and the gastrointestinal tract. In this way the stories and discussions can link the scientific basis of disease with the human and sociocultural aspects of medicine, enriching both perspectives. The facilitator's guide provides information specific to the videos themselves, as well as some more general information about cross-cultural issues in health care. For more detailed information, selected references are provided after each section.

General goals

The overarching goals of these videos, the accompanying materials, and the discussions that follow are for students to:

- Understand that patients and health care professionals often have different perspectives, values, and beliefs about health and illness that can lead to conflict, especially when communication is limited by language and cultural barriers.
- Become familiar with the types of issues and challenges that are particularly important in caring for patients of different cultural backgrounds.
- Think about each patient as an individual, with many different social, cultural, and personal influences, rather than using general stereotypes about cultural groups.
- Understand how discrimination and mistrust affect patients' interaction with physicians and the health care system.
- Develop a greater sense of curiosity, empathy, and respect towards patients who are culturally different, and thus be encouraged to develop better communication and negotiation skills through ongoing instruction.

Suggestions for facilitators

As a facilitator, your role will be to organize and lead an interactive discussion of these videos, to add selected pieces of insight from your own perspective and experience (as well as from the facilitator's guide), and to encourage everyone to participate and contribute. You do not have to be an expert in cross-cultural issues in medicine to be an excellent facilitator for these videos. The stories themselves are full of interesting material and the issues raised lend themselves very well to active discourse. However, it is a good idea to review these issues in advance in the facilitator's guide and think about how best to bring them up in the discussion. The guide presents information that is important to the understanding of the videos and links to key topics in cross-cultural health care. The questions for discussion recommended for each case can serve as guidelines for how to proceed, though discussions will generally follow their own particular course and may not stick to this structure.

- Introduce yourself (name, title, brief experience with the issues of cross-cultural care or other related experience). Describe your role as facilitator.

tor, as above, and the general objectives of the videos if not done previously.

- Establish ground-rules for the group that include listening respectfully to different perspectives without interruption, avoiding monopolization of conversation, and trying to contribute to a constructive and educational discussion.
- Ask students to jot down their ideas about cross-cultural issues and topics for discussion as they are watching the videos. This will allow everyone to be more prepared to participate and will give rise to a more well-rounded discussion.
- Remember that there is a lot of information, opinion, and discussion that can be generated from these videos. Try to get everyone involved and to cover several of the issues raised in the facilitator's guide (covering all of them is probably not feasible). They do not need to follow the specified order, and they can be modified in any way that you see fit in order to highlight key issues. Feel free to go with the flow of conversation and use different questions or prompts accordingly. Note:
 - Quotes from the videos (in italics) have been provided throughout the facilitator's guide. These can be read out loud in order to recall certain issues from the stories.
 - Quotes are followed by some brief comments and then one or two questions to generate discussion about key issues. Several prompts are also provided under these questions for further direction as needed.
 - Important "take-home points" are presented in large, bold face type at the end of each issue. It is helpful to emphasize these points during the discussion in order to clarify the main messages.
- Several minutes prior to the end of the allotted time, bring the conversations to a close in order to summarize the discussion and highlight again the "take-home points" that you feel were most salient.

Mohammad Kochi's story



Brief synopsis

Mohammad Kochi is a 63-year-old man from Afghanistan who came to the United States with his family in 1988. He is a respected elder and leader in his community. When he was diagnosed with gastric cancer he was seen by a surgeon who removed the tumor, which initially led Mr. Kochi and his family to believe that all the cancer was gone and he was cured. His post-operative CT scan showed he had one enlarged lymph node distal to the tumor site. He was sent to Dr. Fisher, an oncologist, to be evaluated for possible chemotherapy and for follow-up care. While Dr. Fisher had told him that there was still some remaining tumor, this was not directly translated by Mr. Kochi's younger daughter (not shown in the video). She withheld this information from Mr. Kochi so that he would remain hopeful and strong-willed, but with his limited English, he was able to understand some of what had been said. The rest of the family was not told that Mr. Kochi still had tumor remaining after the surgery. His older daughter Noorzia (who is shown in the video) was initially unaware that the cancer had not been cured. Dr. Fisher recommended chemotherapy via a continuous pump, but Mr. Kochi refused. Noorzia was not involved in the earlier interactions and decisions. When she decided to accompany her father later and was told of the cancer, she felt that there must have been some miscommunication and that her father should have had chemotherapy. The video shows several segments of clinical interactions, interviews with Mr. Kochi and his daughter, and discussions among the medical staff. These can be used to generate a rich discussion around several important cross-cultural issues in medical care and how medical personnel might best address them.

Medical background information*

A brief discussion of gastric cancer as it pertains to Mr. Kochi and his story will be helpful for the discussion, though not the main focus. Prior to the scenes shown in the video, Mr. Kochi had been suffering from disturbing, chronic abdominal pains and went to see an Afghani family physician in his community. After several failed attempts at treatment, he was sent for an upper endoscopy and diagnosed with gastric cancer, though he wasn't informed of his diagnosis. He was then sent to see the surgeon at a major medical center, who recommended surgery. Interestingly, though the surgeon spoke clearly about his cancer diagnosis, the family members who were serving as interpreters withheld this information from Mr. Kochi. Mr. Kochi agreed to have surgery and the tumor which was found to be locally invasive was removed to the greatest extent possible. His post-operative CT scan showed one enlarged lymph node distal to the original tumor (the technical classification was T3, N1, M0).

Gastric cancer that has only spread locally and involves a small number of lymph nodes can be cured by surgery, but often begins growing back in the same region (presumably due to small numbers of tumor cells that were left behind). Because of the high rate of recurrence, chemotherapy (plus radiation therapy) has been studied. The results of one study in particular have changed the standard of care to include chemoradiotherapy after surgery. The chance of being free of cancer after three years improved from 32% with just surgery to 49% with surgery plus chemoradiotherapy. Previous studies had not been so positive, however, so it is not completely clear that chemotherapy is as beneficial as this study suggests. The fact that Mr. Kochi still had a positive lymph node distal to his original

* Source: www.uptodate.com and Harrison's Principles of Internal Medicine

tumor site made radiation not a viable alternative for him, and it was therefore recommended that he have chemotherapy without radiation. Most oncologists describe all of the side effects and risks of chemotherapy to their patients as well as the potential benefits in order to help patients make decisions for themselves. Mr. Kochi was offered a form of chemotherapy (5-FU) by a continuous pump infusion, which is preferred because it causes significantly fewer side effects while having the same benefits as standard infusion. The study previously cited also used 5-FU, but with much shorter infusion times and without the patient carrying around a pump.

Background on Afghani immigrants in the United States*

Some history of the immigration from Afghanistan to the United States may also be helpful in thinking about this case and its implications. There are approximately 60,000 Afghans in the U.S., with large populations concentrated in the San Francisco Bay Area, followed by Northern Virginia, Los Angeles, New York, Georgia, Oregon, and Texas. Their immigration to the U.S. follows many different trends. Prior to the Soviet invasion of 1979 most Afghani immigrants were relatively well educated people from Kabul. After the Soviet invasion, between 1979 and 1989 many Afghans came to the U.S. as refugees. The first were a wealthy, educated elite, but later, less affluent and less educated Afghans were able to enter through a family reunification program. After 1989, when the Soviets withdrew from the country, factional fighting led to a more educated, professional wave of emigration, but the numbers were small and ceased altogether in 1994. With the rise to power of the Taliban in 1996 many ethnic minorities were persecuted and fled to Pakistan. Those particularly at risk (especially unaccompanied women and children) were allowed to enter the U.S. from Pakistan beginning in 1999. Many of these refugees were victims of violence and torture.

After the 9-11 World Trade Center attack and the

U.S. military invasion of Afghanistan, many Afghans in this country have felt relief at the ousting of the Taliban. This is mixed, however, with some negative feelings towards the attacking of their homeland and fear of discrimination in this country. Some Afghans feel hesitant to divulge their nationality, though this is beginning to change. Afghans are a diverse group, made up of several different ethnicities—most of which in the U.S. are Tajiks or Pashtuns. The great majority is Muslim, following the mainstream Sunni branch of Islam. The languages most commonly spoken are Pashto and Farsi (called Dari). Afghan Farsi is related to Iranian Farsi, but is a different language. The Kochis in this video speak both Farsi and Pashto.

Small group discussion: Questions and information for the facilitator

ISSUE 1

Family decision-making and withholding of information

Noorzia: "So you're basically telling me that my father still has the cancer..."

Mr. Kochi's daughter Noorzia seemed shocked to learn that he still had the cancer. In fact, the cancer had been there all along, even after the surgery, but the family members serving as interpreters had not translated this to Mr. Kochi nor to the rest of the family at home.

How does culture influence the way patients and families discuss medical information and make medical decisions?

- What are some reasons why information might be withheld from a patient by the doctor or the family?
- Is it ever acceptable to withhold information from a patient?

In many cultures it is the norm for the family to make decisions as a unit. They may decide to withhold infor-

* Source: "Afghans in the United States." www.culturalorientation.net

mation about a serious or terminal diagnosis from one member if it is deemed to be in that person's best interest. This is generally done with the idea of protecting patients from the bad news and the emotional distress that comes with it. Additionally, the perception that a terminal diagnosis can lead to a loss of will to live and hastening of death is also well documented in the literature on end-of-life care. This goes against the value of patient autonomy and the right to know which most health care professionals in the U.S. now hold highly (though this was not the case several decades ago). Respecting patient autonomy, however, does not mean that patients must be told their diagnosis and must make their own decisions about care. In fact, patients may waive or relinquish their right to know in favor of allowing a designated individual (a representative of the family, for example) to make decisions on their behalf.

