

# Hold Your Breath

Facilitator's Guide

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## *Facilitator's Guide*

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*Facilitator's Guide by:*

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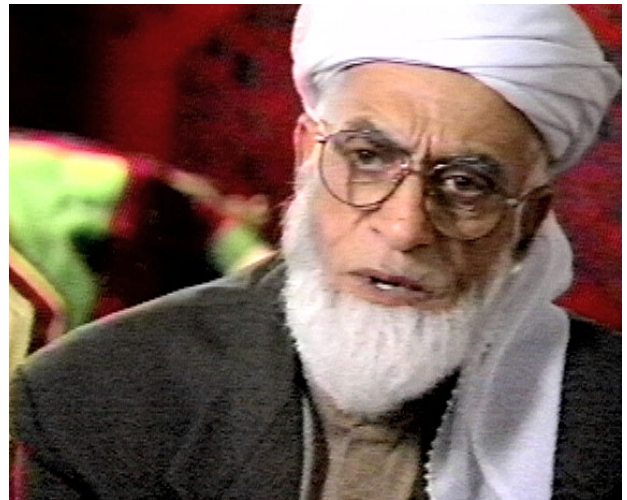
*Film directed by:*

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### *Background*

In 1999, award-winning physician/filmmaker Maren Grainger-Monsen and filmmaker Julia Haslett embarked on a project to develop a documentary film that explores 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. A series of mini-documentary videos was developed from this project that tell the stories of four individuals and their families as they interface with the American health care system, shedding light on how cross-cultural conflicts and challenges arise and affect health decisions and outcomes. One of these stories, that of an Afghani man named Mohammad Kochi struggling with stomach cancer, is the subject of this full-length documentary, *Hold Your Breath*.

The people and the events portrayed in *Hold Your Breath* are real. The documentary style of the video captures live clinical interactions as they happened, as well as interviews with the patient, his family, and the medical staff who cared for him. Mr. Kochi's story highlights a broad range 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. To that end, the video and accompanying facilitator's guide can serve as a valuable educational tool, giving health care professionals and others a lens through which to explore ideas about cross-cultural issues in health care by witnessing the actual events and issues as they happened.



### *Mohammad Kochi's Story*

#### **SYNOPSIS**

Every person has a story. Through this film and facilitator's guide you will have the chance to meet Mohammad Kochi during a brief but intense period at the end of his life. Had you had the opportunity to see him in one of the halls of the hospital where he spent many days after his illness was diagnosed – a thin bearded man dressed in a white or gray turban kneeling and praying – what would you have thought of him? Would you have regarded him as an outsider, a strange Muslim man unwilling to adapt to the traditions of the western world, and then disregarded him? Mohammad Kochi, with his turban, his prayers, and all his idiosyncrasies, as well as his disease, was a real person: a man who enjoyed watching football and

baseball, liked to see the 49ers and Giants games on television, and took his kids to school every day. Mohammad Kochi is much more than a story told by the lens of a camera and interpreted, first by the people that surrounded him, then by the filmmakers and writers of this guide, and lastly by you, the viewer and reader. Mr. Kochi was a real person with an existence full of life, of challenges, of virtues and contradictions, of convictions and fears. And this is but a small part of his story.

Mohammad Kochi, as he will be introduced to you, is a 63-year-old man from Kabul in Afghanistan who arrived in Fremont, California 18 years ago, escaping from a region torn by war after the Russian invasion. Losing family members and leaving a life behind, a much-respected elder and leader in his community, Mohammad Kochi came to the United States in 1988 as a refugee. He came with his wife – who never had the opportunity to learn to read or write – and established a new life with his nine daughters and his only son. Mr. Kochi is a devoted Muslim who prays five times a day, fasts during Ramadan and has done the Haj – the pilgrimage to Mecca and the last pillar of Islamic faith – seven times in his life.

When he is diagnosed with gastric cancer, because his knowledge of the English language is limited, his fourth-oldest daughter Habiba serves as his translator. But it is his son-in-law who takes the lead in the decision to withhold the information about the diagnosis from Mr. Kochi in order to protect him. He tells Habiba to tell Mr. Kochi that he has a bacteria. Later Mr. Kochi would acknowledge that he had heard the word *cancer*, and had always had some idea of his condition. He asks his family to search for a second medical opinion; his family refuses his petition and consents to a surgical procedure to remove the tumor.

After undergoing the operation Mr. Kochi and his family are led to believe that his illness has been cured. The surgeons tell the family that “[they] got it all.” His post-operative CT scan, however, shows he has one enlarged lymph node distal to the tumor site. It had not been completely removed as his surgeons hoped (and implied) and he is referred to an oncologist for possible chemotherapy and follow-up care. However, he refuses the treatment.

Mohammed Kochi complains during one of his post-operative visits that his oncologist Dr. Fisher, cannot

possibly be sure that there is still cancer because the surgeons lost his previous X-rays, the ones on which he believes the decision to perform surgery was based. To Mr. Kochi, the lost set of X-rays hold what, in his mind, remains as an untold truth. Hope, perhaps? Four months after his surgery Mohammad Kochi and Dr. Fisher meet again. Fisher tells Mr. Kochi that, just as they had discussed earlier, chemotherapy is still recommendable; however, he points out that the usual form of this therapy is very toxic, and though approximately 30% of the time it succeeds in shrinking the disease, the result does not last long.



Ramadan is about to start in a few weeks, and Kochi argues that he is feeling better. His plan is to fast the entire month. Fisher opposes this plan, but Kochi refuses chemotherapy again and chooses to fast. When he comes back to the hospital he has only lost a few pounds, has a lot of energy and feels no pain.

As Dr. Fisher presents Kochi's case at the hospital's weekly case conference, he reveals that he is unsure how informed Mr. Kochi had been of the details of his condition at the time he went through the gastrectomy. One of Dr. Fisher's colleagues comments that, in some cultures, the particular words used can have an enormous influence on the patients' views on their illness. Semantics matters. Maybe the word cancer takes all hope away.

Mohammed Kochi decides to do the Haj once more. His daughter Habiba offers her savings for his trip, and he makes it. He thinks perhaps his prayers have blessed his heart, and that maybe Allah has taken his disease away. But Mr. Kochi isn't getting better; he is again in pain. Dr. Fisher mentions that there is a new experimental treatment that would allow them to administer the medication to Mr. Kochi in a different way

than the continuous infusion pump - the only method previously mentioned. But Mr. Kochi and his daughter, Noorzia, upset by the idea that the treatment has only been used in rats, return to their family physician, Dr. Katiby. Dr. Katiby asks Mr. Kochi if he has changed his mind about receiving therapy. Kochi replies he has no intention to undergo it. It is now six months since Kochi had surgery.



The stomach pain, diarrhea, and coughing have returned to Kochi's withering body. The CT scan shows a more precarious scenario than that of January. Dr. Fisher never insists that a patient receives therapy, yet this time he advocates for it: the chance is 40 to 50 percent of reducing the disease. What Mohammed Kochi wants to know, though, is if his illness can be completely cured with this treatment. And what if it causes other problems? What if it makes him weaker? Then, what's the use, asks Kochi.

"We cannot guarantee anything, but therapy might end up shrinking the tumor and you might feel better longer," says Fisher.

Kochi replies: "Our day has been chosen for us by Allah; we cannot force it back nor forth."

Two months later, Kochi undergoes a follow-up CT scan. Noorzia accompanies him and asks Dr. Fisher if her father still has cancer. He has always had it. He was offered chemotherapy and had refused. "But who was translating when he was given the options?" his daughter wonders. Mohammad Kochi seemed to believe that chemotherapy meant hooking him up to a pump through his arm. Did someone forget to tell Mr. Kochi that he had other options as a form of therapy?