This issue will lead to a rich discussion about values with respect to autonomy and disclosure of information to families versus individual patients. Give participants a chance to explain why they feel the way they do and discuss why others may feel differently. In this case, family members translating for Mr. Kochi withheld his diagnosis from him. After the surgery, when the surgeons stated that they had "gotten it all," the family understood that Mr. Kochi had been cured of his disease. Family members acting as interpreters never relayed to Noorzia and others the subsequent discussions with the physicians.

We often assume patients are autonomous decision-makers, but in some cultures (and in some families) decisions are made in a more unified, family-oriented way. Also, certain members may have more say.

How should doctors communicate with families about medical information?

It is important to establish the way a patient and family prefer to receive information and make medical decisions. When the family functions as more of a unit, it is important to call more family meetings and try to discuss decisions in a group or with certain representa-

tive members in addition to the patient. This is more difficult when the family wants to withhold information from the patient. One way to deal with this situation before it becomes a problem is to ask the patient whether he agrees to have his family make medical decisions for him and to be informed of the results of tests, instead of himself. It is even possible to sign a legal waiver of one's right to medical information.

Assess how patients prefer to make medical decisions—individually, as a family, or through a specific authority figure—and try to accommodate.

ISSUE 2

Effects of immigration and acculturation on family dynamics / beliefs

Dr. Fisher: "His disease is incurable...which means that I don't have a drug that will make it go away forever."

Noorzia: "If he can live one minute longer for us it means a lot to me. I know he's, like, a religious person—he accepts his fate. And I believe if there's a disease there has to be something to either kill it or slow it down."

Noorzia: (later—to her father): "No, I blame myself. I should have come with you from the beginning, and you would have started this treatment six months ago."

Why, in this case, does Noorzia (a relatively young daughter—and a woman in a male dominant culture) seem to play a very important role in medical decisions about her father's care?

- How is Noorzia's perspective on her father's health, and the medical system in general, different than her father's?

This is an opportunity to discuss how immigration can affect families and their interaction with the health care system. Noorzia speaks English fluently and is more acculturated into the Western, American perspective than her parents and other members of the family. Because of this she becomes the spokesperson for her father to the health care team. This can put a great deal of stress on a family. Mr. Kochi becomes

somewhat dependent on his daughter and loses some of his previous authority and power. She has a more aggressive approach to illness and wants everything done to prolong her father's life "even for one minute." Her father seems much more resigned to his fate. He is concerned with his quality of life and does not seem to feel that treatments should be tried unless they have a very high likelihood of benefit with little risk. He is more skeptical of Western medicine.

In Afghanistan Noorzia might have a less important role in the family, while in this country the hierarchy is reversed. There is often a tension in immigrant families between the maintenance of the traditional cultural values and customs and the adopting of a new culture and language.

Even within the same culture, there can be very different values and perspectives on health and illness. Acculturation to a more mainstream perspective is one aspect of this heterogeneity within ethnic groups.

ISSUE 3

Language barriers and communication

Dr. Fisher (interview): "When we first spoke about chemotherapy it was very clear that there would be major translational issues."

Noorzia: "When you were...giving him (those) options, was there a translator there or just my sisters?"

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

The issue of miscommunication due to ineffective interpretation (or no interpretation) comes up several times in this video. At one point, Mr. Kochi's daughter seems very upset that when chemotherapy was initially offered, a professional interpreter may not have been present.

How important are professional interpreters (as opposed to family members or no interpreter) in medical interactions like this?

- Could it have changed the situation in this case?
- Are there any laws requiring the use of an interpreter?
- What problems can arise when family members or others act as interpreters?

Discussion can focus around the value of accurate and unbiased communication via a trained, professional interpreter. In crucial decisions of this type where patients are given information and asked to make decisions about their care, good communication is essential, and high quality interpreters should always be used. Professional interpreters understand the subtleties of language and are trained not to shorten or paraphrase what is said, which can change the meaning (one of the surgeons makes joking reference to this pitfall in the video scene showing a medical conference). It's impossible to know whether or not this would have affected Mr. Kochi's decision, but it is possible that it may have been easier for him to ask questions and understand all of the options and the implications of his decision.

Language barriers can lead to miscommunication and poor health outcomes. Patients with limited English proficiency (LEP) have a right to a professional interpreter.

Using family members or "ad hoc" interpreters can lead to miscommunication due to their lack of training and the complexities of the task. Also, they may bring in their own biases and/or inhibit full disclosure of information by the patient.

Related issue: styles of communication

Why might Mr. Kochi not have explained his rationale for refusing chemotherapy to the physician early on in their discussions?

- What was his style of communication like compared to his youngest daughter's?

Focus on Language Barriers

Title VI of the Civil Rights Act prohibits discrimination against any person on the basis of race, color, or national origin in any program receiving federal assistance. Accordingly, the U.S. Department of Health and Human Services Office for Civil Rights, in a clarification of title VI in 2000, views inadequate interpretation in the health care setting as a form of discrimination. This has set a precedent for the use of interpreter services in hospitals and other human services institutions. However, the reality of having professional interpreters available in the out-patient setting is logistically very challenging and expensive. In practice, both in hospitals and clinics, family members and untrained staff commonly serve as “ad hoc” interpreters, and often no interpreter is available. Several lawsuits have been filed and won based on discrimination against people of limited English proficiency (LEP), especially in cases where it was shown to have led to a poor medical outcome. There are also several studies linking ineffective interpretation to worse medical outcomes.

Family members are generally not trained as interpreters even if they have served in this role many times. So the same pitfalls of using untrained staff or other patients as interpreters arise. Words are missed, subtle meaning is changed, and miscommunication is common. Additionally, family members have their own biases that can lead to distortion of the patient’s words. If they feel they already know what the problem is, they may avoid including important details of the patient’s symptoms. They may try to protect their family member, make him appear more ill in order to make sure he is taken seriously, or less ill for other reasons. They may have different opinions about how the patient should be treated and may influence clinical decisions. All of this may be more or less intentional, or even totally subconscious. The patient himself may avoid saying certain things or change the way they are said because of the family member’s presence. Finally, it can be a tremendous emotional burden on the family member and it is especially inappropriate for a child to assume this level of responsibility.

As previously discussed, the family member interpreting may have led to difficulties with communication. For example, Mr. Kochi mentioned to his daughter that he had always been under the impression that chemotherapy automatically meant “the pump,” and that this was the only option he was given for therapy. He did not seem to question this. This may have been due to an indirect, non-confrontational style of communication by both Kochi and his older daughters. Noorzia seemed to be more direct, likely due to more acculturation to an American style of communication. This is a good place to discuss differences in communication styles in general and how to adapt one’s own style as a clinician to best suit the patient’s. Some people express their pain, other symptoms, and the way these affect their lives very vocally. Others are much more reserved and stoic. It is common in many cultures not to want to show disagreement with a physician or other authority figure as a sign of respect. This can make communication and shared decision-making difficult. It is also possible that Mr. Kochi never really wanted chemotherapy in the first place.

Differences in communication style, which are often culturally based, can lead to barriers to mutual understanding. A non-confrontational patient may be agreeing with the physician just to show respect.

ISSUE 4

Religious beliefs, spirituality, and negotiation

Noorzia: “If he had the thing injected into him...the pump...then that would not, kind of, be right according to the religion. So since my dad is religious, he refused.”

Dr. Fisher (later): “I don’t know how much of it relied on his religion or his background or his sense of logic or sense of health or fear of chemotherapy...or how much may have been a miscommunication and maybe he would have accepted chemotherapy had I been more convincing.”

Mr. Kochi is a very religious, devout Muslim. He is shown praying in the mosque, at home, and even at

the hospital. Strict Muslims are expected to pray five times per day, facing East towards the holy land of Mecca. Muslims must cleanse themselves (called ablutions) before each prayer, and are not allowed to have anything coming into or going out of their bodies during prayer. In discussing the pros and cons of having chemotherapy, Mr. Kochi seems concerned that if the treatment is not a complete cure and causes him other problems like feeling weak, then how does it help him. Dr. Fisher explains his perspective on how it might shrink the tumor and make him feel better. The conversation continues:

Mr. Kochi: "We believe our day has been chosen for us and it cannot be pushed up or forced back."

Dr. Fisher: "Our goal is to help you feel as well as you can feel until that day comes."

How might Mr. Kochi's perspective on spirituality and health affect his decisions about chemotherapy?

- Is what Dr. Fisher said the usual perspective of American medicine?
- Can the two somewhat different views be reconciled?
- What could Dr. Fisher have done to discover this issue early on?
- How might Dr. Fisher have modified his approach if he had some idea of this potential conflict?
- What other reasons might Mr. Kochi—or anyone—have for refusing chemotherapy?

While Mr. Kochi demonstrates a strong spiritual belief in fate, this does not necessarily mean that he won't accept treatment. He agreed to the surgery, for example. The concept of fatalism, having one's course already charted, may also take into account medical interventions as part of that predestined course of events. For example, in Christian faith there is the idea that God works through worldly agents. There are actually two levels of negotiation going on at once in this part of the story. There is the usual type of negotiation about the treatment itself and whether Mr. Kochi feels that

the potential benefits outweigh the risks. There is also a negotiation of views or perspectives on health and illness. Mr. Kochi mentions a spiritual/religious view of life and death that is based on fate. Dr. Fisher tries to describe the medical perspective in a way that takes into account Mr. Kochi's view. He explains that the goal of physicians is to help people to feel better until they die. Unfortunately, chemotherapy may also prolong life while making people feel worse.

Beliefs in fatalism can lead a patient to refuse treatment, but they are rarely absolute. It is important to gain a deeper understanding of the patient's beliefs in order to negotiate acceptable management options.

Discuss the importance of exploring the patient's perspective on his/her illness and treatment. Asking certain questions can help the physician understand what's important for the patient. For example:

- "What concerns you most about the idea of having this chemotherapy?"
- "Are there any side effects that you are particularly concerned about?"

There may be other reasons why Mr. Kochi is hesitant to accept chemotherapy. Is there some function that he feels he needs to carry out for his family or community that would be compromised if he became too weak? Does he believe that the medicine will really make him feel better? Is he worried about the cost? There could be many others.

There are often many options and approaches in medicine. Which one is taken depends on the perspective of both physician and patient. In this case, exploring if Mr. Kochi had any other reasons to reject chemotherapy, other than a belief that "our day is set by God," might have allowed the physician to discover that Mr. Kochi had a religious reason for avoiding the continuous infusion pump. *Cross-cultural negotiation* involves gathering information from the patient and family about their perspectives, expressing your own perspective in clear, understandable terms, and then discussing options to reach an agreement.

There are many reasons why patients may refuse a physician's recommendation. It is crucial to explore the patient's perspective and rationale rather than making assumptions that may not be true.

ISSUE 5

The culture of medicine

Nurse: "So, Mr. Kochi...a 60-year-old fellow with a history of locally advanced gastric cancer. Surgery was September of 2000—had a partial gastrectomy. At that time you met with him...recommended chemo..."

Dr. Fisher: "So he's not the least bit interested in chemotherapy?"

There were several segments that showed Dr. Fisher talking to other physicians and health professionals about Mr. Kochi's case. These scenes highlight the perspective of the biomedical culture and how different this can be from the perspective of the patient.

Discuss the term "biomedical culture."

- What aspects of the biomedical culture did you feel were represented in the video?
- How does the "illness" of gastric cancer (through the eyes of Mr. Kochi and his family) differ from the "disease?"

Discuss how an individual's cultural influences are broader than just his or her ethnicity, nationality, or religion. Profession can be a major source of cultural influence, which can help to shape beliefs, values, and behaviors. In this case, the culture of medicine shapes how physicians and other health professionals talk and think about patients and their diseases.

The medical presentation of Mohammad Kochi's case gives some idea of what's important from a disease perspective, whereas the complex family dynamics, hope, disappointment, frustration, pain, loss of control, etc., describe the illness. Biomedicine tends to focus more on the dysfunction of the body as a machine and emphasizes finding the problem and fixing it. With cancer, it is often difficult for the medical profession to accept defeat, and chemotherapy is often tried even when it is unlikely to be of much benefit. The physician, in this respect, is less aggressive than many oncologists might have been. He leaves the decision more to Mr. Kochi and his family rather than emphasizing treatment as the best option.

Culture goes beyond ethnicity or nationality and is influenced strongly by profession, age, religion, and many other factors. Medicine has a definite culture of its own, with its own values, beliefs, language, and customs.

References

1. Carrillo JE, Green AR, Betancourt JR. Cross-Cultural Primary Care: A Patient-Based Approach. *Annals of Internal Medicine* 1999;130:829-834.
2. Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Annals of Internal Medicine* 2000;132:578-583.
3. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "you got to go where he lives." *JAMA* 2001;286:2993-3001.
4. Crawley LM, Marshall PA, Lo B, Koenig BA. Strategies for culturally effective end-of-life care. *Annals of Internal Medicine* 2002;136:673-679.

Justine Chitsena's story



Brief synopsis

Justine Chitsena was born by emergent cesarean section with alpha thalassemia major. While this is normally a fatal condition, she was kept alive by monthly exchange transfusions. At two months of age she was found to have an atrial septal defect (ASD), a hole in the wall that separates the two atrial chambers of the heart. If left unrepaired, this would have complicated and lessened her chances of surviving a bone marrow transplantation for thalassemia.

Justine's grandmother was opposed to both the bone marrow transplant and the ASD repair. Boupheet Chitsena, Justine's mother, took it upon herself to proceed with the transplant, but refused the ASD repair due to fears about the scar and the effect it would have on Justine's spirit in her next lives. The transplant, performed when Justine was two years old, was successful. Two years later, the doctors again began discussing the issue of an ASD repair. Justine's mother still had reservations about this, and her grandmother was strongly opposed. The decision was made increasingly hard for Boupheet Chitsena because she felt her mother and the rest of her family would blame her if anything went wrong with Justine. After several visits and discussions, it was agreed that the family would try their own ways of healing the hole in Justine's heart. They performed ceremonies at home and took her to a Buddhist temple for a special ritual and traditional medicine, but the hole remained open. Finally, a compromise was reached using a new catheter-based technology that allows the atrial septum to be repaired without an invasive, scar-producing operation. It was successful and Justine is doing well.

Medical background information*

A brief discussion of atrial septal defects with respect to Justine Chitsena's case will be helpful for the discussion, though not the main focus. Atrial septal defect is a relatively common congenital heart condition that is rarely symptomatic until adulthood. An opening in the atrial septal wall allows blood to flow from the left to right atrial chamber where the pressure is lower, leading to an increase in the work of the right ventricle and increased flow through the pulmonary system. The defects close spontaneously by one year of age in about 87% of cases—smaller defects being more likely to close. After the first few years of life (as in Justine's case), only a few percent will close without intervention. While there is no urgency in closing a defect from a clinical standpoint, if it grows too large it will no longer be amenable to a catheter-based (minimally invasive) procedure. Still, successful operations are commonly performed in adults. There is a risk, however, that permanent damage will be done, especially if the patient has not been followed closely. The likelihood of developing moderate to severe pulmonary hypertension and right ventricular hypertrophy is rare, though—less than 10%. While it is hard to give patients exact numbers, the risks of surgery are small, and the standard of care has become early intervention.

Background on Khmu/Lao immigrants in the United States*

The Khmu are the indigenous people of Northern Laos. They are the largest ethnic minority in that country with 450,000 inhabitants (about 43,000 were living in northern Vietnam and about 8,000 in the United States as of 1995). They are mostly agriculturalists and speak their own language, Khmu, which has

* Source: www.uptodate.com and Nelson Textbook of Pediatrics: 16th Edition

* Source: "People Groups: Khmu." www.infomekong.com

many dialects and no established written form. Many Khmu are well acculturated into the Laotian mainstream, both in language, custom, and Buddhist religion. Many Khmu maintain their traditional beliefs and language alongside their Laotian ones. The Chitsenas speak Lao and Khmu and Thai and go to a Buddhist temple, but Justine's grandmother holds on to many of the traditional Khmu ways. The tradition of tying a string around the wrist to prevent the loss of the spirit is a common practice among many peoples of South-east Asia. Calling upon the spirits of the ancestors is also common, but the manner in which it is performed is culturally specific. Another practice common among the Khmu and other ethnic minorities within the South-east Asian mainstream cultures (such as the Hmong) is animal sacrifice. Again, this depends on the degree of acculturation both in the country of origin (Laos in this case) or to the American mainstream.

Small group discussion: Questions and information for the facilitator

ISSUE 1

Understanding the family's health and illness beliefs

Grandmother: "The doctors say she is sick, but she looks completely healthy to me...(later)...If you have a mark on your body, whether from a pen or charcoal, or a scar from surgery, it stays with you into the next life, and damages you."

Justine's grandmother voices her own strongly held perspective on Justine's illness and on the consequences that an operation would have in her view. Justine's mother, Boupheet Chitsena, seems caught between believing in what her mother says and believing the physicians' perspective.

What are the grandmother's beliefs about the illness itself and the surgery?

- How do they differ from the medical perspective?
- What is Boupheet Chitsena's perspective, and how is it different than both of the others?

This is an opportunity to discuss patients' (and families') "explanatory models" of illness and treatment (see box,

page 15). These are essentially their health beliefs and the meaning that a particular illness or treatment has for them.

In the case of Justine's grandmother, she feels that Justine is healthy. She looks well and acts completely normally. It is difficult for individuals who have not grown up being exposed to medical technology and preventive medicine to conceptualize an illness that cannot be seen or felt and has no obvious symptoms. In the United States, the public generally hears about and witnesses the ability of medicine to cure disease and relieve symptoms—to the point that it is almost taken for granted. Still, even here, the management of "silent diseases" like hypertension is challenging due to the fact that patients feel well. Justine's grandmother is very skeptical that anything is wrong with her. Even more importantly, it is her belief that the surgery carries consequences that go far beyond those considered by her physicians. She believes that when the body is damaged, the scars are carried with the individual into all of their future lives. "The scars," for her, carry a much deeper negative meaning than for her doctors. Besides this, she is plainly afraid that Justine may die needlessly, since she is currently healthy.