Noorzia wonders. Perhaps a confession, Fisher acknowledges that he had always interpreted Mr. Kochi's refusal as simply a religious objection.

On the day when it is decided that Kochi would begin receiving chemotherapy, there is still at least one question in Kochi's daughter's mind: Why would the doctors keep on seeing Kochi without providing chemotherapy? "I never give chemo to someone who doesn't want it," answers Dr. Fisher.

Mohammad Kochi began chemotherapy one year after his diagnosis. He now walks with a cane. He is visibly thinner. Even the color of his skin has changed. And he will not live much longer.

The film documenting the life of Mohammad Kochi after his diagnosis ends shortly after this. The hope is, however, that through this footage showing clinical interactions, interviews with Mr. Kochi himself and his family and friends, and discussions among the medical staff you, the viewer and reader, will find yourself pondering the issues raised – both the obvious ones and the more subtle ones.

## MEDICAL BACKGROUND

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 tumor site made radiation not a viable alternative for him, and it was therefore recommended that he have chemotherapy without radiation. Oncologists (cancer doctors like Dr. Fisher) describe 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.

Source: [www.uptodate.com](http://www.uptodate.com) and  
Harrison's Principles of Internal Medicine

## 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 are 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.

Source: "Afghans in the United States,"  
[www.culturalorientation.net](http://www.culturalorientation.net)

## Educational goals

When using the *Hold Your Breath* video and facilitator's guide as an educational tool, several general learning goals should be kept in mind. These goals help to extend the value of the video beyond the specifics of this case. The general goals of the video 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.
- 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

The facilitator's role is to organize and lead an interactive discussion of the *Hold Your Breath* video, 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 this video. The story itself 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 video 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 as above, and the general objectives of the video if not done previously.
- Establish ground-rules for small 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 participants to jot down their ideas about cross-cultural issues and topics for discussion as they are watching the video. 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 the *Hold Your Breath* video. 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 video (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 boxes 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.

## Small group discussion

### QUESTIONS & INFORMATION FOR THE FACILITATOR

#### *General Questions to begin discussion:*

- What were your first impressions about this video?
  - What thoughts stuck with you as you watched?
  - What surprised you?
  - What disturbed you?
  - How might Mr. Kochi's care have been better?

**Discussion Points:** 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: Family decision-making and withholding of information*

**Noorzia:** *"So you're basically telling me that my father still has the cancer..."* 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 his daughter (and son-in-law) 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?

**Discussion Points:** In many cultures it is the norm for the family to make decisions as a unit. They may decide to withhold information about a serious or terminal diagnosis if it is deemed to be in the patient's or the family's best interest. This is generally done with the idea of protecting the patient or other family members 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, Kochi's daughter Habiba and son-in-law who translated for Mr. Kochi withheld the 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. The subsequent discussions with the physicians were not relayed to Noorzia and the rest of the family.

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 and who should they speak to?
- How should doctors (and other health professionals) determine what is being communicated by family members to a patient?

**Discussion Points:** 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 representative 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.

## 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' style of practice.



Still, certain elements must be included, such as the major risks and benefits in clear terms.

The medical profession has a strong cultural influence, which can help to

shape beliefs, values, and behaviors. 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.

## 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 does acculturation influence the different individuals in this film, in terms of their perspectives concerning the medical situation they are involved in, and their interactions with each other?

- How is Noorzia's perspective on her father's health, and the medical system in general, different than her father's?
- How acculturated is Mr. Kochi, and how do you think this influences his decisions about his health and medical care?