Boupheet Chitsena seems to agree with her mother to some degree. But she has also acculturated somewhat (though less than Noorzia in the previous video) to a Western/American perspective on illness. She wants the best for her daughter, and has some faith in the American medical system and the well-meaning doctors who have been helping her. She has had to fight against her mother's wishes in order to even continue discussions about the operation. She also seems afraid of the operation herself, and does not want to put her daughter through such a violent-sounding procedure—cutting her chest open.

Patients and families' beliefs about illness and medical procedures can have a major impact on their health care decisions. Exploring beliefs carefully and respectfully is crucial in cross-cultural interactions.

Beliefs, values, and concerns about health and illness are often culturally based, but can

vary greatly within cultural groups (and within families). They may be influenced by acculturation and generational differences.

Bouphet Chitsena: “My Mom, she’s afraid that if you cut you’ll see the scar. My Mom wants me to wait to go to the Lao temple. They have some medicine for her, and she wants to wait for that (...laugh).”

Bouphet Chitsena initially seems reluctant and somewhat uncomfortable discussing her mother’s beliefs, especially since they are so foreign to the doctors. When a patient refuses a recommendation, there is an opportunity to understand the reasons behind her/his different perspective.

How would you explore Bouphet Chitsena’s (or her mother’s) beliefs and perspectives about the atrial septal defect and the operation?

- What questions would you ask?
- How would you have known that it was her mother’s beliefs that were responsible for the initial refusal of surgery?

Discuss the importance of exploring the patient’s explanatory model of illness and treatment. Asking questions like “What do you believe is the problem with Justine’s heart?” and “What are you most concerned about with this operation?” can help the physician understand what’s important for the patient.

ISSUE 2

Family decision-making and authority figures

Bouphet Chitsena: “It was my own decision. My family was against me. They accused me of trying to kill my child. I realized that I would be the one in the hospital with Justine if anything happened. If anything went wrong it would be my responsibility.”

While Justine’s mother is her primary caretaker, and the one interacting with the medical staff, her grandmother clearly plays an important role.

How does the decision-making happen in this family (vs. most American families)?

- What is Justine’s grandmother’s role?
- What is her mother’s role?

Focus on Explanatory Models

Roughly speaking, a patient’s explanatory model is her/his perspective and specific beliefs about her/his illness and its treatment. There are several general questions or areas of inquiry (as modified from Kleinman, et al.) that are useful in trying to understand a patient’s explanatory model. Health care providers should become comfortable with these types of questions and should develop their own which work well for them.

Explanatory Model Questions

- What do you think has caused your problem?
- What do you call it?
- Why do you think it started when it did?
- How does it affect your life?
- How severe is it? What worries you the most?
- What kind of treatment do you think would work?

If patients seem reluctant to discuss their beliefs, it can be helpful to use normalizing statements to make them feel more comfortable. For example, “Many people feel that if a person doesn’t feel sick then there can’t be anything wrong with them. Do you feel that way?” Also, it is important for health care practitioners to realize that it might be someone else’s beliefs that are causing a patient or family member to act in a certain way (e.g., Bouphet refusing the operation due to her mother’s beliefs). Asking questions about that person’s perspective or involving him or her directly in the discussion can be very helpful.

- How would you explore this issue and deal with it in a clinical encounter like this?

Decision-making and the role of the family is an important cross-cultural issue. In medicine we often assume that patients are autonomous decision-makers and that family members play a more peripheral role. In many cultures, however, the family makes decisions in a more unified way. Certain members of the family may have more say in decisions based on hierarchy of gender, age, birth order, etc.

In this case, Justine’s grandmother has a great deal of influence in the family and acts as a behind-the-scenes authority figure. She maintains the traditional and spiritual beliefs of her Khmu ethnicity, though

she is now living in the United States. When Boupheet Chitsena chose to go against her own mother's wishes and advice, she was breaking cultural tradition and significantly strained her relations with her family. In many American families, the decision-making would be left more to the child's mother alone. The value of the family over the individual is reflected in the case of Mr. Kochi as well. It is a core cross-cultural issue that characterizes many cultures, and emphasizes how different the Western European/American values are from much of the rest of the world.

Physicians should ask how families prefer to make decisions, and who is important to consult in these situations. When feasible, family meetings can be arranged or key authority figures in the family, like Justine's grandmother, can be involved in discussions and decisions. Families will often work out their own arrangements and internal dynamics, but medical professionals should be aware of this and should facilitate it whenever possible and appropriate. In this case, Boupheet Chitsena often acted as the intermediary, expressing her mother's concerns and relaying information from the physicians.

Assess how patients prefer to make medical decisions—individually, as a family, or through a specific authority figure—and try to accommodate.

ISSUE 3

Traditional / alternative medical practices

Boupheet Chitsena: "In the string tying ceremony, we tie the string so that the spirit of the child stays with her family."

Grandmother: "The ceremony is for everyone. For the family, for the ancestors, and for the doctors. The ceremony allows the miracle to happen."

Justine's grandmother and others in her family have very different ideas about how she should be treated. Besides feeling that the surgery will have terrible consequences for her, they believe in spiritual healing rituals calling on the spirits of ancestors, both at home and at a Buddhist temple. In a large U.S. survey, 42% of Americans used at least one type of alternative therapy

not prescribed by a physician. More than 60% of these had not discussed their use with a physician.

What are your views on the use of complementary/alternative medicine in general, and in this case specifically?

- Why is it important to know about these practices?
- How do you approach patients about them?

In discussing these issues, it is important to make sure that the students put them into context. While the family in this video seems to believe in traditions that are very strange from the standpoint of what most Americans believe, they are not altogether that different. Alternative practices in this country range from herbal medicines to home remedies, acupuncture, energy healing, homeopathy, massage, and prayer. People turn to forms of therapy that fit their models of how health and illness work and that support their values. Explore students' perspectives on this and try to engage them in an active debate about the relative merits of and problems with these practices. The placebo aspect of these therapies and what this means can be a useful starting point.

Issues to consider with alternative therapies:

- Some may have beneficial effects for patients, whether proven (true in some cases) or subjective.
- Trust can be built by being open to patients' ideas about these.
- Some alternative therapies may be dangerous, either due to their direct side effects or interactions with other medications that the patient takes.
- Patients may avoid using potentially more effective medical treatment due to their use of alternative practices.
- Being judgmental about alternative therapies contributes to patients not revealing their use.

As part of the standard medical history, ask all patients about complementary and alternative practices (including home remedies) that they may be using. Be non-judgmental and respectful of their views and negotiate a plan accordingly.

ISSUE 4

Cross-cultural negotiation

Bouphet Chitsena: “They say that if we take the medicine, the hole will close.”

Doctor: “Traditional healing, yeah...uh huh.”

Bouphet Chitsena: “And I want to try everything, to see if it works or not.”

Doctor: “OK. And then after that, give it some time to work, OK? (laughter), OK...and then we can check again. And there are some holes that can close. And certainly we have a lot of children whose holes have closed without surgery. From our standpoint, we don't see a lot of them close at this age...after a year or two of age. But I think if that's something that makes everyone feel like they've done everything short of an operation to help her, then I think that's appropriate.”

Negotiation is one of the most important skills in dealing with all patients, but especially across cultures when differences in perspective can be greater and communication can be challenging. Physicians often don't feel they should have to negotiate with patients since the medical perspective is based on science and “truth.” But the truth for patients may be different.

What was your impression of negotiation that took place between the family and the medical staff?

- What did you think was appropriate/effective in the staff's approach?
- What would you have done differently?

It is important here to focus the discussion on the negotiation process itself. Negotiations took place in discussing the family's requests to try various traditional forms of treatment, rather than insisting on surgery right away. Also, there was a negotiation that took place in offering a less invasive approach to correcting the atrial septal defect, even though this meant going to another hospital.

Fortunately, in this case the physicians had the luxury of time, as there was no pressing need to proceed with an operation immediately. This allowed them to give Justine's family the opportunity to try several traditional ways of healing her, including the ceremony

at home and the one at the Buddhist temple. Also, while early intervention is clearly the standard of care, the data are not absolutely black-and-white, thus leaving some room for negotiation. The cardiologist listens to Bouphet Chitsena's perspective on this and is willing to let her try the ceremony. But she also seems somewhat uncomfortable about condoning it, which is apparent in her nervous laughter. Still, she does an excellent job of explaining and negotiating. Overall, there is a sense of partnership throughout the interaction, not antagonism. If she were less flexible, trying to push her ideas on the family, they may not have come back and may not have received the procedure.

Another aspect of the negotiation had to do with the catheter-based (minimally invasive) procedure. Knowing that one of the main concerns was the extent of the surgical scar, and all that this meant, the physicians realized that a minimally invasive procedure would be more acceptable to the family. This was something that had recently become approved for use. Since it left only a tiny scar, it would not damage Justine into her next life, and was a crucial step in their eventual acceptance of the procedure. Again, having a deep understanding of what's important to the patient and family can lead to a more successful negotiation.

Negotiation involves understanding the patient/family's perspective, explaining your perspective, being flexible, and coming up with creative ways to meet their needs while aiming for the best possible outcomes.

ISSUE 5

Barriers to effective communication

Doctor: (to Bouphet Chitsena without interpreter): “The reason that we like to take care of these is mainly a long-term consideration that, over many years, having chronic enlargement of the heart can lead to weakness of the heart. And sometimes people can have what we call heart failure. At that point you can't really fix it.”

Communication between doctor and patient is challenging even without language barriers. Bouphet Chitsena speaks English, but it is not her first language and she is not fluent.

What did you think about the communication that happened in the conversation above and throughout this video?

- How could the cardiologist's explanation have been simplified so that Bouphet Chitsena could have understood it better?

Focus on informed consent

Informed consent is based on patients having the right to know all of the risks and potential benefits of a procedure or operation before agreeing to it. In many countries, medicine is more paternalistic, and rarely gives patients this right. While it is designed to protect patients (and the medical system from lawsuits), it can be overwhelming for a patient to hear that he or she may have complications of things like bleeding, infection, and death. Often probabilities and percentages are hard for patients to understand (and in some cases, not available).

The manner in which informed consent discussions are carried out is hardly standardized and often a matter of individual physicians' styles of practice. Still, certain elements must be included, such as the major risks and benefits in clear terms. A discussion of whether or not the physician could have taken the edge off this conversation by explaining that the procedure is generally very safe, and most of these complications are extremely rare, will depend to a large extent on your perspective as the facilitator and the perspectives of the students.

The medical profession has a strong cultural influence, which can help to shape beliefs, values, and behaviors. In this case, the medical culture, like American culture overall, places a high value on autonomy and individual rights. There is also a value of legal protection and the right to sue if one's rights are violated. Informed consent is a product of these values that patients may find strange when not accustomed to it. Also, biomedicine tends to focus more on the dysfunction of the body as a machine and emphasizes finding the problem and fixing it. The physician's description of the catheter-based repair of the atrial septal defect is a good example of this perspective that it is better to do something than do nothing.

- When is it important to use a professional interpreter?
- Are there any laws requiring the use of an interpreter?

Physicians tend to use medical jargon and other complex terminology when dealing with patients. This can both alienate patients and lead to miscommunication. It is important for students to pay careful attention to the way they communicate with patients, simplifying their explanations and using common sense terminology and phrasing. A discussion could focus around how to rephrase the cardiologist's explanation to make it more understandable. For example, "If the hole is not fixed, Justine's heart will have to work much harder. When Justine gets older her heart will be weak. She could get very sick, and it will be too late to fix it." Terms like "long-term consideration" and "chronic enlargement" should be avoided. Even for patients who speak some English, if it is not their native language and they are not fluent, an interpreter may be necessary. This is especially true when dealing with crucial explanations and decisions, as in this case. Even with an interpreter, it is important to use straightforward, common sense language that is more easily understood by both the patient and the interpreter. The previous discussion of Mohammad Kochi's story deals with the issues of interpretation in more detail.

References:

1. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine* 1978;88: 251-258.
2. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA* 1995;274:820-825.
3. Carrasquillo O, Orav EJ, Brennan TA, Burstin HR. Impact of language barriers on patient satisfaction in an emergency department. *Journal of General Internal Medicine* 1999;14:82-87.

Robert Phillips' story



Brief synopsis

Robert Phillips is a 29-year-old African-American man who eloquently recounts his experience as an end-stage renal patient on hemodialysis. He developed renal failure due to focal sclerosis and after five months on dialysis he was put on the waiting list for a renal transplant. At the time of this filming he had been on the list for almost three years. He begins by describing his encounters with the health care system, and although he commends the nursing and technical staff for their services he is disappointed in the quality of physician involvement in his care. Many of his concerns revolve around the lack of supportiveness of physicians in general and of accessibility of renal transplants, particularly for African-Americans. When asked about some of the reasons for this, he attributes it to physicians not readily referring African-American patients for transplantation. He feels that he had to push his own nephrologist into giving him options besides dialysis. In his view, physicians tend to stereotype African-American dialysis patients as being less worthy of receiving kidney transplants since they're "just going to ruin it anyway."

Medical background information*

A brief discussion of end-stage renal disease, hemodialysis, and renal transplants with respect to Robert Phillips' case will be helpful for the discussion, though not the main focus. End-stage renal disease (ESRD) is the term used to describe a state of severe, permanent kidney failure generally requiring either dialysis or renal transplantation. It can be of many causes including diabetes, hypertension, glomerulonephritis, and polycystic kidney disease, among others. There are

over 300,000 patients with ESRD in the U.S., many of whom are maintained on dialysis to replace the function of their kidneys—filtering the blood and maintaining the levels of various electrolytes such as sodium, potassium, and chloride. Hemodialysis, the most common form, involves a catheter inserted into an enlarged blood vessel (fistula) in the arm, which diverts arterial blood through a filtration device and back into circulation. This generally requires the patient to sit in a chair, connected to the dialysis machine, for several hours a day, three days a week. The hemodialysis itself can cause a drop in blood pressure, nausea, headaches, and dizziness, among other side effects. Over the long term, the patients suffer from more chronic problems such as severe hypertension, bone weakness, anemia, and early heart disease.

The option of renal transplantation has become an excellent one for many ESRD patients, and tens of thousands have been performed worldwide. Still, the demand for donor kidneys far exceeds the supply. Transplantation, when successful, can restore most patients to a near-normal lifestyle. Many factors affect kidney survival, including strict adherence to the immunosuppressive regimen and control of other chronic diseases. There are two major sources of donor kidneys: HLA matched relatives that are willing to donate, and cadavers whose organs have been harvested through a nationally coordinated network. Advances in immunosuppressive medication, among other factors, have improved the survival of the transplanted kidneys to 13.8 years for cadaveric donor kidneys, and 21.6 years for related donor kidneys. African-Americans are much less likely than whites to receive renal transplants. Studies have shown that they are referred less frequently for renal transplantation. Once referred,

* Source: www.uptodate.com and Harrison's Principles of Internal Medicine, 15th edition

they wait longer on renal transplant lists, in part due to having fewer HLA matches with cadaveric donor kidneys. Interestingly, recent data have shown that while matching 6 out of 6 HLA antigens is clearly superior to fewer matched antigens, the survival rates for less than perfect matches are not significantly different from each other. This has prompted changes in the transplantation policy that should reduce the disparities.

Background on African-Americans and health care disparities in the United States*

The history of African-Americans in the United States, from slavery to the present, is one of discrimination and segregation in virtually all sectors of society. In the 1800s, pseudo-scientific theories about race and the physical and mental inferiority of blacks attempted to legitimize this discrimination in a country that preached democracy and the rights of individuals. After the Civil War and emancipation, the U.S. government established the “Freedman’s Bureau” to provide assistance to former slaves, including the development of racially segregated hospitals. Segregation persisted for nearly a century under the legal protection of “Jim Crow” laws. The 1960s saw an end to legalized segregation, the passage of federal civil rights legislation, and the creation of Medicare and Medicaid. This brought about the desegregation of hospitals and healthcare systems in this country. Progress in improving African-American health in the U.S. seemed to be on the horizon, when the revelation of medical experimentation (a long-standing issue dating back to slavery) reemerged in the 1970s with an expose of the Tuskegee Syphilis Study. This study, funded by the U.S. government, was designed to follow the natural history and progression of syphilis

in humans. African-Americans with this disease served as the “control group” and did not receive treatment, even after penicillin had become available and was known to be effective. This further contributed to mistrust of the healthcare system by African-Americans.

Obviously, this has taken a severe toll on African-American health and perspectives on health care. Despite advances in medicine that have improved the health of the majority of Americans over the last fifty years, African-Americans have benefited much less from this progress. African-Americans suffer disproportionately from chronic, treatable conditions such as cardiovascular disease, diabetes, cancer, HIV/AIDS, and asthma, just to name a few—all culminating in a lower life expectancy. These “racial and ethnic disparities in health” are in part due to many of the usual suspects in our society—poor education, poverty, and persistent discrimination—that unfortunately plague many Americans, particularly African-Americans. But perhaps even more disturbing is what has more recently been learned about racial and ethnic disparities in the delivery of health care. A 2002 Institute of Medicine Study entitled “Unequal Treatment” found overwhelming evidence that patients were being treated differently by the health care system, based on their race and ethnicity. African-Americans and other minorities, with the same insurance and socioeconomic status as white patients, receive poorer, lower quality care for heart disease, cancer, diabetes, kidney failure, pain management, and the treatment of HIV/AIDS, just to name a few. As the nation struggles with how to deal with these glaring disparities, African-Americans struggle with their own health issues within a health care system that has continued to validate their fears and mistrust.

* Sources:

- “Unequal Treatment.” The Institute of Medicine 2002 (www.nap.org)
- Byrd WM, Clayton LA. *An American Health Dilemma. A Medical History of African Americans and the Problem of Race*. New York, NY: Routledge; 2000.

Small group discussion: Questions and information for the facilitator

ISSUE 1

Disease and illness

Robert Phillips: "I've had to curb my ambition...things I won't get to do...Imagine yourself sitting in that chair for four hours and there're parts of your body you can't move, and then you get uncomfortable towards the end of that four hours. Things start to happen to you that you can't explain, but you still can't get up. You still have to stay there...And, you know, at some point if something goes wrong, you may not make it."

"I just wish medicine weren't such a bureaucracy. I just wish it felt a little more personal."