**Discussion Points:** 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.

Another way in which the hierarchy is reversed for Mr. Kochi is through his loss of status, most apparent as a patient interacting within the framework of the American health care system. Mr. Kochi, a highly respected member of his community in Afghanistan, is now an elderly man, terminally ill, dependent to some extent on his daughter, and able to communicate only through the interpretation of a family friend. Had he been in Afghanistan, tradition would have probably maintained him as a symbol of respect, both for his age and his illness. Whereas in the United States, with age, waning economic resources, and deteriorating health, Mr. Kochi is left with little of the status and respect he was used to. He feels underestimated by those who interact with him whether or not they are conscious of this themselves. At one point Mr. Kochi expresses this concern through his

family friend. He expresses his sensation of not been “seen” by his doctor, even in spite of Fisher’s attempts.

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.”

**Surgeon** (at case conference): “I never operate on someone who has not had an interpreter when I’m speaking to him.”

The issue of miscommunication due to ineffective interpretation (or no interpretation) comes up several times in this video. At one point, 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 Points:** 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.

- How important is the specific language that is used when discussing a diagnosis?

**Discussion Points:** During a weekly case conference documented on the film, a surgeon talks about how he has noticed that, with some families, he cannot use the word “cancer.” He must replace it with words like “tumor” or “mass.” On one of the interviews with Mr. Kochi’s family friend, Dr. Rahmattullah Nazari, the latter talks about how Afghani people employ certain “tricks” when informing patients and/or their families about critical diagnoses. He comments that certain words cannot be used directly, and some information is not shared with the patients by family members who receive it. In Mr. Kochi’s case, Noorzia and Mr. Kochi himself were still asking whether he in fact had cancer a year into the diagnosis. How can a care provider assess the appropriate language to use with each patient in such a way that he ensures an efficient communication of vital information?

Another interesting discussion could be centered around the question of whether or not physicians, by rephrasing the way they express certain information to avoid offense, may be offering different levels of care.

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.

### 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.

### 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?

**Discussion Points:** 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.

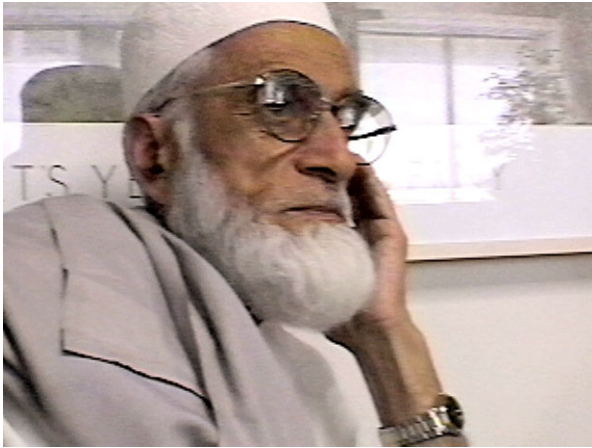
Differences in communication style, which are often culturally based, can lead to barriers to mutual understanding. A non-confrontational patient may be agreeing with the physician just to show respect.

### 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. Fisber (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.”

“I had always interpreted [it] as a simple religious objection to the therapy, but if it was just about a pump I have other treatment options I could give him.”



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? 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? About hospice care?
  - 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 Kochi – or anyone – have for refusing chemotherapy?

**Discussion Points:** 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. 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.

One way to improve cross-cultural communication and negotiation is to involve a "cultural broker" – someone who is familiar with both the patient's culture, religion, and language as well as that of the clinician. In this case a religious leader (imam or Muslim cleric) might have made a difference in Mr. Kochi's interpretation of Islamic Law and may have helped Dr. Fisher to understand the reasons behind Mr. Kochi's refusal of treatment. Clarifying the positions of both sides could have led to better, more informed decisions by both physician and patient.

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.

What if the physician has some bias with respect to the value of a specific treatment option versus another? Addressing this question could lead to an interesting shift in perspective. Could it be that Dr. Fisher forgot to propose other options of treatment simply because he really believed the continuous infusion pump is better (and what he would want himself)? How can a physician prevent his personal biases, however well intentioned they might be, from diminishing the effectiveness of his/her communication with patients?

- 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?"