Robert Phillips gives a very detailed, personal account of what it's like to have end-stage renal disease and be on dialysis. It involves daily inconveniences, discomfort, fear, and changes in his life's goals.

What do end-stage renal disease, dialysis, and renal transplantation mean for Robert Phillips and how are these meanings likely to be different for health care professionals?

- What is the distinction between "disease" and "illness?"
- How should physicians deal with each of these?

Discuss *disease* as the medical perspective on sickness—the dysfunction of organ systems, the physical signs, expected symptoms, prognosis, etc.—basically, everything that you read in a medical textbook. *Illness*, on the other hand, is the patient's experience of being sick. Robert Phillips describes the illness of end-stage renal disease and what it's like to live with it day to day.

The background section for this case describes the disease. The perspectives are very different. Medical education primarily focuses on the learning about disease, and this is often perceived to be the most important aspect of a clinician's role. But if you ask patients, this is only part of what is important to them. They value health care professionals who listen to them, understand their perspective, explain things to them, and treat them as individuals. Essentially, they

value clinicians who understand the illness as they do. The way patients understand and experience an illness is, to a large extent, culturally determined. This video illustrates that Robert Phillips' illness is personal and also influenced by his experience as an African-American.

Health care professionals should try to understand how the patient is experiencing the illness (including cultural factors) in addition to understanding the disease.

ISSUE 2

Discrimination and racial / ethnic disparities in care

"Most of the white patients here either have had transplants or are going to have transplants. Most of the African-American patients here aren't...they're kind of in it for the long haul. Now I know there's research to back that up, a lot of quantitative research to back that up, but anecdotally it just seems like there's a big disparity...a big, big disparity."

The topic of racial and ethnic differences (disparities) in the delivery of health care services has received a great deal of attention in the last several years. Renal transplantation has been one of the areas studied.

Why might African-Americans have to wait longer for renal transplants, and be less likely to receive them overall than whites?

- What research is Robert Phillips referring to?
- For what conditions or procedures have racial/ethnic disparities been documented?
- How could this affect a patient's (such as Robert Phillips') attitude toward doctors and the medical system?
- What could be done to improve health care delivery to racial/ethnic minorities?

This is an opportunity to discuss the issue of racial/ethnic disparities in health care and procedures such as renal transplantation, as well as Robert Phillips' personal experiences. Since this may lead to a heated and challenging discussion, it is particularly important to review the facts about disparities. It would be helpful

to read the article by Ayanian, et al., which shows that African-Americans are less likely to be referred for renal transplantation than whites. There are several possible reasons for these disparities seen that should be discussed:

1) It is often assumed that African-American patients may be less likely to want renal transplantation. While the Ayanian study (among others) shows that there was a small difference in preference, it did not explain the magnitude of the difference in referral for transplantation.

2) Another reason could be physician bias, either conscious or unconscious. While this is a sensitive subject, numerous studies suggest that patient characteristics such as race/ethnicity and socioeconomic status do

affect the way physicians perceive patients and make clinical decisions. This will be discussed more with the next issue on stereotypes.

3) There may be barriers to communication or to the doctor-patient relationship that could affect the decision to refer a patient for transplantation.

4) Finally, the organ transplantation system has been set up to favor giving organs to patients who have a higher number of HLA matches. This results in African-American patients waiting a substantially longer time for organs than white patients due to a lower rate of matches (though this should not affect physician referral patterns). While there is evidence that a complete HLA match (all 6 of 6 HLA matched) has a higher success of organ transplantation, it has

Focus on Racial/Ethnic Disparities in Health Care

Research has uncovered striking disparities in the health care of minority patients relative to whites. The most compelling data focus on African-American patients, but a growing body of work is documenting a similar pattern of lower quality health care for Latinos and other minorities as well as non-English speaking patients. A major review of these disparities entitled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” was undertaken by the Institute of Medicine and released in 2002. The committee for this extensive, high-profile project was comprised of both experts in the area of disparities and also well-respected physicians with no previous research interest in this area of study who were brought in to provide a critical perspective and to assure an unbiased report.

The final report documented that “Evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services” (IOM summary p 4). Studies show that, even when accounting for socioeconomic status and insurance, minorities are less likely than whites to:

- receive appropriate cardiac medications for coronary artery disease
- undergo cardiac catheterization
- undergo bypass surgery
- receive hemodialysis for renal failure
- be referred for renal transplantation once on dialysis

- receive pain medication for long bone fractures in the ER
- receive antiretroviral therapy for HIV
- undergo curative surgery for lung cancer

There have also been disparities found in cancer screening, pediatric care, mental health, and general medical services, among many others. Many of these disparities in care are directly linked to poorer health outcomes. Most take into account factors like insurance, income, age, and symptom expression.

The emphasis in research has shifted from documenting that disparities exist to developing strategies to eliminate them. “Cultural competence” of health care providers, facilities, and the medical system itself has been proposed as one step toward eliminating disparities. Cultural competence has been defined by Lavizzo-Mourey and Mackenzie as a health care system that “acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs.” Educational efforts for students and residents is one example. Others include legislation, research on root causes of disparities, patient education and empowerment, standardization of care, and public health efforts. Allow the students to discuss specific ideas themselves.

not been shown that a higher degree of partial match is beneficial (i.e., 5/6 HLA matches has not been proved to be better than 3/6 HLA matches, etc.). Because of this, several organ transplantation systems are now in the process of changing their criteria.

Racial/ethnic disparities have been well documented for all types of health care services. Focus has shifted toward understanding the root causes and developing effective interventions. Cultural competence (defined broadly) is seen as one important intervention.

ISSUE 3

Stereotyping and clinical decision-making

“There is this perception that an African-American man with hypertension and diabetes is just going to ruin it anyway...which is nonsense...nonsense.” (referring to the transplanted kidney)

Whether we know it or not, we are forming stereotypes about people we meet and patients we take care of—based on race, language, style of dress, personality, etc.—all the time. It is a normal cognitive process to use limited information to make quick judgments and predictions about others. It becomes a problem when those predictions are unsubstantiated and are allowed to affect the way we interact with and make medical decisions about patients.

Discuss the stereotype that Robert Phillips is referring to and its potential effect.

- How might this stereotype affect a physician's medical decision to refer a patient for a transplant?
- What would it be like to be on the other end of a negative stereotype like this?

Robert Phillips is describing the stereotype that as an African-American man, he will not take care of himself or manage his chronic medical conditions adequately, and this will cause his new kidney to fail. He feels that, rather than realizing that he is a very motivated and health-conscious individual, his doctors are lumping

him together with “other African-Americans” whom they stereotype as “non-compliant.” The application of stereotypes is oftentimes automatic, and most likely to be based on race, gender, and age.

It is thought that given the daily information overload in the clinical setting (identification of patient signs and symptoms, knowledge of pathophysiology, choice of diagnostic and therapeutic modalities, etc.), there is an attempt to conserve cognitive resources by using stereotypes to help simplify the volume of information to which we are exposed. The inherent danger in following this process is that providers apply inappropriate group beliefs to individual patients. Perhaps the most fascinating and relevant fact about stereotypes is that individuals tend to activate them the most when stressed, multitasking, and under time pressures...the hallmarks of the environment of daily medical practice.

Discuss the students' own experiences of being stereotyped or how they imagine it would feel (this is a good opportunity for culturally diverse students to teach their colleagues about the realities of prejudice).

Stereotyping is a normal cognitive process that can negatively affect clinical decision-making. Physicians should be careful of the stereotypes they may subconsciously hold, and avoid acting on false assumptions, especially about race, ethnicity, religion, gender, sexual orientation, etc.

ISSUE 4

Mistrust and communication style

“So in the African-American community, you know, Tuskegee is a big part of our experience...particularly for a generation of African-Americans, (it) has colored their behavior when it comes to medicine, right? And that generation just implicitly doesn't trust doctors.”

“So when I first got diagnosed and we started talking about options, he didn't really offer a lot...so I prodded him into what the options could be...”

The U.S. Public Health Service Study in Tuskegee, Alabama of untreated syphilis was discussed briefly in

the background to this story. While this study was not the sole cause of many African-Americans' mistrust of science and medicine, it certainly gave credence to it. Personal experiences of discrimination, disrespect, and stereotyping, as well as documented racial/ethnic disparities in health care, also contribute to mistrust of physicians and the health care system, with good reason.

What are your overall impressions about the issue of patient mistrust of physicians and medicine in general?

- What are the different ways you might expect patients to act when they are mistrustful?
- In what ways could mistrust affect the ability of patients to get good health care?
- How apparent (to the physician) is this mistrust when it is present?

The way patients express their mistrust depends to a large degree on their style of communication. Robert Phillips has a very direct style of communication. People who are more direct may express their mistrust more openly, or even confrontationally. It is important for physicians to avoid taking this personally and to try and build trust and reassure patients of their good intentions.

Mistrustful patients may question the options being offered or the decisions that have been made about their care. When their style of communication is indirect or non-confrontational, they may agree with the physician but then not follow up with treatment plans that they were skeptical about, or simply not come back. They may offer subtle clues that they are mistrustful, like mentioning a negative experience that a relative had with medical care, or the fact that they try to avoid coming to the doctor. It is important to explore these issues further with all patients, but especially when their style of communication is indirect.

Patients who are mistrustful may avoid coming to see doctors in general. They may be skeptical of preventive care, medications, tests, and operations, and thus be less likely to receive these when needed. This may be due to their own preferences, or physicians may be reluctant to offer them. Their attitude toward health care professionals may lead to difficulties in establishing relationships with them, thus leading to poor continuity of care. It is crucial to try and build trust with patients, since a personal relationship with a physician who is perceived to be caring and trustworthy will often override the general mistrust of medicine as a whole.

Mistrust of physicians and medicine may be expressed directly by patients or may remain hidden, and can lead to poor health outcomes. Physicians should be aware of mistrust, avoid taking it personally, and try to build trust with patients.

References:

1. Gamble VN. A legacy of distrust: African Americans and medical research. *American Journal of Preventive Medicine* 1993;9(6 Suppl):35-38.
2. Ayanian JZ, Cleary PD, Weissman JS, Epstein AM. The effect of patients' preferences on racial differences in access to renal transplantation. *New England Journal of Medicine* 1999;341:1661-1669.
3. Van Ryn M. Research on the Provider Contribution to Race/Ethnicity Disparities in Medical Care. *Medical Care* 2002;40(1 Supp):140-151.
4. Byrd WM, Clayton LA. *An American Health Dilemma. A Medical History of African Americans and the Problem of Race*. New York, NY: Routledge; 2000.

Alicia Mercado's story



Brief synopsis

Alicia Mercado is a 60-year-old woman from Puerto Rico who has lived in the “Hell’s Kitchen” neighborhood of New York City for 18 years in the same low-income building. She raised her family here and devoted herself to keeping a good home. As she has gotten older, her day-to-day life has begun to revolve around her chronic illnesses—diabetes, hypertension, and asthma, among others. Since her mother suffered from diabetes complications (and eventually died of cancer), Mrs. Mercado is well aware of the impact that medical conditions can have, especially when left untreated. Still, she has concerns about taking too much medication, and feels that by using home remedies together with the prescriptions she can do better than with either alone. She has recently started to see a new doctor who has found her to be a challenging patient due to poor diabetes control and frequent missed appointments. What her doctor doesn’t realize is how Alicia Mercado’s life has been turned upside down by a corrupt apartment manager forcing her out of her building, causing her to become depressed and to lose the will to keep up with her health care.

Medical background information

Alicia Mercado suffers from a number of chronic conditions, including type 2 diabetes mellitus, hypertension, and asthma, that have a major impact on her daily life. While an extensive discussion about each of these is beyond the scope of this introduction, it will be useful to those who are unfamiliar with these conditions to review some basic information. Chronic disease management is often a source of misunderstanding and conflict between patients and their health care providers. While modern medicine has developed miraculous cures for many serious diseases, there are numerous chronic conditions that can only be con-

trolled, not cured. As the population lives longer, living with and controlling chronic disease is becoming the rule rather than the exception. It is not unusual for people in their 60s like Mrs. Mercado to take eight to ten prescription medications at several different times of day. Most of these have been shown in large scientific studies to reduce the risks of certain disease complications such as renal failure, heart attacks, or stroke. However, the idea that taking this many pills is healthy goes against what many people were raised to believe, and requires a tremendous degree of faith in modern medicine.

Of the three major chronic conditions affecting Mrs. Mercado, diabetes is the one that requires the most sacrifice on her part. Diabetes disproportionately affects Latinos, and the death rates for Latinos from diabetic complications is higher than for non-Hispanic whites. There are two major forms of diabetes mellitus—type 1 diabetes (previously called juvenile onset) and type 2 diabetes (previously called adult onset). Both types lead to elevated levels of glucose (sugar) in the blood and other metabolic abnormalities, but type 1 always requires insulin injections, while type 2 can often be managed with oral medications. The goal of treating diabetes aggressively is to prevent or postpone the common complications of diabetes—kidney failure, nerve damage (which can lead to gangrene, infections, and amputation), and blindness. This requires keeping the glucose within a near normal range and controlling the other metabolic abnormalities by using insulin and/or other medications on a regular, daily schedule. Part of this process involves checking one’s own blood glucose levels by “finger-stick” to make sure they are neither too high (which signifies poor control) or too low (which can be dangerous).

While diabetes may have symptoms when the sugar is not well controlled, hypertension is generally a “silent disease.” Medications for hypertension are

given to try and reduce the risks of heart attack, stroke, and kidney failure, which are increased in patients with high blood pressure. Asthma is common in adults as well as children, and can cause daily wheezing, chest tightness, and cough, as well as episodic attacks of more severe symptoms. When poorly controlled, severe attacks can lead to hospitalization and can occasionally be fatal. Like most chronic diseases, treatment should be taken regularly to be effective, but many people take their inhalers only when they feel they need to.

Background on Hispanic/Latino immigrants in the United States*

Hispanic/Latinos are now the largest minority group in the United States. In 2001, the Census estimated that there were more than 35 million Hispanic/Latinos living in the continental United States, excluding the residents of Puerto Rico (a U.S. territory) and the undocumented. They are among the youngest and fastest growing groups, currently comprising approximately 12.5% of the population. While the term “Hispanic” is commonly used, especially by the government and other institutions, “Latino” is considered by many to be more appropriate. The Latino population in the U.S. is extremely heterogeneous—the majority is of Mexican origin (58%), followed by Puerto Rican (10%) and Cuban (4%). Central Americans (mostly Salvadorans and Guatemalans), South Americans, and others represent approximately 17%. Latinos reside primarily in 10 states: California, Texas, Arizona, New Mexico, New York, New Jersey, Colorado, Illinois, Florida, and Massachusetts, though the numbers are growing rapidly in other states as well. Puerto Ricans are most highly concentrated in New York, Florida, New Jersey, and Massachusetts.

There have been three distinct Hispanic/Latino patterns of immigration:

- Continuous flow of both legal and undocumented immigration from Mexico which intensified in 1980, driven by economic forces and opportunities;
- “Waves” of large-scale immigration from Central and South America, driven by war, conflict, and asylum-seeking;
- A Caribbean pattern of frequent back-and-forth migration between the country of origin and the U.S. (typified by the Puerto Rican experience in the Northeast).

Many new immigrants, including Puerto Ricans, engage in transnationalism—the process of sharing key aspects of life (citizenship, social ties, cultural affinities, finances, etc.) between two countries—in essence leading “dual lives.”

The heterogeneity of the Hispanic population makes generalizations about the needs, and approaches for addressing the challenges facing this “group” impractical. Certain Hispanic/Latino “cultural values” have been described in the literature that are viewed as having relevance to health care and the clinical encounter. These include fatalismo (fatalism), personalismo (warmth), respeto (respect), simpatia (kindness), and familismo (importance of family). It is erroneous to assume, however, that a Latino patient will manifest a certain set of attitudes and values about health and health care. The health care system of many Latin-American nations can be characterized as having limited technology and resources, especially for those who cannot afford it. As a result, this previous health care experience sets an expectation of “one-time” remedies for symptomatic conditions, but less familiarity with ongoing treatment for chronic conditions (such as diabetes).

* Sources:

- Suarez-Orozco MM, Paez MM, eds. *Latinos: Remaking America*. Los Angeles: University of California Press; 2002.
- Collins KS, Hughes DL, Doty MM, Ives BL, Edwards JN, Tenney K. *Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans*. The Commonwealth Fund, March 2002.

Small group discussion: Questions and information for the facilitator

What were your overall impressions about this video?

Start with a general discussion about the video as a whole and what people thought about it. Avoid saying much at this point since the idea is to allow people to express their feelings about the video before moving on to more specific questions and issues.

ISSUE 1

Patients' perspectives on chronic disease

Dr. Forson: "A lot of times we don't ask why they're non-compliant or why they're not coming to their visits. We just sort of put it in their note 'not compliant with care, just not interested,' and usually there are other things that are going on...dynamics that we need to understand."

Alicia Mercado suffers from several chronic medical conditions, including diabetes, hypertension, and asthma, yet her doctor does not feel that she is doing a good job taking care of these (particularly the diabetes). She has missed appointments, stopped medications on her own, and her glucose levels have remained relatively high.

What are some of the reasons (from Mrs. Mercado's perspective) for her lack of ideal adherence to medical therapy and follow-up?

- What are some other reasons why patients are non-adherent to medical therapy, especially for chronic diseases?

There are many reasons for non-adherence, but three stand out in the video as particularly relevant for Mrs. Mercado. Each of these will be discussed in more detail in the subsequent sections:

- Social stressors (being driven out of her apartment) and depression.
- Side effects and fears about potential consequences of medications.
- Use of complementary/alternative therapies (home remedies).

Other potential reasons for non-adherence to medications (especially in cross-cultural interactions) are discussed below.

There are many potential reasons that patients may not adhere to medications and medical advice. Exploring these can lead to a deeper understanding of the patient's perspective and improved cooperation.

ISSUE 2

Social stressors and support networks

Dr. Forson: "Can you tell me why you've missed your appointments?"

Mrs. Mercado: "They told me to call for an appointment but other issues came up. So I had to take care of those other things, not my health."

In a separate interview:

Mrs. Mercado's son: "(Being forced out of her home) basically caused her to get depressed. She did not care whether she took her medications or not. She did not care what her blood sugar was. She did not test herself."