**Discussion Points:** There may be other reasons why 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: Mistrust

**Kochi** (to Rahmattullah): *Seven months and I haven't taken any medicine, why?"*

*"What about my sore throat? Tell him to give me medication...I need some medication. This is a hospital."*

**Noorzia** (to Dr. Fisher): *"Why would you keep seeing my dad without providing chemotherapy?"*

*"I'm sure if I wasn't here...you guys wouldn't have told him about the pills and different options. I know that for a fact."*

**Rahmattullah Nazari** (family friend): *"He wanted to be treated like in Afghanistan. There he is treated as the head of the family. And he is a respected people in the community. He thought Dr. Fisher is not seeing all those other things behind him, or inside him."*

**Kochi:** *"I have the idea...that the surgery might have been a mistake."*

**Rahmattullah Nazari:** *"You think the X-rays would show that [the surgery] was wrong?"*

**Kochi:** *"Why do you think they disappeared?"*

Personal experiences of discrimination, disrespect, and stereotyping contribute to mistrust of physicians and the health care system. This may be based on a number of factors such as race, ethnicity, language, religion, social status, education, and age, which can lead to both conscious and, very often, unconscious stereotyping and bias.

- 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?

**Discussion Points:** The way patients express their mistrust depends to a large degree on their style of communication. People who are more direct may express their mistrust more openly, or even confrontationally. Health professionals should avoid taking this personally and to try and build trust and reassure patients of their good intentions. In general, when patients express strong emotions, it is important to acknowledge those feelings rather than trying to avoid them. For example, when Noorzia expressed her anger about her father not starting chemotherapy earlier, Dr. Fisher might have said, "I know you're upset about this and I understand. Can you tell me your concerns specifically so we can talk about them."

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. Mistrust sometimes

is not apparent to physicians, and often the respect that patients give their doctors can be misinterpreted as trust. Notice how, in spite of Mr. Kochi's expressions of mistrust, even when he visits Dr. Fisher with his daughter to inform him of their intention to seek a second opinion, Mr. Kochi still never ceases to convey to Dr. Fisher his respect. In that instance, Mr. Kochi tells Fisher, "We will consult you with all our decisions because you are my first doctor."

- How do you think the fact that Mr. Kochi could not express himself in English influenced the way in which Dr. Fisher referred to him?
  - Does it seem that Dr. Fisher treats Mohammad Kochi as an equal or does he take a paternalistic role?
  - In what way does the patient-doctor interaction determine the way a patient responds to medical advice? (For example, do you think Mr. Kochi's response to his physician's advice would have been different had Mr. Kochi felt that he was been respected and "seen" by Dr. Fisher?)
- How did Mr. Kochi express his lack of trust?

**Discussion Points:** 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.



## Issue 6: The culture of medicine

**Nurse:** "So, Mr. Kochi...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?"
  - Why did Dr. Fisher never fully explore Mr. Kochi's perspective on the use of a pump to deliver chemotherapy?

**Discussion Points:** 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.

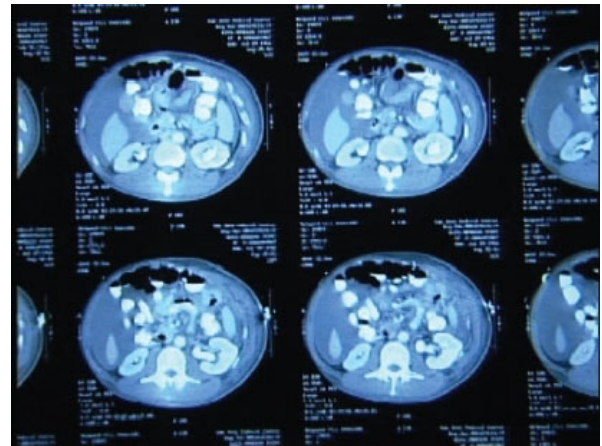
The medical presentation of Kochi's case gives some idea of what's important from a disease perspective, whereas the complex family dynamics, hope, disappointment, frustration, pain, loss of control, etc., describe the illness. Biomedicine tends to focus more on the dysfunction of the body as a machine 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 Kochi and his family rather than emphasizing treatment as the best option.