In medical care, clinicians often see only the tip of the iceberg of social problems that patients may be facing in their lives. It can be difficult for us to imagine how anything could be more important, or more immediately pressing, than one's health. However, for many people, especially within lower socioeconomic and minority populations, the struggles of daily life can overshadow the long-term goals of careful chronic disease management.

Put yourself in the position of Dr. Forson caring for Mrs. Mercado when she was missing appointments and not caring for herself. How would you discuss her situation and what could you do to help (i.e., what is your role as a physician)?

- To what extent would you focus on her chronic disease management in the context of these severe social stressors and depression?
- Who would you look to for help with her situation and how?

Focus on Non-Adherence to Medications

Non-adherence serves as an excellent window into many cross-cultural issues in health care. It is a common and under-recognized problem and a major reason for poor diabetes and blood pressure control across populations. Some 50% of all patients with hypertension are not in good control due to non-adherence, and the numbers are similar for diabetes.

It is preferable to refer to “non-adherence” to medical therapy rather than “non-compliance.” Compliance implies following orders without having any say in the matter. Adherence has to do with following a prearranged plan, and does not specify how this plan was developed. “Cooperation” is an even more patient-centered term, which implies that both the patient and clinician were involved in developing the plan. The following are possible causes of non-adherence that were not the case with Mrs. Mercado, but which are important to explore:

- **Different beliefs about the illness (explanatory models)**

Patients who have a different understanding about their illness, whether culturally based or otherwise, may be less likely to believe that standard medical therapy will work. While Mrs. Mercado does not understand her conditions in quite the same way as her physicians, there is no particular belief or explanatory model about the illness itself that prevents her from believing in medical treatment (though she does have some strong beliefs about the medications themselves).

- **Financial barriers to obtaining medication**

Inability to afford medications, co-payments, or the costs of visits themselves (especially for uninsured

patients) could certainly compromise a patient’s adherence to treatment. This was not the case with Mrs. Mercado, whose visits and medications were covered by Medicaid.

- **Poor health literacy and lack of understanding about how the medication is to be taken**

Inability to read and to understand medical information, especially for patients with no family support, can affect adherence to therapy. Mrs. Mercado is able to read and her son helps her a great deal with her medications.

- **Mistrust of physicians and modern medicine**

Following a complex medical regimen requires a great deal of faith and trust in the health care system. Without this, patients are not likely to believe in and modify their lifestyle in accordance to their physicians’ recommendations. While Mrs. Mercado is not always completely cooperative with her physicians, she does believe that they are looking out for her best interests on the whole.

- **Previous health care experience**

The way patients were used to receiving health care in their home country, or a situation they may have encountered with the health care system in this country could affect their adherence. For instance, those used to “one-shot” remedies and limited follow-up may have difficulty understanding the concept of chronic disease management. This may have been the case for Mrs. Mercado to some extent, though she has been in the U.S. health care system now for many years.

This video shows very clearly how cultural issues are not the only important issues to focus on in cross-cultural interactions. Sometimes social and psychological factors are at the root of the difficulties in providing good medical care. Without first addressing these issues, it is unlikely that Mrs. Mercado’s chronic disease management will improve. The discussion here can focus on the many ways that clinicians can get involved

in helping a patient through a difficult social situation. First and foremost is shifting the discussion away from the strictly medical issues and focusing on her social situation and psychological wellbeing directly. By showing that this is important to you and to her medical care, this will gain her trust and allow for a more open discussion. Other things to do include:

- Assess for depression and deal with this effectively. This is crucial since depression is one of the most common reasons for non-adherence and is a major cause of morbidity across cultures.
- Provide support and consider brief counseling in the office.
- Consider treatment with anti-depressants if indicated.
- Enlist the support of key family members or other individuals who provide social support (friends, social or religious groups, etc.).
- Involve a social worker either as part of your own practice or in a community health center in the patient's neighborhood.
- Refer to mental health professionals when indicated. Make sure to discuss this carefully with the patient and family. There is still a negative stigma associated with mental illness and it may be more prevalent among immigrants and minorities.

Dealing with social stressors and depression may be an essential first step in achieving good control of chronic medical conditions.

ISSUE 3

Fears about potential consequences of medications

Mrs. Mercado: "In the past they gave me Glucophage."

Dr. Forson: "And you stopped that because..."

Mrs. Mercado: "I stopped because my hair came out in clumps...and it upset my stomach."

In a separate interview:

Mrs. Mercado: "I think that my mother became sick from too much medicine. She died of cancer. A doctor in Puerto Rico told me that, possibly, all of the medicine she had taken had accumulated, rather than going where it was supposed to go."

Side effects of medications, whether actual or perceived, can be a major deterrent to adherence. Glucophage (metformin) is an oral medication for type 2 diabetes that can cause upset stomach, but is not known to cause hair loss. There is no evidence that taking too much medication can lead to cancer.

How would you describe Mrs. Mercado's general attitude toward medications and how might she (or any patient) have developed this perspective?

- How would you respond to her concerns about side effects and about what happened to her mother?

This issue can generate a rich discussion about patients' fears of medication—both founded and unfounded. While clinicians often assume that patients want treatment for their conditions, this is not always the case. Medications have many side effects ranging from annoying to potentially life-threatening. Patients get information about these in the directions from the pharmacy, through discussion with others who have taken similar prescriptions (or rumors from those who haven't), and from the media. They have also usually experienced some side effects from other medications they have taken which may make them wary. The less confident individuals are with the value of medications in achieving improved health, the more likely they are to attribute negative symptoms to their medications (e.g., hair loss from Glucophage). Mrs. Mercado has a general skepticism about medications, and a concern that the risks often outweigh the potential benefits. Her attitude could be based on several factors:

- Her previous health care experience (prior to coming to the U.S.), especially the misinformation given her by a physician in Puerto Rico. Also, her experience may have focused on short-term remedies rather than chronic disease management (as described previously). She may have lacked access to health care and medications while growing up, which could have led to more self-reliant behavior (home remedies) and fear of the unfamiliar.
- An orientation to the present rather than the future (in large part due to lower socioeconomic status). This is also referred to as one's "time horizon" and relates to the value that an individual places on immediate concerns (such as side effects or inconvenience) versus planning for the future (such as preventing diabetes complications years from now).

- A general mistrust or skepticism about technology and particularly, chemicals, or unnatural substances taken into the body.

The most important point in responding to Mrs. Mercado's concerns is to address them directly and with respect. While it is important to try and educate patients and correct any dangerous misconceptions, it requires tact and trust building. Validating and normalizing her concerns while presenting your perspective on why they are not the case is important. For example:

"I can understand why you would be concerned about taking several different medications, but I want to assure you that this cannot cause cancer. Let's see if we can limit the number of pills you have to take to just those which are essential." Introducing her to other patients who have been taking a certain medication without any problems can also be helpful. These are aspects of negotiation which can build trust and may also improve adherence.

Asking patients to discuss their concerns about side effects or dangers of medications can identify major reasons for non-adherence. Addressing these directly can lead to better trust and cooperation.

ISSUE 4

Complementary/alternative therapies (home remedies)

Mrs. Mercado: "When I feel my sugar level rising I drink lime juice and I can control it. Or water, lots of water. I control my high blood pressure with pills, and also with garlic. Garlic is good for that. It controls it very well. In reality, I couldn't do it with one thing alone. Not only the garlic, nor only the pills."

Mrs. Mercado has strong beliefs about the role of medicine and the role of her own home remedies in managing her chronic illnesses. In a large U.S. survey, 42% of Americans used at least one type of alternative therapy not prescribed by a physician. More than 60% of these had not discussed their use with a physician.

What are your views on the use of complementary/alternative medicine in general, and in this case specifically?

- What home remedies did your family use when you were growing up?
- Why is it important to know about these practices?
- How do you approach patients about them?

In discussing these issues, it is important to make sure that the students put them into context. Most of us have experience with our parents or grandparents using home remedies when we were growing up. This is a good way to link students' own experiences to those of their patients and generate a rich discussion around the various remedies, which will differ with the cultural background of the student. Alternative practices in this country range from herbal medicines to home remedies, acupuncture, energy healing, homeopathy, massage, and prayer. People turn to forms of therapy that fit their models of how health and illness work and that support their values. Explore students' perspectives on this and try to engage them in an active debate about the relative merits of and problems with these practices. The placebo aspect of these therapies and what this means can also be a useful point of discussion.

Issues to consider with alternative therapies:

- Some may have beneficial effects for patients, whether proven (true in some cases) or subjective.
- Trust can be built by being open to patients' ideas about these.
- Some alternative therapies may be dangerous, either due to their direct side effects or interactions with other medications that the patient takes.
- Patients may avoid using potentially more effective medical treatment due to their use of alternative practices.
- Being judgmental about alternative therapies contributes to patients not revealing their use.

As part of the standard medical history, ask all patients about traditional and alternative practices that they may be using. Be non-judgmental and respectful of their views and negotiate a plan accordingly.

References:

1. Green AR, Betancourt JR, Carrillo JE. The social history revisited: integrating social factors into cross-cultural medical education. *Acad Med* 2002;77:193-197.
2. Eisenberg DM, Davis RB, Ettner SL, Appel S, Wilkey S, Van Rompay M, Kessler RC. *JAMA* 1998;280:1569-75.
3. Betancourt JR, Carrillo JE, Green AR. Hypertension in multicultural and minority populations: linking communication to compliance. *Curr Hypertens Rep* 1999;1:482-488.

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