One example of the difference between the medical culture and the culture of most patients is how each views the idea of experimentation and medical research. Most physicians feel positively toward the idea of medical research involving patients to study the effects of new drugs and treatments. However, many patients are very skeptical of this kind of research, fearing that they will be used as guinea pigs or worse. It is important for health professionals to take into account patients' perspectives on this and other issues that may not be so obvious when one is firmly entrenched in the medical culture.

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.

**Dr. Fisher:** *"I was so concerned with translation of issues that I didn't get to ask those open ended questions, the bigger, maybe more important questions in his care."*

In the film, Dr. Fisher faces the challenge of a less-than-ideal clinical situation with language barriers, miscommunication, and differing health beliefs. Later, he expresses an openness to the idea that he might have done things differently in retrospect, and a willingness to engage in self-improvement. This is an excellent example of the reflective, life-long learning process that all physicians should strive for in their clinical practice.



- Consider how Dr. Fisher deals with this situation and reflects on the challenges that he faces. What concepts of mentoring and role modeling are highlighted in Dr. Fisher's words?
- Reflect on Dr. Fisher's statement above. How pressing is the sense of obligation to document the presentation of all the information, compared with creating rapport with the patient and family members?

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*Another award-winning resource on cross-cultural issues in healthcare:*

# Worlds Apart

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A shorter version of Mr. Kochi's story is presented in Dr. Monsen's award-winning series, **Worlds Apart**. These unique trigger films follow patients and families faced with critical medical decisions, as they navigate their way through the health care system. Filmed in patients' homes, neighborhoods and places of worship, as well as hospital wards and community clinics, **Worlds Apart** provides a balanced yet penetrating look at both the patients' cultures and the culture of medicine. This series is an invaluable tool for raising awareness about the role sociocultural barriers play in patient-provider communication and in the provision of healthcare services for culturally and ethnically diverse patients.

The interactions between these patients and their health-care providers reveal a great deal about both problems and opportunities in cross-cultural healthcare. The study guide for this documentary series was designed by cross-cultural medicine educators Drs. Alexander Green, Joseph Betancourt, and Emilio Carrillo.

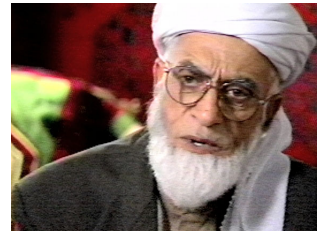
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## Stories from the **Worlds Apart Series:**

**Justine Chitsena** needs surgery for a congenital heart defect, but her mother and grandmother, refugees from Laos, worry that the scar left by the operation will damage her in her next reincarnation. They want to seek advice from the local Buddhist temple. **11 Minutes**

**Mohammad Kochi**, a devout Muslim from Afghanistan, had surgery for stomach cancer, but is now refusing the chemotherapy recommended by his physician. His daughter thinks he may fear that the kind of chemotherapy offered will prevent him from observing daily prayer, and wonders if a professional translator might have avoided misunderstandings. **14 Minutes**

**Alicia Mercado**, a Puerto Rican immigrant, has strong beliefs about using natural home remedies rather than prescription medications. Her diabetes, hypertension, asthma and depression have been aggravated by her recent eviction from her apartment of eighteen years, which has also disrupted the continuity of her care. Her son worries about the "assembly line" care he feels she is receiving. **13 Minutes**

**Robert Phillips**, a health policy analyst who is African-American, believes he's likely to wait twice as long as a white patient for the kidney transplant he needs. He's looking for a new nephrologist — someone who will be more sensitive to his concerns. **10 Minutes**

**Combined Running Time: 47 Minutes**